“My heart still aches with sadness”:
Epidemiological Relationships Between Perinatal Grief, Major Depressive Disorder, and Personality Disorders

by

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Abstract

The experience of perinatal bereavement can be devastating for women and their loved ones, and yet the experience has largely been overlooked by researchers. It is only recently that, along with changed sociocultural conditions, technological advances in neonatal care, and advanced understanding of maternal/fetal attachment, women's experiences of perinatal loss have been empirically recognised. With an estimated 1 in 3 women experiencing perinatal loss, the profound sorrow that can accompany miscarriage, stillbirth, ectopic pregnancy, and terminations is now more readily acknowledged. Although some women accommodate perinatal loss in the longer-term, previous research has shown that approximately 20% continue to carry disabling symptoms in the years after perinatal loss. The challenge remains for researchers and practitioners alike to identify factors which influence longer-term perinatal grief trajectories. The present study aimed to examine perinatal grief experiences and mental health in a group of community-dwelling Australian women. One hundred and ninety-seven women participated in a clinical interview to assess perinatal history, depression, and personality disorders. It was hypothesised that previously-healthy women who developed *de novo* Major Depressive Disorder after experiencing perinatal loss would report more intense grief, with depression acting as a significant risk factor for complications in grief. Further, it was hypothesised that women with personality disorders would report more intense grief responses, with the presence of any personality disorder acting as a significant risk factor for greater complications in perinatal grief. These hypotheses were all supported. After an median 11 years post-loss, 6.5% of women continued to report clinically significant levels of perinatal grief. One in four women who were previously mentally healthy responded to perintal loss

with the development of *de novo* depression. For women who did develop *de novo* depression, and for women with personality disorders, the risk of developing more problematic grief was between two and four times greater than women without such features. It may be that women with personality disorders are more at risk of developing a despair-related form of prolonged grief, whereas women with depression may be at risk of developing a form of prolonged grief associated with poorer coping. Such findings have theoretical and clinical implications whereby certain groups of women appear at greater risk of developing more complicated grief after perinatal loss. Further research should continue to identify these and other risk factors that modulate grief responses, so as to inform diagnosis and treatment of Persistent Complex Bereavement Disorder.

Declaration

I, Lisa Burke, declare that the Doctor of Psychology (Clinical) thesis entitled *"My heart still aches with sadness": Epidemiological Relationships Between Perinatal Grief, Major Depressive Disorder, and Personality Disorders"* is no more than 40,000 words in length including quotes and exclusive of tables, figures, appendices, bibliography, references and footnotes. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work.

Signature: Lisa Burke

Date: 17 March 2017

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Behind every final product, there's a cast of unsung heroes. This dissertation is no different. To the participants first and foremost, the women who shared their stories, I thank you. You wore your hearts on their sleeves as you opened sometimes painful wounds. This research would not be without you.

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This work is dedicated to the little girl who was so tiny she couldn't stay. It is for the little girl so perfect, God gave her wings. For the little girl whose life and death changed us all. Chloe, when you died, everyone added something to your tribute box. Except me. I did not know what to add. It took me 15 years to realise that what I could add was knowledge and healing. And here it is.

This is the work that this tiny girl inspired.

This is the salve to pain.

This is for Chloe and for Sharon ♥♥

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Chapter 1: Literature Review

"Although we know that after such a loss the acute state of mourning will subside, we also know we shall remain inconsolable and will never find a substitute, no matter what may fill the gap, even if it be filled completely, it nevertheless remains something else. And actually this is how it should be... It is the only way of perpetuating that love which we do not want to relinquish."

Sigmund Freud (1920a, p. 386) on the death of his daughter Sophie

For some women and their loved ones, childbearing and birth is a period of jubilation. For others, the anticipation of new life gives way to devastation. Perinatal loss of a desired child through ectopic pregnancy, miscarriage, termination, stillbirth, and neonatal death is a common experience which impacts health and wellbeing for individuals, couples, and families (Lang et al., 2011; Mander, 2006).

Loss is the severing of an attachment to a person or object that results in a changed relationship (Hollins Martin & Forrest, 2013). Losses can reflect both physical and tangible dimensions of one's functioning (e.g., home, wallet, body part), and psychosocial and symbolic dimensions (e.g., divorce, retirement, loss of meaning). Loss through death involves both changed tangible and symbolic dimensions (Love, 2007).

Bereavement is the objective state of having experienced loss (Rando, 1995). The use of this noun in definition reflects the accepted practice of describing an individual as bereaved, rather than as bereaving (Servaty-Seib, 2004).

By comparison to the objective nature of bereavement, *grief* refers to one's subjective responses to the state of being bereaved. Grief is a term often used to reflect the state of bereavement (e.g., a grieving person). The complexity of individual grief responses is reflected in the wide-ranging effects of bereavement on affective, cognitive, physical, behavioural, social, and spiritual domains of human functioning (Corr & Corr, 2013; Rando, 1995; Worden, 2008).

Attributes of grief include: A) that grief is *pervasive* in its wide-ranging psychological, social, physical, cognitive, behavioural, and affective effects; B) that grief is *dynamic*, involving an ever-changing interplay of emotions, thoughts, and behaviours; C) that despite being a universal human experience, grief responses are highly *individualised* and manifest in many different ways from one person to the next; and D) that grief is a *process* that is enduring and has no time limits (Cowles & Rodgers, 2000). One's experience and expression of grief is one's own, with grief being particularly influenced by the meaning of the loss to the person (Miles, 2012; Neimeyer, Klass, & Dennis, 2014). Thus the process of grief, while universal, is individual, dynamic, and pervasive (Capitulo, 2005).

Mourning is the outward expression of one's grief to the world. Mourning reflects the active processes an individual engages in to cope with grief, such as rituals, funerals, and memorialisation (Walter, 2008). As this often involves outward expressions of grief, mourning is embedded in culture and customs (Rosenblatt, 2008). Such active attempts at mourning not only demonstrate ritualised sociocultural processes, but also reflect one's attempt to integrate the loss experience (Badenhorst & Hughes, 2007; Corr & Corr, 2013; Wortman & Silver, 2001).

Although this framework presents the key concepts of bereavement, grief, and mourning as distinct, they can be difficult to distinguish in practice (Stroebe, Hansson, Schut, & Stroebe, 2008). For example, an overt expression of distress can be a reflection of emotion (grief) or it can be a reflection of a cultural norm of emotional expression (mourning). Grief likely influences mourning, just as mourning influences grief (Rosenblatt, 2008; Stroebe et al., 2008). Notwithstanding, the above represents the commonly accepted framework in the field of thanatology research and as such, is the framework which will be used in the present research.

1.1 Theories of Grief

1.1.1 Traditional psychoanalytic models of grief. One of the earliest academic attempts to capture grief reactions was led by Erich Lindemann in 1944. Lindemann's (1944) seminal publication detailed reactions of family members whose loved ones died in a nightclub fire. Lindemann and his team detailed characteristics of 'normal grief', including somatic or bodily distress, preoccupation with images of the deceased, guilt, hostility and altered personal conduct.

Lindemann (1944) coined the enduring term 'grief work' to represent that coping with bereavement is not a static or passive state, but rather an active process (Mander, 2006). According to Lindemann, grief work involves efforts to emancipate oneself from bonds to the deceased, readjust to an altered environment without the loved one, and form new relationships. Individuals who attempt to avoid, delay, inhibit, or complicate their grief work would be at risk of 'morbid' or unhealthy grief experiences (Lindemann, 1944).

Grief work was also central in Sigmund Freud's conceptualisation of grief. In *Mourning and Melancholia* (1917/1957), Freud described one's investment of psychological energy in a person or object as subsequently resulting in pain when that person or object is lost. Mourning, or *Trauerarbeit*, thus represents the work involved in uncoupling or detaching from that person or object (Freud, 1917/1957). Freud believed that individuals must withdraw libido (psychic energy) from the lost object, thus freeing the ego for new and healthy attachments. This notion that bonds to the deceased serve no healthy purpose and should be severed took strong hold in the field, with professionals labelling the failure of relinquished attachments and formation of new attachments 'pathological grief' (Neimeyer et al., 2014). It is noted however that despite his oft-cited professional theory of mourning, Freud later expressed his personal reluctance to relinquish bonds after the death of his daughter Sophie, as expressed in the opening epigraph. In a letter to a friend Freud lamented of his parental grief, "Deep down I sense a bitter, irreparable narcissistic injury" (Freud, 1920b, p. 328).

1.1.2 Attachment models of grief. Drawing on a variety of perspectives, attachment theory seeks to explain the development and impact of affectional bonds. John Bowlby's and Mary Ainsworth's theories of attachment merged psychoanalysis with evolution and ethology to form a biological framework of responses to separation and loss (Ainsworth & Bowlby, 1991; Bretherton, 1992).

Viewing attachment as a reciprocal relationship resulting from long-term interactions between an infant and his/her parents, Bowlby refuted tenets of the psychoanalytic conceptualisation of grief (Corr & Corr, 2013). In particular, Bowlby's third seminal paper challenged Anna Freud's contention that young children were

unable to mourn (Bowlby, 1960). Instead Bowlby countered that children mourned for as long as attachment figures continued to be unavailable, and that children would be unable to go on to form deep relationships if a succession of substitute attachment figures was too frequent (Bowlby, 1960). Further, Bowlby contended that rather than being inherently and solely pathological, separation and grief responses could also be seen as instinctual, adaptive, and valuable to survival (Bowlby, 1970, 1973, 1980).

Bowlby's then-controversial paper on childhood mourning attracted the attention of thanatologist Colin Murray Parkes, who saw the relevance of this work to adult grief (Corr & Corr, 2013). Working together at the Tavistock Institute, Bowlby and Parkes (1970) began to chart the course of grief in a group of London widowers. Their findings characterised grief as an inherent response to separation, with the adult grieving process following a predictable orderly pattern of response to the loss. Four specific grief phases were described – numbness, yearning/protesting, disorganisation/despair, and reorganisation (Bowlby & Parkes, 1970; Parkes, 1972). Thus urges to reunite with a loved one, along with anxiety, anger, and protest, were not seen by Bowlby and Parkes as pathological in themselves, but rather were part of a constructive process of making real in one's inner world what was already real in the external world. Bowlby and Parkes (1970) acknowledged that over time, difficulties accepting the permanence of a death-related loss could lead to chronic or conflicted grief.

One important implication of attachment theory for bereavement research is that childhood attachment style may be later reflected in one's adult interpersonal or relational dynamics (e.g., affect regulation, intimacy, jealousy, and responses to subsequent losses). As detailed by theorists, researchers, and practitioners (e.g.,

(Ainsworth & Bell, 1970; Bowlby, 1980; Hazan & Shaver, 1994; Main & Solomon, 1990; Neimeyer, 2014), individuals are characterised as representing either secure or one of four insecure adult attachment styles:

- *Secure attachment:* Observed via Ainsworth's Strange Situation Protocol (Ainsworth, Blehar, Waters, & Wall, 1978) secure attachment is an interpersonal or relational style characterised by some distress on separation from attachment figure followed by assurance on his/her return. As adults, an interpersonal or relational style characterised by regard for self and others as safe, loving, responsive, dependable, and accepting.
- *Anxious/preoccupied attachment:* As children, suspicious of strangers and distressed on the departure of attachment figure, with little sense of reassurance and/or overt rejection on caregiver's return. As adults, desiring of close relationships yet hesitant to form deeply committed relationships for fear of abandonment and distress should relationship end and the dependent individual be left without a partner.
- *Dismissive/avoidant attachment:* As children, restricted emotional range with similar avoidance or ignoring of caregivers and others. As adults, characterised by high level of independence and avoidance of attachment and closeness, with those in relationships believing intimacy to be relatively unimportant and thus distancing oneself to avoid rejection.
- *Fearful/avoidant attachment:* As children, negative view of self and others as unlovable and untrustworthy. As adults, characterised by ambivalence towards

relationships, with a desire to feel close to others mixed with a discomfort with, and mistrust of, emotional closeness.

- *Disorganised attachment:* As children and adults, lack of a coherent coping style for interpersonal relationships, with human interactions observed as erratic.

More recent work has suggested early childhood attachment patterns may affect childhood and adult grief through one's construction of the personalised meaning of the loss (Field, Gao, & Paderna, 2005; Gillies & Neimeyer, 2006; Zech & Arnold, 2011). For example, a death may have a significant detrimental effect on an individual with a less secure attachment style, by undermining their sense of self, meaning, and world (Gillies & Neimeyer, 2006; Scheidt et al., 2012; Zech & Arnold, 2011). By contrast, individuals characterised by a more secure attachment style may be observed to use memories and contact with others to successfully frame the permanence and meaning of the loss for self and world (Field et al., 2005).

1.1.3 Stage models of grief. Before the publication of his 1970 joint paper with Bowlby describing four phases of grief, Colin Murray Parkes visited psychiatrist Elisabeth Kubler-Ross in the United States. Kubler-Ross was gathering data for what would become her landmark thanatology book, *On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy, and Their Own Families* (Kubler-Ross, 1969). Kubler-Ross's original aim was to give the dying a voice, by describing interviews she conducted with patients who were dying. She described five stages of adjustment observed in patients with terminal illnesses – denial, anger, bargaining, depression, and acceptance (Kubler-Ross, 1969).

This resonated with professionals and laypeople alike, as people appeared to take comfort in the presumed predictability of reactions to death. With her first book lauded as one of the most important humanitarian works on the care of the dying, Kubler-Ross went on to publish 23 books in some 35 languages worldwide. Readers today continue to describe their positive reactions to Kubler-Ross's insights and empathic descriptions of the psychosocial world of the dying.

However Kubler-Ross's work has also generated controversy. Despite Kubler-Ross (1969, p. xvii) stating that her book was "not meant to be a textbook on how to manage dying patients" nor "intended as a complete study of the psychology of the dying", critics cite the lack of independent confirmation of the reliability or validity of this stage model, with Kubler-Ross advancing no further evidence before her death in 2004 (Corr & Corr, 2013). With no empirical confirmation of the notion of linear progress through defined stages of grief, critics have described the model as an inadequate, simplistic, superficial, and misleading view of the complexities of grief and bereavement (Wortman & Silver, 2001).

Proponents of Kubler-Ross's work state that *On Death and Dying* was not intended to be a study of bereavement but rather a portrait of individual's psychosocial reactions to dying; that the book has been mistakenly construed as a research study; that the 'stage-theory' of grief is merely a heuristic device rather than a prognostic tool; and that many of the stages have been simplified and satirised (Corr & Corr, 2013). Proponents of Kubler-Ross's work discourage a focus on the idea of prescriptive, linear stages of grief and instead encourage focus on the importance of listening to what the dying state as their needs and wants (Corr & Corr, 2013). As such, Kubler-Ross's work serves to bridge academic, professional, and public discussions about death and dying.

1.1.4 Task models of grief. By contrast to stage-based models of grief, task-based models seek to avoid metaphors that emphasise passive ways of coping. Tasks refer to work undertaken when coping with grief (Hall, 2014). The choice of task is active in that one can choose to proceed or not proceed with a task, reflecting that coping is an active process with a positive orientation that seeks to resolve problems or adapt to challenges.

Corr (1992) proposed that individuals who are dying may be observed to attend to any of four tasks that reflect the four dimensions of life – physical (e.g., satisfy bodily needs, minimise physical distress), psychological (e.g., maximise security and autonomy), social (e.g., enhance interpersonal attachments), and spiritual tasks (e.g., address meaningfulness, connectedness, transcendence, and hope).

Worden (2008) extended this focus from tasks associated with dying, to tasks associated with grief and mourning. According to Worden, a bereaved individual is presented with four tasks: 1) Accept the reality of the loss, 2) process the pain of grief, 3) adjust to a world without the deceased, and 4) find an enduring connection with the deceased amid embarking on a new life. Worden also identified seven important psychosocial factors impacting on mourning: 1) The deceased's identity to the survivor, 2) nature of their attachment, 3) circumstances of death, 4) historical antecedents, 5) personality variables, 6) social mediators, and 7) concurrent stressors. In particular, Worden identified empirically-supported protective and risk factors for grief, thus emphasising the idiosyncratic nature of the grief process.

1.1.5 Process models of grief. With earlier conceptualisations of grief centred on severing bonds or progressing through distinct stages, grief is now considered not an

intrapersonal state, but rather an interpersonal process (Lindstrom, 2002; Stroebe et al., 2008). Newer models of grief have emphasised the importance of using both scientific empiricism and humanistic principles to promote better understanding of the grieving process (Bonanno & Kaltman, 1999; Hall, 2014; Neimeyer, 2013; Wortman & Silver, 2001).

By contrast to earlier conceptualisations involving severing of bonds, now acknowledged is the importance of continuing healthy bonds with lost loved ones whilst also attempting to reinvest in one's ongoing life (Field, 2006; Klass, Silverman, & Nickman, 1996; Silverman, Nickman, & Worden, 1992; Stroebe & Schut, 2005). The recognition that death ends a life, but not necessarily a relationship, reflects the possibility that the deceased can be both physically absent and psychologically present at the same time (Hall, 2014).

The notion that an individual could be engaged in numerous coping processes at any given time is reflected in the Dual Process Model (Stroebe & Schut, 1999; Stroebe & Schut, 2010). The Dual Process Model emphasises an individual's oscillation through two complementary sets of coping process – one loss-oriented (concerned primarily with coping with the loss) and the other restoration-oriented (concerned primarily with attending to change). Hence, a bereaved individual is effortfully and dynamically moving between these processes to actively grieve his/her loss while also adapt to a new and altered world. The Dual Process Model has been praised for acknowledgement of individual and cultural differences in bereavement (Corr & Corr, 2013).

Praised for theoretical, clinical, and research utility, the Two-Track Model of Bereavement proposes that bereavement responses occur along two multidimensional

axes – Track I emphasising affective, interpersonal, somatic, and psychiatric functioning and Track II emphasising relationships with the deceased (Malkinson, Rubin, & Witztum, 2006; Rubin, 1999). The Two-Track Model was first described in 1981 after the in-depth study of young mothers whose child had died through Sudden Infant Death Syndrome (Rubin, 1981). It was observed that more recently bereaved mothers demonstrated significantly greater disturbance on Track I functioning than non-recently bereaved mothers and non-bereaved mothers (Malkinson & Rubin, 2007). On Track II however, no significant differences were observed between recently-bereaved mothers and non-recently bereaved mothers, suggesting that mothers continued to experience an ongoing relationship with their child regardless of passage of time. These results support the theoretical notion of ongoing maternal involvement with the deceased infant and the impact of loss on personality functioning, with the impact of loss neither time-limited nor reflective of complete separation from the deceased child (Klass et al., 1996; Rubin, 1999).

Bonanno and colleagues propose an integrated model of bereavement that incorporates principles of scientific empiricism, cognitive theory, attachment theory, trauma, and social-emotional functioning (Bonanno & Kaltman, 1999; Bonanno et al., 2002). Four features are highlighted – the context of the loss, the subjective meaning attributed to the loss, the changing nature of the lost relationships, and the individual's coping and emotional regulation processes in adapting to the loss. According to Bonanno (2009), studies with both clinical and non-clinical bereaved samples challenge the automatic expectation of grief involving distress or negative emotions. Instead, grief may be painful but also an opportunity for individuals to demonstrate resilience. Indeed it is claimed that this is the most common and natural response to bereavement

with as many as 46% of bereaved people falling into this ‘resilience’ category, compared to 10% to 20% of bereaved people who demonstrate clinically significant symptomatology (Bonanno, 2004; Bonanno et al., 2002). Counter to earlier theories emphasising the importance of overt ‘grief work’, Bonanno’s research suggests that those who openly express negative emotions have greater difficulty with long-term adjustment to loss term, whereas features of hardiness, self-enhancement, positive emotion, laughter, and even repressive coping in the face of bereavement can indicate healthy coping (Bonanno, 2004; Wortman & Silver, 2001). In particular, those who experience high levels of distress have been observed to exhibit high levels of personal dependency prior to the death of a loved one (Bonanno, 2009). Although Bonanno’s work has generated controversy (e.g., Balk, 2011; Hoy, 2011), it can be viewed as further reinforcing the importance not of stages in adaptation to loss, but of the qualitatively different intrapersonal and interpersonal paths through bereavement.

1.1.6 Social constructionist models of grief. Postmodern social constructionist approaches view grief as a potential catalyst for personal change, leading to a re-framing of self and enriched functioning (Fenstermacher & Hupcey, 2013; Neimeyer et al., 2014). Building from the observation that most humans naturally seek to make sense of life events, Robert Neimeyer and colleagues conceptualise grief as involving a process of reconstructing a world of meaning when one has been challenged by loss (Holland, Currier, & Neimeyer, 2006; Neimeyer, Baldwin, & Gillies, 2006). To do so, the bereaved individual engages in a meaning-making process to incorporate the loss into his/her new worldview. This incorporates two particular concepts; making sense of the loss (e.g., circumstances of death, or religious or spiritual beliefs), and finding

meaning or benefits from the loss (e.g., personal growth, strengthened relationships, changed perspectives) (Currier, Holland, & Neimeyer, 2008). The importance of attachment is also acknowledged, with attachment style and capacity for continuing bonds said to play a key role in meaning reconstruction (Neimeyer et al., 2006).

Meaning-making techniques used to facilitate grief therapy include storytelling, narratives, journaling, loss characterisation, metaphorical and cognitive reframing, spiritual devotions, mindfulness, body work, and artistic expression (Neimeyer, 2012). Research shows that failure to find meaning following loss (and in particular to make sense of the loss itself), as well as a perceived lack of closeness with the deceased, are factors associated with higher levels of complicated grief, including for women who lose their child (Black, 2014; Bogensperger & Lueger-Schuster, 2014; Holland et al., 2006; Keesee, Currier, & Neimeyer, 2008; Lichtenthal, Currier, Neimeyer, & Keesee, 2010; Neimeyer, 2006; Rozalski, Holland, & Neimeyer, 2016).

In summary, the scientific study of grief is a relatively young enterprise. Notable developments in the conceptualisation of grief have been observed across the last century. Grief is no longer considered solely in terms of the severing of emotional bonds (psychoanalytic models), progression through distinct phases (stage-based models), or an automatically negative or meaningless experience (process and social constructionist models) after the death of a loved one. Instead, grief is respected as a dynamic, active, individual process highlighting features of culture, meaning, and attachment relationships (Capitulo, 2005; Field et al., 2005; Neimeyer, 2014; Stroebe & Schut, 2005).

1.2 Grief as a Clinical Disorder

Acknowledging that grief is a universal and natural human phenomenon would not preclude the notion that for some, the bereavement experience can be difficult to the point of functional impairment. Grief first appeared in the 3rd edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM),* with clinicians instructed to classify 'uncomplicated bereavement' under code V62.82 (American Psychiatric Association [APA], 1980, 1987). Although acknowledging 'normal' grief in this fashion, *DSM-III* made no reference to 'abnormal' grief reactions beyond acknowledging bereavement as a potential etiological contributor to a number of psychiatric conditions, such as Adjustment Disorder, Posttraumatic Stress Disorder (PTSD), Depersonalisation Disorder, and brief reactive psychosis (Marwit, 1991).

1.2.1 The bereavement exclusion criteria. Grief was further referenced in *DSM-III* and *DSM-IV* in the form of the bereavement exclusion criterion which attempted to aid delineation between grief and clinical depression (American Psychiatric Association, 1980, 1987, 1994, 2000). According to this criterion, a diagnosis of Major Depressive Disorder (MDD) was not to be made if the individual's mood symptoms were regarded as due to bereavement (APA, 1987). The Manual stated that as a depressive syndrome was a normal reaction to bereavement, symptoms of mood, sleep, appetite and weight disturbance could be expected without this requiring a diagnosis of clinical depression (APA, 1987).

To more carefully delineate grief from MDD, *DSM-IV-TR* (APA, 2000) offered the following clinical guidelines: That a bereaved individual would typically regard depressed mood as a natural reaction rather than a defining feature and thus seek

treatment not for mood per se but for relief of associated symptoms such as insomnia; that a diagnosis of MDD would not be offered unless the symptoms were still present at least 2 months after the loss; and that MDD should be considered more likely in the presence of recurrence and certain symptoms not characteristic of a normal grief reaction, such as worthlessness, psychomotor retardation, suicidal ideation, and hallucinations about the deceased (Wakefield, 2013b; Zisook, Shear, & Kendler, 2007). Despite these guidelines, clinicians continue to report finding it challenging to discern between clinical depression and grief (Friedman, 2012).

The bereavement exclusion criterion in *DSM-IV-TR* effectively stated that low mood and distress could be so commonly expected after bereavement that a clinician should refrain from diagnosing the disorder of depression in the first 2 months of bereavement (APA, 1994). The more recently released *DSM-5* has removed the bereavement exclusion criterion, ostensibly to improve diagnostic specificity and thus facilitate patient access to appropriate treatment (APA, 2013).

The removal of the *DSM* bereavement exclusion criterion has been cited as "the most controversial diagnostic proposal since depathologization of homosexuality" (Wakefield, 2013b, p. 148). Proponents state that the removal of the bereavement exclusion criterion does not compel clinicians to diagnose depression in grieving clients, pointing to the International Classification of Disorders nosology never having had a bereavement exclusion criterion (Kendler, 2010; Zisook et al., 2012). Proponents cite empirical work showing systematic discernible differences between bereavement-related depression and non-bereavement related depression, thus arguing the *DSM-IV-TR* bereavement exclusion criterion is not serving its purpose and is not logically

defensible (First, 2011; Iglewicz, Seay, Zetumer, & Zisook, 2013; Zisook & Kendler, 2007).

Detractors however cite the risk of pathologising grief, raising the potential for unnecessary pharmacological interventions for an otherwise natural process (First, 2011; Iglewicz et al., 2013; Searight, 2014). They further cite the potential for mistaken false-positive MDD diagnoses, with individuals bereaved only two weeks prior being potentially diagnosed with and treated for depression despite their symptoms being natural, expected, and momentary (Wakefield, 2013a). Detractors claim there is a lack of empirical work supporting the removal of the bereavement exclusion criteria from *DSM-5* (Wakefield & First, 2012; Wakefield & Schmitz, 2013), however it is noted that this is in contrast to proponents who strongly hold to this scientific rationale being sound (Prigerson & Maciejewski, 2005; Zisook et al., 2012).

1.2.2 Prolonged or complicated grief. In addition to removal of the bereavement exclusion criteria, a further *DSM-5* point of contention was the inclusion of a diagnosis of disordered grief. Prolonged or complicated grief refers to grief that deviates from the norm in duration and symptom intensity (Howarth, 2011). In theorising a task model of grief, Worden (2008) portrayed disordered grief on a chronicity continuum. This continuum included the intensification of grief to a degree such that the person feels overwhelmed, resorts to maladaptive behaviour, or remains fixed in a state of grief without forward progress. Portraying grief as a continuum emphasises extremes of effect, intensity, and time scale reflected in pathology, rather than the presence of any one particular defining symptom (Worden, 2008).

Others however have described this disturbance in the natural grief process as a syndrome with defining symptoms (Prigerson et al., 2009; Shear, 2012; Shear et al., 2011). Alternately termed prolonged or complicated grief, this syndrome encompasses prolonged, severe, and disabling grief responses not seen to have abated 6 or 12 months post-death (Bryant, 2014). Core features include persistent yearning/longing for the deceased, intense sorrow and emotional pain, and/or preoccupation with the deceased or circumstances of death beyond cultural expectations (Boelen & Prigerson, 2012). Other symptoms include difficulty accepting the death, intense anger, emptiness, diminished sense of self, difficulty planning for the future, and marked impairment in social and other engagements since the death (Boelen & Prigerson, 2012). In total, these symptoms point to difficulty accommodating a new life without the deceased.

Epidemiological research suggests that whilst most individuals accommodate grief naturally, between 3% and 26% of individuals experience prolonged or complicated grief (Bonanno & Kaltman, 2001; Kersting, Wagner, Brähler, & Glaesmer, 2011; Middleton, Burnett, Raphael, & Martinek, 1996; Rajkumar, Mohan, & Tharyan, 2015; Sung et al., 2011). This wide range in prevalence is indicative of the field's emergent nature, with differences in symptomatic definitions of complicated grief, post-death time points, and samples (e.g., hospitalised participants, participants with psychiatric comorbidities, cross-cultural samples, participants bereaved by different modes such as homicide, illness, accident, disaster, and terrorism). Considering research with more representative population samples, it appears that 3% to 10% of individuals experience symptoms consistent with complicated or prolonged grief (Bryant, 2014; Currier, Holland, & Neimeyer, 2012; Forstmeier & Maercker, 2007;

Fujisawa et al., 2010; Kersting et al., 2011; Newson, Boelen, Hek, Hofman, & Tiemeier, 2011; Prigerson, Maciejewski, et al., 1995).

A body of research has assessed the validity of a prolonged or complicated grief syndrome, focusing on the distinction between this and other disorders. Cross-cultural factor analytic research with adults and children supports this pattern of symptoms being a specific syndrome, distinct from normal grief and other psychiatric disorders such as mood and anxiety disorders and PTSD (Bryant, 2014; Prigerson, Frank, et al., 1995; Shear, 2012).

Neurocognitive and immunological research has attempted to delineate prolonged/complicated grief from non-complicated grief and other disorders. O'Connor (2012) found that compared with non-complicated grief, complicated grief is associated with activation of the nucleus accumbens, suggesting reminders of the deceased may activate the neural reward system and interfere with adaptation. A study comparing women who delivered a healthy child with women who experienced a loss of an unborn child found that acute grief was closely related to the activation of the physical pain network (e.g., cingulate gyrus, inferior frontal gyrus, thalamus, and brainstem) (Kersting, Ohrmann, et al., 2009).

Studies have shown the experience of prolonged/complicated grief is associated with, and predictive of, a range of impairments including psychological (depression, suicidality, substance abuse), behavioural (poor sleep, cigarette smoking, substance abuse, sick leave, health care usage), and physical dysfunction (elevated cancer rates, immune and cardiovascular disorders, cardiac events, and abnormal blood pressure) (Bryant, 2014; Lannen, Wolfe, Prigerson, Onelov, & Kreicbergs, 2008; Prigerson & Maciejewski, 2005; Schultze-Florey et al., 2012).

Research has also investigated treatment implications of a dysfunctional grief syndrome, showing that whilst antidepressant medication can be efficacious in alleviating bereavement-related aspects of depression, medication has not been efficacious in alleviating complicated grief symptoms such as yearning (Reynolds et al., 1999). By contrast, randomised controlled trials have demonstrated that cognitive behaviour therapy, interpersonal therapy, and a specific intervention known as Complicated Grief Therapy have aided symptoms of prolonged/complicated grief for children and adults (Boelen, de Keijser, van den Hout, & van den Bout, 2007; Mancini, Griffin, & Bonanno, 2012; Rosner, Pfoh, Kotoučová, & Hagl, 2014; Shear, Frank, Houck, & Reynolds, 2005; Shear et al., 2014).

1.2.3 Persistent Complex Bereavement Disorder. Despite compelling research pointing to prolonged/complicated grief being a distinct syndrome associated with marked impairment, this was relegated in *DSM-5* to an "Emerging Measures and Models" appendix (Boelen & Prigerson, 2012; Bryant, 2014). Labelled Persistent Complex Bereavement Disorder (PCBD) the duration requirement of 12 months before diagnosis allays fears of false-positive diagnoses that pathologise normal grief. Detailed in Appendix A, *DSM-5* diagnostic criteria for PCBD require at least one of four core "separation distress" symptoms (yearning/longing, intense sorrow, preoccupation with the deceased, preoccupation with the circumstances of death). In addition, at least 6 out of 12 additional symptoms are required for diagnosis (difficulty accepting, shocked/stunned/numb, difficulty with positive reminiscing, bitterness/anger, self-blame, avoidance of reminders, difficulty trusting or envying the non-bereaved,

wanting to join the deceased, loneliness/detachment, meaninglessness/emptiness, role confusion, and difficulty pursuing interests or plans).

By contrast to the *DSM* with its intended audience of psychologists and psychiatrists, the *International Classification of Diseases (ICD)* is produced by the United Nations' global health agency, the World Health Organization (WHO). With a wider intended audience, the *ICD* is considered the global health information standard for defining and reporting physical and mental disorders and diseases (Bryant, 2014; WHO, 2014). It has been acknowledged that grief is of particular concern to the mission of the WHO, because many countries who rely on *ICD* are frequently affected by disaster, war, conflict, disease, and mortality (Bryant, 2014).

The current tenth edition of *ICD* was endorsed in 1990, and whilst a new eleventh edition was planned for release in 2015, this has been delayed until 2018 (WHO, 2014). With one goal being to help WHO member nations reduce the burden of disease of mental disorders, it has been proposed to include a diagnosis of Prolonged Grief Disorder (PGD) in *ICD-11* (Prigerson et al., 2009; WHO, 2014). As per Appendix B, proposed *ICD-11* diagnostic criteria for PGD centre on continued yearning at least 6 months after the loss, along with 5 or more of 9 symptoms (i.e., difficulty accepting the loss, shocked/stunned/numb, bitterness/anger, avoidance of reminders, difficulty trusting others, meaningless/ emptiness, role confusion, difficulty pursuing interests and plans, and numbness).

Whilst is remains unclear whether *ICD-11* will include disordered grief, it is noted that the APA has moved away from notating *DSM* editions with roman numerals, citing the intention to make future revision processes faster and more responsive to research breakthroughs (APA, 2014). Hence it is likely that the next iterations of the

DSM-5 (known as *DSM-5.1*, *5.2*, etc.) will review the validity, reliability, sensitivity, specificity, and diagnostic efficiency of PCBD as further research emerges (Boelen & Prigerson, 2012; Wakefield, 2013b).

1.3 Grief Trajectories

With debate continuing over the inclusion of a diagnosis of disordered grief in formal classification systems, more generally identifying and distinguishing different patterns of grief (both functional and dysfunctional) is of clinical relevance in determining those bereaved who are likely to benefit from clinical interventions (Ott, Lueger, Kelber, & Prigerson, 2007). It is equally relevant to epidemiological researchers working at a population-level, whereby the aim is to gauge the breadth and depth of grief reactions (Kersting et al., 2011).

In his clinically-oriented paradigm, Worden (2008) described 5 responses to bereavement: *Normal/uncomplicated grief; chronic grief* (responses continue for an excessive period of time without reaching a satisfactory conclusion); *delayed grief* (reactions occur at some period later in time); *exaggerated grief* (individual is overwhelmed and/or engages maladaptive behaviour, including psychiatric disorders); and *masked grief* (individual experiences symptoms and behaviours resulting in difficulty, without recognising relationship of these to the loss).

Rando (1993) suggested that individuals can be characterised into one of 7 bereavement syndromes: *Absent*, *delayed*, and *inhibited mourning* (all related to problematic experience of grief), *distorted mourning* (characterised by anger or guilt), *conflicted* and *unanticipated mourning* (skewed perspectives on grief), and *chronic mourning* (prolonged grief). Rando's work identified risk factors for mourning,

including sudden, unanticipated, and traumatic death, death from lengthy illness, loss of a child, a sense of preventability of the death, the bereaved individual's prior or concurrent mental health, perceived lack of social support, and premorbid deceased-bereaved relationships marked by anger, dependence, or ambivalence (Rando, 1993).

George Bonanno's work has also highlighted different patterns in grief responses, portraying these as trajectories (Bonanno, 2009). Bonanno and colleagues have studied mental health and wellbeing indicators in individuals prior to and after the death of their spouses (Bonanno, 2004; Bonanno et al., 2002; Galatzer-Levy & Bonanno, 2012; Lotterman, Bonanno, & Galatzer-Levy, 2014). Results from these longitudinal studies illuminate prototypical bereavement responses; in particular, the three predominant grief trajectories displayed in Figure 1.

By way of contrast to the field's characteristic focus on dysfunctional or symptomatic responses to bereavement, the most commonly observed response in Bonanno's studies has been *resilience* (Bonanno et al., 2002; Galatzer-Levy & Bonanno, 2012). With approximately half of Bonanno's samples labelled resilient, this grief trajectory is characterised by "the ability of adults in otherwise normal circumstances who are exposed to an isolated and potentially highly disruptive event such as the death of a close relation or a violent or life-threatening situation to maintain relatively stable, healthy levels of psychological and physical functioning … as well as the capacity for generative experiences and positive emotions (Bonanno, 2004, p. 21). Inherent in this is the acknowledgement that although bereavement can result in distress, disruption to self-regulatory equilibrium, and minor depression, many individuals have natural resources that permit continued post-bereavement function (Galatzer-Levy & Bonanno, 2012).

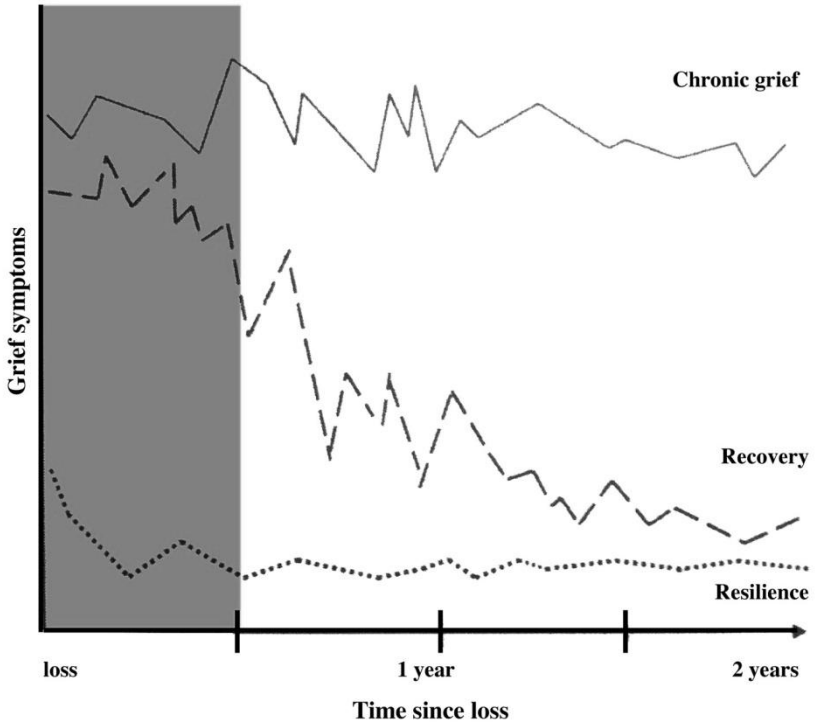

Figure 1. Three commonly observed grief trajectories. Reprinted from *"The other side of sadness: What the new science of bereavement tells us about life after loss"* (p. 7) by G. A. Bonanno, 2009, New York, NY: Basic Books. Copyright 2009 by George A. Bonanno.

Compared with approximately 50% of participants in Bonanno's studies demonstrating resilience, 10% of participants have been observed to engage in a more gradual *recovery* trajectory (Bonanno et al., 2002; Bonanno, Wortman, & Nesse, 2004). Seen in Figure 1, this pattern involves greater acute suffering (potentially in the form of threshold psychopathology) in the immediate post-death aftermath before slowly and steadily functioning returns to pre-event levels. Other theorists and researchers argue that this description of *recovery* is a semantic difference, preferring the terms *normal, common,* or *uncomplicated grief* for this trajectory which they claim is more common than Bonanno describes (Ott et al., 2007). Be it *resilience* or the ongoing *recovery*

observed by Bonanno, these findings support the earlier cited prevalence studies which implied the most predominant bereavement response is individuals wayfinding through the acute experience of grief using natural resources and supports (Shear et al., 2011).

Bonanno is in agreement with Worden (2008) and Rando (1993) with another commonly observed grief trajectory labelled *chronic* grief. Here, the pain of grief is overwhelming and the suffering prolonged, possibly for years. As portrayed in Figure 1, this appears reminiscent of a syndrome of prolonged or complicated grief (Shear, 2012). As compared to other academicians, Bonanno and colleagues have found no support for a trajectory of *delayed* grief (Bonanno & Field, 2001).

Such research has challenged the automatic assumption that grief is an experience largely associated with negative outcomes (Bonanno, 2001). A self-identified empiricist, Bonanno claimed his rigorous longitudinal and prospective research demonstrates the most common grief reaction is resilience, rather than distress, unhappiness, or disturbance. His work is not without controversy however, with Bonanno's work said to be too heavily focused on clinical depression as a pseudo-measure of resilience and as an outcome measure of grief (O'Rourke, 2010). Not only does this potentially under-appreciate the role of other potentially problematic grief outcomes, it is questionable whether the observed low depression scores 6 or 18 months post-bereavement automatically equate to 'resilience', as resilience is a multi-faceted concept and not just the mere absence of depression (Southwick, Litz, Charney, & Friedman, 2011). Additionally although Bonanno states his work is driven by strong empirical principles, it has been argued his research does not adequately encompass individuals' efforts to cope with grief, is of limited clinical utility, and essentially portrays resilience reactions in a group of people without pre-existing mental illness or

other notable life stressors (Archer, 2001; Stroebe, 2001). Further research with broad samples is thus encouraged to identify grief trajectories and mediating factors such as mental illness.

1.3.1 Factors affecting grief trajectories. Research has identified several categories of risk factors that may place individuals at increased risk of chronic, delayed, or complicated grief (Currier, Holland, & Neimeyer, 2006; Kersting & Nagl, 2015; Kersting et al., 2011; Neimeyer et al., 2006; Prigerson et al., 2009; Rozalski et al., 2016; Shear, 2012; Worden, 2008). These factors include:

- Death circumstances (e.g., multiple concurrent losses, violent or traumatic loss);
- mourner's grief experience history (e.g., extensive history of losses);
- mourner's wellbeing and functioning (e.g., mental illness, personality traits, shame, guilt);
- social factors surrounding the loss (e.g., social context of the death, availability of perceived social support; lack of religious or spiritual connections);
- characteristics of the deceased (e.g., death of a child);
- and the mourner's relationship with the deceased (e.g., ambivalence; emotional dependency).

An intriguing area of research concerns the role of attachment as a risk factor for complicated grief. Research suggests that mourners' insecure attachment style, and

anxious attachment in particular, is predictive of complicated grief (Bryant, 2014; Field & Filanosky, 2009; Scheidt et al., 2012; Worden, 2008). The potential mechanisms of this remain unclear, although it is purported that individuals with an insecure attachment style may be more likely to perceive loss as traumatic and appraise loss as beyond one's coping capacities (Field & Filanosky, 2009). However individual personality factors are also seen to play a role, with individuals scoring higher on measures of neuroticism in research shown to be at higher risk of complicated grief (Kersting & Wagner, 2012). This may potentially represent difficulties regulating the waves of intense emotion characterised by grief (Gupta & Bonanno, 2011; Hooghe, Neimeyer, & Rober, 2012), however again precise mechanisms remain unclear.

Hence the present research aims to explore grief trajectories in the context of two identified risk factors – mental illness and personality functioning. The present research aims to investigate these in relation to a third identified risk factor – death of a child – and in particular, death of a child during pregnancy.

1.4 Perinatal Loss

Childbearing is a major life transition for many adults, the expected result being the birth of a healthy child. Deriving from the Greek *peri* (around/about) and Latin *natus* (born/birth), 'perinatal' refers to the period from conception to birth, usually expressed as weeks. 'Neonatal' refers to the first 28 days, or month, of an individual's life (WHO, 2006).

This research uses the term 'perinatal loss' to encompass a range of deaths that occur during pregnancy, including miscarriage, stillbirth, ectopic pregnancy, and termination. Note that whilst neonates die of other causes in the first month of life such

as Sudden Infant Death Syndrome, this research focuses on death during the perinatal period whereby the mother and child have no living contact (DeBackere, Hill, & Kavanaugh, 2008). A comprehensive view of childbearing loss would also acknowledge forms of symbolic and non-death losses such as infertility or sterility, relinquishing via adoption, losing the dream of a 'healthy' child through impairment, prematurity, or illness, and legal termination of parental rights by social workers (DeSpelder & Strickland, 2011). However for the purposes of the current investigation, the focus is on loss through death during the perinatal period.

The forms of perinatal loss under current investigation are summarised in Table 1 as they pertain in Australian and international contexts. As seen in Table 1, particularly with miscarriage and stillbirth, definitions of perinatal loss are inconsistent. This lack of clarity has in turn hindered recognition of perinatal loss as a public health concern (Lawn et al., 2009). In addition to definitional inconsistency, misclassification of perinatal deaths has also been observed (Cousens et al., 2011). For example, live-born infants who die in the first few minutes of life may be misclassified as stillbirths for clinical, sociocultural, or documentation reasons (Lawn et al., 2009). Some countries do not report, or potentially underreport, perinatal cause of death data to the United Nations (Froen et al., 2009; Lawn et al., 2009). As expressed by Mullan and Horton (2011), "Tracking numbers and causes of stillbirth is hampered by variations in the definition of stillbirth and the baffling array of classification systems in existence … there are at least 35 published classification systems for the causes of stillbirth, and it is almost impossible to compare them" (p. 1291).

Table 1

Australian and International Definitions of Perinatal Deaths

	Australia	International
Miscarriage (Spontaneous abortion)	Intrauterine death of an embryo or fetus occurring prior to 20th gestational week and/or weighing less than 400 grams [a]	Intrauterine death of an embryo or fetus occurring prior to 20th gestational week (or 24th week in the United Kingdom; 28th week in some states of United States and internationally) and/or weighing less than 500 grams (*ICD* code O03) [a]
Stillbirth	Intrauterine death of a fetus occurring at or after the 20th gestational week and/or weighing at least 400 grams, resulting in delivery of a deceased baby [a]	Intrauterine death of a fetus occurring at or after the 20th (some states in the United States), 24th (United Kingdom), or 28th (other US states and internationally) gestational week or weighing at least 500 grams (US/UK) or 1000 grams (internationally), resulting in delivery of a deceased baby (*ICD* codes P95, Z37) [a b c]
Ectopic pregnancy	A non-viable pregnancy, and potentially life-threatening maternal condition, in which a fertilized ovum grows outside of the uterus, usually in one of the fallopian tubes (*ICD* codes O00) [b]	A non-viable pregnancy, and potentially life-threatening maternal condition, in which a fertilized ovum grows outside of the uterus, usually in one of the fallopian tubes (*ICD* codes O00) [b]
Therapeutic or medical termination	Intentional termination of pregnancy by mechanical or pharmaceutical means, as elected for medical conditions that pose maternal or child health risk or medical conditions of the fetus that render the fetus incompatible with life (*ICD* code Z33.2) [b]	Intentional termination of pregnancy by mechanical or pharmaceutical means, as elected for medical conditions that pose maternal or child health risk or medical conditions of the fetus that render the fetus incompatible with life (*ICD* code Z33.2) [b]
Elective termination	Intentional termination of pregnancy by mechanical or pharmaceutical means, as elected for non-medical reasons (*ICD* code Z33.2) [b]	Intentional termination of pregnancy by mechanical or pharmaceutical means, as elected for non-medical reasons (*ICD* code Z33.2) [b]

[a] World Health Organization (1992)
[b] World Health Organization (2006)
[c] Cousens et al. (2011)

All of these factors likely contribute to perinatal deaths being misrecorded, underreported, and thus overlooked as a public health concern (Alston & Samuels, 2014; Cousens et al., 2011; Flenady & Ellwood, 2012; Froen et al., 2009). In turn this may contribute to a sense of disenfranchised grief for women and their loved ones after they experience perinatal loss (Cacciatore, 2013; Douglas, 2014; Flenady et al., 2014). Disenfranchised grief refers to "grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported" (Doka, 1989, p. 4). Perinatal loss has been categorised as a form of disenfranchised grief, whereby parents and family are denied a socially recognised right to grieve (Alston & Samuels, 2014; Rosenzweig, 2010). For example, a woman who experiences a miscarriage at 10 weeks gestation may not have revealed her pregnancy to others, hence her grief remains silent. Those who reveal pregnancy have also reported disenfranchisement, with early pregnancy loss not being considered as valid as late pregnancy loss or stillbirth (Rosenzweig, 2010).

1.4.1 Miscarriage. Miscarriage refers to the unintended, spontaneous end of a pregnancy resulting in fetal death (Nguyen & Wilcox, 2005). Perinatal loss is characterised as early (loss occurring during the first 12 gestational weeks), middle (13 to 20 weeks), or late (later than 20 weeks gestation) (Alston & Samuels, 2014). Epidemiologists report that 95 to 98% of miscarriages are early losses, with the remaining 2 to 5% middle losses (Balk, 2013; Edlow, Srinivas, & Elovitz, 2007; Michels & Tiu, 2007; Oliver-Williams, Heydon, Smith, & Wood, 2013). It has been argued that in particular, early pregnancy loss within the first 12 weeks is one form of bereavement that has been overlooked on the whole in the literature (Balk, 2013).

As seen in Table 1, international classification of miscarriage varies. UK policy defines miscarriage as loss before the 24th gestational week and US vary in definition from the 20th to the 28th week (van den Akker, 2011). Being an Australian sample, the current study considers miscarriage to be unintended, spontaneous pregnancy loss before 20 weeks gestation (Balk, 2013).

Population rates of miscarriage differ according to whether miscarriage occurs with or without clinical confirmation of pregnancy. Broadly speaking, miscarriage is cited to occur in 12 to 33% of all pregnancies (Ammon Avalos, Galindo, & Li, 2012; Balk, 2013; Blohm, Fridén, & Milsom, 2008; Maconochie, Doyle, Prior, & Simmons, 2007; Pallikadavath & Stones, 2005; Scotchie & Fritz, 2006; Simmons, Singh, Maconochie, Doyle, & Green, 2006; Wang et al., 2003; Wilcox et al., 1988). However this broad range represents women estimated to experience miscarriage prior to self and/or clinical recognition of pregnancy, as well as miscarriage after clinical recognition of pregnancy. Medical studies indicate a miscarriage rate of 12 to 24% after clinical recognition of pregnancy, with rates increasing due to technological advances resulting in earlier detection of pregnancy (Oliver-Williams et al., 2013; Regan, Braude, & Trembath, 1989; Tong et al., 2008). By contrast, the higher incidence rates of 25 to 33% of all pregnancies are said to represent self-reported experiences of miscarriage, including those not recognised clinically or brought to clinical attention by the woman.

It has been estimated that 50,000 Australian women experience miscarriage each year (Frost & Condon, 1996). As part of the Australian Longitudinal Study on Women's Health In Australia, retrospective reproductive histories were obtained from 5806 women aged 31 to 36 years (Hure et al., 2012). An overall rate of 25 miscarriages per 100 live births was observed, although large variations in rates were observed as a

function of individual characteristics. Increased risk of miscarriage was associated with increased maternal age at first birth, lower number of prior live births, smoking, lower education levels, reduced physical activity, IVF, and infertility (Hure et al., 2012). Further, the experience of miscarriage has been correlated with the experience of another form of perinatal loss in stillbirth.

Such findings suggest that the road to parenthood may be lined with grief for some women, who appear at greater risk for multiple losses stemming from infertility, miscarriage, and stillbirth. It appears that a woman who miscarriages is at significantly increased risk for recurrent loss in her subsequent pregnancy/pregnancies, however the interaction between parity, infertility, and prior loss appears complex and as yet not well understood (Bhattacharya, Townend, & Bhattacharya, 2010; Edlow et al., 2007; Maconochie et al., 2007). It remains that approximately 10% of all women who miscarry are experiencing recurrent (three or more consecutive) miscarriages (Maconochie et al., 2007). As reviewed earlier, a history of multiple losses and the loss of children are both considered factors that may place individuals at increased risk of chronic, delayed, or complicated grief (Kersting & Nagl, 2015; Kersting et al., 2011; Neimeyer et al., 2006; Shear, 2012).

1.4.2 Stillbirth. As seen in Table 1, in Australia a stillbirth is defined as fetal death where the fetus weighs at least 400 grams at delivery and/or whose gestational age is a least 20 weeks. The stillbirth gestational age worldwide varies from 20 to 28 weeks, and birth weight from 400 to 1000 grams, with the cut-off generally earlier in gestation and lower in weight in higher-income countries based on standards of viability (Alston & Samuels, 2014; Lawn et al., 2009; Nguyen & Wilcox, 2005).

Hure et al. (2012) reported a stillbirth rate of 11 deaths per 1000 live births (as compared to 25 miscarriages per 100 live births) when analysing data from the Longitudinal Study on Women's Health in Australia. This rate was based on self-reported stillbirth experiences, whereas Cousens et al. (2011) used government registration data to calculate a much lower rate of 2.9 stillbirths per 1000 live Australian births. Froen et al. (2009), who found that whilst the Australian Bureau of Statistics (ABS) reported a stillbirth rate in 2006 of 5.2 per 1000 live births, the other official Australian agency (National Perinatal Statistics Unit; NPSU) reported the 2006 rate as 7.4 stillbirths per 1000 live births. This discrepancy represents differing classification systems, with the ABS placing precedence on birth weight over gestational age and the NPSU using both birth weight and gestation. Thus, reporting practices influence variations in reported stillbirth rates, making it difficult to ascertain the extent of the stillbirth experience for women and families (Froen et al., 2009).

Aside from the rate per 1000 live births, it has been estimated that eight stillbirths occur every day in Australia and more than 8,000 worldwide (McSpedden, 2011; Scott, 2011). It is estimated that 98% of the world's stillbirth deaths occur in low- and middle-income countries (Lawn et al., 2009). Major causes of stillbirth in developing countries include birth complications, maternal pregnancy infections, maternal illnesses such as hypertension and diabetes, fetal growth restriction, placental dysfunction and congenital abnormalities (Flenady et al., 2016; Lawn et al., 2009; Mullan & Horton, 2011). Disparity in education, nutrition, and antenatal care has also been linked to increased risk of stillbirth, with women living in disadvantage in India, Pakistan, Nigeria, and Bangladesh shown to have amongst the highest global stillbirth

rates (WHO, 2006). Such risk has been shown to persist even after migration to higher-income countries such as Australia (Flenady et al., 2011).

By contrast, some stillbirths in higher-income countries have been attributed to risk factors such as maternal smoking, obesity, advanced maternal age, and primiparity, whilst other causes remain unknown (Flenady et al., 2011). In Australia and other high-income countries, stillbirth rates have shown little or no improvement over the past few decades and recent research suggests rates in industrialised countries may be increasing (Flenady et al., 2011; Joseph et al., 2013).

1.4.3 Ectopic pregnancy. As compared to inconsistencies in the international classification of miscarriage and stillbirth, the medical experience of ectopic pregnancy is more consistently defined. As detailed in Table 1, an ectopic pregnancy refers to a non-viable pregnancy in which the fertilised ovum has grown outside the uterus, usually in the fallopian tubes (WHO, 2006). Ectopic pregnancy is an acute condition that leads to definitive loss of the fetus and possible threat to the woman's own life (Trabert, Holt, Yu, Van Den Eeden, & Scholes, 2011).

From the 1970s to 2000s, there was a significant increase in ectopic pregnancy rates in many industrialised countries. In Australia, incidence per 1000 live births was reported as 4.9 in 1971, rising to 16.2 in 1997/1998 (Boufous, Quartararo, Mohsin, & Parker, 2001). This trend appears to mirror worldwide trends, with similar fourfold increases observed in United States incidence rates, and threefold increases in the United Kingdom and New Zealand (Boufous et al., 2001; Trabert et al., 2011). However research is typically conducted in inpatient surgical settings, thus excluding women who are increasingly managed either non-surgically or as outpatients (Farquhar,

2005). Data from population-based epidemiological studies suggests that increased rates are stabilising, with approximately 2% of all reported pregnancies ending in ectopic pregnancy (Farquhar, 2005; Stulberg, Cain, Dahlquist, & Lauderdale, 2013; Trabert et al., 2011).

Researchers have suggested this trend of sharp incidence increases before then possible stabilisation parallels developments in the use of Assisted Reproductive Technologies (ARTs). Anecdotally it is reported that the first human ART attempt resulted in an ectopic pregnancy, and since then research has linked ARTs with increased risk of ectopic pregnancy (Santos-Ribeiro, Tournaye, & Polyzos, 2016). The mechanisms of this remain unclear, with suggestions of relationships between use of ARTs and known infertility risk factors such as tubal disease from sexually transmitted infections (STIs), endometrial damage or scarring, and advanced maternal age (Boufous et al., 2001; Riaz, Williams, Craig, & Myers, 2015). It has been suggested that the possible stabilising of ectopic pregnancy rates may be linked to ART improvements, decreased incidence of STIs and thus related tubal disease, and reduced use of intrauterine devices (Santos-Ribeiro et al., 2016).

A significant risk factor for this form of loss is prior experience of ectopic pregnancy, with research confirming a tenfold risk of recurrent ectopic loss compared to women with no such history (Panelli, Phillips, & Brady, 2015). What is of note in this research body (as well as that of miscarriage and stillbirth) is that infertility, previous pregnancy losses, and ectopic pregnancy appear related. Again it would appear that women who are already coping with perinatal loss seem at greater risk of future perinatal losses, with these multiple losses possibly acting as a risk factor for complicated grief (Egerup et al., 2016).

1.4.4 Terminations. Known colloquially as abortion, the intentional cessation of pregnancy through mechanical or pharmaceutical means remains the focus of ethical, legal, and clinical debate (Lafarge, Mitchell, & Fox, 2013). Research typically divides terminations into two categories, as seen in Table 1; therapeutic or medical terminations and elective terminations. Although the two share similar clinical processes, the decision-making process is said to differ. Therapeutic or medical terminations are effected primarily due to medical conditions that pose maternal or child health risk or medical conditions of the fetus that render the fetus incompatible with life, whereas elective terminations typically involve non-medical reasons such as social or psychological factors (WHO, 2006).

Terminations are said to be one of the most common gynaecological procedures performed, yet it is difficult to obtain accurate incidence rates due to the complex moral and sociolegal issues involved (de Costa, Douglas, Hamblin, Ramsay, & Shircore, 2015; Klemetti, Gissler, Niinimäki, & Hemminki, 2012). Terminations are a criminal act in most Australian states and territories, and can be performed lawfully in others only if strict criteria are met regarding protection of maternal health and life. In recent decades, screening and diagnosis of fetal abnormalities in the first 20 weeks of pregnancy has been funded by the federal government's Medicare program however this stops short of the clinical implication of then considering medical terminations (de Costa et al., 2015). As such, terminations are regarded as common but not acknowledged as part of mainstream gynaecological care, with most performed in the private healthcare sector or via so-called 'underground' services.

Hence with no national data set in existence, epidemiological estimates suggest that over 80,000 Australian women undergo a termination each year, equating to

approximately 1 in 4 pregnancies (de Costa et al., 2015). In 2005, it was estimated that 19.7 terminations were performed per 1,000 Australian women aged 15 to 44 years, being highest in the 20-24 year age group (32.7 per 1,000 women) and lowest in the 40-44 year age group (6.7 per 1,000 women) (Chan & Sage, 2005; Hargreaves, Grayson, & Sullivan, 2005).

This appears to mirror international estimates for developed countries, with North American termination rates estimated at 21 per 1,000 women aged 15-44 years; 18 per 1,000 women in southern Europe, and 17 per 1,000 women in northern Europe (Sedgh, Henshaw, Singh, Ahman, & Shah, 2007). Sedgh et al. (2007) also estimated rates in Africa, Latin America, and Asia to range from 22 to 39 terminations per 1,000 women aged 15-44 years.

Worldwide estimates suggest around 22 million legal terminations and 20 million illegal terminations are performed each year (Sedgh et al., 2007). Illegal and unsafe terminations performed by unskilled individuals and/or in unsuitable environments remain a significant concern in developing countries in particular, contributing to high maternal mortality rates (Grimes et al., 2006).

Despite the apparently common nature of terminations, the experience often remains hidden in shadows. It is only recently that terminations, and in particular medical terminations, have been acknowledged in the research and clinical literature as being a perinatal grief experience (McCoyd & Walter, 2015; Thachuk, 2007). It had previously been considered that terminations being elective (as compared to other forms of perinatal loss that do not involve choice) necessitated excluding terminations from perinatal grief research. This has recently shifted however with acknowledgement that even if a woman elects medically or non-medically to terminate a pregnancy, she may

also grieve (Thachuk, 2007). Research has demonstrated no discernible differences in grief reactions observed in women who experience miscarriage compared to women who experience terminations, with the latter observed to be capable of experiencing intense grief (Curley, 2012; Keefe-Cooperman, 2004; Kersting, Dorsch, et al., 2009; Maguire et al., 2015). Whilst some women who experience terminations respond with relief or neutrality, others continue to feel decades-long sadness and distress, particularly if they feel their grief is not acknowledged or is negatively judged (Goodwin & Ogden, 2007). Such disenfranchisement may mirror the experience of other forms of perinatal loss, and may again serve as risk factor for complicated grief. Hence it is important that the grief experiences of women experiencing terminations are afforded due consideration in research and clinical settings.

1.4.5 Women's experiences with perinatal loss. Responses to perinatal loss vary widely, with poignant sorrow one commonly observed experience (Alston & Samuels, 2014). This sorrow has not always been acknowledged. In a 1950s Australian research publication, a medical practitioner expressed surprise at a patient's report that she was equally upset at a stillbirth as her mother's death (Giles, 1970). In another 1950s paper, maternal distress was regarded sympathetically however the baby was removed without viewing and the mother was advised to 'put the loss behind her and have another baby', befitting the predominant theories of the time that grief work involves breaking bonds with the deceased (Bowlby, 1977; Elia, 1959).

The seminal research of Kennell, Slyter, and Klaus (1970) documented empirically the magnitude of women's grief following perinatal death, prompting further research on perinatal bereavement through the 1980s (Fenstermacher & Hupcey,

2013). Three major factors have said to have contributed to the recognition of perinatal loss as a meaningful psychological phenomenon – changing sociocultural conditions which acknowledged the suffering of women experiencing perinatal loss; technological advances in neonatal care; and understanding via attachment theory of maternal/child bonding during pregnancy (Bowlby, 1980; Fenstermacher & Hupcey, 2013).

Parent/infant attachment has been observed to begin before, and continue during, pregnancy with parents dreaming of the future for themselves and their child (Adeyemi et al., 2008; Bangal, Sachdev, & Suryawanshi, 2013; Miles, 2012; van den Akker, 2011). There has been a recent proliferation of research into the biological, psychological, and social development of this perinatal attachment and its ongoing impact through the lifespan (McCoyd & Walter, 2015).

A recent Cochrane review highlighted that the historical practice of separation between mother and her deceased fetus or infant was rooted in the belief that total separation would prevent development of attachment in particular, thus circumventing any grief (Koopmans, Wilson, Cacciatore, & Flenady, 2013). However research and subsequent practice has clarified this, and women and families are now encouraged to spend time and honour attachments to their deceased child should they wish (Ryninks, Roberts-Collins, McKenzie-McHarg, & Horsch, 2014; Surkan, Rådestad, Cnattingius, Steineck, & Dickman, 2008). It is interesting to note that Bowlby himself supported change to hospital protocols, encouraging women to have contact with their deceased babies, name their offspring, and conduct funerals (Bowlby, 1980). Bowlby (1980) recognised the need to acknowledge the baby's existence as a valid attachment and thus a separate entity to mourn. Bowlby described perinatal bereavement reactions as "[n]umbing, followed by somatic distress, yearning, anger, and subsequent irritability

and depression… [and] preoccupations with the image of the dead baby and dreams about him" (1980, p. 122), also reflecting the predominant stage-based models of grief at that time (Maciejewski, Zhang, Block, & Prigerson, 2007).

Research has attempted to document perinatal grief reactions, noting similarities between perinatal bereavement and other forms of bereavement such as spousal death (Brier, 2008; Koopmans et al., 2013). Reactions include profound sadness, disappointment, irritability, doubt, guilt, confusion, preoccupation, anger, anxiety, somatic symptoms, and altered eating and sleeping patterns (Badenhorst & Hughes, 2007; Bangal et al., 2013; Black & Wright, 2012; Koopmans et al., 2013). As with other modes of loss no specific timeframe is indicated, with research showing that for some individuals perinatal grief symptoms subside six to 12 months post-loss, whilst for approximately 20% of women, disabling symptoms continue past the first year post-loss (Badenhorst & Hughes, 2007; Brier, 2008; Janssen, Cuisinier, & Hoogduin, 1996).

More recent research has observed that perinatal grief experiences can continue to manifest symptomatically four years to 18 years post-loss (Fenstermacher & Hupcey, 2013; Gravensteen, Helgadottir, Jacobsen, Sandset, & Ekeberg, 2012; Heazell et al., 2016; Hutti, 2005). Some have suggested that perinatal bereavement has no end-point as parents continue to carry grief through their lifetime (Avelin, Rådestad, Säflund, Wredling, & Erlandsson, 2013; Capitulo, 2005; Hutti, Armstrong, Myers, & Hall, 2015; Theut, Zaslow, Rabinovich, Bartko, & Morihisa, 1990). It may be that symptomatic expressions of grief typically peak in the first 6 to 12 months post-loss, with approximately 20% of women continuing to experience symptoms beyond 12 months post-loss, possibly for many years or a lifetime.

This seems to reflect Bonanno's (2009) grief trajectories, where some women appear to follow a *resilience* path whilst others seem to follow *recovery* or *chronic* trajectories. Indeed, some research has suggested that although some women respond to perinatal loss with ongoing profound distress, others may be more characterised by resilience, posttraumatic growth, or transformation, however research is yet to fully explore these outcomes of perinatal grief (Black, Wright, & Limbo, 2016).

More intense and/or prolonged grief has been associated with longer gestation of pregnancy, poorer perceived social support, maternal guilt and shame-based cognitions, pre-loss psychiatric symptomatology, ambivalence towards the pregnancy, history of perinatal loss, and pre-existing neurotic personality features (Badenhorst & Hughes, 2007; Black et al., 2016; Gold, Dalton, Schwenk, & Hayward, 2007; Goldbach, Dunn, Toedter, & Lasker, 1991; Janssen, Cuisinier, Hoogduin, & De Graauw, 1997; Rosenzweig, 2010; van den Akker, 2011).

By contrast, research has found no significant relationships between intensity/duration of perinatal grief and culture, difficulty conceiving, advanced maternal age, sex of fetus, socioeconomic status, or religious observance; whilst research investigating the relationship between intensity of grief and childlessness has produced inconsistent results (Badenhorst & Hughes, 2007; Sutan & Miskam, 2012).

In summary, extant research suggests that women's responses to perinatal loss vary in expression and duration (Brier, 2008). Some women appear to carry perinatal grief for lengthy periods, possibly decades or lifetimes. Mediators of the loss-grief relationship may include biopsychosocial factors such as gestational age of the fetus/baby, social support, cognitive and mental health, feelings towards the baby, previous losses, and personality features.

Brier's (2008) comprehensive review of the field suggests further research is needed to clarify the incidence and nature of grief following perinatal loss, including potential factors that mediate grief intensity and the experiences of other parties such as fathers and grandparents. Brier encouraged researchers to employ theory-based definitions of grief; clearly-stated definitions of the different forms of perinatal loss; standardised perinatal grief-specific measures; representative samples; and standardised assessment intervals. In addition, research in this area has been characterised by the potentially biased use of targeted samples of women hospitalised for perinatal losses or who are accessing grief support services, rather than more broadly representative samples and comparison groups of women who have not experienced loss. The present research therefore aims to respond to such recommendations. The research aims to examine the above-mentioned relationships (such as maternal and gestational age, perinatal loss history, mental health, and personality dysfunction) using theory-based definitions of grief, perinatal-specific measures, and standardised clinical assessments in a cohort of community-dwelling women.

1.5 Psychological Responses to Perinatal Loss

Research has attempted to identify factors involved in the development of post-loss psychopathology including depressive and anxiety disorders, PTSD, and variants of the recent *DSM-5* category of PCBD such as complicated grief (APA, 2013). Research has shown that bereaved parents are at increased risk of developing psychopathology (Adolfsson, 2011; Bennett, Lee, Litz, & Maguen, 2005; Koopmans et al., 2013; Rosenzweig, 2010).

In a population-based sample of 1,445 individuals bereaved by different means, complicated grief prevalence rates (23.6%) were highest in those who had lost a child (Kersting et al., 2011). Of note however this sample was not exclusively parents who had experienced perinatal loss, but rather loss of a child, however it offers a glimpse into the difficult experience of being a bereaved parent. Perinatal deaths in particular are characterised by unique features that potentially accentuate negative psychological reactions, including the perception that a baby dying is unnatural in the expected life course; that the event is often so sudden and unexpected it negates any anticipatory grief; that may be no mourning rituals such as funerals; that perinatal loss can result in maternal trauma; that a large proportion of perinatal deaths are due to unknown causes; that women may feel a heightened sense of responsibly for the loss including helplessness, guilt, and shame; and as discussed earlier, the possible disenfranchisement of the perinatal grief experience (Adolfsson, 2011; Frost & Condon, 1996; McSpedden, 2014). For all these reasons, the unique features of perinatal loss may place women at greater risk of developing psychopathology.

Research investigating psychopathological outcomes of perinatal loss has most commonly focused on depression (Adolfsson, 2011). Hogue et al. (2015) analysed 2006 to 2008 data from the US population-based case-control Stillbirth Collaborative Research Network. Hogue et al. found that in the 6 months following stillbirth, women with no previous history of depression were twice as likely to develop *de novo* depression, and this risk, whilst lessening, continued to be higher at various time points to 24 months after stillbirth. Some research has shown that risk of depression may be accentuated for those who have a history of perinatal loss, however findings are inconsistent (Bicking Kinsey, Baptiste-Roberts, Zhu, & Kjerulff, 2015) . It appears

that women who experience stillbirth grieve acutely and potentially develop depressive disorders in the first 6 months post-loss, with a smaller but significant continued increased risk of incident depressive illness among women with no previous history of depression.

Hogue et al.'s (2015) analysis however only included women who had experienced stillbirth. Lok, Yip, Lee, Sahota, and Chung (2010) found that after miscarriage, 26.8% of the Chinese women in their sample demonstrated clinically symptomatic levels of depression. One strength of this study was the presence of a comparative control group of women with no psychiatric history, however the control group was non-pregnant women seeking contraception advice thus potentially limiting comparisons (Frost & Condon, 1996; Toedter, Lasker, & Campbell, 1990). Notwithstanding, the incidence rate observed by Lok et al. (2010) concurs with other follow-up studies where approximately 25% of women who experience miscarriage or stillbirth go on to develop psychopathology (Adolfsson, 2011; Bennett, Litz, Maguen, & Ehrenreich, 2008; Robinson, 2014; Scheidt et al., 2012). Janssen et al. (1996) also reported that 20% of women continue to exhibit psychological symptoms more than two years after perinatal loss, with suggestions just 10% of such women seek professional assistance. Bennett et al. (2008) found that symptoms persisted five years post-loss, while Turton, Evans, and Hughes (2009) found significantly higher levels of post-stillbirth psychopathology persisted for mothers seven years later, suggesting again that perinatal grief may be associated with ongoing long-term impairment.

The research body investigating psychopathological sequalae of perinatal loss is dominated by miscarriage and stillbirth. A confusing body of research exists investigating relationships between psychopathology and terminations; whereas there is

a paucity of research investigating ectopic pregnancy. In addition, research typically considers differing forms of perinatal loss in isolation from one another.

One study attempted to bridge this gap, by comparing mental health outcomes in groups of Norwegian women who had experienced miscarriage and elective termination (Broen, Moum, Bødtker, & Ekeberg, 2005). Using a five-year longitudinal design, results showed that women who experienced miscarriage had significantly higher distress scores in the short-term post-loss aftermath (10 days and 6 months), however these women showed significantly more rapid improvement in distress over the longer-term than women who had experienced termination. Women who elected termination had higher distress scores at the longer-term time points (2 and 5 years post-loss). Hence it would appear that women who experienced miscarriage reported more acute distress before apparently following a recovery trajectory, however women who elected termination experienced longer-term levels of distress. Although distress and depressive illness are different conceptually and biopsychosocially, these findings offer interesting insight into grief trajectories after miscarriage and elective termination.

Kersting et al. (2007) found that recently bereaved mothers who had a medical termination were significantly more likely than control women to suffer from a range of psychiatric disorders for up to 14 months after their loss. Further analyses revealed acute disorders such as PTSD were mostly resolved at 14 months post-loss, while anxiety and episodic mood disorders were the most common diagnoses which continued 14-months post-loss (Kersting et al., 2007).

Extant research investigating both elective and medical terminations and psychopathology however has produced inconsistent findings, with some studies suggesting a negative effect on subsequent mental health including trauma reactions and

suicidality. Coleman's (2011) comprehensive analysis showed that women who had elected to terminate experienced an 81% increased risk of mental health problems, with nearly 10% of the incidence attributed to termination. An emerging body of research has investigated this further and suggested the possibility of a 'post abortion trauma syndrome', however this research and the field itself has been characterised by methodological, sociocultural, ethical, and legal debate (Robinson, Stotland, Russo, Lang, & Occhiogrosso, 2009). The American Psychological Association conducted an extensive review of the relationship between termination and subsequent mental illness, concluding that although some women responded with grief, sadness, depression, and anxiety, terminations themselves were not linked with significant deleterious effects on mental health (American Psychological Association Task Force on Mental Health and Abortion, 2008). The Task Force identified several factors predictive of more negative psychological responses following termination, including perceptions of stigma, need for secrecy, commitment to the pregnancy, low social support, prior mental health problems, and dysfunctional personality factors. It is noted that these conclusions mirror the earlier reviewed risk factors for complicated grief after other forms of loss (Major et al., 2009; Robinson et al., 2009).

Research investigating psychopathology after ectopic pregnancies is rare, however one study used a prospective cohort design to compare mental health outcomes for women who had experienced miscarriage with ectopic pregnancies (Farren et al., 2016). The study found no significant difference in severity of distress between ectopic pregnancy and miscarriage. Compared to control participants however, 28% of the women who had experienced these forms of perinatal loss met criteria for PTSD, 32% for anxiety, and 16% for depression 1 month after loss; and 38%, 20%, and 5%

respectively at 3-months post-loss. It is noted that as compared to depression and anxiety, more women in the Farren et al. (2016) study met criteria for PTSD at 3-months post-loss than 1-month post-loss. It is important to consider however that both Farren et al. (2016) and the Norwegian study by Broen et al. (2005) did not clinically assess mental health and instead utilised commonly available measures such as the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). Notwithstanding, these results suggest that there are few quantitative differences in the grief experience of women after different forms of perinatal loss.

One welcome addition to the literature was the publication of research investigating longer-term impact of loss via ectopic pregnancy (Lasker & Toedter, 2003). Lasker and Toedter (2003) re-interviewed women who had been previously interviewed 16 years earlier after experiencing ectopic pregnancy. The interview consisted of questions about adaptation to loss. Many women in the study described an ongoing perception that ectopic pregnancy was a traumatic experience that impaired fertility, strained relationships, and led to crises of faith. Although women overall described finding a way to adapt to the loss and find meaning in their lives, as Lasker and Toedter stated, “Despite the passage of more than 15 years, we were surprised to find that more than half (54%) of the women said that they still think about the loss “a lot” or that it is “something that is always with” them.” (p. 213). Hence this research provides rare insight into the longer-term experience of perinatal loss via ectopic pregnancy, with women confirming qualitatively that they continued to reflect often on their loss 15 years later.

Although utilising different methodologies, the above reviewed research shares the commonality of typically investigating sequelae of perinatal loss via general

measures of distress and lowered mood (Adeyemi et al., 2008; Broen et al., 2005; Farren et al., 2016). The most commonly observed methodology centres on general self-report measures of symptomatology administered to outpatient samples in the immediate or short-term aftermath of perinatal loss. For example, Adeyemi et al. (2008) invited women who had been hospitalised for perinatal loss to participate in a study investigating depressed mood. The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) and the Edinburgh Postnatal Depression Scale (Cox, Holden, & Sagovsky, 1987) were administered to women within four weeks of loss, with findings showing women who had experienced perinatal loss score highly on both measures. Whilst these findings offer insight into the general experiences of women who have experienced perinatal loss, what is evident is that the most predominant methodology in psychology/perinatal loss research is short-term samples using generalised measures and as such, a gap remains in the literature with regards to the use of standardised clinical measures of psychiatric functioning (Brier, 2008; Geller, Kerns, & Klier, 2004).

1.6 Complicated Perinatal Grief

With a focus on distress and lowered mood as an outcome of perinatal loss, there remains a paucity of research specifically investigating prolonged/complicated grief generally or PCBD specifically (APA, 2013). However two recent studies have attempted to bridge this gap. Kulathilaka, Hanwella, and de Silva (2016) studied relationships between depression (as assessed via clinical interview conducted by a psychiatrist and the Patient Health Questionnaire) and grief following miscarriage before 28 weeks gestation. A comparison group of pregnant women was also included.

In Kulathilaka et al.'s (2016) sample, 18.6% of women with perinatal loss met criteria for depression, compared to 9.5% of women in the comparison group. The relative risk of developing a depressive episode after miscarriage was 1.96 (95 % CI, 1.04–3.73); however it is unclear whether this was *de novo* depressive episodes (e.g., women who were previously healthy and had not had a depressive episode prior to the loss). Further, when adjusted for age and gestational length of pregnancy, there was no significant increase in relative risk (adjusted RR 1.42 [0.65-3.07], p = .38).

Further findings included that 55% of post-loss women scored in the clinically significant range for complicated perinatal grief. Kulathilaka et al.'s (2016) showed that in this 'complicated grief' group, 26.6 % also fulfilled criteria for a depressive episode. However this finding should be interpreted with caution, as women were interviewed between 6 and 10 weeks after loss; which is earlier than criteria would suggest as 'complicated grief' (*DSM-5*; APA, 2013). It is likely that a proportion of these women represent false-positives for complicated grief.

Kulathilaka et al. (2016) concluded that the relative risk of developing a depressive episode after miscarriage was not significantly higher after taking into account maternal age and gestational length of the pregnancy. Notwithstanding methodological concerns over the conceptualisation of complicated grief, this study did utilise psychiatric interviews to diagnose depression and as such, provides useful insights into the experience of clinical depression after perinatal loss. The research was also conducted with Sri Lankan women (thus the longer WHO gestational cut-off of 28 weeks for miscarriage) and thus applicability to the Australian context is uncertain.

Recent unpublished research has investigated rates and predictors of complicated grief in an Australian sample (McSpedden, 2014). The sample consisted of

121 women who were clients at a bereavement support agency after perinatal or neonatal death (miscarriage, termination, stillbirth, neonatal, or child death up to 1 year of age). McSpedden (2014) found the only significant predictor of complicated perinatal grief was the absence of any other living children, with history of perinatal losses and type of loss not significant predictors of complicated grief. Results indicated 18% of women experienced complicated grief symptoms up to 5 years post-loss. This prevalence rate concurs with other similar findings showing around 20% of women continue to experience disabling symptoms more than two years after perinatal loss (Badenhorst & Hughes, 2007; Brier, 2008; Janssen et al., 1996).

McSpedden's (2014) research offers as strengths the inclusion of multiple forms of loss within the one sample, however the sample included not only perinatal losses during the pregnancy period but also neonatal and child losses during the first year of life. Additionally, the women were all clients at a bereavement support agency suggesting a possible bias towards those seeking assistance from a grief-specific support agency. What McSpedden's research offers though, like Kulathilaka et al. (2016), is rare consideration specifically of complicated grief after perinatal loss. The research field more typically examines other indicators of psychopathology after perinatal loss, such as depressed mood or distress.

Hence what remains is a need for further research investigating potentially longer-term grief trajectories after differing forms of perinatal loss, including any possible relationships between clinical depressive illness and chronic or prolonged grief. That is, there exists a solid body of research showing that pre-existing mental illness is a significant risk for complications in perinatal grief, and that women can respond to perinatal loss with lowered mood and clinical depression (Badenhorst & Hughes, 2007;

Brier, 2008; Broen et al., 2005; Coleman, 2011; Gold et al., 2007; Hogue et al., 2015; Janssen et al., 1996; Kersting & Nagl, 2015; Lok et al., 2010). Emergent research such as McSpedden's (2014) suggests women appear at risk of developing forms of complicated grief possibly akin to PCBD in *DSM-5* (APA, 2013). However it is unclear whether these two experiences (clinical depression and complications in grief) may be linked. It may be that women who develop *de novo* depression are more at risk for developing more prolonged or complicated grief, than women who do not develop depressive illness after perinatal loss. Further research in the field has been encouraged to draw samples from sources wider than those engaged in formal psychological services and to utilise standardised measures of clinical symptomatology as opposed to measures of general distress or low mood (Geller et al., 2004). Thus the present research proposes to examine in a heterogenous sample of women who have experienced different forms of perinatal loss relationships between Major Depressive Disorder (MDD), prolonged grief, and a third factor in personality disorders.

1.7 Personality, Personality Disorders, and Perinatal Grief

Theoretically, Worden's (2008) task-based model of grief and the Two-Track Model (Malkinson & Rubin, 2007) both acknowledge the impactful role of personality on mourning. Research investigating personality and grief has linked dysfunctional personality traits (e.g., neuroticism, introversion, closededness to experience, disagreeableness, undependability, uncooperativeness, inflexibility, dependence) with complicated grief following loss of adults and children (Boogar & Talepasand, 2015; Drapeau, Cerel, & Moore, 2016; Mash, Fullerton, Shear, & Ursano, 2014; Pai & Ha, 2012; Riley, LaMontagne, Hepworth, & Murphy, 2007). Of these, neuroticism in

particular has been found to be a significant predictor of complicated grief, suggesting the importance of possessing a dispositional capacity for emotion regulation.

Ogrodniczuk, Piper, Joyce, McCallum, and Rosie (2003) studied relationships between NEO Five-Factor personality traits and outcomes for outpatients in therapy for complicated grief (Costa & McCrae, 1992). Ogrodniczuk et al. (2003) found extraversion, conscientiousness, openness, and to a lesser extent agreeableness to be related to favourable treatment outcomes; by contrast neuroticism was predictive of poorer treatment outcomes.

By extension, the dispositional trait of neuroticism has been linked with the presence of diagnosable personality disorders. A meta-analysis of research investigating relationships between each of the Five-Factor model dimensions and the *DSM-IV* personality disorder categories found that each personality disorder displays a distinct and meaningful Five-Factor profile that predicts the diagnostic criteria (Saulsman & Page, 2004). Results suggested that borderline, paranoid, schizotypal, avoidant, and dependent personality disorders were associated with significant degrees of neuroticism (Saulsman & Page, 2004).

The relationship between personality traits and personality disorders has been the source of research and clinical debate. Some have argued that personality traits and personality disorders are conceptually and clinically different, in that individuals can be characterised by constellations of maladaptive personality traits that are not represented as, or indicative of, personality disorders (Trull & Durrett, 2005). Others argue there are no qualitative or dimensional differences between personality traits and personality disorders, and that fundamental symptomatology of personality disorders can be understood as maladaptive variants of personality traits evident within the normal

population (Widiger, 2003). In a wider sense, this mirrors the debate between categorical and dimensional models of personality disorders accentuated by the release of *DSM-5* (APA, 2013). In addition to the earlier-reviewed changes to grief-related nosologies, *DSM-5* also presented significant changes in the conceptualisation and classification of personality disorders (Bornstein, 2011).

DSM defines a personality disorder (PD) as an enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual's culture and is manifested in two or more of cognition, affectivity, interpersonal functioning, and/or impulse control (Skodol, 2012). The PD must have begun by early adulthood, and be characterised by the hallmark features of being pervasive, inflexible across time and circumstance, causing distress or functional impairment, and not better accounted for by a general medical condition or substance use (APA, 2000, 2013).

In *DSM-IV-TR*, PD diagnoses were described on a separate axis (Axis II) to other mental disorders (Axis I) and thus PDs were conceptualised categorically; that is, Axis II represented "the categorical perspective that Personality Disorders are qualitatively distinct clinical syndromes" (APA, 2000, p. 689). As seen in Table 2, categorical PDs in *DSM-IV-TR* included Paranoid, Schizoid, and Schizotypal PDs (referred to as 'Cluster A' PDs, characterised by odd or eccentric behaviour); Antisocial, Borderline, Narcissistic, and Histrionic PDs ('Cluster B' PDs characterised by dramatic or erratic behaviour); and Dependent, Avoidant, and Obsessive-Compulsive PDs ('Cluster C' PDs characterised by anxiety and fearfulness); as well as Passive-Aggressive PD, Depressive PD, and PD Not Otherwise Specified (Clifton, Turkheimer, & Oltmanns, 2009).

Table 2

Core Diagnostic Features of DSM-IV-TR Personality Disorders (APA, 2000)

Diagnosis	Features
Cluster A:	
Paranoid PD	Pervasive suspiciousness that others are trying to incur harm or exploitation; isolated; hostile
Schizotypal PD	Eccentric beliefs and behaviour; cognitive and perceptual anomalies; social discomfort
Schizoid PD	Emotional coldness; emotional unavailability; social isolation; low desire for relationships
Cluster B:	
Antisocial PD	Violation of laws and morality; manipulation of others for own benefit; lack of empathy
Borderline PD	Emotional instability; turbulent relationships; impulsivity; fear of abandonment; unstable sense of self
Histrionic PD	Attention seeking; exaggerated expression of emotion; overly concerned with appearance and approval
Narcissistic PD	Inflated sense of importance; grandiosity; self-focus; feelings of entitlement; lack of empathy
Cluster C:	
Avoidant PD	Extreme shyness; interpersonal sensitivity; social avoidance; fear of evaluation; low self-esteem
Dependent PD	Need for reassurance and caretaking; fear of being alone; passive in interpersonal relationships
Obsessive-Compulsive PD	Rigid adherence to rules and/or lists; perfectionism; cognitive inflexibility; need for control and order
Passive-Aggressive PD	Covert obstructionism; deliberate inefficiency; sullenness; alternates between defiance and contrition
Depressive PD	Pervasive dejected mood; cognitions of guilt and inadequacy; self-critical; negativistic; pessimistic
PD Not Otherwise Specified	Personality dysfunction that does not meet criteria for any one specific personality disorder

After extensive debate over whether PDs represent discrete categorical diagnostic entities, the multiaxial structure was removed in *DSM-5* (APA, 2013). This was seen as a move away from a categorical approach and towards a dimensional approach to diagnosing PDs, without fully committing to a dimensional approach (Widiger, 2011; Zachar, Krueger, & Kendler, 2016). A categorical approach is retained in *DSM-5* with PD diagnoses included as per *DSM-IV-TR*, however a dimensional approach is included in a *DSM-5* appendix entitled "Emerging Measures and Models" (same location as PCBD described earlier).

The dimensional approach emphasises degrees, or severity levels, or personality functioning. The dimensional approach incorporates into *DSM-5* a four-part assessment process, including a list of 37 pathological personality traits, including those associated with six specific personality disorder types, as well as general criteria for severity of personality disorder impairment (Porter & Risler, 2014; Skodol et al., 2011; Zachar et al., 2016). Using such a dimensional approach endorses the view that PDs constitute incremental trait expression resulting in functional impairment (Porter & Risler, 2014).

With *DSM-5* presenting both categorical and dimensional approaches, the *DSM-5* Personality and Personality Disorders (P&PD) Work Group encourages clinicians and researchers to use a 'hybrid' categorical/dimensional approach to PDs (Skodol et al., 2011). Doing so represents people with PDs as a discrete class of people who are functionally impaired by incremental trait expression (Porter & Risler, 2014).

This *DSM* change in approach to PDs presented implications for the present research. Although changes had been purported for PDs in the next iteration of *DSM* for some time, it wasn't until *DSM-5* was released mid-2013 that these could be confirmed; it then was not until October 2015 that the *DSM-5* versions of the desired

instruments (the Structured Clinical Interviews) were developed and released (First, Williams, Karg, & Spitzer, 2015; First, Williams, Benjamin, & Spitzer, 2015). The present research was conceptualised and initial data collection had commenced before the release of *DSM-5*, and thus clinical assessment proceeded according to *DSM-IV-TR* classification of PDs (First, Gibbon, Spitzer, Williams, & Benjamin, 1997; First, Spitzer, Gibbon Miriam, & Williams, 2002).

1.7.1 Personality disorders and perinatal grief. Despite research investigating relationships between *personality* and grief, there is a paucity of research examining relationships between *personality disorders* and grief. Despite extensive literature searches, this researcher was unable to find any publications using the terms "personality disorders" and "perinatal [pregnancy] grief" or "perinatal [pregnancy] loss". By extension clinically, little may be known regarding the potentially unique needs of women with personality disorders. The International Marce Society aims to further this by focusing on research and translational care of prenatal & postpartum mental health for mothers, fathers and babies. The International Marce Society recommends women in the perinatal period be comprehensively assessed for current and long-standing psychological, social, and cultural risk factors that may make adjustment to parenting more difficult, which may potentially include personality disorders, however there remains a lack of research specifically investigating relationships between personality disorders and perinatal loss (Austin, 2014).

Kersting and Nagl (2015), Badenhorst and Hughes (2007), and Janssen et al. (1997) have all linked pre-loss dysfunctional personality traits (specifically neuroticism, shame- and guilt-based personality features) to more complicated grief reactions in

women who had lost babies. Sugiura-Ogasawara et al. (2002) also found a positive relationship between neuroticism and recurrent miscarriage rates, however the research was unable to establish directionality of this relationship. Such research however has not examined relationships between personality disorders and perinatal loss.

With an apparent lack of published research investigating relationships between perinatal grief and PDs, one may consider more generally research investigating relationships between grief and PDs. More generally with grief, a small body of mainly anecdotal literature suggests that individuals with personality disorders may be at greater risk of developing complications in grief. Alarcon (1984) presented a case study of a 28-year-old woman whose nephew was murdered. Sixteen months after his death, the woman was hospitalised after experiencing depression, auditory and visual hallucinations, paranoia, substance abuse, and suicidality. The woman was assessed as having features of Histrionic and Antisocial PDs although she did not meet criteria for Borderline PD. Alarcon suggested that the woman's historic features saw her "use depression as a way to manipulate situations, gratify dependence needs, express deep-seated hostility, and yet attain help from others without resorting to more grotesque and stigmatising symptoms" (Alarcon, 1984, p. 46). Alarcon concluded that the histrionic personality disorder features were a "pivotal pathogenic… complicating factor of bereavement" (Alarcon, 1984, p. 46). Additional personality features cited by Alarcon as complicating the grief responses were impulsivity, immaturity, suggestibility, dependence, and egocentrism, with Alarcon purporting disordered attachment to also play a role in this woman's experiences. Although this paper could be regarded as dated and primarily anecdotal, it offers a glimpse into a potential clinical relationship between PDs and sibling grief.

Bowlby (1977) also suggests the mourner's personality structure be recognised when considering an individual's response to loss. More recently Piper, Ogrodniczuk, et al. (2001) assessed empirically the role of ambivalence and other predictors of grief in psychiatric outpatients. Piper and colleagues reported that both Axes I and II diagnoses were made using structured clinical interviews, and that 55.6% of the psychiatric outpatients received an Axis II diagnosis (most prevalent were Avoidant and Dependent PDs each at 16.0%, Obsessive-Compulsive PD at 15.2%, and Borderline PD at 7.2%). Beyond this prevalence reporting however, no further analysis of PDs as possible predictors of grief response was reported (Piper, Ogrodniczuk, et al., 2001).

Similarly, members of the same research team investigated predictors of complicated grief therapy outcomes, including NEO personality traits (Ogrodniczuk et al., 2003). SCID interviews were conducted with 107 psychiatric outpatients for the then *DSM-III-R*, with 55.1% of the sample receiving an Axis II diagnosis. Mirroring their earlier study the most prevalent diagnoses were Avoidant (26.2%), Dependent (13.1%) and Borderline PD (9.3%), however again these diagnoses were not further reported (Ogrodniczuk et al., 2003).

Taken together, it is evident that there is a gap in the literature with regards to relationships between PDs and grief in general, and in particular relationships between PDs and perinatal grief. Few studies have been identified that explore such relationships, and those that are published are characteristically anecdotal or lacking in detail. The small body of research however does suggest the possibility of relationships between dysfunctional personality features and complicated grief reactions. When one considers more generally research between personality traits and grief, it appears that certain personality traits such as neuroticism act as a risk factor for complications in

grief. Thus an encouraging rationale exists for further research investigating relationships between personality dysfunction in the form of PDs and perinatal grief.

1.8 Rationale for the Present Research

Taken together, extant research from the past three decades suggests that responses to perinatal loss can vary but typically include poignant sorrow, disappointment, depressed mood, irritability, doubt, guilt and shame, preoccupation, anxiety, anger, somatic symptoms, and altered eating and sleeping patterns (Badenhorst & Hughes, 2007; Bangal et al., 2013; Black & Wright, 2012; Black et al., 2016; Koopmans et al., 2013). High prevalence of acute symptomatology has been observed 6 to 12 months post-loss, though for approximately 20% of women grief reactions seem to manifest symptomatically for many years afterwards as parents make ongoing attempts to accommodate their loss (Fenstermacher & Hupcey, 2013; Gravensteen et al., 2012; Heazell et al., 2016; Hutti, 2005). This has implications in terms of theoretical approaches to grief, such as the Dual Process Model (Stroebe & Schut, 2010) and Bonanno's (2009) grief trajectories.

Although research with other modes of bereavement has identified a number of factors that may predict complications in grief, such as death circumstances, mourner's wellbeing and functioning, social factors surrounding the loss, characteristics of the deceased, and the mourner's relationship with the deceased (Currier et al., 2006; Kersting & Nagl, 2015; Kersting et al., 2011; Neimeyer et al., 2006; Prigerson et al., 2009; Rozalski et al., 2016; Shear, 2012; Worden, 2008); little is known about mediating factors for perinatal grief. Notably, few publications have explicitly addressed the role of personality disorders in grief. Research in the field has typically

focused on investigating outcomes of perinatal loss in outpatient samples or samples recruited from loss-related self-help groups or professional mental health services (Toedter, Lasker, & Janssen, 2001). Depressed mood appears the most common variable investigated in response to perinatal loss, as measured using self-report measures of wellbeing, distress, or postnatal depression. In addition, research in this field has typically investigated short-term outcomes after perinatal loss and has focused on singular forms of perinatal loss (notably stillbirth, and to a lesser extent miscarriage) at the potential expense of others forms of perinatal loss.

There is a paucity of research investigating complicated grief after perinatal loss; however recent research conducted with Sri Lankan and Australian samples offers contradictory findings. Kulathilaka et al. (2016) found that whilst 18.6% of Sri Lankan women met criteria for depression after miscarriage (loss <28 weeks gestation), no significant increase in relative risk of developing a depressive episode was observed after adjustment for potential confounders of maternal age and gestational length of pregnancy. Fifty five percent of this sample scored in the clinically significant range for complicated perinatal grief, however the study interviewed outpatients soon after loss and thus a proportion of these women likely represent false-positive identification of complicated grief.

By contrast, McSpedden's (2014) research found the only significant predictor of complicated perinatal grief was the absence of any other living children. McSpedden's results indicated 18% of women experienced complicated grief symptoms up to 5 years post-loss. McSpedden's research included a heterogenous sample of different types of loss, but also include loss of children up to 1 year of age and all participants were recruited from a bereavement support agency, possibly representing a

bias towards self-identified complications in grief and thus the seeking of professional support. Combined with Kulathilaka et al.'s (2016) sample of outpatients, these studies provide rare insight into relationships between complications in perinatal grief and clinical depression however research has yet to extend this focus to community samples. Further, no research was identified focusing on relationships between perinatal grief, *de novo* clinical depression, and personality disorders.

Numerous authors identify as a research agenda priority the identification of individuals vulnerable to psychological complications following perinatal loss (Badenhorst & Hughes, 2007; Brier, 2008; Rowsell, Jongman, Kilby, Kirchmeier, & Orford, 2001). Kristjanson, Lobb, Aoun, Monterosso, and Halkett (2005) concluded that research is needed to identify risk factors for complicated grief after perinatal loss. Given that the present research was unable to identify any published literature investigating relationships between personality disorders and perinatal grief, this presents an opportunity to explore personality disorders as a potential risk factor for complications in perinatal grief. Such research would also complement recent changes in *DSM-5* (APA, 2013), which included the addition of a diagnosis of PCBD as a category for further study. Condon (2010) also identified a women's health 'wish list' for future *DSM* iterations, including adequate recognition of evidence-based perinatal bereavement disorders.

This research priority is echoed in the words of Bennett et al. (2005, p. 185): "At present, we do not have sufficient knowledge about the risk and resilience factors that shape the trajectory of adaption to perinatal loss. We also do not know whether standard care is necessary or sufficient, or, in the worst case, iatrogenic. Thus, future research requires … well-designed cross-sectional and longitudinal epidemiological

studies that will generate knowledge of the impact, course, and predictors of perinatal bereavement and the mental health outcomes associated with this unique loss."

Hence the present study intends to respond to these identified research needs by using a psychiatric epidemiological framework to explore women's self-reported perinatal grief experiences and thus illuminate predictors of more prolonged or complicated perinatal grief. Taking a theory-based stance and using standardised clinical measures, relationships between psychopathology (specifically, Major Depressive Disorder and personality disorders) and perinatal grief will be investigated, and a sample of women who have not experienced pregnancy loss will be included where possible for comparative purposes. In addition, with research to date focusing more on the immediate aftermath of stillbirth and late miscarriage, the present research intends to sample community-dwelling women and thus both short- and long-term grief experiences are expected to be reported, as well as different types of losses including early and middle miscarriage, stillbirth, ectopic pregnancy, and medical and elective terminations.

1.9 Aims and Hypotheses

The present research intends to use an epidemiological framework to explore relationships between perinatal grief, depressive illness, and personality disorders in a sample of Australian women. Women will be invited to participate from a cohort that previously participated in a study of antenatal physical health 10 years ago. Thus this study represents an opportunity to follow-up with these women and ascertain the extent of self-reported perinatal loss as well as relationships between perinatal grief, MDD, and personality disorders. This study aims to determine:

- The proportions of women reporting perinatal loss in a sample of Australian community-dwelling women recruited from an antenatal clinic;
- The proportion of women reporting the development of *de novo* Major Depressive Disorder (MDD) after perinatal loss;
- The average perinatal grief scores reported by women who developed *de novo* MDD after perinatal loss and women with personality disorders; and
- Relationships between *de novo* MDD, personality disorders, and perinatal grief.

Three hypotheses will be assessed in the current research:

1. It is hypothesised that women who report developing *de novo* MDD after perinatal loss will report more intense perinatal grief, as indicated by higher scores on the Perinatal Grief Scale (Potvin, Lasker, & Toedter, 1989).
2. It is hypothesised that women with personality disorders will report more intense perinatal grief, as indicated by higher scores on the Perinatal Grief Scale (Potvin et al., 1989).
3. It is hypothesised that the presence of personality disorders and *de novo* MDD will act as significant risk factors for more intense perinatal grief.

Chapter 2: Method

2.1 Participants

The present research was nested within the Vitamin D in Pregnancy (VIP) Study. The VIP is a longitudinal birth cohort study based in Geelong, Victoria, Australia. From 2002 to 2004, pregnant women less than 16 weeks gestation were invited to participate in the VIP Study via the Geelong Hospital antenatal clinic. Baseline participants (N = 475) attended the VIP centre twice during pregnancy: at recruitment and at 28- to 32-weeks gestation. A range of anthropometric measures was undertaken, with the original intention to investigate sequelae of vitamin D intake for maternal-infant dyads (Hyde, Brennan-Olsen, Wark, Hosking, & Pasco, 2017).

With the existing VIP Study undertaking a 10-year follow up to further investigate relationships between maternal and child physical health markers, an opportunity arose at this follow-up to extend the study to women's self-reported psychiatric and obstetric outcomes.

This sample was followed-up when the VIP children had aged to a median age of 11 years (Hyde et al., 2017). Of the original 475 baseline participants, 400 remained eligible for participation in the 10-year follow up. Of these 400, 210 were contactable and participated in the 10-year VIP Study physical health follow-up (52.5%) and 197 consented to participate in this psychiatric extension of the study (49.3%). Participant numbers and reasons for non-participation are summarised in Figure 2.

The average age of the 197 women who participated in this study was 41.55 years of age (SD = 4.41; range 30 to 54 years). Further sample demographics are detailed in Table 3.

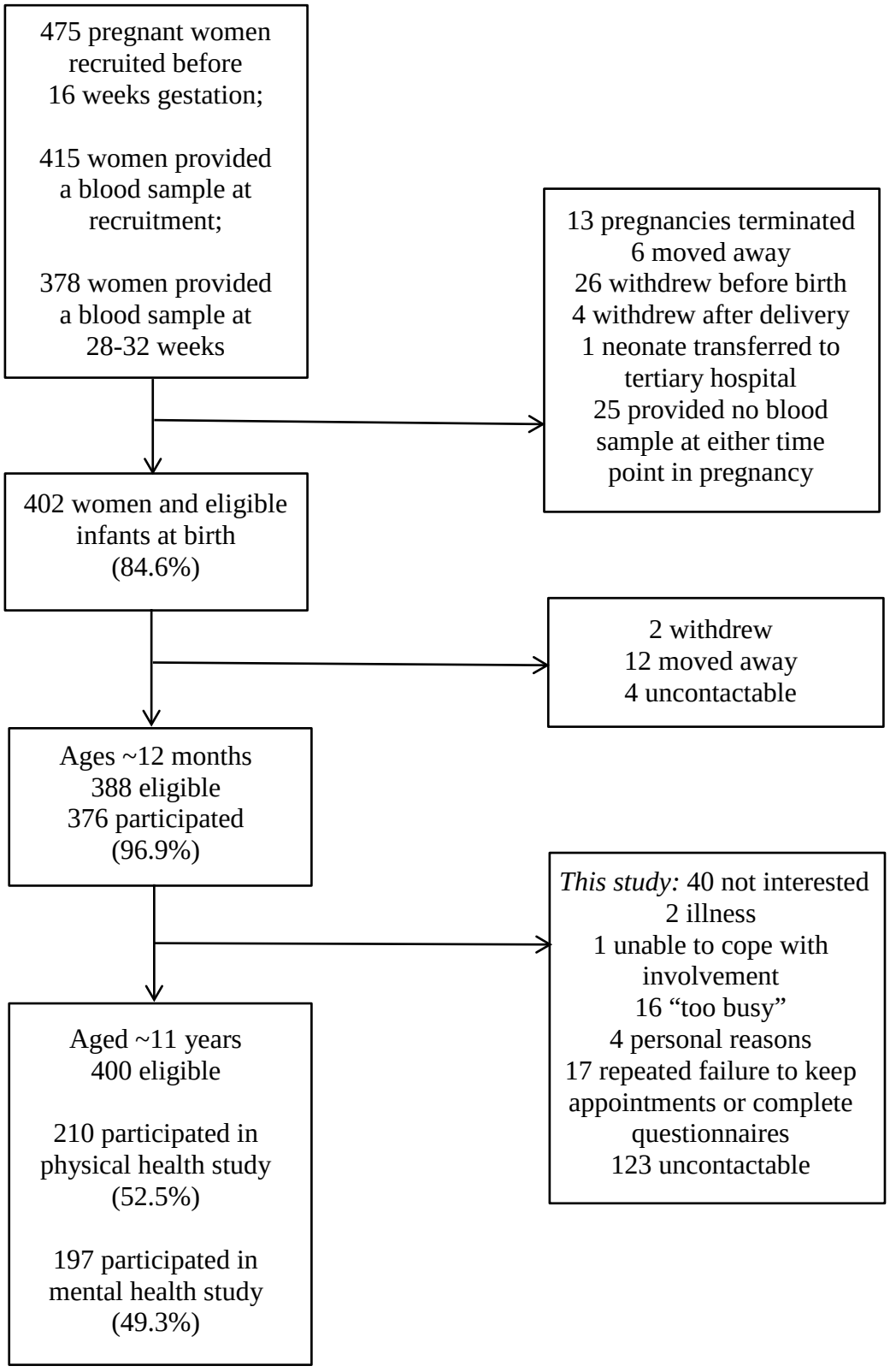

Figure 2. Summary of participants and non-participants in the present study.

Table 3

Whole Sample Demographics at Time of Participation (N = 197)

	n	%
Maternal age at time of participation		
30 to 34 years	10	5.08
35 to 39 years	55	27.92
40 to 44 years	83	42.13
45 to 50 years	42	21.32
51 to 54 years	7	3.55
Current marital status		
Married/domestic partnership	168	85.28
Separated/divorced	21	10.66
Single	7	3.55
Widowed	1	0.51
Country of birth		
Australia	166	84.26
United Kingdom	6	3.05
New Zealand	3	1.52
Ireland	3	1.52
Scotland	1	0.51
USA	1	0.51
Hong Kong	1	0.51
Bosnia	1	0.51
No response	15	7.61
Education		
Primary school	1	0.51
Completed secondary school (Years 7 to 11)	55	27.92
Completed secondary school (Year 12)	44	22.33
TAFE/Trade	45	22.84
Undergraduate	35	17.77
Postgraduate	17	8.63

Table 3 Continued

	n	%
Employment		
Professional/Managerial	50	25.38
Community/Personal Services	41	20.81
Clerical/Administrative	24	12.18
Customer Service	21	10.66
Home Duties	20	10.15
Technical/Trade	13	6.60
Machinery Operators/Labourers	13	6.60
Student	5	2.54
Not currently working	5	2.54
Not reported	5	2.54
Smoker		
No	147	74.62
Yes	41	20.81
No response	9	4.57
Number of living children at time of participation		
1	9	4.57
2	86	43.65
3	53	26.90
4	38	19.29
5	5	2.54
6 to 9	6	3.05

2.2 Measures

Measures used in the present study included a perinatal history proforma and standardised assessments of perinatal grief, depressive episodes, and personality disorders.

2.2.1 Perinatal history proforma. Being primarily a study of perinatal grief experiences in community-based women, perinatal histories were sought via self-report as part of the clinical interview process. Although by extension this likely incorporated recall bias into the research design, it was considered important that the research counter any sense of disenfranchised grief by ascertaining women's own perspectives on perinatal loss, irrespective of clinical confirmation or recognition of the pregnancy. Such an approach also concurs with methods observed in population-based research in perinatal loss (Ammon Avalos et al., 2012; Maconochie et al., 2007; Wang et al., 2003).

A standard interview proforma was used to obtain women's self-reported perinatal histories (see Appendix C). Women were asked their date of birth; their living children's dates of birth and genders; and if they had experienced any perinatal loss/es. Note that any loss/es did not have to be in relation to the original pregnancy by which the woman enrolled in the wider VIP study; rather all experienced perinatal loss/es were recorded across the woman's lifetime.

Where women reported loss/es, then type and date of loss, gestational age at time of loss, and marital status at time of loss was recorded for each loss. Where women were unable to recall an exact date of loss, they were supported to indicate a more specific date with probing questions specific to each woman (e.g., "Was that loss between the births of your other two children?", "What role were you working in at that time?", or "How old do you think you were you at that time?"). Dates were then calculated from these estimates such that where women reported losses per month (e.g., "June 2005"), this was entered as the monthly median point (June 15th 2005).

Where women reported multiple losses, these were acknowledged separately in frequency counts. Where a participant reported multiple losses, 'time since loss' was

calculated as time since most recent loss, as per population-based research examples (Shreffler, Greil, & McQuillan, 2011).

2.2.2 Assessment of perinatal grief. Various quantitative measures of grief symptomatology were considered in the design of this research, as identified in literature searches and published compendiums (Horrocks, 2006; Kristjanson et al., 2005). Scales considered were the Inventory of Complicated Grief (ICG; Prigerson, Maciejewski, et al., 1995), Texas Revised Inventory of Grief (TRIG; Faschingbauer, 1981), Perinatal Bereavement Scale (PBS; Theut et al., 1989), Perinatal Bereavement Grief Scale (PBGS; Ritsher & Neugebauer, 2002), Perinatal Grief Intensity Scale (PGIS; Hutti, dePacheco, & Smith, 1998), and the Perinatal Grief Scale (PGS) long and short versions (Potvin et al., 1989; Toedter, Lasker, & Alhadeff, 1988).

The TRIG (Faschingbauer, 1981) and ICG (Prigerson, Maciejewski, et al., 1995) are two of the most widely utilised measures to assess grief symptomatology (Kristjanson et al., 2005). The 21-item TRIG is designed to measure pathological grief at two time points; immediately after death and at time of data collection. Kristjanson et al.'s (2005) review recommended that clinicians, counsellors, and health care professionals use the ICG as a complicated grief screening tool in practice, however research priorities for this field include that standardised measures specific to perinatal loss are used (Brier, 2008; Geller et al., 2004; Kristjanson et al., 2005). Research has demonstrated that use of a non-specific grief measure such as the ICG does not adequately identify cases of complicated perinatal grief (Bennett et al., 2005; Bennett et al., 2008; McSpedden, 2014).

Considering perinatal-specific measures, the PBS was designed by Theut et al. (1989, p. 635) to determine "whether parents who have experienced a late perinatal loss (stillbirth or neonatal death) display more unresolved grief during a subsequent pregnancy" as compared to miscarriage. As such, the PBS was considered not the most suitable scale for the present research with community-dwelling women expected to report different types of loss and different gestational ages at time of loss.

Similarly, the 14-item PGIS was developed by Hutti et al. (1998) to predict intensity of grief response to early pregnancy loss. Whilst PGIS subscales such as 'Reality of the Pregnancy and Baby Within' and 'Ability to Confront Others' may have been interesting to study in the present sample, the sample was expected to have experienced losses in a wide range of gestational ages, and thus the PGIS was removed from further consideration.

The 15-item PBGS assesses grief following reproductive loss with a focus on yearning and preoccupation with the deceased (Ritsher & Neugebauer, 2002). Although these symptoms are key components of PCBD (APA, 2013), the present research sought to assume a wider focus than the singular foci of yearning and preoccupation.

The long and short versions of the PGS (Potvin et al., 1989; Toedter et al., 1988) thus remained for consideration. The PGS offered numerous advantages over other measures of perinatal grief symptomatology, including its suitability for heterogenous samples of types of loss and gestational age, its utility in a range of settings (including clinical, research, and community settings), its consideration of perinatal loss as a biopsychosocial experience, and its inclusion of three specific subscales of loss that seem ostensibly relevant to mental health – Active Grief, Difficulty Coping, and Despair (Adolfsson, 2011; Hunfeld et al., 1993). The PGS has been used widely in

research, including with culturally and linguistically diverse samples to assess the impact of miscarriage, stillbirth, termination, and adoption (Adolfsson & Larsson, 2006; Capitulo, Ramirez, Grigoroff-Aponte, & Vahey, 2010; Kulathilaka et al., 2016; Maniatelli et al., 2017; Yan, Tang, & Chung, 2010).

As compared to the 104-item version, the PGS authors recommend the 33-item short version of the PGS for efficiency in research (Potvin et al., 1989). The 33-item PGS has been used widely in research and is regarded as psychometrically sound; Cronbach's alpha is cited by the scale's authors as .95 (Potvin et al., 1989). Research has supported construct validity of the PGS, concurrent validity when compared with the Symptom Checklist-90 (SCL-90; Derogatis, Rickels, & Rock, 1976) and Beck Depression Inventory (BDI; Beck, Steer, & Brown, 1996), and convergent validity with distress measures (Kristjanson et al., 2005; Lai, Chung, Lee, Kong, & Lok, 2013; Toedter et al., 2001).

Thus the 33-item short version of the PGS was employed in the present research (see Appendix D). Participants rated the degree to which each item described their present thoughts and feelings specifically about perinatal loss/es. A 4-point Likert scale was used, from 1 (*not at all)* to 5 *(very much).* Items assessed affective, social, cognitive, and somatic domains such as *"I feel empty inside", "I feel I have adjusted well to the loss", and "I blame myself for the baby's death"*. Total PGS scores range from 33 to 165, with the PGS creators stating that higher scores indicate more intense grief (Potvin et al., 1989).

After reverse coding selected items (see Appendix E), responses were totalled to form three subscales each with a possible range of 11 to 55:

- Active Grief (a representation of sadness, missing the baby, and crying for the baby).
- Difficulty Coping (difficulty dealing with usual activities and people; withdrawal; low mood).
- Despair (worthlessness; hopelessness).

Average Cronbach alphas for Active Grief, Difficulty Coping, and Despair have been reported as .92, .89, and .88 respectively (McSpedden, 2014; Toedter et al., 2001).

PGS scores have been used for normative purposes to indicate the presence of a clinical degree of distress symptomatology. Total PGS scores equal to or higher than 91 are widely used as a clinical cut-off, with cut-offs for the subscales reported as 34 for Active Grief; 30 for Difficulty Coping; and 27 for Despair (Toedter et al., 2001).

The PGS was purposefully designed with an ordinal tripartite structure. Toedter et al. (2001) stated that means for each subscale (Active Grief, Difficulty Coping, and Despair) can be expected to be progressively smaller whereby "analyses have supported the idea that they represent increasingly severe responses to grief" (p. 408). The Active Grief subscale was designed to be more indicative of acute grief responses, particularly in the immediate aftermath of loss. Difficulty Coping and Despair were designed to indicate higher risk for poorer long-term outcomes. Subsequent research has shown that higher scores on Difficulty Coping and Despair subscales are strong predictors of longer-term difficulties adapting to perinatal grief (Lasker & Toedter, 1991; Toedter et al., 2001).

However it is important to note that the PGS is not an indicator of complicated grief per se. The PGS has been shown to distinguish between grief and depression

(making it particularly suitable for the present research), however it does not clinically indicate the presence of complicated grief in the form described in *DSM-5* as PCBD (McSpedden, Mullan, Sharpe, Breen, & Lobb, 2017). Although measuring levels of women's active grief, difficulty coping, and despair via items such as *"I very much miss the baby"*, it notably does not explicitly measure the core PCBD diagnostic criteria of separation distress (symptoms of yearning/longing and preoccupation). As explained earlier, to the author's knowledge there currently exists no preferable option for assessing longer-term complications in a heterogenous sample of women who have experienced perinatal grief. As such in the present study PGS scores are conceptualised as representing one's difficulty accommodating grief, as distinct from a clinical diagnosis of complicated grief. Hereafter, acknowledging the conceptual points above, higher scores on the PGS in this study are said to indicate as the PGS authors originally intended; more intense perinatal grief.

2.2.3 Assessment of Major Depressive Disorder. Psychiatric symptomatology was assessed via mental health interviews with participants. Mental health interviews have been used extensively in epidemiological research and have been shown to result in participants feeling positive and valued as a participant (Surkan, Steineck, & Kreicbergs, 2008).

Lifetime history of depressive episodes was identified using a semi-structured clinical interview. The Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Non-Patient edition (SCID-I/NP; see Appendix F) was completed with each participant (First et al., 2002). Women were assessed for a range of *DSM-IV-TR* mood disorders, including MDD, minor depression,

bipolar disorder, dysthymia, mood disorder due to a general medical condition, and substance induced mood disorder, with the focus for the analysis remaining on episodes of MDD. Information regarding age of onset, duration of illness, hospitalisation, psychotropic medication use, and professional diagnoses was also gathered from each woman to supplement the clinical interview and improve specificity of timing and nature of depressive episodes. Use of the SCID-I/NP enabled identification of women categorised as *de novo* cases if there was no pre-existing MDD and symptoms met diagnostic criteria for *DSM-IV-TR* MDD after perinatal loss (APA, 2013).

As opposed to versions designed for use with psychiatric inpatients and patients with psychosis, the Non-Patient edition is designed to be used with research/community samples (First & Gibbon, 2004). The SCID-I/NP uses a clinical interview proforma, with various diagnostic hypotheses being successively tested via questions that elicit relevant diagnostic information (First & Gibbon, 2004). The procedure involves progressing through questions in sequential order, the goal being to elicit the necessary information to permit decision on whether criteria are met (see Appendix F).

Thus each participant in this study was interviewed beginning with the SCID-I/NP overview section to seek demographic information, education and work history, and a broad history of illness and treatments, which built rapport and facilitated basic timelines. The more specific SCID-I/NP modules were then utilised to assess lifetime and current diagnostic mood disorders (First & Gibbon, 2004).

The SCID-I is regarded as the 'gold standard' clinical interview tool (Stuart et al., 2014). Psychometric properties have been investigated in inpatient, outpatient, and community settings (Lobbestael, Leurgans, & Arntz, 2011; Zanarini et al., 2000).

When used to assess *DSM-IV* MDD, alpha coefficients range from .61 to .80 (Zanarini et al 2000; Lebbestael et al., 2010).

2.2.4 Assessment of personality disorders. The Structured Clinical Interview for *DSM-IV* Axis II PDs (SCID-II) by First et al. (1997) was employed to assess personality disorders (see Appendix G). Paranoid, Schizoid, Schizotypal, Passive-Aggressive, Depressive, Histrionic, Narcissistic, Borderline, Antisocial, Avoidant, Dependent, and Obsessive-Compulsive PDs and PD Not Otherwise Specified were assessed categorically as the presence or absence of each PD (First et al., 1997; First & Gibbon, 2004). Hence the present research represents the use of the current diagnostic system at the time of data collection, that being *DSM-IV-TR* (APA, 2000).

The SCID-II permitted determination of whether criteria for personality disorders were met. Each PD was evaluated in turn, with the presence or absence of each diagnostic criterion rated (1 = not present; 3 = criterion met for pathological, persistent, and pervasive personality disorder trait). Diagnostic criterion was only met where the question was answered with a convincing elaboration or example that met guidelines provided in the SCID-II, and/or where the participant demonstrated the behaviour during the interview (First & Gibbon, 2004).

As with the SCID-I, the SCID-II is regarded as the highest quality tool for identifying PDs in psychiatric research (Stuart et al., 2014). Research investigating psychometric properties of the SCID-II suggests the tool has strong test-retest reliability, as well as high sensitivity, moderate specificity, and low false-positive rates (Ekselius, Lindström, Knorring, Bodlund, & Kullgren, 1994; First et al., 1995; First &

Gibbon, 2004; Germans, Van Heck, Masthoff, Trompenaars, & Hodiamont, 2010; Nussbaum & Rogers, 1992).

2.3 Procedure

Participants attended the VIP Study centre for an appointment at which various physical health and anthropometric measures were taken from both mother and child for studies nested within the VIP. The psychiatric component of the interview was then conducted in private with only the mother and interviewer present. Maternal pregnancy history was recorded, then the SCID I/NP and SCID-II were administered. Where preference or need for ongoing psychiatric support was identified, participants were offered appropriate referrals in line with duty of care. Interviews lasted approximately 30 to 40 minutes. All interviews were conducted after training using live and videotaped training interviews, under the supervision of a psychiatrist.

All procedures performed in this research were in accordance with the ethical standards of the institutional research committees (see Appendix H). The study received approval from Barwon Health Human Research Ethics Committee (reference 01/43_E2) and Deakin University Human Research Ethics Committee (reference 2013-116), with notification to the Victoria University Human Research Ethics Committee (see Appendix I). Written informed consent was obtained from all individual participants in the study, as per the Participant Information and Consent Form in Appendix J.

2.4 Design and Analysis

The study used a retrospective cohort design to investigate perinatal grief as the main dependent/criterion variable. Independent/predictor variables included *de novo* MDD as per SCID-I/NP, and presence/absence of personality disorders as per SCID-II.

Statistical analyses were performed using SPSS Statistics for Windows (version 23; IBM Corp, Armonk, NY). Differences in characteristics between the groups were determined using Kruskal–Wallis for non-parametric continuous variables, and for discrete variables chi-square tests or Fisher's exact test when expected cell counts were less than five. Logistic regression was used to calculate odds ratios (OR) with 95% confidence interval (95% CI) to determine the association between psychiatric symptomatology and perinatal grief, as per current epidemiological research examples (Currier et al., 2006; Sanna et al., 2014; Williams et al., 2015).

Chapter 3: Results

3.1 Data Screening

The major dependent/criterion variables (PGS total score; Active Grief subscale total; Difficulty Coping subscale total; and Despair subscale total) were assessed with regards to the assumptions required for planned tests of group differences (ANOVA procedures) and prediction (regression). Assumptions included accuracy of data entry, normality, outliers, sample size/minimum expected frequencies, and multicollinearity (Allen, Bennett, & Heritage, 2014; Pallant, 2016). Whilst accuracy of data entry, normality, and outliers are reported herewith, the remaining test-specific data screening procedures are reported subsequently as part of the test procedures results themselves.

Upon conclusion of data entry, the SPSS file was checked for accuracy of data entry using the Frequencies and Descriptives functions. No out of range data was detected. No missing data was detected on the primary variables of interest (SCID-I markers; SCID-II markers; PGS scores and subscale scores). Missing data was detected on secondary variables such as education and smoking status; this was random and not indicative of a pattern, thus data was to be excluded pairwise where such data was included in analyses (Pallant, 2016).

Normality and outliers were first assessed together via SPSS Explore procedure for four key variables: PGS total, and three PGS subscale scores (Active Grief, Difficulty Coping, Despair). Shapiro-Wilks statistics suggested all four variables were not normally distributed. Visual inspection of histograms with normal curves confirmed positive skew in all four variables, and boxplots suggested this was likely due to the influence of the same case as an outlier in all four variables. Calculation of Z-scores confirmed this case was an outlier on all four key variables ($z > 3.29$). After

considering options presented in the statistical literature, the case was winsorised to the largest score +1 on each variable, thus still retaining its position as the upper score on each variable whilst reducing its extreme nature (Tabachnick & Fidell, 2013). After winsorising was performed, no outliers were detected. Re-examination of normality statistics and histograms confirmed a mild positive skew on all variables which was considered representative and thus acceptable for analysis to proceed. However in exercising caution, the non-parametric alternative to the planned ANOVAs (Kruskal-Wallis test) was used due to the mild positive skew and the group sizes at times being small and unequal (Hills, 2011).

3.2 Perinatal Losses

Extending from the overarching sample descriptives presented in Table 3, the data was assessed as a function of self-reported perinatal losses. As detailed in Table 4, 41.62% of the sample reported experiencing perinatal loss. Of the 197 women interviewed, miscarriage was the most common type of loss with 69 women reporting having had miscarriages (35.03% of the entire sample). Fourteen women (7.11%) reported having had elective terminations; five women ectopic pregnancies (2.54%); and four women respectively medical termination and stillbirth (2.03% respectively).

A Kruskal Wallis test confirmed there was no significant difference between the age of women who reported perinatal loss (M = 41.23, SD = 4.35) and the age of those who did not (M = 41.78, SD = 4.49), χ^2 (1, N = 197) = 0.65, p = .42. Non-significant differences were also observed in number of perinatal losses as a function of marital status (χ^2 (4, n = 82) = 3.67, p = .45); education level (χ^2 (5, n = 82) = 3.41, p = .64);

Table 4

Self-Reported Perinatal Loss in Entire Sample (N = 197)

	n	% of entire sample
Experienced perinatal loss (*N* = 197)		
Yes	82	41.62
No	115	58.38
Proportions of total women who experienced types of loss (*N* = 197)		
Miscarriage	69	35.03
Stillbirth	4	2.03
Elective termination	14	7.11
Medical termination	4	2.03
Ectopic pregnancy	5	2.54

and occupation (χ^2 (9, *n* = 79) = 6.11, *p* = .73). No significant difference was observed between the mean number of losses reported by smokers (*M* = 1.52, *SD* = 0.81) and non-smokers (*M* = 1.78, *SD* = 1.09), χ^2 (1, *n* = 79) = 0.90, *p* = .34. Thus with demographic factors such as smoking status, marital status, education, and occupation seemingly not impacting on number of perinatal losses in this sample, analysis proceeded accordingly without further inclusion of these as covariates. This was particularly important given the desire to guard against unnecessary inclusion of covariates in analyses to retain power and promote generalisability of the findings with the current sample size (Pallant, 2016). Maternal age at time of loss however remained

a potential confounder as observed in previous research (e.g., Maconochie et al., 2007) and thus was retained in the later model.

Table 5 presents closer inspection of the data from the 82 women who reported perinatal loss. As seen in Table 5, the total number of losses reported by individual women ranged from a single loss (58.54% of those who had experienced perinatal loss) to five losses (2.44%). In total, the 82 women reported experiencing 131 perinatal losses. The largest proportion represented in these multiple losses was miscarriage (n = 102 total losses, 77.86%), followed by elective termination (n = 16, 12.21%), ectopic pregnancy (n = 5, 3.82%), and stillbirth and medical terminations (n = 4 each; 3.05% each). Although not unexpected, the small proportions of women in the sample experiencing ectopic pregnancy, medical terminations, and stillbirth precluded further analyses as a function of loss type beyond PGS score (see section 3.3).

Within the perinatal loss group, there was no significant difference between the number of losses experienced by median split older (M = 1.61, SD = 1.08) and younger women (M = 1.61, SD = 0.78), t (80) = 0.03, p = .97. The average gestational age at time of loss was 9.60 weeks (n = 131 losses, SD = 4.12, range 4 to 30 weeks), with first trimester losses being the most common in this sample (n = 102; 2nd trimester n = 24; 3rd trimester n = 5). A Kruskal-Wallis test indicated that although women with third trimester losses appeared to report somewhat higher PGS scores, there were no statistically significant differences between PGS total scores as a function of trimester of loss, χ^2 (2) = 5.69, p = .06. Further, no significant relationship was observed between gestational age at time of loss and PGS total score, Pearson's r (129) = .14, p = .12.

Table 5

Total Perinatal Loss Experiences as a Function of Type and Gestation

	n	%
Number of perinatal losses (*n* = 82 women)		
One	48	58.54
Two	25	30.49
Three	4	4.88
Four	3	3.66
Five	2	2.44
Total types of perinatal losses (*n* = 131 losses)		
Miscarriage	102	77.86
Elective termination	16	12.21
Ectopic pregnancy	5	3.82
Stillbirth	4	3.05
Medical termination	4	3.05
Trimester of perinatal loss (*n* = 131 losses)		
First trimester	102	77.86
Second trimester	24	18.32
Third trimester	5	3.82
Gestation at time of perinatal loss (*n* = 131 losses)		
0 – 4 weeks	2	1.53
4.1 – 8 weeks	56	42.75
8.1 – 12 weeks	53	40.46
12.1 – 16 weeks	13	9.92
16.1 – 20 weeks	3	2.29
20.1 – 24 weeks	3	2.29
24.1 – 28 weeks	0	0.00
≥ 28.1 weeks	1	0.76

Where a participant reported multiple losses, as per previous population-based research, 'time since loss' was calculated as time since most recent loss (Shreffler et al., 2011). Being a community-based study that did not purposefully recruit women who had experienced recent perinatal loss, weeks since most recent loss was expected to vary widely in this study. Time since most recent loss did range widely, from a minimum of 1 week prior to interview to a maximum of 1465 weeks (≈28 years). Average time since most recent loss was 572.24 weeks (≈11.00 years, *SD* = 302.84, *Mdn* = 577 weeks, *n* = 82 women).

Given the wide variation in time since most recent loss, the variable 'weeks since loss' was divided into quartiles and average PGS total scores were examined as a function of quartile grouping to ascertain any potential group differences in grief scores. Ranges, medians, and mean total PGS scores for the quartiles were as follows: Quartile 1, 0 to 367 weeks since most recent loss (*n* = 20, *M* = 53.80, *SD* = 18.96, *Mdn* = 51); Quartile 2, 368 weeks to 577 weeks (*n* = 21; *M* PGS total = 64.14, *SD* = 23.67, *Mdn* = 69); Quartile 3, 578 weeks to 727 weeks (*n* = 21; *M* PGS total = 48.10, *SD* = 14.95, *Mdn* = 43); and Quartile 4, 728+ weeks (*n* = 20; *M* PGS total = 55.75, *SD* = 19.14, *Mdn* = 53). That is, mean PGS total scores appeared to vary as a function of time since loss. Total PGS scores were highest in the second quartile of time since loss and lowest in the third quartile of time since loss. A Kruskal Wallis non-parametric test however showed that 4 quartile groups did not differ on PGS total score, χ^2 (3, *n* = 82) = 5.15, *p* = .16. Pearson's *r* showed no significant relationship between time since most recent loss and PGS total score, *r* = -.06, *n* = 82, *p* = .60.

3.3 Perinatal Grief

For the 82 women who reported experiencing perinatal losses, PGS total scores were calculated in addition to the three subscale total scores (Active Grief, Difficulty Coping, and Despair). Results showed that for the 82 women who reported loss, the average PGS total score was 55.46 (*SD* = 19.95; range 33 to 105). The average subscale scores were Active Grief *M* = 21.05 (*SD* = 7.95; range 11 to 41); Difficulty Coping *M* = 17.24 (*SD* = 6.41; range 11 to 35); and Despair *M* = 17.23 (*SD* = 6.93; range 11 to 34). There was no significant relationship between the total number of perinatal losses experienced by individuals and PGS total scores (Pearson's $r = .09$, $n = 82$, $p = .45$). Likewise, there was no significant relationship between maternal age at time of loss and PGS scores (Pearson's $r = .01$, $n = 82$, $p = .93$).

Total PGS scores as a function of perinatal loss type are presented in Table 6. Although stillbirth (*M* = 78.00, *SD* = 21.74) and elective terminations (*M* = 66.50, *SD* = 16.36) appeared to be associated with somewhat higher PGS total scores than the other three loss types, the small group numbers of 4 for stillbirth and 5 for elective terminations (and 4 for medical terminations) preclude any firm conclusions. In respect of small and unequal group sizes, a non-parametric Kruskal-Wallis test was conducted to assess between group differences in PGS total scores as a function of loss type. Results showed overall, there were differences in PGS total scores among the five perinatal loss type groups, χ^2 (4, $n = 131$) = 10.36, $p = .04$, $\eta^2 = .08$. Pairwise comparisons were conducted using the Mann-Whitney test with adjusted *p* values to guard against undue inflation of family-wise error rate (Field, 2013). Pairwise comparisons with adjusted p-values showed although women who experienced stillbirth and elective termination reported higher PGS total scores than those who experienced

other forms of losses, pairwise comparisons were not significant and thus no women who experienced any one loss type reported higher PGS scores than any other loss type.

Table 6

Average Perinatal Grief Scale Scores as a Function of Loss Type

	Total PGS scores		X^2	*p*
	M	*SD*		
Miscarriage (*n* = 102)	54.38	20.08		
Stillbirth (*n* = 4)	78.00	21.74		
Elective termination (*n* = 16)	66.50	16.36	10.36	.04
Medical termination (*n* = 4)	55.75	19.62		
Ectopic pregnancy (*n* = 5)	54.00	29.22		

Previous research has established that a total PGS score of 91 or above indicates clinically significant grief symptoms (McSpedden, 2014; Potvin et al., 1989; Toedter et al., 2001). To explore this, the women who reported experiencing perinatal loss in the present study were divided into those who did and did not continue to experience clinically significant grief symptoms using a cut-off of 91 and above.

Results showed that 6.49% of women (*n* = 5) in the current sample reported PGS scores equal to or higher than the clinical cut-off of 91 (range 98 to 105, *M* = 101.20, *SD* = 3.11) after a median 9.05 years post-loss (range 1.34 to 15.03 years post-loss, *M* = 8.77, *SD* = 4.88). This was compared to 77 women (93.90%) who scored under the clinical cut-off of 91 (*M* = 52.49, *SD* = 16.65, range 33 to 85) after a median 10.63 years post-loss (range 0 to 24.02 years post-loss, *M* = 10.53 years, *SD* = 5.34).

Given the unequal nature of these groups based on a clinical cut-off of 91, it was decided to divide the group based on median split into 'High Grief' (high scores on PGS total) and 'Low Grief' (low scores on PGS total). This procedure resulted in two equal sized groups which could be then compared to ascertain the potential role of psychiatric disorders in coping with perinatal grief.

Means and standard deviations for PGS total score and the three subscales as a function of High/Low Grief group are presented in Table 7, as well as the results of Kruskal Wallis tests confirming significant differences between the median split High and Low Grief groups.

Table 7

Mean Perinatal Grief Scale and Subscale Scores for High and Low Grief Groups

Scale/subscale	*M* for 'Low Grief' group (*n* = 42)	*M* for 'High Grief' group (*n* = 40)	X^2	*p*
PGS Total	39.05 (5.67)	72.70 (14.07)	60.86	<.001
Active Grief	15.02 (4.40)	27.28 (5.77)	53.11	<.001
Difficulty Coping	12.38 (1.62)	22.35 (5.51)	56.90	<.001
Despair	11.55 (1.23)	23.20 (5.17)	62.94	<.001

Note: Figures in parentheses are standard deviations

3.4 *de novo* Major Depressive Disorder

For women who reported perinatal loss (n = 82), age of onset for episodes of MDD were calculated via the SCID-I NP interview (First et al., 2002). Age of onset of MDD was then compared with age at which the woman experienced perinatal loss, to identify *de novo* cases of depressive illness that developed after any perinatal loss.

Analysis of patterns between occurrence of perinatal loss and onset of MDD showed that 21 women who experienced perinatal loss subsequently developed MDD (25.61%). That is, 1 in 4 women who experienced perinatal loss went on to later experience a first episode of MDD.

Of the remaining 61 women, 10 reported pre-existing MDD prior to perinatal loss; 16 women reported either pre-existing or other *de novo* disorders that are beyond the scope of this study (such as Bipolar Disorder, PTSD, and Phobias); and 35 women reported no Axis I or II symptomatology either before or after experiencing perinatal loss.

Hence from this analysis, a dichotomous variable was formed to represent women who developed *de novo* MDD after experiencing perinatal loss (n = 21, dummy coded as 1) as distinct from women who did not develop *de novo* MDD after perinatal loss (n = 61; dummy coded as 0).

PGS total scores were assessed as a function of *de novo* MDD group. As shown in Table 8, women who developed *de novo* MDD after perinatal loss had higher PGS total and subscale scores than women who did not develop *de novo* MDD. Kruskal-Wallis test results confirmed that compared to women who did not develop *de novo* MDD, women who developed *de novo* MDD reported significantly higher PGS total scores, χ^2 (1, n = 82) = 10.25, p = .001, η^2 = .13; Active Grief subscale scores, χ^2 (1, n =

82) = 7.67, p = .006, η^2 = .09; Difficulty Coping subscale scores, χ^2 (1, n = 82) = 7.20, p = .007, η^2 = .09; and Despair subscale scores, χ^2 (1, n = 82) = 9.29, p = .002, η^2 = .11.

Table 8

Mean Perinatal Grief Scores (n = 82) as a Function of de novo MDD Group

Scale/Subscale	Developed *de novo* MDD (n = 21)	Did not develop *de novo* MDD (n = 61)	X^2	p
PGS Total	66.57	51.64	10.25	.001
	(18.31)	(19.17)		
Active Grief	25.19	17.63	7.67	.006
	(7.03)	(7.80)		
Difficulty Coping	20.43	16.15	7.20	.007
	(6.65)	(6.00)		
Despair	20.95	15.95	9.30	.002
	(6.65)	(6.59)		

Note: Figures in parentheses are standard deviations

3.5 Personality Disorders

Of the 197 women who participated in the entire sample, 47 (23.86%) met criteria for at least one personality disorder as assessed via the SCID-II (First et al., 1997). As shown in Table 9, similar proportions of women appeared to meet criteria for PDs in the perinatal loss and non-loss groups. A Pearson's chi-square test of contingencies confirmed that there was no significant difference in the proportions of

women meeting criteria for PDs in the perinatal loss and non-loss groups, χ^2 (1, *n* = 197) = 0.04, p = .85, ϕ = -.01.

Table 9

Results of Chi-Square Assessing Perinatal Loss by Personality Disorder Group

	Perinatal Loss	No Perinatal Loss
Met criteria for any personality disorder	*n* = 19 (23.2%)	*n* = 28 (24.3%)
Did not meet criteria for any personality disorder	*n* = 63 (76.8%)	*n* = 87 (75.7%)

Note. χ^2 = 0.04, p = .85. Numbers in parentheses indicate column percentages.

As seen in Table 9, of the 82 women reporting perinatal loss, almost one quarter met criteria for any personality disorder. Seven of these (36.8%) met criteria for a single PD; eight (42.1%) met criteria for two PDs; three (15.8%) met criteria for three PDs; and one woman (5.3%) met criteria for 4 PDs.

The most predominant PD was Borderline with 11 women in the perinatal loss group meeting criteria for this PD; followed by Avoidant (*n* = 5 women); OCPD (*n* = 4), Passive-Aggressive (*n* = 4), Paranoid (*n* = 4); PD NOS (*n* = 3); Antisocial (*n* = 2); Depressive (*n* = 1); Dependent (*n* = 1), and Schizotypal (*n* = 1) PDs. No women in the perinatal loss group met criteria for Schizoid, Narcissistic, or Histrionic PD.

Thus a dichotomous variable was created for all participants which indicated the presence of any PD (dummy coded 0 = no, 1 = yes) which could be used either as a grouping variable or in regression analyses.

PGS total scores were assessed as a function of this dichotomous PD variable. As seen in Table 10, in the perinatal loss group (n = 82) women who met criteria for any PD had higher PGS total and subscale scores than women who did not meet criteria for any PD. Kruskal-Wallis test results confirmed that compared to women who did not meet PD criteria, women who met criteria for any PD reported significantly higher PGS total scores, χ^2 (1, n = 82) = 10.25, p = .001, η^2 = .13; Active Grief subscale scores, χ^2 (1, n = 82) = 9.94, p = .001, η^2 = .12; Difficulty Coping subscale scores, χ^2 (1, n = 82) = 9.97, p = .001, η^2 = .12; and Despair subscale scores, χ^2 (1, n = 82) = 7.60, p = .001, η^2 = .09.

Table 10

Mean Perinatal Grief Scores (n = 82) as a Function of Any Personality Disorder

Scale/Subscale	PD group (n = 19)	No PD group (n = 63)	X^2	p
PGS Total	69.47	51.24	10.25	.001
	(23.02)	(16.97)		
Active Grief	26.42	19.43	9.94	.001
	(8.57)	(7.05)		
Difficulty Coping	21.74	15.89	9.97	.001
	(7.96)	(5.22)		
Despair	21.58	15.92	7.60	.001
	(8.48)	(5.85)		

Note: Figures in parentheses are standard deviations

3.6 Predictors of Perinatal Grief Scores

Logistic regression procedures were used to assess whether *de novo MDD* (dichotomous variable; dummy coded no = 0, yes = 1) and *any personality disorder*

(dichotomous variable; dummy coded no = 0, yes = 1) were significant predictors of grief total and subscale scores (dichotomous variable; dummy coded low = 0, high = 1).

Although earlier analyses suggested no significant relationships in this study between PGS scores and number of perinatal losses, gestational length, maternal age, or time since loss, these variables were included in regression procedures in respect of sample variability and to promote comparability between the present findings and those of Kulathilaka et al. (2016) and McSpedden (2014).

Number of perinatal losses was recoded as a dichotomous variable representing 'multiple losses' (dummy coded no = 0, yes = 1). Maternal age at time of most recent loss was median split into younger and older (dummy coded younger = 0, older = 1). Weeks since most recent loss was recoded dichotomously based on median split (dummy coded 0 = more distant loss, 1 = more recent loss), and gestational length was re-coded dichotomously as early or late loss (dummy coded <12 weeks = 0; 12+ weeks = 1).

Because the stepwise procedure has been criticised for potentially permitting undue influence of random variation in the model (Tabachnick & Fidell, 2013), forced entry method was chosen where all predictor variables were tested in one block to assess unique predictive ability whilst controlling for the effects of other predictors in the model (Pallant, 2016). Logistic regression was used to calculate odds ratios (OR) with 95% confidence interval (95% CI) determine the associations between high/low perinatal grief and the predictor variables.

Logistic regression in particular holds the advantage of not making assumptions regarding the distribution of scores for the predictor variables (Pallant, 2016). However the procedure is sensitive to violations of the assumptions of sample size,

multicollinearity, and outliers; hence each assumption was assessed accordingly. The assumption of logit linearity was not required to be assessed with all predictors being dichotomous (Allen et al., 2014).

Sample size relates to generalisability of findings, with smaller samples potentially not being generalisable with other samples. Van Voorhis and Morgan (2007) present a formula for calculating desired sample size incorporating the number of predictor variables proposed: $n = 50 + m;$ where m equals number of predictor variables. Applying this formula to a design with 6 predictor variables shows a desired sample size of 56. Thus the current sample size of 82 was regarded as appropriate. In addition, it is recommended that logistic regression be performed only where minimum expected cell frequencies are 5 or greater; the proposed analysis met this requirement (Allen et al., 2014).

Multicollinearity was assessed amongst the dichotomous variables via Spearman's correlations for ordinal data. Results confirmed that the predictors were not strongly related with one another (intercorrelations between predictors ranged from 0.07 to 0.42). Hence with these correlations being well below .8, the assumption of multicollinearity was not violated (Tabachnick & Fidell, 2013).

Regression procedures are particularly sensitive to outliers (Pallant, 2016). Although the continuous variables of PGS total and the three PGS subscales had previously been screened for outliers before any analysis proceeded with one outlier subsequently winsorised, here the dichotomous variables were examined for outliers at this more specific stage of analyses. Outliers were assessed as part of the logistic regression procedure via Cook's Distance, DFbeta values, and zRedisual values,

showing that no outliers were present that would be expected to have an undue influence on the analyses (Allen et al., 2014).

Thus a binary logistic regression proceeded to predict high or low total grief scores for women who reported perinatal loss (n = 82). Grief scores were estimated from six predictor variables: The presence of any personality disorder; the development of *de novo* MDD following perinatal loss; multiple losses; recent loss; later pregnancy gestation; and older maternal age at time of loss.

The omnibus model for logistic regression analysis was statistically significant, χ^2 (df = 5, n = 82) = 16.54, p = .011. The model was 71% accurate in predicting grief score. Hosmer and Lemeshow test results confirmed that the model was a good fit for the data, χ^2 (df = 8, n = 82) = 3.00, p = .93.

As displayed in the coefficients in Table 11, inclusion of the variables Any Personality Disorder and *de novo* MDD significantly improved the model's predictive capability. The stronger of the two predictors was *de novo* MDD, with an Odds Ratio (OR) of 4.66. This indicated that women who developed MDD after perinatal loss were over 4.5 times more likely to score highly on a total measure of perinatal grief, than women who did not develop MDD after perinatal loss. The presence of any personality disorder was also a significant predictor, with an OR of 3.07. This indicates that women with any personality disorder were over three times more likely to score highly on a total measure of perinatal grief than women without personality disorders. History of multiple losses, advanced maternal age, more recent loss, and later gestational age were not significant predictors of total perinatal grief scores.

Table 11

Logistic Regression Coefficients for the Model Predicting Total Grief Score

	b	*SE*(*b*)	*p*	*Odds Ratio* [95% *CI*]
Constant	-1.00			
Any Personality Disorder	1.12	0.64	.077	3.07 [0.88, 10.69]
de novo MDD	1.54	0.62	.013	4.66 [1.39, 15.62]
Multiple losses	-0.63	0.55	.256	0.53 [0.18, 1.58]
More recent loss	0.17	0.54	.759	1.18 [0.41, 3.43]
Later gestational age	0.71	0.58	.220	2.03 [0.66, 6.28]
Older maternal age	0.61	0.56	.272	1.84 [0.62, 5.48]

Note. CI = confidence interval.

To further explore relationships between personality disorders, *de novo* MDD, and perinatal grief, the PGS subscales were more closely examined. Logistic regressions were conducted using median split Active Grief, Difficulty Coping, and Despair subscale scores (all dichotomous variables, dummy coded 0 = low; 1 = high). Given that history of multiple losses, advanced maternal age, more recent loss, and later gestational age were not significant predictors of total perinatal grief scores, these were removed from subscale logistic regressions to preserve power (Van Voorhis & Morgan, 2007).

For Active Grief, the omnibus model for logistic regression analysis was statistically significant, χ^2 (df = 2, n = 82) = 11.57, p = .003. The model was 70% accurate in predicting Active Grief score. Hosmer and Lemeshow test results confirmed

that the model was a good fit for the data, χ^2 (*df* = 1, *n* = 82) = 1.39, *p* = .50. As seen in the coefficients presented in Table 12, inclusion of the variables 'Any Personality Disorder' and '*de novo* MDD' significantly improved the model's predictive capability. Odds ratios showed that women who developed *de novo* MDD after perinatal loss (OR = 3.62), and women with any personality disorder (OR = 3.28), were over three times more likely to score highly on a measure of active perinatal grief total, than women without *de novo* MDD or personality disorders.

Table 12

Logistic Regression Coefficients for the Model Predicting Active Grief Subscale Score

	b	*SE*(*b*)	*p*	*Odds Ratio* [95% *CI*]
Constant	-0.68			
Any Personality Disorder	1.29	0.60	.032	3.62 [1.12, 11.73]
de novo MDD	1.19	0.60	.037	3.28 [1.08, 10.01]

Note. CI = confidence interval.

For Difficulty Coping, the omnibus model for logistic regression analysis was statistically significant, χ^2 (*df* = 2, *n* = 82) = 10.41, *p* = .005. The model was 68% accurate in predicting Difficulty Coping score. Hosmer and Lemeshow test results confirmed that the model was a good fit for the data, χ^2 (*df* = 1, *n* = 82) = 0.71, *p* = .70. As seen in the coefficients presented in Table 13 however, '*de novo* MDD' was the only significant predictor which statistically improved the model's predictive capability; women who developed MDD after perinatal loss were 3.5 times more likely to score

highly on a measure of difficulty coping with perinatal grief than women without *de novo* MDD. Women with any personality disorder were over 2.5 times more likely to score highly on a measure of difficulty coping with perinatal grief than women without personality disorders, however this predictor was not statistically significant in this sample ($p = .08$).

Table 13

Logistic Regression Coefficients for the Model Predicting Difficulty Coping Subscale Score

	b	*SE*(*b*)	*p*	*Odds Ratio* [95% *CI*]
Constant	-0.70			
Any Personality Disorder	1.01	0.58	.082	2.74 [0.88, 8.52]
de novo MDD	1.28	0.56	.023	3.60 [1.19, 10.87]

Note. CI = confidence interval.

For the final Despair subscale, the omnibus model for logistic regression analysis was statistically significant, χ^2 ($df = 2$, $n = 82$) = 10.98, $p = .004$. The model was 68% accurate in predicting grief score. Hosmer and Lemeshow test results confirmed that the model was a good fit for the data, χ^2 ($df = 1$, $n = 82$) = 2.00, $p = .37$. As seen in the coefficients presented in Table 14 however, 'Any Personality Disorder' was the only significant predictor which statistically improved the model's predictive capability; women with a personality disorder were over four times more likely to score highly on a measure of despair in perinatal grief than women without personality

disorders. Women who developed *de novo* MDD were over 2.5 times more likely to score highly on a measure of despair in perinatal grief than women who did not develop *de novo* MDD, however this predictor was not statistically significant in this sample ($p = .09$).

Table 14

Logistic Regression Coefficients for the Model Predicting Despair Subscale Score

	b	*SE*(*b*)	*p*	*Odds Ratio* [95% *CI*]
Constant	-0.49			
Any Personality Disorder	1.47	0.63	.019	4.36 [1.27, 14.97]
de novo MDD	0.96	0.57	.093	2.61 [0.85, 8.01]

Note. CI = confidence interval.

Chapter 4: Discussion

This research addressed gaps in the literature by examining relationships between perinatal grief, *de novo* depressive disorder, and personality disorders. The study aimed to determine proportions of women reporting perinatal losses; the proportion of women reporting the development of *de novo* Major Depressive Disorder (MDD) after perinatal loss; the average perinatal grief scores reported by women who developed *de novo* MDD and women with personality disorders; and whether there were relationships between *de novo* MDD, personality disorders, and perinatal grief scores.

Hypotheses one and two (that women who reported developing *de novo* MDD after perinatal loss and women with personality disorders would report more intense perinatal grief, as indicated by higher scores on the PGS) were both supported.

Hypothesis three (the presence of personality disorders and *de novo* MDD would act as significant risk factors for more intense perinatal grief) was supported. However as individual predictors, the predictive capacity of each differed depending on what PGS component (total, Active Grief, Difficulty Coping, or Despair) was being examined.

4.1 Perinatal Loss Rates

In the present study of 197 community-dwelling women, 82 (42%) reported experiencing perinatal loss. Those 82 women reported experiencing a total of 131 perinatal losses, the most predominant of which was miscarriage (35% of total losses), followed by elective terminations (7%), ectopic pregnancies (2.5%), and medical terminations and stillbirth (2% each).

As compared to previous research, the proportion of women reporting perinatal loss seemed higher at 42% of the total sample. A study by Gold et al. (2007) calculated that 31% of women in the sample experienced pregnancy loss. However Gold et al. utilised a retrospective cohort design with clinical data from the US National Comorbidity Study, and as such is likely to reflect a lower proportion than that observed in the current sample of community-dwelling women recruited from an antenatal clinic who self-reported perinatal losses.

When examining the proportional rate of as a function of loss type, both similarities and differences are evident between the present and previous findings. The proportion of women self-reporting ectopic pregnancy in this study (2.5%) aligns with incidence estimates of 2% from population-based epidemiological studies (Farquhar, 2005; Stulberg et al., 2013; Trabert et al., 2011).

Stillbirth incidence rates do vary per classification system, hence although ABS statistics suggest a stillbirth rate of around 0.3 to 0.7% (Froen et al., 2009), self-reported rates of stillbirth have been established as 1.1% in Hure et al.'s (2012) Australian study. Thus the present study's finding that 2% of self-reported perinatal losses were stillbirths seems higher, though must be interpreted with caution given the smaller group sizes.

There exists no official Australian data set for terminations, however incidence rates of 1.9% for terminations have been reported (Chan & Sage, 2005; Hargreaves et al., 2005). Similarly rates in the US have been estimated at 1.6 to 1.9%, Eastern Europe 4.3%, and Western Europe 1.2% (Sedgh et al., 2007). Recent analysis suggested a global rate of approximately 3.5% of women having terminations, with a 1.9% rate in Oceania (Sedgh et al., 2016). Hence the present study's proportions of 2% for medical terminations and 7% for elective terminations do not align with epidemiological

estimates from previous research, acknowledging that it is inherently difficult to directly compare epidemiological incidence rates with the currently observed proportions of loss self-reported by women.

It is difficult to interpret the observed proportions of the current sample reporting elective terminations due to difficulties establishing incidence rates of elective terminations. Terminations are thought to be one of the most common gynaecological procedures performed, yet with no official databases and complex moral and sociolegal issues involved, it is difficult to ascertain accurate rates (de Costa et al., 2015; Klemetti et al., 2012). In the absence of context, no firm conclusions can be drawn. However the present findings suggest that many more women self-report terminations than official incidence data captures. Indeed with terminations being described as hidden in shadows, it may be that the current observed proportion of 7% of women reporting elective terminations is lower if some women did not report terminations in the current study due to fear or guilt, or reported them as another less stigmatised form of loss such as miscarriage (Cockrill, Upadhyay, Turan, & Greene Foster, 2013).

Miscarriage rates cited in previous studies vary widely. As reviewed earlier, miscarriage is thought to occur in 12 to 33% of all pregnancies, however this broad range represents both differing definitions of miscarriage and differing degrees of self/clinical recognition (Ammon Avalos et al., 2012; Balk, 2013; Blohm et al., 2008; Maconochie et al., 2007; Pallikadavath & Stones, 2005; Scotchie & Fritz, 2006; Simmons et al., 2006; Wang et al., 2003; Wilcox et al., 1988). Hence the lower end of this range (estimated to be 12 to 24%) likely represents miscarriage rates after clinical recognition of pregnancy and is thus not directly comparable with the current research. However the higher cited incidence rates of 25 to 33% of all pregnancies is a more

likely representation of self-reported experiences of miscarriage including those not recognised clinically or brought to clinical attention by the woman. Thus, 35% of the total losses reported in this sample being miscarriage appears to correspond with the higher end of other reported incidence rates of miscarriage.

4.2 Perinatal Grief Experiences

No significant relationships were observed in the present research between between perinatal loss rates and eduation, occupation, smoking status, marital status, or maternal age. Some differences were initially suggested in type of loss, whereby women who experienced stillbirth or elective terminations seemed to report somewhat higher grief scores than women who experienced medical termination, miscarriage, or ectopic pregnancy. However pairwise comparisons confirmed no significant differences between types of loss and perinatal grief scores. These results should be intrepreted with caution due to the low numbers in some groups. The current finding does concur with the findings of recent Australian research showing no differences in the reported grief experiences of women as a function of stillbirth compared to other loss types (McSpedden, 2014; McSpedden et al., 2017).

The literature is in a current state of flux with regards to grief experiences after elective termination. Until recently, this type of loss was excluded from perinatal grief research as it was deemed that women's active decision-making process in electing termination inherently countered a grief experience. However this and other research suggests that women's self-reported grief experiences after elective termination do not differ from the grief reported after other types of loss, with some studies showing more intense grief responses (Broen et al., 2005; Curley, 2012; Goodwin & Ogden, 2007;

Keefe-Cooperman, 2004; Kersting, Dorsch, et al., 2009; Maguire et al., 2015). That elective terminations were both more common and rated as a grief experience comparable to that indicated by other forms of loss suggests the exclusion in perinatal grief research of elective terminations may have disenfranchised these women's experiences. Thus this type of loss deserves further research and clinical recognition as a perinatal grief experience (McCoyd & Walter, 2015; Thachuk, 2007).

The average gestational age at time of loss in the present study was 10 weeks, with a range 4 to 30 weeks. As expected first trimester loss was more common, with epidemiologists estimating that 95 to 98% of perinatal losses occur early (<12 weeks) (Balk, 2013; Edlow et al., 2007; Michels & Tiu, 2007; Oliver-Williams et al., 2013). No relationships were presently observed between grief scores and gestational age at time of loss. The literature in this area is contradictory; whilst some studies suggest no significant relationship, other studies conclude significant relationships whereby longer gestation is observed in relation to more intense or prolonged grief (Barr & Cacciatore, 2007; Bennett et al., 2008; Brier, 2008; Goldbach et al., 1991; Janssen et al., 1996; Kulathilaka et al., 2016; Lasker & Toedter, 2000; McSpedden, 2014).

Time since loss was expected to vary widely given the nature of the design as a follow-up study of a sample recruited via an antenatal physical health study one decade earlier. Time since most recent loss varied from just one week prior to interview for the current study, to a maximum of 28 years. Average time since most recent loss was 11 years and hence this sample presents a curious picture of timing of perinatal grief experiences. When grief scores were examined as a function of time since loss, no group differences were observed. There was close to zero statistical correlation between time since most recent loss and PGS score (r = -.06).

The wide spectrum of time since loss from 1 week to 28 years seems unique to this study; most other studies in the field employ retrospective designs using a shorter timeframe, whilst others involve women in the short- to medium-term aftermath of loss. The most typical research timeframes examine perinatal grief experiences at 3, 6, 12, or 18 months post-loss (e.g., Adeyemi et al., 2008; Farren et al., 2016; Janssen et al., 1996; Kersting et al., 2007; Lok et al., 2010; Robinson, 2014). As McSpedden (2014) observed, most studies of perinatal grief are conducted within 13 months of the death, which may not be an appropriate duration for reliably assessing PCBD (APA, 2013).

Both Bennett et al. (2008) and Broen et al. (2005) studied medium-term perinatal grief experiences through a five-year lens, whilst Turton et al. (2009) found significantly higher levels of post-stillbirth psychopathology persisted for some mothers seven years after the loss. Gravensteen et al. (2012) used an epidemiological case-control design to investigate relationships between perinatal loss, quality of life, and depression in a longer-term sample (women who experienced loss between 5 and 18 years earlier). Although Gravensteen et al.'s timespan since loss is more comparable to that in the present study, direct comparisons between the depression findings are challenging given the current study utilised clinical assessment of MDD as compared to Gravensteen et al.'s use of a general self-report measure of depressed mood. This may account for the differences between Gravensteen et al.'s finding of no significant relationship between global depression scores and perinatal loss, whereas the current findings suggest strong relationships.

Amongst a sea of quantitative research, Lasker and Toedter (2003) qualitatively investigated longer-term effects of perinatal loss by re-interviewing women who had experienced ectopic pregnancy some 16 years earlier. Results confirmed that, akin to

the Dual Process Model (Stroebe & Schut, 2010), women's efforts to continually balance loss-oriented and restoration-oriented coping continued even 16 years after loss. Although differing to the present quantitative methodology, taken together these results suggest that perinatal grief continues to have a long-term impact on women.

Whilst most other studies tend to purposefully recruit samples of women who have specifically experienced perinatal loss (e.g., Broen et al., 2005; Lasker & Toedter, 2003), or mine databases to facilitate case-control population-based analysis (e.g., Gravensteen et al., 2012; Hogue et al., 2015), this study engaged women to provide a diverse snapshot of their naturalistic perinatal grief experiences. It provided insight into their day-to-day experiences managing perinatal grief, some short-term, others long-term. Results confirm the unique nature of the perinatal loss experience. Whilst it may seem intuitively that grief experiences reflect time since loss whereby more recent losses may reflect more acute grief, data from the present study and other studies cited above do not support this proposition. Individuals vary in their responses to perinatal loss as a function of time and no timeframe can be accurately specified; whereas some women continue to feel the poignant effect of loss, others do not. As Robinson (2014, p. 176) astutely summarises, "The effect of a pregnancy loss is associated with the meaning of the pregnancy to the patient, not the duration of the gestation."

What the present research has shown is that after an average of almost ten years post-loss, 6% of women continued to meet or exceed the PGS clinical cut-off score to indicate prolonged, problematic grief. This result portrays a picture of the long-term reality of day-to-day coping with perinatal loss for some women. As compared to McSpedden's (2014) Australian research where 18% of women demonstrated complicated grief symptoms as measured by the PGS to up 5-years post-loss, the

present research suggests that a proportion of such women continue to experience a prolonged or chronic form of grief even beyond this point.

4.3 Depressive Disorder After Perinatal Loss

The literature demonstrates that pre-existing mental illness is a risk factor for complications in perinatal grief (e.g., Janssen et al., 1997). Whilst it remains important to respect women's prior functioning and incorporate this clinically via referral, the present results also confirm the importance of considering post-loss psychological functioning. Clinical interview data in the present studied showed that 1 in 4 women (25.6%) developed *de novo* depressive illness after perinatal loss. That is, there is a considerable group of women who, despite being previously healthy and with no depressive illness, develop a first episode of MDD after perinatal loss.

In Lok et al.'s (2010) study, 27% of women demonstrated clinically symptomatic levels of depression after miscarriage; although not specified it is unlikely that this represents *de novo* depression only. In Kulathilaka et al.'s (2016) study of MDD and grief after miscarriage in Sri Lankan woman, 19% of the sample met criteria for clinical depression; a number comparable to the proportions of women observed in the present study to develop *de novo* MDD after perinatal loss. Again however, it is unclear whether this was women with pre-existing MDD and/or women with *de novo* MDD.

Hogue et al. (2015) utilised a case-control design to analyse data from the Stillbirth Collaborative Research Network. Hogue et al. found that in the 6 months following stillbirth, women with no previous history of depression were twice as likely to develop *de novo* depression, and this risk, whilst lessening, continued to be higher at

various time points to 24 months after stillbirth. Kulathilaka et al. (2016) also calculated a relative risk of developing a depressive episode after miscarriage of 1.96. Although this relationship did not hold true after adjustment for age and gestational length of pregnancy, each of these studies provide insight into the complex dynamics between depression and perinatal grief. Of the women in Kulathilaka et al.'s sample who met criteria for 'complicated grief', 1 in 4 also met criteria for a depressive episode, again suggesting there is an important relationship between the two experiences.

In a wider sense, these figures mirror wider findings that approximately 20 to 25% of women develop some form of psychopathology after perinatal loss (Adolfsson, 2011; Badenhorst & Hughes, 2007; Bennett et al., 2008; Brier, 2008; Janssen et al., 1996; Lok et al., 2010; Robinson, 2014; Scheidt et al., 2012; Turton et al., 2009). Indeed, the true incidence rate of psychopathology after perinatal loss would be higher in the present sample as the figure of 26% of the current sample represents only those women who developed *de novo* MDD after perinatal loss and does not include women who had both pre-existing and post-loss MDD episodes, nor women who developed other forms of psychopathology such as anxiety disorders; both of which that were beyond the scope of this study.

Subsequent analyses confirmed the first hypothesis (that women who reported developing *de novo* MDD after perinatal loss would report more intense perinatal grief, as indicated by higher scores on the PGS). This gives an indication that in otherwise previously healthy women, the experience of perinatal grief was later associated with the development of depressive illness. Further analysis showed that the development of *de novo* depression after perinatal loss places women at significantly increased risk of

more intense grief. This indicated that women who developed MDD after perinatal loss were over 4.5 times more likely to score highly on a measure of total perinatal grief than women who did not develop MDD after perinatal loss.

It is therefore important that practitioners do not focus exclusively on pre-existing mental illness as a risk factor for complications in perinatal loss. Women who go on to develop first-episode depression after perinatal loss seem at risk of developing complications in grief; and yet just 10% of women are said to access professional support after perinatal loss (Janssen et al., 1996). Hence, there appears to be a group of women who are falling through the proverbial cracks.

In exploring these findings, it must also be considered whether the relationship observed in the current study between depression and perinatal grief represents a conceptual or psychometric overlap between the two experiences. That is, it may be that the elements of the clinical assessment of depressive disorder via the SCID-I/NP overlap conceptually or psychometrically with the elements measured in the PGS. The differences between depression and complicated grief have been considered extensively in the literature, with neuroimaging, immunological, and psychiatric research showing they are different syndromes with distinct biopsychosocial profiles (Bryant, 2014; Lichtenthal, Cruess, & Prigerson, 2004; O'Connor, 2012; Prigerson, Frank, et al., 1995; Shear, 2012). As Adolfsson's (2011) meta-analysis concluded, although symptoms of depression and grief can seem similar, use of a measurement scale such as the PGS identifies grief as a syndrome, as opposed to depression as an illness. One of the primary intentions in developing the PGS was to develop a scale that measured grief rather than general depressed mood, distress, or somatic symptoms (Hunfeld et al.,

1993). That is, the PGS appears to accurately capture the distinct nature of grief, as opposed to depression or distress.

Lasker and Toedter (2000) reviewed 22 international studies that utilised the PGS to assess grief following perinatal loss, finding that although most studies find an overlap between perinatal grief and depressed mood, studies showed that the two are not the same. Studies reviewed by Lasker and Toedter showed correlations between the PGS and Beck Depression Inventory (Beck et al., 1996) of 0.65. Further research has demonstrated correlations between the PGS and the Depression subscale of the SCL-90 (Derogatis et al., 1976) in the order of 0.57 to 0.78 (Lasker & Toedter, 2000; Potvin et al., 1989). This is not a surprising finding, given that there is conceptual overlap between grief and depression, and the BDI, SCL-90, and the PGS are all symptom-based self-report measures that require retrospection (Potvin et al., 1989; Toedter et al., 1988).

Interestingly research shows that the Difficulty Coping PGS subscale is more strongly related to the depression subscale of the SCL-90 (0.77 to 0.79 in the different studies) and less so the Active Grief (0.62) and Despair (0.57 to 0.68) subscales (Potvin et al., 1989; Toedter et al., 1988). The developers of the PGS state that the scale was intentionally designed in this manner, with its tripartite structure illuminating three different components of perinatal grief. That is, the Difficulty Coping subscale was designed to be the subscale which "most represents a picture of depressive reaction… [whereas the Despair and Active Grief subscales] represent different and important dimension[s] of grief which are not assessed by standard measures of depression" (Potvin et al., 1989, p. 39). The PGS developers state that whilst the Difficulty Coping subscale more reflects symptom-based experiences of perinatal grief such as social

withdrawal and lowered mood, the subscale Despair is more associated with cognitive or affective variables such as self-esteem and hopelessness (Toedter et al., 1988).

A wider research body has confirmed the construct, convergent, and concurrent validity of the PGS (Hunfeld et al., 1993; Potvin et al., 1989; Toedter et al., 2001), thus it is unlikely that those in the present study who scored highly on a measure of perinatal grief symptomatology did so because they were instead representing depression, and vice versa. That depression was assessed not via self-report symptom scales, but by clinical assessment using the SCID-I/NP also likely improves measurement qualities.

It remains that even if researchers and academicians can ascertain the differences between grief and depression, practitioners continue to find this challenging (Friedman, 2012). The revisions in the recently released *DSM-5* represent an attempt to aid clinician diagnosis of grief versus depression, however with clinicians continuing to report they find it difficult to ascertain differences between grief and depression, it may be that post-loss women who present for support are mistakenly diagnosed as being depressed instead of having a potential form of complicated grief recognised, and vice versa (Friedman, 2012; Kersting & Wagner, 2012; McCabe & Christopher, 2016; Shear et al., 2011).

4.4 Personality Disorders and Perinatal Grief

Of the 197 women in this sample, 23.9% met criteria for at least one personality disorder (PD) as assessed via the SCID-II (First et al., 1997). This proportion mirrors PD prevalence rates of 21.5% observed in Australian and US population studies (Lenzenweger, Lane, Loranger, & Kessler, 2007; Quirk et al., 2017; Trull, Jahng, Tomko, Wood, & Sher, 2010). However other studies utilising semi-structured clinical

interviews estimate PD prevalence rates to be lower at around 9.5% (Trull et al., 2010). There are likely a number of reasons for this discrepancy, including that this study's sample comprised younger and middle-aged women (age range 30 to 54 years) where PDs have been shown to be more prevalent (Quirk et al., 2017). Notwithstanding discrepancies, the current findings taken together with extant Australian research suggests that PDs are relatively common in community samples, with approximately 1 in 5 women meeting criteria for any PD (Quirk et al., 2017).

Based on extensive literature searches, it appears that this study is the first to offer insight into the perinatal grief experiences of women with personality disorders. This study found support for the second hypothesis, that women with personality disorders would report more intense perinatal grief, as indicated by higher scores on the PGS. The group differences were striking; women with PDs scored on average 18 points higher than women without PDs on the PGS in total, as well as scoring 5 to 6 points higher on average on each PGS subscale.

Further analyses confirmed that the presence of any PD was a significant risk factor for developing more intense grief as indicated by higher PGS scores. Women with personality disorders were three times more likely to score highly on a measure of total perinatal grief than women who did not meet criteria for a PD. Being the first study to explore such relationships, further research is required to confirm relationships between PDs and perinatal grief and to ascertain the mechanisms of this relationship. Being that significant co-morbidity has been observed between PDs and other indicators of mental health (Clark, 2007; Friborg et al., 2014), it may be that PDs fall under the umbrella of the 'pre-loss mental health' that previous research has ascertained is a risk factor for complications in perinatal grief (e.g., Hogue et al., 2015). However the

observation in the present study of a relationship between PDs and perinatal grief suggests this would be too narrow a view. PDs indicate an enduring pattern of inner experience, cognition, affect, interpersonal functioning, and impulse control that develops early in life and is pervasive, impairing, and inflexible across time and circumstance (APA, 2000, 2013). A defining feature of PDs is their impact on interpersonal relationships and coping mechanisms. Individuals with PDs tend to respond to differing situations and demands with characteristically rigid constellations of feelings, thoughts, and behaviours (van Wijk-Herbrink, Andrea, & Verheul, 2011; Widiger, 2003). The breadth and magnitude of this description of PDs hints at a likelihood of a relationship between PDs and perinatal grief irrespective of other acute pre-existing mental illnesses formerly known as Axis I disorders (APA, 2000).

Such a relationship may reflect psychosocial, attachment, emotional, interpersonal, and/or cognitive mechanisms (Malkinson, 2007; Scheidt et al., 2012; Tunaley, Slade, & Duncan, 1993). For example, individuals with PDs frequently experience unstable and tumultuous interpersonal relationships, have self-identity difficulties and poor impulse and affect regulation, endorse maladaptive and rigid coping mechanisms, and engage in self-harm and other risky behaviour (APA, 2000; Dimaggio, Nicolò, Semerari, & Carcione, 2013). Bereavement may exacerbate and highlight these features, having an overall negative impact on coping with grief (Hansen et al., 2009).

As described in the earlier literature review, the experience of perinatal grief may also present unique challenges as compared to other modes of bereavement, and these factors may be particularly relevant to women with PDs. Features of perinatal deaths that potentially accentuate negative responses include the perception of perinatal

deaths being unnatural and unexpected in life course; that losses are often sudden and unexpected thus negating anticipatory grief opportunities; that mourning rituals such as funerals may not be observed; that maternal trauma from the loss itself may be present; that the reasons for perinatal deaths are often unknown and thus seem ambiguous; that women may feel a heightened sense of responsibly for the loss; and the possible disenfranchisement of the perinatal grief experience (Adolfsson, 2011; Frost & Condon, 1996; McSpedden, 2014).

People with PDs have been observed to cope less well with significant life events (van Wijk-Herbrink et al., 2011). Pregnancy and motherhood may represent a stressor for some women, notwithstanding perinatal loss. Attachment to the lost fetus or baby may be more complicated for women with PDs, further impacting on grief responses and presenting implications for care providers interacting with women, such as maternal-child health nurses (McCoyd & Walter, 2015; Scott et al., 2013). The role of attachment in perinatal loss is an emerging research area, emboldened by findings that insecure attachment styles, childhood separation anxiety, and overly dependent or ambiguous relationships (including potential relationships with the fetus and feelings about the pregnancy) may be linked with development of prolonged or complicated grief (McCoyd & Walter, 2015; Prigerson et al., 2009; Scheidt et al., 2012). Further synergetic research in this area fits within Condon's (2010) 'wish-list' for *DSM-5*, including research investigating perinatal bereavement and disorders of maternal/infant attachment.

Recent research has linked PDs with deficits in the metacognitive system of mentalisation. In particular Dimaggio et al. (2013) described people with PDs as having deficits in alexithymia, or one's capacity to identify and communicate somatic arousal

with emotional words; to focus on inner states rather than external events; and to form higher-order representations of integrated self-other relationships. This may include difficulty in forming metacognitive representations of lost relationships, such as perinatal grief.

As the Dual Process Model of grief further suggests, coping with grief represents successfully oscillating between grief-focused and restoration-focused processing of loss (Stroebe & Schut, 2010). PDs, particularly Cluster B PDs, are characterised by emotional dysregulation and underlying deficits in self- and emotion-regulation (Robinson & Gordon, 2011). This potentially corresponds with research linking deficits in emotional regulation and expressive inflexibility with complicated grief reactions after bereavement (Gupta & Bonanno, 2011). Although the numbers of women experiencing PDs in the current study precluded analysis of grief as a function of type or cluster of PDs, future research could consider such comparisons to further elucidate any relationship observed between specific PDs and perinatal grief.

Bonanno and Kaltman (2001) described five aspects of the grieving process, including cognitive disorganisation (including disorganisation resulting from the reality of loss, sense of abandonment, disorder, and preoccupation); dysphoria (emotional stress, remorse, sorry, guilt, fear, hostility, resignation, yearning, social loneliness, emotional loneliness; profound isolation); health deficits (physical symptomatology, mortality; morbidity); disrupted social and occupational functioning (disruptions in social role identity; reduced sense of belonging and purpose; dissatisfaction with social support); and changes in personal identity (possible positive changes in perception of life, passion, humility, freedom, future-focus). Adolfsson and Larsson (2010) recently considered these five factors in the context of miscarriage, with their qualitative analysis

of interviews showing that in all 25 women interviewed, cognitive disorganisation, dysphoria, and health deficits were described. In 22 of the 25 women, disrupted social/occupational functioning and positive aspects of bereavement were represented. Thus, these five categories appear characteristic of women's natural reactions to perinatal loss, leading one to wonder as to their possible relation to PDs.

Examined in the context of personality disorders, there exists an encouraging rationale for future research. That is, the element described by Bonanno and Kaltman (2001) as 'cognitive disorganisation' may include features particularly pertinent to women with PDs. For example, adjusting to cognitive disorganisation following loss involves processing the preoccupative nature of grief and accommodating the reality of loss and sense of abandonment imposed by the loss. This may be particularly challenging for women with Borderline Personality Disorder (BPD), for example, whereby a defining symptom of BPD is sensitivity to abandonment (APA, 2000, 2013). Research has suggested that women with BPD are characterised by preoccupied attachment styles, which is in turn associated with hyperactivation of the attachment system in the face of emotional distress or threat and thus emotion dysregulation in the event of perceived abandonment (Scott et al., 2013). Hence again, further research with specific types or clusters of PDs is recommended.

Likewise Bonanno and Kaltman's (2011) four remaining features of grief (dysphoria, health deficits, disrupted social and occupational functioning, and changes in personal identity) may be particularly challenging for women with BPD as they seem to parallel key diagnostic criteria for women with BPD such as instability in self-image and pervasive sense of emptiness (APA, 2000, 2013). Hence, further research is

recommended to investigate theorised mechanisms between PDs and perinatal grief, not only for women with BPD, but women with other types or clusters of PDs.

4.5 Implications of the Current Findings

An intriguing implication of the current findings centres on the third hypothesis, that the presence of personality disorders and *de novo* MDD would act as significant risk factors for more intense perinatal grief. This hypothesis was supported for total PGS scores, however as individual predictors the predictive capacity of each differed depending on which PGS subscale (Active Grief, Difficulty Coping, or Despair) was being examined.

In the present study, both the presence of PDs and the development of *de novo* MDD were equally significant risk factors for more intense active grief responses, as indicated by higher scores on the Active Grief subscale. Developing *de novo* MDD after perinatal loss or having any PD conferred three times the risk of more intense active grief responses.

However on the Difficulty Coping subscale, *de novo* MDD was the only significant predictor which statistically improved the model's predictive capability; women who developed MDD after perinatal loss were 3.5 times more likely to score highly on a measure of difficulty coping with perinatal grief than women without *de novo* MDD. Having a personality disorder was a risk factor, however not to a statistically significant degree.

The results were the opposite for the Despair subscale, whereby having any PD conferred 4.5 times the risk of scoring highly on a measure of despair in perinatal grief.

Although developing *de novo* MDD also conferred some risk, this predictor was not statistically significant in this sample.

Hence it appears from the findings that developing *de novo* MDD after perinatal loss and having any personality disorder are risk factors for more intense Active Grief reactions; however developing *de novo* MDD is more so a risk factor for greater difficulty coping, whereas having any PD is more so a risk factor for more intense despair in perinatal loss.

These findings have both psychometric implications for the PGS (Potvin et al., 1989; Toedter et al., 1988) and theoretical implications for the field of grief and loss. As discussed earlier, the PGS was designed with an ordinal tripartite structure; the subscale of Active Grief was said to reflect natural grief responses, such as sadness, missing the baby, and crying as per items such as *"I feel a need to talk about the baby"* and *"I cry when I think about him/her"*. The second, Difficulty Coping, suggested difficulty dealing with other people and activities of daily living. Typical Difficulty Coping items include *"I can't keep up with my normal activities"* and *"I find it difficult to make decisions since the baby died."* The final subscale, Despair, suggested difficulty regulating the at times intense cognitions and emotions in perinatal grief. Typical PGS Despair items include *"The best part of me died with the baby"* and *"It is safer not to love"*.

Research shows that the Difficulty coping subscale is associated with depression, in that it incorporates symptomatic expressions of mood disorder such anhedonia and social withdrawal (Lasker & Toedter, 1991; Toedter et al., 2001). Research shows that high scores on the Despair subscale may indicate potential for serious and long-lasting effects of the loss, although the mechanisms of this remain

unknown (Lasker & Toedter, 1991; Toedter et al., 2001). The current findings confirm previous research suggesting that the Difficulty Coping subscale was more strongly related to MDD, however the current findings are the first to suggest that the Despair subscale is more strongly associated with personality disorders. In this study, meeting criteria for a PD conferred four and a half times the risk of scoring highly on the Despair subscale of the PGS. In the same way that high scores on the Despair subscale are said to reflect potential for serious and chronic grief, so too PDs are considered to reflect serious and chronic impairment.

This idea also extends to theories of grief and loss. It was recently suggested by leading academicians Therese Rando, Kenneth Doka, Colin Murray Parkes, and colleagues that rather than a single unitary form of complicated grief, there may be variants of complicated grief (Rando et al., 2012). The authors called for continued research that would underlie the delineation of such variants. The present research may offer insight into such variants, in that two syndromes appeared to present. One appeared to be a more depressive-style complicated grief, linked to the Difficulty Coping subscale in particular and possibly reflecting cognitive, psychomotor, and social aspects of perinatal grief (such as guilt, hopelessness, worthlessness, lethargy, and isolation). A potential second form may be the more emotive- or cognitive-style complicated grief, linked to the Despair subscale (such as difficulty managing emotions, perceptions of lack of safety or guilt, and fear of the future). Thus, depending on a woman's biopsychosocial presentation, she may be more likely to fall into one of these syndromes. Women with a personality disorders for example, appear more at risk of developing a despair-laden form of complicated grief after perinatal loss, whereas women who develop depression may follow a pathway into a form of complicated grief

marked by difficulty coping. If replicated, such findings have clinical care implications, including matching targeted therapeutic interventions for different syndromal expressions of complicated perinatal grief.

Fenstermacher and Hupcey's (2013) article offers further insight into this possibility. Fenstermacher and Hupcey conducted a principle-based concept analysis investigating the definitional meaning of the term 'perinatal bereavement'. Noting that whilst this is a widely-used practice-based concept, the authors also noted however that the field is marked by the intermingling of different concepts. They concluded that perinatal bereavement is a multifaceted phenomenon and one that lacks conceptual clarity in the field. Hence Fenstermacher and Hupcey recommended that researchers and theorists more closely examine the precise conceptual nature of perinatal bereavement to then advance research and theory development. As such, it is important to consider whether underneath the broad umbrella of 'perinatal grief' may be different syndromes for different women.

Considering the findings more broadly in terms of grief and loss theories, the findings support the notion of individuality in the perinatal grief experiences. Grouping factors such as time since loss, maternal age at time of loss, gestational length of pregnancy, and history of multiple losses bore no relationship to intensity of grief as measured by the PGS. Findings in the area are inconsistent, suggesting that it is difficult to reliably capture in research the individuality of women's experiences (Kulathilaka et al., 2016; McSpedden, 2014). For some women, perinatal loss represents a significant challenge; for others, the loss appears more readily accommodated. Research investigating the way these two types of women can be reliably differentiated is encouraged, such that women who are challenged by loss can

then be supported. The magnitude of loss for some women should not be underestimated. A Finnish epidemiological study found a significantly higher mean annual suicide rate for women who had miscarried in the year prior (18.1 out of 100,000) compared with women who had delivered a live baby (5.9 out of 100,000) highlighting the complex and potentially intense nature of acute perinatal grief (Gissler, Hemminki, & Lonnqvist, 1996).

In the present study, various grief trajectories were observed. Irrespective of all other factors, the mean PGS score was 55.46 (from a possible range of 33 to 105) after an average timespan of 11 years post-loss. This score suggests that as a group of women, the participants in this study continued to carry some representation of perinatal loss with them even after a reasonably lengthy period of time. It is likely that for some women, experiencing a perinatal loss ultimately results in following a path akin to Bonanno's (2009) resilience trajectory. However for other women, the grief trajectory appears more challenging. If it is considered that high scores on the PGS represent more intense grief to the point where 91 acts as a clinical cut-off to indicate maladaptive response (Toedter et al., 2001), then 6.5% of the current sample continued to score in this clinically significant range after an average 9 years post-loss. Such women appear to be experiencing what Bonanno (2009), Worden (2008), and Rando (1993) describe as *chronic grief* whereby the pain of grief is overwhelming and the suffering prolonged. It cannot be said based on the current study design that these women met criteria for PCBD and further research is needed to explore more specific relationships between perinatal loss and the development of PCBD (APA, 2013).

4.6 Future Research Recommendations

Previous research has acknowledged the role of personality traits in coping with perinatal loss (Janssen et al., 1997; Ogrodniczuk et al., 2003; Piper, McCallum, Joyce, Rosie, & Ogrodniczuk, 2001; Sugiura-Ogasawara et al., 2002). The present study furthered this by examining clinically-assessed personality disorders. Results suggest that women with personality disorders are at increased risk of developing complications in perinatal grief. One interesting implication of the current findings involves consideration of the possibility of a bidirectional relationship between perinatal loss and personality disorders. That is, it may be that the presence of PDs not only confers risk of prolonged or more complicated perinatal grief; but it may equally be that the presence of PDs acts as a risk factor for perinatal loss itself. Research could extend this to examine not only personality disorders as a risk factor for perinatal loss, but other psychopathology as well.

Amongst the scant literature exploring personality dysfunction and perinatal loss is Gannon's (1994) publication critiquing whether psychological factors could be aetiological causes of recurrent miscarriage. Acknowledging the role of physical and hormonal factors, Gannon also explores the possibility of a relationship between personality types and recurrent miscarriage rates. Gannon reviewed the possibility that intrapsychic conflicts manifesting in personality disturbance may be more commonly observed in women experiencing recurrent miscarriage, however he ultimately concluded little empirical support for the hypothesis that women suffering from recurrent miscarriage are characterised by a unique form of personality disturbance that plays a causal role in perinatal loss. Rather, Gannon purported that personality disturbance is more likely a consequence of repeated perinatal loss rather than a cause.

Hence further research is needed to investigate potential bidirectional relationships between perinatal loss and personality disorders, in addition to research investigating bidirectional relationships between perinatal loss and psychopathology more generally.

For example, Gold et al. (2007) used assessed pre-pregnancy mental health diagnoses as a risk factor for subsequent miscarriage or stillbirth. Regression analyses confirmed that having been diagnosed with any mental health disorder prior to pregnancy conferred a 1.8 times risk of subsequent perinatal loss. Specifically, diagnoses of affective disorders and substance use disorders were significant risk factors, and these risks remained even when controlling for other health and behavioural risk factors linked to perinatal loss (Gold et al., 2007). Interestingly, it was noted that an anxiety disorder diagnosis was not a significant risk factor for perinatal loss.

Further prospective research has demonstrated that pre-conception depressive symptoms significantly predicted later perinatal loss in women suffering multiple miscarriages, suggesting the possibility that psychiatric symptoms act as a risk factor for perinatal loss at least in this high-risk population (Sugiura-Ogasawara et al., 2002). Although any potential neuroendocrine, behavioural, or genetic mechanisms remain poorly understand, these results are consistent with studies demonstrating mental illness to be independently associated with mortality and morbidity in other physical illnesses such as heart disease, cancer, and stroke (Gold et al., 2007).

Other research has ascertained mental illnesses such as schizophrenia and depressive disorders as risk factors for adverse obstetric outcomes, however the focus is often obstetric and birth-related complications such as preeclampsia and haemorrhage, as opposed to perinatal death (MacCabe et al., 2007; Thornton, Guendelman, & Hosang, 2010). Thus the scope remains for further research to extend this research body,

including replicating the current findings and the findings of studies such as Gold et al. (2007) to further ascertain existing mental illness as a consequence of, and a risk factor for, perinatal loss. Such research should include focus on comorbidity, such as the co-existence of depressive and personality disorders.

By extension, future research should also consider interventions for women with complicated grief after perinatal loss (Capitulo, 2005). Interventions that have shown promise for complicated grief in general may be appropriate for perinatal grief, such as cognitive behaviour therapy, interpersonal therapy, meaning making therapy, and complicated grief therapy (Boelen et al., 2007; Mancini et al., 2012; Neimeyer, 2012; Rosner et al., 2014; Shear et al., 2005; Shear et al., 2014). Ogrodniczuk et al. (2003) presented an account of therapy for complicated grief that acknowledged dysfunctional personality traits, hence further research is encouraged to assess interventions that may address issues for women with personality disorders who experience perinatal loss. In addition, this research has focused on the individual woman experiencing perinatal loss; however perinatal loss affects many individuals and communities beyond the woman herself. In the event that a woman has a personality disorder, or has developed depression after perinatal loss, it is particularly important that professionals be able to accurately identify such women and respond to her and her family's needs (Hughes & Goodall, 2013).

4.7 Strengths and Limitations of the Present Research

The present research has responded to a gap in the literature to explore relationshps between personality disorders, *de novo* MDD, and perinatal grief in a sample of community-dwelling women. Working from an epidemiological framework

to explore grief in a sample of women who were not purposefully recruited because they had experienced perinatal loss offers both strengths and challenges. Although it allows for the assessment of grief in a more naturalistic sample, the resultant group of women was characterised by wide variation in time since loss, for example. In the present study, time since most recent loss varied from 1 week to 28 years. The wide variation proved statistically insignificant; however it raises an interesting point regarding retrospective recollection of the loss event and by extension, of psychiatric events. Cognitive research shows that one's current emotional experiences affect retrospective reflection on other past experiences (Raphael & Cloitre, 1994). That is, a woman who participated in the study and was currently depressed, may be more likely to complete the PGS reflecting this depressive state. As such, her responses may reflect grief but they may also reflect her current emotional and psychological state. Both mood congruence and recall bias may also have affected women's accounts of grief, reports of depressive history, and responses to the SCID-II (Frost & Condon, 1996). Raphael and Cloitre (1994) advise researchers to be cautious about the effects of mood congruence when conducting epidemiological research.

The validity of the current study relied upon women's accuracy in self-reporting their grief experiences, perinatal losses, and psychiatric history, and this is an implicit limitation inherent in the current convenience sample. What one apparently gains in an attempt to study naturalistic, unprompted accounts of perinatal grief, one may potentially lose in terms of validity of self-reported experiences. This is a particular challenge for epidemiological bereavement work (Hansson, Carpenter, & Fairchild, 1993). As Tunaley et al. (1993) point out, in research there is a need to consider not only the psychological and emotional consequences of perintal loss, but also the

potential cogntive mediators that might influence such responses. Hence the present research is considered a small step towards understanding the perintal grief experiences of women with mental illness, however future research is requited to disentangle the role of cognitive elements.

Further, there are challenges inherent in this being a convenience sample of women who had already participated in a prior physical health study recruited via an antenatal clinic. This study was nested within a larger epidemiological study, whereby a 10-year follow up was being initiated with women and their offspring. Thus all women in the present study were pregnant when they decided to participate in the original VIP Study, and at the 10-year follow-up they all had living children. As such, it cannot be ascertained in the present study to what degree childlessness affects perinatal grief. Some research suggests that the absence of any living children is a risk factor for complications in perintal grief (McSpedden, 2014) however this study was unable to explore that. It is also noted that although the sample was heterogenous with regards to education and occupation, the women in this study were predominantly Australian-born married women, thus limiting generalisability.

Being a 10-year follow-up study of baseline participants, attrition was noted. Of the 400 women eligible to particpicate in the 10-year follow-up study, 197 (49%) participated in this perintatal loss component. The most predominant reasons for not particpating was being uncontactable (n = 123; 31%). Although an apparently large proprotion, this is not unique to this study. For example, Gravensteen et al. (2012) identified 379 cases of perinatal loss via hospital records that had occurred between five and 18 years earlier. In attempting to recruit these participants, 240 (63%) were uncontactable and only 106 (30%) women eventually participated.

Thus contacting participants remains a challenge when conducting such studies. In the case of the VIP Study, all women were of childbearing age and they went on to have a live infant. Ten years later, a high proportion were likely uncontactable because they had moved away from the geographic study area, potentially due to changed family arrangements. Establishing families may be more likely to relocate more often than those in other life stages due to increased need for larger, more affordable housing. In addition, technological changes across the decade have now seen the widespread use of mobile telephones, however the baseline phase of the VIP Study was conducted before these were ubiquitous, with people instead having now-disconnected landline telephones. Recent changes to privacy legislation in Australia also meant that previously available opportunities to find relocated women (e.g., electoral rolls) were no longer available to the public.

Notwithstanding the limitations inherent in the use of a follow-up convenience sample, the study does offer as strengths clinical assessment of depressive and personality disorders in a wide-ranging sample community-dwelling sample of women. Research investgiating links between perinatal grief and psychiatric outcomes typically recruits samples from hospital records or professional loss-related support agencies, thereby implying clinical recogntion of the pregnancy and/or some form of support or intervention have occurred (Toedter et al., 2001). The predominant losses under investigation in previous research have been stillbirth and to a lesser extent miscarriage, at the potential expense of others forms of loss. In this study, women living in their natural communities were interviewed about different types of perinatal losses, be they clinically and/or personally recognised. Although small numbers precluded individual analyses as a function of type of loss, this limitation has also characterised other

epidemiological research in perinatal grief (e.g., Turton et al., 2009). Regardless, the prevailing research philosophy was that perinatal loss, irrespective of type or clinical confirmation of pregnancy, may represent a grief experience for individual women and hence wide-ranging experiences would be respected.

In addition, depressed mood is the most common outcome focus for research in this field however this is typically assessed both as a short-term outcome after loss and via generalist measures of low mood, wellbeing, or distress. Geller et al. (2004) encouraged further research in perinatal loss to draw samples from sources wider than those engaged in formal psychological services and to utilise standardised measures of clinical symptomatology as opposed to measures of general distress or low mood (Geller et al., 2004). That the present research utilised 'gold standard' measures of psychiatric symptomatology, including personality disorders, is a strength.

4.8 Summary and Conclusions

The present research explored generally the perinatal grief experiences of Australian community-dwelling women, and specifically, the experiences of women with personality disorders and women who develop *de novo* depression after perinatal loss. Women who had experienced different forms of perinatal loss/es across a wide time range detailed their grief responses and psychiatric experiences as part of a clinical interview. Whilst some women appear to accommodate perinatal loss, findings showed that for other women, the experience is best expressed by this sentiment expressed by a participant: *"My heart still aches with sadness."*

After an median 11 years post-loss, a small proportion of women (6.5%) continued to report clinically signiifcant levels of perinatal grief. One in four women

who were previously mentally healthy responded to perinatal loss with the development of *de novo* Major Depressive Disorder. For women who did develop *de novo* MDD, and for women with personality disorders, the risk of developing more problematic grief symptoms was between two and four times greater than women without such features. Hence it seems that there are a group of women who are at greater risk of developing complicated grief after perinatal loss. Further research should continue to identify these and other risk factors that modulate grief responses, to more widely inform the *DSM-5* inclusion of Persistent Complex Bereavement Disorder as well as develop effective interventions to support such women.

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Appendix A: *DSM-5* Diagnostic Criteria for Persistent Complex Bereavement Disorder

Table A1

DSM-5 Diagnostic Criteria for Persistent Complex Bereavement Disorder (APA, 2013)

		Symptoms
A.	**Event**	The person experienced the death of a close relative or friend at least 12 months earlier (or 6 months if death of a child)
B.	**Core symptom/s**	Since the death at least 1 of the following symptoms is experienced on more days than not and to a clinically significant degree: 1. Persistent yearning/longing for the deceased 2. Intense sorrow and emotional pain because of the death 3. Preoccupation with the deceased person 4. Preoccupation with the circumstances of the death
C.	**Other symptoms**	Since the death at least 6 of the following symptoms are experienced on more days than not and to a clinically significant degree: *Reactive distress to the death* 1. Marked difficulty accepting the death 2. Feeling shocked, stunned or emotionally numb over the loss 3. Difficulty in positive reminiscing about the deceased 4. Bitterness or anger related to the loss 5. Maladaptive appraisals about oneself in relation to the deceased or the death (e.g., self-blame) 6. Excessive avoidance of reminders of the loss (e.g., avoiding places or people associated with the deceased) *Social/identity disruption* 7. A desire not to live in order to be with the deceased 8. Difficulty trusting other people since the death 9. Feeling alone or detached from other people since the death 10. Feeling that life is meaningless or empty without the deceased, or the belief that one cannot function without the deceased 11. Confusion about one's role in life or a diminished sense of one's identity (e.g., feeling that a part of oneself died with the deceased) 12. Difficulty or reluctance to pursue interests since the loss or to plan for the future (e.g., friendships, activities)
D.	**Timing**	Diagnosis should not be made until at least 12 months have elapsed since the loss (or 6 months if death of a child)
E.	**Impact**	The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning. Mourning shows substantial cultural variation; the bereavement reaction must be out of proportion or inconsistent with cultural or religious norms.
F.	**Specifiers & Differential Diagnoses**	Specify if with traumatic bereavement: Following a death that occurred under traumatic circumstances (e.g., homicide, suicide, disaster, or accident), there are persistent, frequent, and distressing thoughts, images, or feelings related to traumatic features of the death (e.g., the deceased's degree of suffering, gruesome injury, blame of self or others for the death), in response to reminders of the loss

Note. Adapted from "Commentary on the inclusion of Persistent Complex Bereavement-Related Disorder in *DSM-5*", by P. A. Boelen & H. G. Prigerson, 2012, *Death Studies, 36,* pp774-777. Copyright 2012 by Death Studies.

Appendix B: *ICD-11* Diagnostic Criteria for Prolonged Grief Disorder

Table B1

Proposed ICD-11 Diagnostic Criteria for Prolonged Grief Disorder (WHO, 2014)

Category	Definition
A	*Event:* Bereavement (loss of a significant other)
B	*Core symptom:* Separation distress; the bereaved person experiences yearning (e.g., craving, pining, or longing for the deceased; physical or emotional suffering as a result of the desired, but unfulfilled, reunion with the deceased) daily or to a disabling degree
C	*Cognitive, emotional, and behavioural symptoms:* The bereaved person must have five (or more) of the following symptoms experienced daily or to a disabling degree: 1) Confusion about one's role in life or diminished sense of self (ie., feeling that a part of oneself has died) 2) Difficulty accepting the loss 3) Avoidance of reminders of the reality of the loss 4) Inability to trust others since the loss 5) Bitterness or anger related to the loss 6) Difficulty moving on with life (e.g., making new friends, pursuing interests) 7) Numbness (absence of emotion) since the loss 8) Feeling that life is unfulfilling, empty, or meaningless since the loss 9) Feeling stunned, dazed, or shocked by the loss
D	*Timing:* Diagnosis should not be made until at least 6 months have elapsed since the loss
E:	*Impairment:* The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning (e.g., domestic responsibilities)
F:	*Relation to other mental disorders:* The disturbance is not better accounted for by Major Depressive Disorder, Generalised Anxiety Disorder, or Posttraumatic Stress Disorder

Note. Adapted from "Prolonged Grief Disorder: Psychometric validation of criteria proposed for *DSM-V* and *ICD-11*", by H. G. Prigerson et al, 2009, *PLoS Medicine, 6,* p. 9.

Appendix C: Perinatal Grief Proforma for Participant Interviews

Verbal introduction to the Perinatal Grief component of VIP Study appointments

We are also asking today about reproductive history, to get a clearer idea of what motherhood has been like for you, both mentally and physically.

This questionnaire asks about all of your pregnancies, including any perinatal losses you may have experienced. That is, losses at any time during pregnancy or up until birth. Perinatal losses are more common than people often acknowledge, so even though it might be difficult to talk about it today, it helps us understand better what that experience may have been like for you.

So if that's ok, let's start with any children you have given birth to…

- *Record names, genders, birth dates on form. Example is overleaf.*

Have you ever experienced perinatal loss (loss of a fetus/baby/child at any time from conception to birth)?

- YES
  - *Complete table to record self-reported details.*
  - *Sensitively move through the Brief Perinatal Grief Scale (how you feel now). If the participant has had multiple losses, they may complete the questionnaire based on how they feel about the losses in totality today.*
  - *On conclusion, verbally check that participant is ok, then conduct SCID-II.*
- NO or prefer not to answer
  - *Thank participant and move to next stage of appointment.*

Appendix D: Perinatal Grief Scale (Short Version)

Protocol no: 1111001
Date: 25/12/13

What are the dates of birth of your biological children?
1. 11/08/01 (F) 2. 04/04/03 (F) 3. 30/11/08 (M) 4.

Have you ever experienced perinatal loss (loss of a fetus/baby/child at any time from conception to birth)? X Yes ☐ No

Type of loss (eg., miscarriage stillbirth, ectopic pregnancy, elective termination, medical termination)	Date of loss	Baby's gestational age	Marital status at time of loss
Miscarriage	20/04/06	16th week of pregnancy	De facto
Elective termination	20/12/07	10th week of pregnancy	De facto

Each of these items is a statement of thoughts and feelings that some people have concerning a loss/losses such as these. There are no right or wrong response to these statements. Please indicate the extent of agreement with each statement below at the present time.

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
1. I feel depressed					
2. I find it hard to get along with people					
3. I feel empty inside					
4. I can't keep up with my normal activities					
5. I feel a need to talk about the baby					
6. I am grieving for the baby					
7. I am frightened					
8. I have considered suicide since the loss					
9. I take medicine for my nerves					
10. I very much miss the baby					
11. I feel I have adjusted well to the loss					
12. It is painful to recall memories of the loss					
13. I get upset when I think about the baby					
14. I cry when I think about him/her					
15. I feel guilty when I think about the baby					
16. I feel physically ill when I think about the baby					
17. I feel unprotected in a dangerous world since he/she died					
18. I try to laugh, but nothing seems funny anymore					
19. Time passes so slowly since the baby died					
20. The best part of me died with the baby					
21. I have let people down since the baby died					
22. I feel worthless since he/she died					
23. I blame myself for the baby's death					
24. I get cross at my friends and relatives more than I should					
25. Sometimes I feel like I need a professional counselor to help me get my life back together					
26. I feel as though I'm just existing and not really living since he/she died					
27. I feel so lonely since he/she died					
28. I feel somewhat apart and remote, even amongst friends					
29. It's safer not to love					
30. I find it difficult to make decisions since the baby died					
31. I worry about what my future will be like					
32. Being a bereaved parent means being a "second class citizen"					
33. It feels great to be alive					

Appendix E: Perinatal Grief Scale (Short Version) Scoring System

The total PGS score is arrived at by first reversing all of the items except 11 and 33. By reversing the items, higher scores now reflect more intense grief. Then add the scores together. The result is a total scale consisting of 33 items with a possible range of 33–165. The three subscales consist of the sum of the scores of 11 items each, with a possible range of 11–55.

Subscale 1 *Active Grief*	Subscale 2 *Difficulty Coping*	Subscale 3 *Despair*
1	2	9
3	4	15
5	8	16
6	*11	17
7	21	18
10	24	20
12	25	22
13	26	23
14	28	29
19	30	31
27	*33	32

* Do not reverse.

Reprinted from “Measuring grief: A short version of the Perinatal Grief Scale,” by L. Potvin, J. Lasker, and L. Toedter, 1989, *Journal of Psychopathology and Behavioral Assessment, 11(1)*, p. 225.

Appendix F: Structured Clinical Interview for *DSM-IV-TR*, Non-Patient Edition (SCID- I/NP)

STRUCTURED CLINICAL INTERVIEW FOR DSM-IV-TR AXIS I DISORDERS

Non-patient Edition (November 2002)

S C I D - I / NP

Michael B. First, M.D.; Robert L. Spitzer, M.D.;
Miriam Gibbon, M.S.W.; and Janet B.W. Williams, D.S.W.

Study: _____ Study No.: _ _ _ _ NP1

Subject: _____ I.D. No.: _ _ _ _ NP2

Rater: _____ Rater No.: _ _ _ NP3

Date of Interview: _ _ / _ _ / _ _ NP4
Mo. Day Year

Sources of information (check all that apply): NP5
__ Subject
__ Family/friends/associates NP6
__ Health professional/chart/referral note NP7

Edited and checked by: _____ Date: _____

The development of the SCID was supported in part by NIMH Contract #278-83-0007(DB) and NIMH Grant #1 R01 MH40511. DSM-IV-TR criteria are reprinted with permission of the American Psychiatric Association.

For citation: First, Michael B., Spitzer, Robert L., Gibbon, Miriam, and Williams, Janet B.W.: "Structured Clinical Interview for DSM-IV-TR Axis I Disorders – Non-patient Edition (SCID-I/NP, 11/2002 revision)"
Biometrics Research Department
New York State Psychiatric Institute
1051 Riverside Drive - Unit 60
New York, New York 10032

Web page: **http://www.scid4.org**

DSM-IV Axis V: Global Assessment of Functioning Scale

Consider psychological, social, and occupational functioning on a hypothetical continuum of mental health-illness. Do not include impairment in functioning due to physical (or environmental) limitations

CODE (Note: Use intermediate codes when appropriate, e.g., 45, 68, 72). NP105

100 — — **Superior functioning in a wide range of activities, life's problems never seem to get out of hand, is sought out by others because of his many positive qualities. No symptoms.**
91

90 — — **Absent or minimal symptoms** (e.g., mild anxiety before an exam); **good functioning in all areas, interested and involved in a wide range of activities, socially effective, generally satisfied with life, no more than everyday problems or concerns** (e.g., an occasional argument with family members).
81

80 — — **If symptoms are present, they are transient and expectable reactions to psychosocial stressors** (e.g., difficulty concentrating after family argument); **no more than slight impairment in social, occupational, or school functioning** (e.g., temporarily falling behind in school work).
71

70 — — **Some mild symptoms** (e.g., depressed mood and mild insomnia) **OR some difficulty in social, occupational, or school functioning** (e.g., occasional truancy, or theft within the household), **but generally functioning pretty well, has some meaningful interpersonal relationships.**
61

60 — **Moderate symptoms** (e.g., flat affect and circumstantial speech, occasional panic attacks) **OR moderate difficulty in social, occupational, or school functioning** (e.g., few friends, conflicts with peers or
51 coworkers).

50 — **Serious symptoms** (e.g., suicidal ideation, severe obsessional rituals, frequent shoplifting) **OR any serious impairment in social, occupational, or school functioning** (e.g., no friends, unable to keep a
41 job).

40 — — **Some impairment in reality testing or communication** (e.g., speech is at times illogical, obscure, or irrelevant) **OR major impairment in several areas, such as work or school, family relations, judgment, thinking, or mood** (e.g., depressed man avoids friends, neglects family, and is unable to work; child frequently beats up younger children, is defiant at home, and is failing at school).
31

30 — — **Behavior is considerably influenced by delusions or hallucinations OR serious impairment in communication or judgment** (e.g., sometimes incoherent, acts grossly inappropriately, suicidal preoccupation) **OR inability to function in almost all areas** (e.g., stays in bed all day; no job, home, or
21 friends).

20 — — **Some danger of hurting self or others** (e.g., suicide attempts without clear expectation of death, frequently violent, manic excitement) **OR occasionally fails to maintain minimal personal hygiene** (e.g., smears feces) **OR gross impairment in communication** (e.g., largely incoherent or mute).
11

10 — **Persistent danger of severely hurting self or others** (e.g., recurrent violence) **OR persistent inability to maintain minimal personal hygiene OR serious suicidal act with clear expectation of death.**
1

0 Inadequate information.

OVERVIEW

I'm going to be asking you about problems or difficulties you may have had, and I'll be making some notes as we go along. Do you have any questions before we begin?

DEMOGRAPHIC DATA

SEX: 1 male 2 female — NP106

What's your date of birth? DOB: ___ ___ ___ AGE___ ___ (mon day year) — NP107 NP108

Are you married? MARITAL STATUS (most recent): — NP109

1 married or living with someone as if married
2 widowed
3 divorced or annulled
4 separated
5 never married

IF NO: Were you ever?

Any children? What are their ages?)

IF YES: How many? _____

Where do you live _____

Who do you live with? _____

EDUCATION AND WORK HISTORY

How far did you get in school? EDUCATION: — NP110

1 grade 6 or less
2 grade 7 to 12 (without graduating high school)
3 graduated high school or high school equivalent
4 part college
5 graduated 2 year college
6 graduated 4 year college
7 part graduate/professional school
8 completed graduate/professional school

IF FAILED TO COMPLETE A PROGRAM IN WHICH THEY WERE ENROLLED: Why didn't you finish? _____

What kind of work do you do? (Do you work outside of your home?) _____

Are you working now? _____

IF YES: How long have you worked there? _____

IF LESS THAN 6 MONTHS: Why did you leave your last job? _____

Have you always done that kind of work? _____

IF NO: Why is that? What kind of work have you done? _____

How are you supporting yourself now? _____

IF UNKNOWN: Has there ever been a period of time when you were unable to work or go to school? _____

IF YES: Why was that? _____

PAST PERIODS OF PSYCHOPATHOLOGY

(THE LIFE CHART ON PAGE V OF OVERVIEW MAY BE USED TO SUMMARIZE A COMPLICATED HISTORY OF PSYCHOPATHOLOGY AND TREATMENT.)

Have you ever seen anybody for emotional or psychiatric problems? Treatment for emotional problems with a physician or mental health professional — 1 NO 2 YES — NP111

IF YES: What was that for? (What treatment(s) did you get? Any medications?) _____

IF NO: Was there ever a time when you, or someone else, thought you should see someone because of the way you were feeling or acting? _____

What about treatment for drugs or alcohol? _____

Have you ever been a patient in a psychiatric hospital? Number of previous hospitalizations (Do not include transfers) — 1 2 3 4 5 (or more) — NP112

IF YES: What was that for? (How many times?) _____

IF GIVES AN INADEQUATE ANSWER, CHALLENGE GENTLY: e.g., Wasn't there something else? People don't usually go to psychiatric hospitals just because they are tired or nervous. _____

Have you ever been in a hospital for treatment of a medical problem?

IF YES: What was that for?

Thinking back over your whole life, when were you the most upset?

(Why? What was that like? How were you feeling?)

When were you feeling the best you have ever felt?

PSYCHOPATHOLOGY DURING PAST MONTH

Now I would like to ask you about the past month. How have things been going for you?

Has anything happened that has been especially hard for you?

What about difficulties at work or with your family?

How has your mood been?

How has your physical health been? (Have you had any medical problems?) (USE THIS INFORMATION TO CODE AXIS III)

Do you take any medications or vitamins?

IF YES: How much and how often do you take (MEDICATION)? (Has there been any change in the amount you have been taking?)

How much have you been drinking (alcohol) (in the past month)?

Have you been taking any drugs (in the past month)? (What about marijuana, cocaine, other street drugs?)

CURRENT SOCIAL FUNCTIONING

How have you been spending your free time?

Who do you spend time with?

MOST LIKELY CURRENT DIAGNOSES:

DIAGNOSES THAT NEED TO BE RULED OUT:

SCID SCREENING MODULE (OPTIONAL)

Now I want to ask you some more specific questions about problems you my have had. We'll go into more detail about them later.

RESPOND TO POSITIVE RESPONSES WITH: We'll talk more about that later.

	1	2	3	
1. Has there been any time in your life when you had five or more drinks (beer, wine, or liquor) on one occasion?	CIRCLE "NO" ON E. 1	CIRCLE "YES" ON E. 1		S1
2. Have you ever used street drugs?	CIRCLE "NO" ON E. 9	CIRCLE "YES" ON E. 9		S2
3. Have you ever gotten "hooked" on a prescribed medicine or taken a lot more of it than you were supposed to?	CIRCLE "NO" ON E. 9	CIRCLE "YES" ON E. 9		S3
4. Have you ever had a panic attack, when you suddenly felt frightened or suddenly developed a lot of physical symptoms?	CIRCLE "NO" ON F. 1	CIRCLE "YES" ON F. 1		S4
5. Were you ever afraid of going out of the house alone, being in crowds, standing in a line, or traveling on buses or trains?	CIRCLE "NO" ON F. 7	CIRCLE "YES" ON F. 7		S5
6. Is there anything that you have been afraid to do or felt uncomfortable doing in front of other people, like speaking, eating or writing?	CIRCLE "NO" ON F. 11	CIRCLE "YES" ON F. 11		S6
7. Are there any other things that you have been especially afraid of, like flying, seeing blood, getting a shot, heights, closed places, or certain kinds of animals or insects?	CIRCLE "NO" ON F. 16	CIRCLE "YES" ON F. 16		S7

1=not present 2=unsure or equivocal 3=present

	1	2	3	
8. Have you ever been bothered by thoughts that didn't make any sense and kept coming back to you even when you tried not to have them?	CIRCLE "NO" ON F. 20	CIRCLE "YES" ON F. 20		S8
9. Was there ever anything that you had to do over and over again and couldn't resist doing, like washing your hands again and again, counting up to a certain number, or checking something several times to make sure that you'd done it right?	CIRCLE "NO" ON F. 21	CIRCLE "YES" ON F. 21		S9
10. In the last six months, have you been particularly nervous or anxious?	CIRCLE "NO" ON F. 31	CIRCLE "YES" ON F. 31		S10
11. Have you ever had a time when you weighed much less than other people thought you ought to weigh?	CIRCLE "NO" ON H. 1	CIRCLE "YES" ON H. 1		S11
12. Have you often had times when your eating was out of control?	CIRCLE "NO" ON H. 4	CIRCLE "YES" ON H. 4		S12

1=not present 2=unsure or equivocal 3=present

SCID-I/NP (for DSM-IV-TR) (NOV 2002) Summary Score Sheet i

DX code	Diagnosis	Lifetime Prevalence: Inadequate info.	Absent	Sub-Threshold	Threshold	Meets Symptomatic Dx. Crit. past Month: Absent	Present	
	MOOD DISORDERS							
01	Bipolar I Disorder (D. 1)	?	1	2	3 →	1	3	NP8
	Single Manic Episode / Recurrent				1 / 2			NP9 NP10 NP11
	Current episode: 1 manic, 2 mixed, 3 hypomanic, 4 major depressive, 5 unspecified							
	Without Rapid Cycling / With Rapid Cycling				0 / 1			NP12 NP13
	Neither Melancholic, Atypical, Nor catatonic; Melancholic; Atypical; Catatonic							0 / 1 / 2 / 3 NP14
	W/O Seasonal Pattern / With Seasonal Pattern				0 / 1			
	(only if not current): In Partial Remission / In Full Remission				6 / 7			NP15 NP16
	Current severity: 1 mild, 2 moderate, 3 severe, without psychotic features, 4 with mood-congruent psychotic features, 5 with mood-incongruent psychotic features							
02	Bipolar II Disorder (D. 2)	?	1	2	3 →	1	3	NP17 NP18 NP19
	Current episode: 1 hypomanic, 2 major depressive							
	Without Rapid Cycling / With Rapid Cycling				0 / 1			NP20 NP21
	Neither Melancholic, Atypical, Nor catatonic; Melancholic; Atypical; Catatonic							0 / 1 / 2 / 3 NP22
	W/O Seasonal Pattern / With Seasonal Pattern				0 / 1			
	(only if not current): In Partial Remission / In Full Remission				6 / 7			NP23 NP24
	Current severity: 1 mild, 2 moderate, 3 severe, without psychotic features, 4 with mood-congruent psychotic features, 5 with mood-incongruent psychotic features							
03	Other Bipolar Disorder (D. 5)	?	1	2	3 →	1	3	NP25 NP26 NP27
	1 Cyclothymic Disorder; 2 Intermittent hypomanic episodes; 3 Manic or hypomanic episode superimposed on Psychotic Disorder; 4 Bipolar Disorder NOS with subthreshold manic episodes; 5 Other							

SCID-I/NP (for DSM-IV-TR) (NOV 2002) Summary Score Sheet ii

DX code	Diagnosis	Lifetime Prevalence: Inadequate info.	Absent	Sub-Threshold	Threshold	Meets Symptomatic Dx. Crit. past Month: Absent	Present	
	MOOD DISORDERS (continued)							
04	Major Depressive Disorder (D. 6)	?	1	2	3 →	1	3	NP28 NP29
	Single Episode / Recurrent				1 / 2			NP30 NP31
	Type of current episode: 0 Neither Melancholic, Atypical, Nor catatonic; 1 Melancholic; 2 Atypical; 3 Catatonic							NP32
	W/O Seasonal Pattern / With Seasonal Pattern				0 / 1			
	(only if not current): In Partial Remission / In Full Remission				6 / 7			
	Current severity: 1 mild, 2 moderate, 3 severe, without psychotic features, 4 with mood-congruent psychotic features, 5 with mood-incongruent psychotic features							NP33 NP34
05	Dysthymic Disorder (current only) (A. 41)	?	1	2	3			NP35
	1 Early onset; 2 Late onset							NP36
	0 Without Atypical Features; 1 With Atypical Features							NP37
06	Depressive Disorder Not Otherwise Specified (D. 9)	?	1		3 →	1	3	NP38 NP39
	1 Postpsychotic Depressive Disorder of Schizophrenia; 2 Major Depressive Episode superimposed on a Psychotic Disorder; 3 Premenstrual dysphoric disorder; 4 Minor depressive disorder; 5 Recurrent brief depressive disorder; 6 Other							NP40
07	Mood Disorder Due to A General Medical Condition (A. 44) Specify GMC:_____	?	1		3 →	1	3	NP41 NP42
	1 With major depressive-like episode; 2 With depressive features; 3 With manic features; 4 With mixed features							NP43
08	Substance-Induced Mood Disorder (A. 46) Specify Substance:_____	?	1		3 →	1	3	NP44 NP45
	1 With depressive features; 2 With manic features; 3 With mixed features							NP46
	PSYCHOTIC SYMPTOMS							
01	Primary Psychotic Symptoms (not part of Mood Disorder) (B/C. 4)	?	1	2	3 →	1	3	NP47 NP48

SCID-I/NP (for DSM-IV-TR) (NOV 2002) Summary Score Sheet iii

DX code	Diagnosis	Lifetime Prevalence: Inadequate info.	Absent	Sub-Threshold	Threshold	Meets Symptomatic Dx. Crit. past Month: Absent	Present	
SUBSTANCE USE DISORDERS								
17	Alcohol (E. 3/E. 6)	?	1	2	3 →	1	3	NP49 NP50
18	Sedative-Hypnotic-Anxiolytic (E. 22/E. 16)	?	1	2	3 →	1	3	NP51 NP52
19	Cannabis (E. 22/E. 16)	?	1	2	3 →	1	3	NP53 NP54
20	Stimulants (E. 22/E. 16)	?	1	2	3 →	1	3	NP55 NP56
21	Opiod (E. 22/E. 16)	?	1	2	3 →	1	3	NP57 NP58
22	Cocaine (E. 22/E. 16)	?	1	2	3 →	1	3	NP59 NP60
23	Hal./PCP (E. 22/E. 16)	?	1	2	3 →	1	3	NP61 NP62
24	Poly Drug (E. 16)	?	1		3 →	1	3	NP63 NP64
25	Other (E. 22/E. 16)	?	1	2	3 →	1	3	NP65 NP66

SCID-I/NP (for DSM-IV-TR) (NOV 2002) Summary Score Sheet iv

DX code	Diagnosis	Lifetime Prevalence: Inadequate info.	Absent	Sub-Threshold	Threshold	Meets Symptomatic Dx. Crit. past Month: Absent	Present	
ANXIETY DISORDERS								
26	Panic Disorder (F. 3)	?	1	2	3 →	1	3	NP67 NP68 NP69
	1 without Agoraphobia 2 with Agoraphobia							
27	Agoraphobia without History of Panic Disorder (AWOPD) (F. 9)	?	1	2	3 →	1	3	NP70 NP71
28	Social Phobia (F. 14)	?	1	2	3 →	1	3	NP72 NP73
29	Specific Phobia (F. 18)	?	1	2	3 →	1	3	NP74 NP75
30	Obsessive Compulsive (F. 23)	?	1	2	3 →	1	3	NP76 NP77
31	Posttraumatic Stress (F. 29)	?	1	2	3 →	1	3	NP78 NP79
32	Generalized Anxiety (current only) (F. 34)	?	1	2	3			NP80
33	Anxiety Disorder Due To a General Medical Condition (F. 37) Specify GMC:_____	?	1		3 →	1	3	NP81 NP82
	1 With Generalized Anxiety 2 With Panic Attacks 3 With Obsessive-Compulsive Symptoms							NP83
34	Substance-Induced Anxiety Disorder (F. 39) Specify Substance_____	?	1		3 →	1	3	NP84 NP85
	1 With Generalized Anxiety 2 With Panic Attacks 3 With Obsessive-Compulsive Symptoms 4 With Phobic Symptoms							NP86
35	Anxiety Disorder NOS (F. 40)	?	1		3 →	1	3	NP87 NP88

DX code	Diagnosis	Lifetime Prevalence: Inadequate info.	Absent	Sub-Threshold	Threshold	Meets Symptomatic Dx. Crit. past Month: Absent	Present	
SOMATOFORM DISORDERS								
36	Somatization Disorder (current only) (G. 5)	?	1	2	3			NP89
37	Pain Disorder (current only) (G. 6)	?	1	2	3			NP90
38	Undifferentiated Somatoform Disorder (current only) (G. 8)	?	1	2	3			NP91
39	Hypochondriasis (current only) (G. 9)	?	1	2	3			NP92
40	Body Dysmorphic (current only) (G. 10)	?	1	2	3			NP93
EATING DISORDERS								
41	Anorexia Nervosa (H. 2)	?	1	2	[3] →	1	3	NP94 NP95
42	Bulimia Nervosa (H. 5)	?	1	2	[3] →	1	3	NP96 NP97
43	Binge Eating Disorder (H. 7)	?	1	2	[3] →	1	3	NP98 NP99
44	**ADJUSTMENT DISORDER** (current only) (I. 2)	?	1	2	3			NP100
45	**OTHER DSM-IV AXIS I DISORDER:** Specify: _____	?	1	2	[3] →	1	3	NP101 NP102

PRINCIPAL AXIS I DIAGNOSIS (i.e., the disorder that is [or should be] the main focus of current clinical attention).

Enter Dx Code number from scoresheet for principal diagnosis: __ __ NP103
Note: Code 00 if no current Axis I disorder. Code 99 if unknown.

INTERVIEWER'S DIAGNOSES, IF DIFFERENT FROM SCID DIAGNOSES:

_____ _____ _____

DSM-IV Axis IV: Psychosocial and Environmental Problems

Check:

___ **Problems with primary support group (childhood, adult, parent-child).** Specify: _____ NP104
___ **Problems related to the social environment.** Specify: _____ NP104a
___ **Educational problems.** Specify: _____ NP104b
___ **Occupational problems.** Specify: _____ NP104c
___ **Housing problems.** Specify: _____ NP104d
___ **Economic problems.** Specify: _____ NP104e
___ **Problems with access to health care services.** Specify: _____ NP104f
___ **Problems related to interaction with the legal system/crime.** Specify: _____ NP104g
___ **Other psychosocial problems.** Specify: _____ NP104h

LIFE CHART

Age (or date)	Description (symptoms, triggering events)	Treatment

RETURN TO OVERVIEW PAGE iii, **PSYCHOPATHOLOGY DURING PAST MONTH.**

A. MOOD EPISODES

IN THIS SECTION, MAJOR DEPRESSIVE, MANIC, HYPOMANIC EPISODES, DYSTHYMIC DISORDER, MOOD DISORDER DUE TO A GENERAL MEDICAL CONDITION, SUBSTANCE-INDUCED MOOD DISORDER, AND EPISODE SPECIFIERS ARE EVALUATED. MAJOR DEPRESSIVE DISORDER AND BIPOLAR DISORDERS ARE DIAGNOSED IN MODULE D.

CURRENT MAJOR DEPRESSIVE EPISODE	MDE CRITERIA		
Now I am going to ask you some more questions about your mood	A. Five (or more) of the following symptoms have been present during the same two-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood, or (2) loss of interest or pleasure.		
In the last month . . .	(1) depressed mood most of the day, nearly every day, as indicated either by subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful). Note: in children or adolescents, can be irritable mood.	? 1 2 3	A1
. . . has there been a period of time when you were feeling depressed or down most of the day nearly every day? (What was that like?)			
IF YES: How long did it last? (As long as two weeks?)			
. . . what about losing interest or pleasure in things you usually enjoyed?	(2) markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated either by subjective account or observation made by others).	? 1 2 3	A2
IF YES: Was it nearly every day? How long did it last? (As long as two weeks?)			

IF NEITHER ITEM (1) NOR ITEM (2) IS CODED "3," GO TO **"PAST MAJOR DEPRESSIVE EPISODE,"** A. 12.

NOTE: WHEN RATING THE FOLLOWING ITEMS, CODE "1" IF CLEARLY DUE TO A GENERAL MEDICAL CONDITION, OR TO MOOD-INCONGRUENT DELUSIONS OR HALLUCINATIONS

FOR THE FOLLOWING QUESTIONS, FOCUS ON THE WORST TWO WEEKS IN THE PAST MONTH (OR ELSE THE PAST TWO WEEKS IF EQUALLY DEPRESSED FOR ENTIRE MONTH)

During this (TWO WEEK PERIOD) . . .

..how was your appetite? (What about compared to your usual appetite?) (Did you have to force yourself to eat?) (Eat [less/more] than usual?) (Was that nearly every day?) (Did you lose or gain any weight) (How much?) (Were you trying to [lose/gain] weight?)	(3) significant weight loss when not dieting, or weight gain (e.g., a change of more than 5% of body weight in a month) or decrease or increase in appetite nearly every day. Note: in children, consider failure to make expected weight gains.	? 1 2 3	A3
	Check if: ____ weight loss or decreased appetite		A4
	____ weight gain or increased appetite		A5
. . how were you sleeping? (Trouble falling asleep, waking frequently, trouble staying asleep, waking too early, OR sleeping too much? How many hours a night compared to usual? Was that nearly every night?)	(4) insomnia or hypersomnia nearly every day	? 1 2 3	A6
	Check if: ____ insomnia		A7
	____ hypersomnia		A8
. . were you so fidgety or restless that you were unable to sit still? (Was it so bad that other people noticed it? What did they notice? Was that nearly every day?)	(5) psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down)	? 1 2 3	A9
	NOTE: CONSIDER BEHAVIOR DURING THE INTERVIEW		
IF NO: What about the opposite -- talking or moving more slowly than is normal for you? (Was it so bad that other people noticed it? What did they notice? Was that nearly every day?)	Check if: ____ psychomotor retardation		A10
	____ psychomotor agitation		A11
. . what was your energy like? (Tired all the time? Nearly every day?)	(6) fatigue or loss of energy nearly every day	? 1 2 3	A12

During this time . . .

. . how did you feel about yourself? (Worthless?) (Nearly every day?) IF NO: What about feeling guilty about things you had done or not done? (Nearly every day?)	(7) feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick) NOTE: CODE "1" OR "2" IF ONLY LOW SELF-ESTEEM Check if: ____ worthlessness ____ inappropriate guilt	?	1	2	3	A13 A14 A15
. . did you have trouble thinking or concentrating? (What kinds of things did it interfere with?) (Nearly every day?) IF NO: Was it hard to make decisions about everyday things? (Nearly every day?)	(8) diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others) Check if: ____ diminished ability to think ____ indecisiveness	?	1	2	3	A16 A17 A18
. . were things so bad that you were thinking a lot about death or that you would be better off dead? What about thinking of hurting yourself? IF YES: Did you do anything to hurt yourself?	(9) recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide NOTE: CODE "1" FOR SELF-MUTILATION W/O SUICIDAL INTENT Check if: ____ thoughts of own death ____ suicidal ideation ____ specific plan ____ suicide attempt	?	1	2	3	A19 A20 A21 A22 A23
	AT LEAST FIVE OF THE ABOVE SXS [A (1-9)] ARE CODED "3" AND AT LEAST ONE OF THESE IS ITEM (1) OR (2) NOTE: DSM-IV criterion B (i.e., does not meet criteria for a Mixed Episode) has been omitted from the SCID.		1 GO TO ***PAST MAJOR DEPRES-SIVE EPISODE*** A. 12		3	A24

?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

IF UNCLEAR: Has (DEPRESSIVE EPISODE/OWN WORDS) made it hard for you to do your work, take care of things at home, or get along with other people?	C. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning	?	1 GO TO ***PAST MAJOR DEPRES-SIVE EPISODE*** A. 12	2	3	A25
Just before this began, were you physically ill? IF YES: What did the doctor say? Just before this began, were you using any medications? IF YES: Any change in the amount you were using? Just before this began, were you drinking or using any street drugs?	D. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition IF THERE IS ANY INDICATION THAT THE DEPRESSION MAY BE SECONDARY (I.E., A DIRECT PHYSIOLOGICAL CONSEQUENCE OF A GMC OR SUBSTANCE, GO TO ***GMC/SUBSTANCE,*** A.43, AND RETURN HERE TO MAKE A RATING OF "1" OR "3."	?	1 DUE TO SUB-STANCE USE OR GMC GO TO ***PAST MAJOR DEPRESSIVE EPISODE*** A. 12		3 PRIMARY MOOD EPISODE CONTINUE BELOW	A26

Etiological general medical conditions include: degenerative neurological illnesses (e.g., Parkinson's disease), cerebrovascular disease (e.g., stroke), metabolic conditions (e.g., Vitamin B-12 deficiency), endocrine conditions (e.g., hyper- and hypothyroidism, hyper- and hypoadrenocorticism); viral or other infections (e.g., hepatitis, mononucleosis, HIV), and certain cancers (e.g., carcinoma of the pancreas).

Etiological substances include: alcohol, amphetamines, cocaine, hallucinogens, inhalants, opioids, phencyclidine, sedatives, hypnotics, anxiolytics. Medications include antihypertensives, oral contraceptives, corticosteroids, anabolic steroids, anticancer agents, analgesics, anticholinergics, cardiac medications.

?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

SCID-I (for DSM-IV-TR) Current MDE (NOV 2002) Mood Episodes A. 5

Did this begin soon after someone close to you died?

E. Not better accounted for by bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than 2 months or are characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation.

1 SIMPLE BEREAVE-MENT **GO TO *PAST MAJOR DEPRES-SIVE EPISODE*** A. 12

3 NOT SIMPLE BEREAVE-MENT CONTINUE BELOW

A27

MAJOR DEPRESSIVE EPISODE CRITERIA A, C, D AND E ARE CODED "3"

1 GO TO ***PAST MAJOR DEPRES-SIVE EPISODE*** A. 12

3 CURRENT MAJOR DEPRES-SIVE EPISODE

A28

How many separate times in your life have you been (depressed/ OWN WORDS) nearly every day for at least two weeks and had several of the symptoms that you described, like (SXS OF WORST EPISODE)?

Total number of Major Depressive Episodes, including current (CODE 99 IF TOO NUMEROUS OR INDISTINCT TO COUNT)

NOTE: TO RECORD DETAILS OF PAST EPISODES, GO TO J. 9 (OPTIONAL).

__ __

A29

?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

SCID-I (for DSM-IV-TR) Postpartum/Catatonic (NOV 2002) Mood Episodes A. 6

CURRENT MAJOR DEPRESSIVE EPISODE SPECIFIERS

WITH POSTPARTUM ONSET

WITH POSTPARTUM ONSET

IF UNKNOWN: When did (DEPRESSIVE SXS) start?

Onset of episode within 4 weeks postpartum ? 1 3 WITH POST-PARTUM ONSET A30

WITH CATATONIC FEATURES

CATATONIC FEATURES CRITERIA

BY OBSERVATION OR HISTORY

The clinical picture is dominated by at least 2 of the following:

(1) motoric immobility as evidenced by catalepsy (including waxy flexibility) or stupor ? 1 2 3 A31

DESCRIBE SPECIFIC BEHAVIOR:

(2) excessive motor activity (that is apparently purposeless and not influenced by external stimuli) ? 1 2 3 A32

DESCRIBE SPECIFIC BEHAVIOR:

(3) extreme negativism (an apparently motiveless resistance to all instructions or maintenance of a rigid posture against attempts to be moved) or mutism ? 1 2 3 A33

DESCRIBE SPECIFIC BEHAVIOR:

(4) peculiarities of voluntary movement as evidenced by posturing (voluntary assumption of inappropriate or bizarre postures), stereotyped movements, prominent mannerisms, or prominent grimacing ? 1 2 3 A34

DESCRIBE SPECIFIC BEHAVIOR:

?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

SCID-I (for DSM-IV-TR) Catatonic Features (NOV 2002) Mood Episodes A. 7

(5) echolalia (the pathological parrotlike and apparently senseless repetition of a word or phrase just spoken by another person) or echopraxia (the repetitive imitation of the movements of another person) ? 1 2 3 A35

DESCRIBE SPECIFIC BEHAVIOR:

AT LEAST 2 ITEMS ARE CODED "3" 1 3 A36

GO TO ***MELANCHOLIC FEATURES*** A. 8

WITH CATATONIC FEATURES

GO TO ***CURRENT MANIC EPISODE*** A. 18

?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

SCID-I (for DSM-IV-TR) Melancholic Features (NOV 2002) Mood Episodes A. 8

WITH MELANCHOLIC FEATURES*

IF UNKNOWN: During (PERIOD OF CURRENT EPISODE), when were you feeling the worst?

During that time when you were feeling the worst . . .

MELANCHOLIC FEATURES CRITERIA

A. Either of the following, occurring during the most severe period of the current episode:

IF UNKNOWN: did you completely lose interest or pleasure in everything?

(1) loss of pleasure in all, or almost all, activities ? 1 2 3 A37

If something good happens to you or someone tries to cheer you up, do you feel better at least for awhile?

2) lack of reactivity to usually pleasurable stimuli (does not feel much better, even temporarily, when something good happens) ? 1 2 3 A38

IF NEITHER A(1) OR A(2) ARE CODED 3 GO TO ***ATYPICAL FEATURES*** A. 10

During that time when you were feeling the worst . . .

B. Three (or more) of the following:

Was your feeling of (OWN WORDS FOR DEPRESSED MOOD) different from the kind of feeling you would get if someone close to you died? (Or something else bad happened to you?)

(1) distinct quality of depressed mood (i.e., the depressed mood is perceived as distinctly different from the kind of feeling experienced after the death of a loved one) ? 1 2 3 A39

IF YES: How is it different?

Did you usually feel worse in the morning?

(2) the depression is regularly worse in the morning ? 1 2 3 A40

?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

SCID-I (for DSM-IV-TR) Melancholic Features (NOV 2002) Mood Episodes A. 9

IF UNKNOWN: What time did you wake up in the morning? (How much earlier is it than your usual time [before you were depressed]?)	3) early morning awakening (at least two hours before usual time of awakening)	?	1	2	3	A41
IF UNKNOWN: Were you talking or moving very slowly during the time, as if you were doing things in slow motion? IF UNKNOWN: How about being extremely restless or unable to sit still? (Were you pacing around a lot or wringing your hands?)	(4) marked psychomotor retardation or agitation	?	1	2	3	A42
IF UNKNOWN: Did you virtually stop eating or lose a great deal of weight?	(5) significant anorexia or weight loss	?	1	2	3	A43
IF UNKNOWN: Were you feeling guilty about tings you had done or not done?	(6) excessive or inappropriate guilt	?	1	2	3	A44
	AT LEAST THREE B ITEMS ARE CODED "3"		1		3	A45
			GO TO ***ATYPICAL FEATURES*** A. 10			
	CRITERIA A AND B ARE CODED "3"		1		3	A45a
					WITH MELAN-CHOLIC FEATURES	
					GO TO ***CURRENT MANIC EPISODE*** A. 18	

?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

SCID-I (for DSM-IV-TR) Atypical Features (NOV 2002) Mood Episodes A. 10

WITH ATYPICAL FEATURES **ATYPICAL FEATURES CRITERIA**

IF CURRENT EPISODE HAS MELANCHOLIC OR CATATONIC FEATURES, CHECK HERE ____ AND GO TO ***CURRENT MANIC EPISODE,*** A. 18 . A45b

The following features must predominate during the most recent two weeks of the Major Depressive Episode:

IF UNKNOWN: During the (LAST TWO WEEKS OF CURRENT MDE), If something good happens to you or someone tries to cheer you up, do you feel better, at least for a while?	A. Mood reactivity (i.e., mood brightens in response to actual or potential positive events.)	?	1	2	3	A46
			GO TO ***CURRENT MANIC EPISODE*** A. 18			
	B. Two (or more) of the following features:					
IF UNKNOWN: Has your appetite increased a lot or have you gained a lot of weight? (How much?)	(1) significant weight gain or increase in appetite	?	1	2	3	A47
How many hours (in a 24 hour period) do you usually sleep (including naps)?	(2) hypersomnia NOTE: CODE "3" IF MORE THAN 10 HOURS A DAY	?	1	2	3	A48
Do your arms or legs often feel heavy (as though they were full of lead)?	(3) leaden paralysis (i.e., heavy, leaden feelings in arms or legs)	?	1	2	3	A49
Are you especially sensitive to how others treat you? What happens to you when someone rejects, criticizes or slights you? (Do you get very down or angry?) (For how long?) (How has this affected you?) (Is your reaction more extreme than most people's?) Have you avoided doing things or being with people because you were afraid of being criticized or rejected?	(4) long-standing pattern of interpersonal rejection sensitivity (not limited to episodes of mood disturbance) that results in significant social or occupational impairment	?	1	2	3	A50

?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

SCID-I (for DSM-IV-TR) Atypical Features (NOV 2002) Mood Episodes A. 11

AT LEAST TWO "B" CRITERIA ARE CODED "3"

1 3 A51

GO TO ***CURRENT MANIC EPISODE*** A. 18

C. Criteria are not met for "With Melancholic Features" or "With Catatonic Features" during the same episode.

1 3 A51a

GO TO ***CURRENT MANIC EPISODE*** A. 18

CRITERIA A, B, AND C ARE CODED "3"

1 3 A51b

WITH ATYPICAL FEATURES

GO TO ***CURRENT MANIC EPISODE*** A. 18

?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

SCID-I (for DSM-IV-TR) Past MDE (NOV 2002) Mood Episodes A. 12

PAST MAJOR DEPRESSIVE EPISODE

→ IF NOT CURRENTLY DEPRESSED:
Have you ever had a period when you were feeling depressed or down most of the day nearly every day? (What was that like?)

→ IF CURRENTLY DEPRESSED BUT FULL CRITERIA ARE NOT MET, SCREEN FOR PAST MDE:
Has there ever been another time when you were depressed or down most of the day nearly every day? (What was that like?)

IF YES: When was that? How long did it last? (As long as two weeks?)

→ IF PAST DEPRESSED MOOD:
During that time, did you lose interest or pleasure in things you usually enjoyed? (What was that like?)

→ IF NO PAST DEPRESSED MOOD:
What about a time when you lost interest or pleasure in things you usually enjoyed? (What was that like?)

IF YES: When was that? Was it nearly every day? How long did it last? (As long as two weeks?)

Have you had more than one time like that? (Which time was the worst?)

IF UNCLEAR: Have you had any times like that in the past year?

MDE CRITERIA

A. Five or more of the following symptoms have been present during the same two-week period and represent a change from previous functioning; at least one of the symptoms was either (1) depressed mood or (2) loss of interest or pleasure.

(1) depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g. , feels sad or empty) or observation made by others (e.g., appears tearful). Note: in children and adolescents, can be irritable mood.

? 1 2 3 A52

(2) markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated either by subjective account or observation made by others).

? 1 2 3 A53

IF NEITHER ITEM (1) NOR (2) IS CODED "3", GO TO ***CURRENT MANIC EPISODE*** A. 18

NOTE: IF MORE THAN ONE PAST EPISODE IS LIKELY, SELECT THE "WORST" ONE FOR YOUR INQUIRY ABOUT A PAST MAJOR DEPRESSIVE EPISODE. HOWEVER, IF THERE WAS AN EPISODE IN THE PAST YEAR, ASK ABOUT THAT EPISODE EVEN IF IT WAS NOT THE WORST.

?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

FOR THE FOLLOWING QUESTIONS, FOCUS ON THE WORST TWO WEEKS OF THE PAST MAJOR DEPRESSIVE EPISODE THAT YOU ARE INQUIRING ABOUT

NOTE: WHEN RATING THE FOLLOWING ITEMS, CODE "1" IF CLEARLY DIRECTLY DUE TO A GENERAL MEDICAL CONDITION, OR TO MOOD-INCONGRUENT DELUSIONS OR HALLUCINATIONS

During that (TWO WEEK PERIOD) . . .

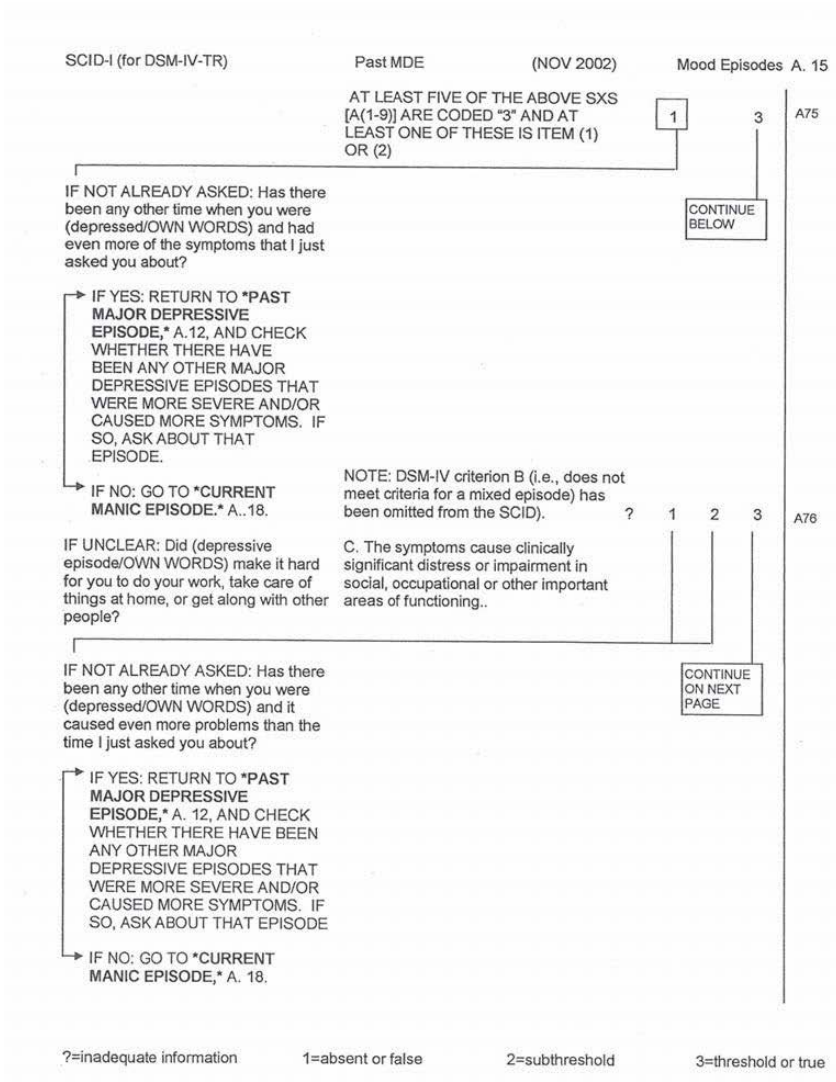
..how was your appetite? (What about compared to your usual appetite?) (Did you have to force yourself to eat?) (Eat [less/more] than usual?) (Was that nearly every day?) (Did you lose or gain any weight?) (How much?) (Were you trying to [lose/gain] weight?)	(3) significant weight loss when not dieting, or weight gain (e.g., a change of more than 5% of body weight in a month) or decrease or increase in appetite nearly every day. Check if: ____ weight loss or decreased appetite ____ weight gain or increased appetite	?	1	2	3	A54 A55 A56
. . how were you sleeping? (Trouble falling asleep, waking frequently, trouble staying asleep, waking too early, OR sleeping too much? How many hours a night compared to usual? Was that nearly every night?	(4) insomnia or hypersomnia nearly every day Check if: ____ insomnia ____ hypersomnia	?	1	2	3	A57 A58 A59
. . were you so fidgety or restless that you were unable to sit still? (Was it so bad that other people noticed it? What did they notice? Was that nearly every day?) IF NO: What about the opposite -- talking or moving more slowly than is normal for you? (Was it so bad that other people noticed it? What did they notice? Was it nearly every day?)	(5) psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down) Check if: ____ psychomotor agitation ____ psychomotor retardation	?	1	2	3	A60 A61 A62
. . what was your energy like? (Tired all the time? Nearly every day?)	(6) fatigue or loss of energy nearly every day	?	1	2	3	A63

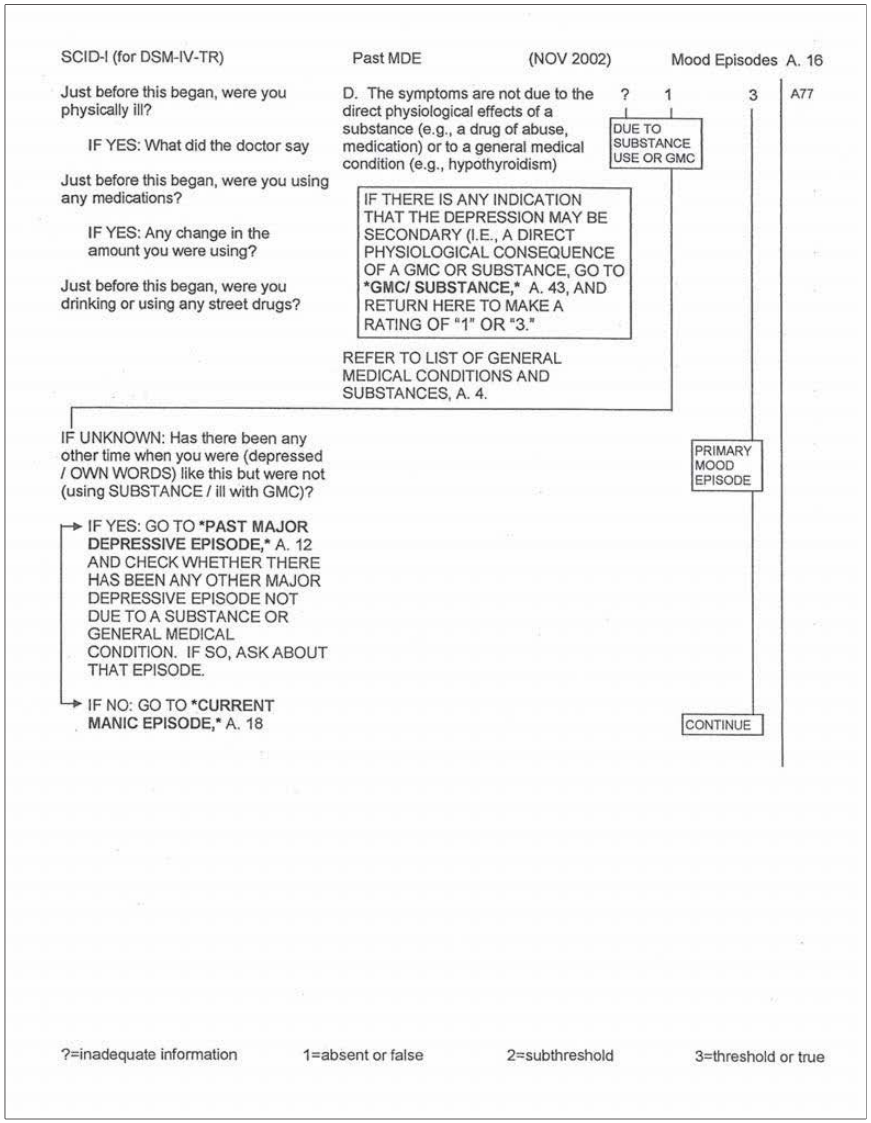
?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

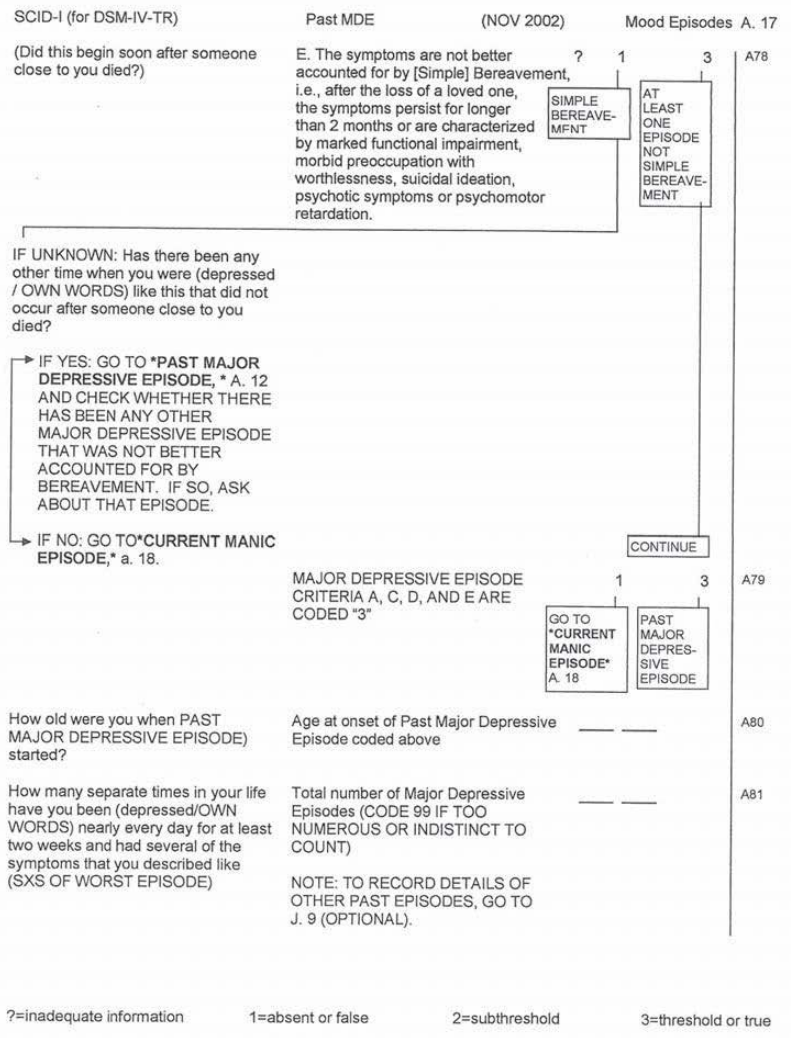
During that time . . .

. . how did you feel about yourself? (Worthless?) (Nearly every day?) IF NO: What about feeling guilty about things you had done or not done? (Nearly every day?)	(7) feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick) NOTE: CODE "1" OR "2" FOR LOW SELF-ESTEEM BUT NOT WORTHLESSNESS Check if: ____ worthlessness ____ inappropriate guilt	?	1	2	3	A64 A65 A66
. . did you have trouble thinking or concentrating? (What kinds of things did it interfere with?) (Nearly every day?) IF NO: Was it hard to make decisions about everyday things? (Nearly every day?)	(8) diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others) Check if: ____ diminished ability to think ____ indecisiveness	?	1	2	3	A67 A68 A69
. . were things so bad that you were thinking a lot about death or that you would be better off dead? What about thinking of hurting yourself? IF YES: Did you do anything to hurt yourself?	(9) recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide NOTE: CODE "1" FOR SELF-MUTILATION W/O SUICIDAL INTENT Check if: ____ thoughts of own death ____ suicidal ideation ____ specific plan ____ suicide attempt	?	1	2	3	A70 A71 A72 A73 A74

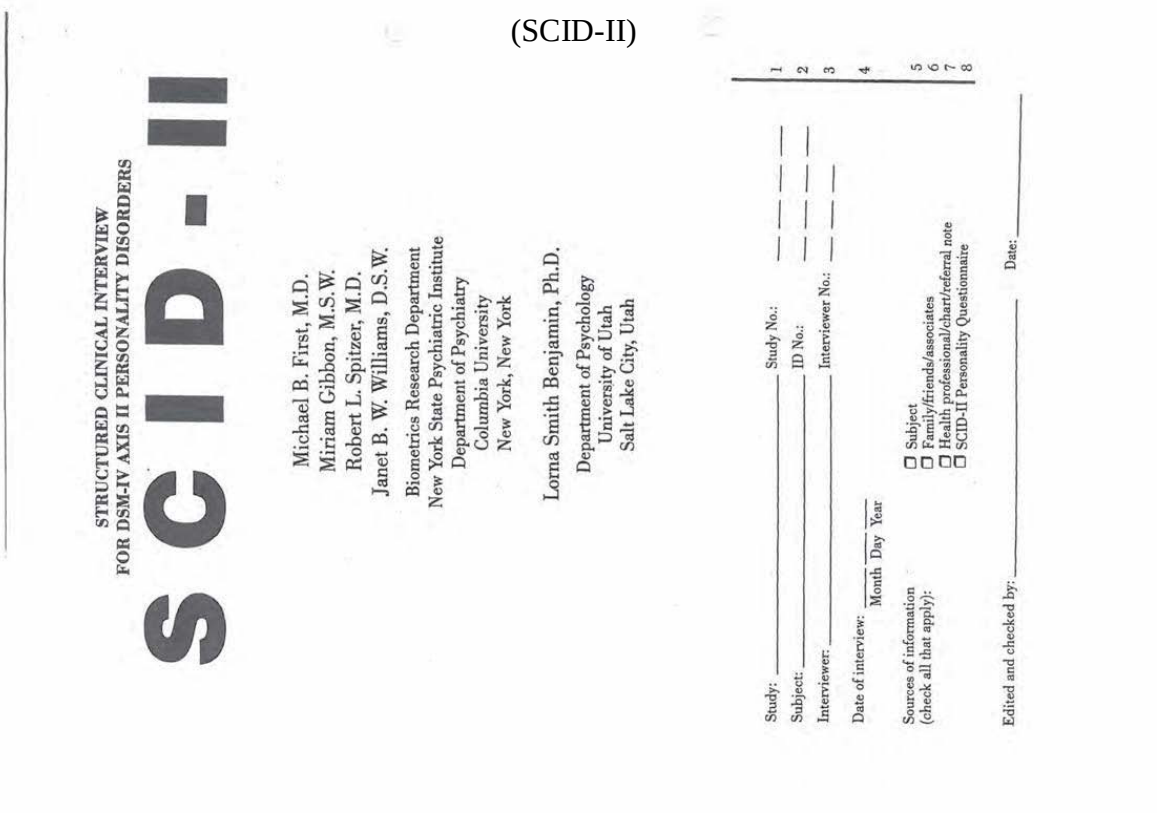
?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true


SCID-I (for DSM-IV-TR)
Past MDE
(NOV 2002)
Mood Episodes A. 15
AT LEAST FIVE OF THE ABOVE SXS [A(1-9)] ARE CODED "3" AND AT LEAST ONE OF THESE IS ITEM (1) OR (2)
1
3
A75
CONTINUE BELOW
IF NOT ALREADY ASKED: Has there been any other time when you were (depressed/OWN WORDS) and had even more of the symptoms that I just asked you about?
IF YES: RETURN TO *PAST MAJOR DEPRESSIVE EPISODE,* A.12, AND CHECK WHETHER THERE HAVE BEEN ANY OTHER MAJOR DEPRESSIVE EPISODES THAT WERE MORE SEVERE AND/OR CAUSED MORE SYMPTOMS. IF SO, ASK ABOUT THAT EPISODE.
IF NO: GO TO *CURRENT MANIC EPISODE.* A..18.
NOTE: DSM-IV criterion B (i.e., does not meet criteria for a mixed episode) has been omitted from the SCID).
C. The symptoms cause clinically significant distress or impairment in social, occupational or other important areas of functioning..
? 1 2 3
A76
IF UNCLEAR: Did (depressive episode/OWN WORDS) make it hard for you to do your work, take care of things at home, or get along with other people?
IF NOT ALREADY ASKED: Has there been any other time when you were (depressed/OWN WORDS) and it caused even more problems than the time I just asked you about?
CONTINUE ON NEXT PAGE
IF YES: RETURN TO *PAST MAJOR DEPRESSIVE EPISODE,* A. 12, AND CHECK WHETHER THERE HAVE BEEN ANY OTHER MAJOR DEPRESSIVE EPISODES THAT WERE MORE SEVERE AND/OR CAUSED MORE SYMPTOMS. IF SO, ASK ABOUT THAT EPISODE
IF NO: GO TO *CURRENT MANIC EPISODE,* A. 18.
?=inadequate information
1=absent or false
2=subthreshold
3=threshold or true


SCID-I (for DSM-IV-TR)
Past MDE
(NOV 2002)
Mood Episodes A. 16
Just before this began, were you physically ill?
IF YES: What did the doctor say
Just before this began, were you using any medications?
IF YES: Any change in the amount you were using?
Just before this began, were you drinking or using any street drugs?
D. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition (e.g., hypothyroidism)
? 1 3
A77
DUE TO SUBSTANCE USE OR GMC
IF THERE IS ANY INDICATION THAT THE DEPRESSION MAY BE SECONDARY (I.E., A DIRECT PHYSIOLOGICAL CONSEQUENCE OF A GMC OR SUBSTANCE, GO TO *GMC/ SUBSTANCE,* A. 43, AND RETURN HERE TO MAKE A RATING OF "1" OR "3."
REFER TO LIST OF GENERAL MEDICAL CONDITIONS AND SUBSTANCES, A. 4.
IF UNKNOWN: Has there been any other time when you were (depressed / OWN WORDS) like this but were not (using SUBSTANCE / ill with GMC)?
PRIMARY MOOD EPISODE
IF YES: GO TO *PAST MAJOR DEPRESSIVE EPISODE,* A. 12 AND CHECK WHETHER THERE HAS BEEN ANY OTHER MAJOR DEPRESSIVE EPISODE NOT DUE TO A SUBSTANCE OR GENERAL MEDICAL CONDITION. IF SO, ASK ABOUT THAT EPISODE.
IF NO: GO TO *CURRENT MANIC EPISODE,* A. 18
CONTINUE
?=inadequate information
1=absent or false
2=subthreshold
3=threshold or true


SCID-I (for DSM-IV-TR)
Past MDE
(NOV 2002)
Mood Episodes A. 17
(Did this begin soon after someone close to you died?)
E. The symptoms are not better accounted for by [Simple] Bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than 2 months or are characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms or psychomotor retardation.
? 1 3
A78
SIMPLE BEREAVE-MENT
AT LEAST ONE EPISODE NOT SIMPLE BEREAVE-MENT
IF UNKNOWN: Has there been any other time when you were (depressed / OWN WORDS) like this that did not occur after someone close to you died?
IF YES: GO TO *PAST MAJOR DEPRESSIVE EPISODE, * A. 12 AND CHECK WHETHER THERE HAS BEEN ANY OTHER MAJOR DEPRESSIVE EPISODE THAT WAS NOT BETTER ACCOUNTED FOR BY BEREAVEMENT. IF SO, ASK ABOUT THAT EPISODE.
IF NO: GO TO *CURRENT MANIC EPISODE,* a. 18.
CONTINUE
MAJOR DEPRESSIVE EPISODE CRITERIA A, C, D, AND E ARE CODED "3"
1 3
A79
GO TO *CURRENT MANIC EPISODE* A. 18
PAST MAJOR DEPRES-SIVE EPISODE
How old were you when PAST MAJOR DEPRESSIVE EPISODE) started?
Age at onset of Past Major Depressive Episode coded above
___ ___
A80
How many separate times in your life have you been (depressed/OWN WORDS) nearly every day for at least two weeks and had several of the symptoms that you described like (SXS OF WORST EPISODE)
Total number of Major Depressive Episodes (CODE 99 IF TOO NUMEROUS OR INDISTINCT TO COUNT)
NOTE: TO RECORD DETAILS OF OTHER PAST EPISODES, GO TO J. 9 (OPTIONAL).
___ ___
A81
?=inadequate information
1=absent or false
2=subthreshold
3=threshold or true

Appendix G: Structured Clinical Interview for *DSM-IV* Axis II Personality Disorders (SCID-II)



STRUCTURED CLINICAL INTERVIEW
FOR DSM-IV AXIS II PERSONALITY DISORDERS

SCID-II

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University of Utah
Salt Lake City, Utah

Study: _____ Study No.: ___ ___ ___ 1
Subject: _____ ID No.: ___ ___ ___ 2
Interviewer: _____ Interviewer No.: ___ ___ 3
Date of interview: Month Day Year 4
Sources of information (check all that apply): ☐ Subject ☐ Family/friends/associates ☐ Health professional/chart/referral note ☐ SCID-II Personality Questionnaire 5 6 7 8
Edited and checked by: _____ Date: _____

STRUCTURED CLINICAL INTERVIEW FOR DSM-IV AXIS II PERSONALITY DISORDERS

SCID-II

COMPATIBLE WITH BOTH DSM-IV AND DSM-IV-TR

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SCID-II SUMMARY SCORESHEET

Overall quality and completeness of information:

1 = poor, 2 = fair, 3 = good, 4 = excellent 9

Duration of interview (minutes) ___ ___ ___ 10

Personality Disorder	Number of Items Coded "3" (*Boxed numbers indicate threshold required for a diagnosis.*)									
01 Avoidant *(pp. 3–4)*	1	2	3	[4]	5	6	7			11
02 Dependent *(pp. 5–7)*	1	2	3	4	[5]	6	7	8		12
03 Obsessive-Compulsive *(pp. 8–10)*	1	2	3	[4]	5	6	7	8		13
04 Passive-Aggressive *(pp. 11–12)*	1	2	3	[4]	5	6	7			14
05 Depressive *(pp. 13–14)*	1	2	3	4	[5]	6	7			15
06 Paranoid *(pp. 15–16)*	1	2	3	[4]	5	6	7			16
07 Schizotypal *(pp. 17–20)*	1	2	3	4	[5]	6	7	8	9	17
08 Schizoid *(pp. 21–22)*	1	2	3	[4]	5	6	7			18
09 Histrionic *(pp. 23–24)*	1	2	3	4	[5]	6	7	8		19
10 Narcissistic *(pp. 25–28)*	1	2	3	4	[5]	6	7	8	9	20
11 Borderline *(pp. 29–32)*	1	2	3	4	[5]	6	7	8	9	21
12 Antisocial *(pp. 33–40)*	1	2	[3]	4	5	6	7			22
13 Not Otherwise Specified (NOS) *(p. 41)*	[1]									23

PRINCIPAL AXIS II DIAGNOSIS (i.e., the Personality Disorder that is—or should be—the main focus of clinical attention).

Enter code number from left of diagnosis above: ___ ___ 24
Note: Enter 99 if no Axis II disorder.

OVERVIEW FOR PERSONALITY DISORDERS

Now I am going to ask you some questions about the kind of person you are—that is, how you generally have felt or behaved.

IF A CIRCUMSCRIBED OR EPISODIC AXIS I DISORDER HAS BEEN PRESENT: I know that there have been times when you have been [AXIS I SYMPTOMS]. I am not talking about those times; you should try to think of how you *usually* are when you are not [AXIS I SYMPTOMS]. Do you have any questions about this?

How would you describe yourself as a person (before [AXIS I SYMPTOMS])?

IF CAN'T ANSWER, MOVE ON.

How do you think other people would describe you as a person (before [AXIS I SYMPTOMS])?

Who have been the important people in your life?

(IF MENTIONS ONLY FAMILY: What about friends?)

How have you gotten along with them?

Do you think that the usual way that you react to things or behave with people has caused you problems with anyone? (At home? At school? At work?) (In what way?)

What kinds of things have you done that other people might have found annoying?

How do you spend your free time?

If you could change your personality in some ways, how would you want to be different?

→ IF PERSONALITY QUESTIONNAIRE HAS BEEN COMPLETED: Now I want to go over the questions to which you answered "yes" on the questionnaire.

→ IF PERSONALITY QUESTIONNAIRE HAS NOT BEEN COMPLETED: Now I want to ask you some more specific questions.

AVOIDANT PERSONALITY DISORDER

AVOIDANT PERSONALITY DISORDER CRITERIA

A pervasive pattern of social inhibition, feelings of inadequacy, and hypersensitivity to negative evaluation, beginning by early adulthood and present in a variety of contexts, as indicated by four (or more) of the following:

1. You've said that you have *[Have you]* avoided jobs or tasks that involved having to deal with a lot of people. Give me some examples. What was the reason that you avoided these [LIST JOBS OR TASKS]? (Have you ever refused a promotion because it would involve dealing with more people than you would be comfortable with?)	(1) avoids occupational activities that involve significant interpersonal contact because of fears of criticism, disapproval, or rejection 3 = at least two examples	? 1 2 3	25
2. You've said that *[Do]* you avoid getting involved with people unless you are certain they will like you. If you don't know whether someone likes you, would you ever make the first move?	(2) is unwilling to get involved with people unless certain of being liked 3 = almost never takes the initiative in becoming involved in a social relationship	? 1 2 3	26
3. You've said that *[Do]* you find it hard to be "open" even with people you are close to. Why is this? (Are you afraid of being made fun of or embarrassed?)	(3) shows restraint within intimate relationships because of the fear of being shamed or ridiculed 3 = true for almost all relationships	? 1 2 3	27

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

4. You've said that *[Do]* you often worry about being criticized or rejected in social situations. Give me some examples. Do you spend a lot of time worrying about this?	(4) is preoccupied with being criticized or rejected in social situations 3 = a lot of time spent worrying about social situations	? 1 2 3	28
5. You've said that you're *[Are you]* usually quiet when you meet new people. Why is that? (Is it because you feel in some way inadequate, or not good enough?)	(5) is inhibited in new interpersonal situations because of feelings of inadequacy 3 = acknowledges trait and many examples	? 1 2 3	29
6. You've said that *[Do]* you believe that you're not as good, as smart, or as attractive as most other people. Tell me about that.	(6) views self as socially inept, personally unappealing, or inferior to others 3 = acknowledges belief	? 1 2 3	30
7. You've said that you're *[Are you]* afraid to try new things. Is that because you are afraid of being embarrassed? Give me some examples.	(7) is unusually reluctant to take personal risks or to engage in any new activities because they may prove embarrassing 3 = several examples of avoiding activities because of fear of embarrassment	? 1 2 3	31
	AT LEAST FOUR ITEMS ARE CODED "3"	1 3 ↓ **AVOIDANT PERSONALITY DISORDER**	32

? = inadequate information **1 = absent or false** **2 = subthreshold** **3 = threshold or true**

DEPENDENT PERSONALITY DISORDER	**DEPENDENT PERSONALITY DISORDER CRITERIA** A pervasive and excessive need to be taken care of that leads to submissive and clinging behavior and fears of separation, beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:		
8. You've said that *[Do]* you need a lot of advice or reassurance from others before you can make everyday decisions—like what to wear or what to order in a restaurant. Can you give me some examples of the kinds of decisions you would ask for advice or reassurance about? (Does this happen most of the time?)	(1) has difficulty making everyday decisions without an excessive amount of advice and reassurance from others 3 = several examples	? 1 2 3	33
9. You've said that you *[Do you]* depend on other people to handle important areas in your life such as finances, child care, or living arrangements. Give me some examples. (Is this more than just getting advice from people?) (Has this happened with MOST important areas of your life?)	(2) needs others to assume responsibility for most major areas of his or her life [Note: Do not include merely getting advice from others or subculturally expected behavior.] 3 = several examples	? 1 2 3	34

? = inadequate information **1 = absent or false** **2 = subthreshold** **3 = threshold or true**

10. You've said that *[Do]* you find it hard to disagree with people even when you think they are wrong.

    Give me some examples of when you've found it hard to disagree.

    What are you afraid will happen if you disagree?

(3) has difficulty expressing disagreement with others because of fear of loss of support or approval (**Note:** Do not include realistic fears of retribution.)

3 = acknowledges trait or several examples

? 1 2 3 — 35

11. You've said *[Do]* you find it hard to start or work on tasks when there is no one to help you.

    Give me some examples.

    Why is that? (Is this because you are not sure you can do it right?)

(4) has difficulty initiating projects or doing things on his or her own (because of a lack of self-confidence in judgment or abilities rather than a lack of motivation or energy)

3 = acknowledges trait

? 1 2 3 — 36

12. You've said that you have *[Have you]* often volunteered to do things that are unpleasant.

    Give me some examples of these kinds of things.

    Why is that?

(5) goes to excessive lengths to obtain nurturance and support from others, to the point of volunteering to do things that are unpleasant

[Note: Do not include behavior intended to achieve goals other than being liked, such as job advancement.]

3 = acknowledges trait and at least one example

? 1 2 3 — 37

13. You've said that *[Do]* you usually feel uncomfortable when you are by yourself. Why is that? (Is it because you need someone to take care of you?)

(6) feels uncomfortable or helpless when alone, because of exaggerated fears of being unable to care for himself or herself

3 = acknowledges trait

? 1 2 3 — 38

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

14. You've said that when a close relationship ends you *[When a close relationship ends, do you]* feel you immediately have to find someone else to take care of you.

    Tell me about that.

    (Have you reacted this way almost always when close relationships have ended?)

(7) urgently seeks another relationship as a source of care and support when a close relationship ends

3 = happens when most close relationships end

? 1 2 3 — 39

15. You've said that *[Do]* you worry a lot about being left alone to take care of yourself.

    Are there often times when you keep worrying about this?

    Do you have periods when you worry about this all the time?

(8) is unrealistically preoccupied with fears of being left to take care of himself or herself

3 = persistent unrealistic worry

? 1 2 3 — 40

AT LEAST FIVE ITEMS ARE CODED "3"

1 3 — 41

DEPENDENT PERSONALITY DISORDER

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

OBSESSIVE-COMPULSIVE PERSONALITY DISORDER

OBSESSIVE-COMPULSIVE PERSONALITY DISORDER CRITERIA

A pervasive pattern of preoccupation with orderliness, perfectionism, and mental and interpersonal control, at the expense of flexibility, openness, and efficiency, beginning by early adulthood and present in a variety of contexts, as indicated by four (or more) of the following:

16. You've said that you are *[Are you]* the kind of person who focuses on details, order, and organization or likes to make lists and schedules.

    Give me some examples.

    Do you sometimes get so caught up with [EXAMPLES] that you lose sight of what you are trying to accomplish? (. . . Like you can't see the forest for the trees?)

    (Does this happen often?)

    (1) is preoccupied with details, rules, lists, order, organization, or schedules to the extent that the major point of the activity is lost

    3 = acknowledges trait and at least one example

    ? 1 2 3 | 42

17. You've said that *[Do]* you have trouble finishing jobs because you spend so much time trying to get things exactly right.

    Give me some examples.

    (How often does this happen?)

    (2) shows perfectionism that interferes with task completion (e.g., is unable to complete a project because his or her own overly strict standards are not met)

    3 = several examples of tasks not completed or significantly delayed because of perfectionism

    ? 1 2 3 | 43

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

18. You've said that you or other people feel that you *[Do you or other people feel that you]* are so devoted to work (or school) that you have no time left for anyone else or for just having fun.

    Tell me about it.

    (3) is excessively devoted to work and productivity to the exclusion of leisure activities and friendships (not accounted for by obvious economic necessity)

    [Note: Also not accounted for by temporary job requirements.]

    3 = acknowledges trait or has been told by other people

    ? 1 2 3 | 44

19. You've said that *[Do]* you have very high standards about what is right and what is wrong.

    Give me some examples of your high standards.

    (Do you follow rules to the letter of the law, no matter what?)

    IF GIVES RELIGIOUS EXAMPLE: Do even people who share your religious views say you're too strict about right and wrong?

    (4) is overconscientious, scrupulous, and inflexible about matters of morality, ethics, or values (not accounted for by cultural or religious identification)

    3 = several examples of holding self or others to rigidly high moral standards

    ? 1 2 3 | 45

20. You've said that *[Do]* you have trouble throwing things out because they might come in handy some day.

    Give me some examples of things that you're unable to throw out.

    (How cluttered does your place get because you don't throw things out?)

    (5) is unable to discard worn-out or worthless objects even when they have no sentimental value

    3 = results in a cluttered environment

    ? 1 2 3 | 46

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

21. You've said that it is *[Is it]* hard for you to let other people help you unless they agree to do things exactly the way you want. Tell me about that. (Does this happen often?) (Do you often end up doing things yourself to make sure they are done right?)	(6) is reluctant to delegate tasks or to work with others unless they submit to exactly his or her way of doing things 3 = acknowledges trait and at least one example	? 1 2 3	47
22. You've said that it is *[Is it]* hard for you to spend money on yourself and other people even when you have enough. Why? (Is this because you're worried about not having enough in the future when you really need it?) Tell me about some things you haven't spent money on because you have to save for the future.	(7) adopts a miserly spending style toward both self and others; money is viewed as something to be hoarded for future catastrophes 3 = acknowledges trait and at least one example	? 1 2 3	48
23. You've said that you are *[Are you]* often so sure you are right that it doesn't matter what other people say. Tell me about it. 24. You've said that other people have told you *[Have other people told you]* that you are stubborn or rigid. Tell me about that.	(8) shows rigidity and stubbornness 3 = acknowledges trait or has been told by other people	? 1 2 3	49
	AT LEAST FOUR ITEMS ARE CODED "3"	1 3 ↓ **OBSESSIVE-COMPULSIVE PERSONALITY DISORDER**	50

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

PASSIVE-AGGRESSIVE PERSONALITY DISORDER

PASSIVE-AGGRESSIVE PERSONALITY DISORDER CRITERIA

A pervasive pattern of negativistic attitudes and passive resistance to demands for adequate performance, beginning by early adulthood and present in a variety of contexts, as indicated by four (or more) of the following:

25. You've said that when someone asks you to do something that you don't want to do, you *[When someone asks you to do something that you don't want to do, do you]* say "yes" but then work slowly or do a bad job. Give me some examples of this. 26. You've said that if you don't want to do something you *[If you don't want to do something, do you]* often just "forget" to do it. Give me some examples of this.	(1) passively resists fulfilling routine social and occupational tasks 3 = acknowledges trait and at least one example	? 1 2 3	51
27. You've said that *[Do]* you often feel that other people don't understand you or don't appreciate how much you do. Tell me more about that. (Do you complain to other people about this?)	(2) complains of being misunderstood and unappreciated by others 3 = acknowledges trait	? 1 2 3	52
28. You've said that you're *[Are you]* often grumpy and likely to get into arguments. Tell me when this happens.	(3) is sullen and argumentative 3 = acknowledges trait	? 1 2 3	53

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

29. You've said that you've *[Have you]* found that most of your bosses, teachers, supervisors, doctors, and others who are supposed to know what they are doing really don't. Tell me about that.	(4) unreasonably criticizes and scorns authority 3 = several examples	? 1 2 3	54
30. You've said that *[Do]* you often think that it's not fair that other people have more than you do. Tell me more about that.	(5) expresses envy and resentment toward those apparently more fortunate 3 = examples of envy and resentment	? 1 2 3	55
31. You've said that *[Do]* you often complain that more than your share of bad things have happened to you. Looking back on your life, do you feel that bad things are always happening to you?	(6) voices exaggerated and persistent complaints of personal misfortune 3 = says bad things always happen (not limited to particularly bad times in the person's life)	? 1 2 3	56
32. You've said that *[Do]* you often angrily refuse to do what others want and then later feel bad and apologize. Tell me more about this.	(7) alternates between hostile defiance and contrition 3 = acknowledges trait and at least one example	? 1 2 3	57
	AT LEAST FOUR ITEMS ARE CODED "3"	1 3 ↓	58
		PASSIVE-AGGRESSIVE PERSONALITY DISORDER	

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

DEPRESSIVE PERSONALITY DISORDER	**DEPRESSIVE PERSONALITY DISORDER CRITERIA**		
Note: The DSM-IV criterion excludes a diagnosis of Depressive Personality Disorder if the behavior occurs only during Major Depressive Episodes or is better accounted for by Dysthymic Disorder. Refer to the User's Guide for a discussion of options for operationalizing this criterion.	A pervasive pattern of depressive cognitions and behaviors, beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:		
33. You've said that *[Do]* you usually feel unhappy or that life is no fun. Tell me about that.	(1) usual mood is dominated by dejection, gloominess, cheerlessness, joylessness, unhappiness 3 = acknowledges trait	? 1 2 3	59
34. You've said that *[Do]* you believe that you are basically an inadequate person and often don't feel good about yourself. Tell me about that.	(2) self-concept centers around beliefs of inadequacy, worthlessness, and low self-esteem 3 = acknowledges trait	? 1 2 3	60
35. You've said that you *[Do you]* often put yourself down. Tell me about that. (Do you often blame yourself for things that haven't worked out?)	(3) is critical, blaming, and derogatory toward self 3 = acknowledges trait	? 1 2 3	61
36. You've said that *[Do]* you keep thinking about bad things that have happened in the past or worry about bad things that might happen in the future. Tell me about that.	(4) is brooding and given to worry 3 = acknowledges trait	? 1 2 3	62

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

37. You've said that *[Do]* you often judge others harshly and easily find fault with them.

    Give me some examples of the kinds of things you are critical of.

(5) is negativistic, critical, and judgmental toward others

3 = acknowledges trait and at least one example

? 1 2 3 | 63

38. You've said that you *[Do you]* think that most people are basically no good.

    Tell me about that.

39. You've said that you *[Do you]* almost always expect things to turn out badly.

    Tell me about that.

(6) is pessimistic

3 = acknowledges trait

? 1 2 3 | 64

40. You've said that you *[Do you]* often feel guilty about things you have or haven't done.

    What kinds of things?

(7) is prone to feeling guilty or remorseful

3 = acknowledges trait and at least one example

? 1 2 3 | 65

AT LEAST FIVE ITEMS ARE CODED "3"

1 3 ↓ | 66

DEPRESSIVE PERSONALITY DISORDER

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

PARANOID PERSONALITY DISORDER

Note: Behavior should NOT be considered characteristic of Paranoid Personality Disorder if it occurs exclusively during the course of Schizophrenia, a Mood Disorder With Psychotic Features, or another Psychotic Disorder or is due to the direct physiological effects of a general medical condition.

PARANOID PERSONALITY DISORDER CRITERIA

A pervasive distrust and suspiciousness of others such that their motives are interpreted as malevolent, beginning by early adulthood and present in a variety of contexts, as indicated by four (or more) of the following:

41. You've said that *[Do]* you often have to keep an eye out to stop people from using you or hurting you.

    Tell me about that.

(1) suspects, without sufficient basis, that others are exploiting, harming, or deceiving him or her

3 = acknowledges trait and at least one example

? 1 2 3 | 67

42. You've said that you *[Do you]* spend a lot of time wondering if you can trust your friends or the people you work with.

    Describe situations where you've gotten that feeling.

    (Do you feel this way often?)

(2) is preoccupied with unjustified doubts about the loyalty or trustworthiness of friends or associates

3 = acknowledges that this is characteristic of almost all relationships

? 1 2 3 | 68

43. You've said that *[Do]* you find that it is best not to let other people know much about you because they will use it against you.

    When has this happened? Tell me about it.

(3) is reluctant to confide in others because of unwarranted fear that the information will be used maliciously against him or her

3 = acknowledges that reluctance to confide in others is due to mistrust (not merely fear of rejection)

? 1 2 3 | 69

44. You've said that *[Do]* you often detect hidden threats or insults in things people say or do.

    Give me some examples.

(4) reads hidden demeaning or threatening meanings into benign remarks or events

3 = acknowledges trait and at least one example

? 1 2 3 | 70

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

45. You've said that you're *[Are you]* the kind of person who holds grudges or takes a long time to forgive people who have insulted or slighted you.

    Tell me about that.

46. You've said that there are *[Are there]* many people you can't forgive because they did or said something to you a long time ago.

    Tell me about that.

(5) persistently bears grudges (i.e., is unforgiving of insults, injuries, or slights)

3 = acknowledges trait and at least one example

? 1 2 3 71

47. You've said that *[Do]* you often get angry or lash out when someone criticizes or insults you in some way.

    Give me some examples.

    (Do others believe that you often take offense too easily?)

(6) perceives attacks on his or her character or reputation that are not apparent to others and is quick to react angrily or to counterattack

3 = acknowledges trait and at least one example

? 1 2 3 72

48. You've said that you have *[Have you]* often suspected that your spouse or partner has been unfaithful.

    Tell me about that.

    (What clues did you have? What did you do about it? Were you right?)

(7) has recurrent suspicions, without justification, regarding fidelity of spouse or sexual partner

3 = examples of unjustified suspicions with several partners or on several occasions with the same partner OR acknowledges trait

? 1 2 3 73

AT LEAST FOUR ITEMS ARE CODED "3"

1 3 ↓ 74

PARANOID PERSONALITY DISORDER

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

SCHIZOTYPAL PERSONALITY DISORDER

Note: Behavior should NOT be considered characteristic of Schizotypal Personality Disorder if it occurs exclusively during the course of Schizophrenia, a Mood Disorder With Psychotic Features, another Psychotic Disorder, or a Pervasive Developmental Disorder.

SCHIZOTYPAL PERSONALITY DISORDER CRITERIA

A pervasive pattern of social and interpersonal deficits marked by acute discomfort with, and reduced capacity for, close relationships as well as by cognitive or perceptual distortions and eccentricities of behavior, beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:

49. You've said that when you are out in public and see people talking *[When you are out in public and see people talking, do]* you often feel that they are talking about you.

    Tell me more about this.

50. You've said that you *[Do you]* often get the feeling that things that have no special meaning to most people are really meant to give you a message.

    Tell me more about this.

51. You've said that when you are around people, you *[When you are around people, do you]* often get the feeling that you are being watched or stared at.

    Tell me more about this.

(1) ideas of reference (excluding delusions of reference)

3 = several examples

? 1 2 3 75

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

52. You've said that you have *[Have you ever]* felt that you could make things happen just by making a wish or thinking about them.

    Tell me about that.

    (How did it affect you?)

(2) odd beliefs or magical thinking that influences behavior and is inconsistent with subcultural norms (e.g., superstitiousness, belief in clairvoyance, telepathy, or "sixth sense"; in children and adolescents, bizarre fantasies or preoccupations)

3 = several examples of such phenomena that influenced behavior and are inconsistent with subcultural norms

? 1 2 3 | 76

53. You've said that you have *[Have you]* had personal experiences with the supernatural.

    Tell me about that.

    (How did it affect you?)

54. You've said that you *[Do you]* believe that you have a "sixth sense" that allows you to know and predict things that others can't.

    Tell me about that.

    (How does it affect you?)

55. You've said that it often seems *[Does it often seem]* that objects or shadows are really people or animals or that noises are actually people's voices.

    Give me some examples.

    (Were you drinking or taking drugs at the time?)

(3) unusual perceptual experiences, including bodily illusions

3 = several examples of unusual perceptual experiences not due to drugs or a general medical condition

? 1 2 3 | 77

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

56. You've said that you have *[Have you]* had the sense that some person or force is around you, even though you cannot see anyone.

    Tell me more about that.

    (Were you drinking or taking drugs at the time?)

57. You've said that you *[Do you]* often see auras or energy fields around people.

    Tell me more about that.

    (Were you drinking or taking drugs at the time?)

OBSERVED DURING INTERVIEW

(4) odd thinking and speech (e.g., vague, circumstantial, metaphorical, over-elaborate, or stereotyped)

? 1 2 3 | 78

CODE "3" IF ANY OF PARANOID CRITERIA (1), (2), (3), (4), OR (7) ARE CODED "3"

(5) suspiciousness or paranoid ideation

? 1 3 | 79

OBSERVED DURING INTERVIEW

(6) inappropriate or constricted affect

? 1 2 3 | 80

OBSERVED DURING INTERVIEW

(7) behavior or appearance that is odd, eccentric, or peculiar

? 1 2 3 | 81

58. You've said that there are *[Are there]* very few people that you're really close to outside of your immediate family.

    How many close friends do you have?

(8) lack of close friends or confidants other than first-degree relatives

3 = no close friends (other than first-degree relatives)

? 1 2 3 | 82

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

59. You've said that *[Do]* you often feel nervous when you are with other people.

What are you nervous about?

(Are you still anxious even after you've known them for awhile?)

(9) excessive social anxiety that does not diminish with familiarity and tends to be associated with paranoid fears rather than negative judgments about self

3 = acknowledges excessive anxiety related to suspiciousness about other people's motives

? 1 2 3 83

AT LEAST FIVE ITEMS ARE CODED "3"

1 3 84

↓

SCHIZOTYPAL PERSONALITY DISORDER

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

SCHIZOID PERSONALITY DISORDER

Note: Behavior should NOT be considered characteristic of Schizoid Personality Disorder if it occurs exclusively during the course of Schizophrenia, a Mood Disorder With Psychotic Features, another Psychotic Disorder, or a Pervasive Developmental Disorder or is due to the direct physiological effects of a general medical condition.

SCHIZOID PERSONALITY DISORDER CRITERIA

A pervasive pattern of detachment from social relationships and a restricted range of expression of emotions in interpersonal settings, beginning by early adulthood and present in a variety of contexts, as indicated by four (or more) of the following:

60. You've said that it is *[Is it]* NOT important to you whether you have any close relationships.

Tell me more about that.

(What about your family?)

(1) neither desires nor enjoys close relationships, including being part of a family

3 = acknowledges trait

? 1 2 3 85

61. You've said that you would *[Would you]* almost always rather do things alone than with other people.

(Is that true both at work and during your free time?)

(2) almost always chooses solitary activities

3 = acknowledges trait

? 1 2 3 86

62. You've said that you could *[Could you]* be content without ever being sexually involved with anyone.

Tell me more about that.

(Have you always had little interest in having sex?)

(3) has little, if any, interest in having sexual experiences with another person

3 = acknowledges trait

? 1 2 3 87

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

63. You've said that there are *[Are there]* really very few things that give you pleasure. Tell me about that. (What about physical things like eating a good meal or having sex?)	(4) takes pleasure in few, if any, activities [Note: Absence of pleasure especially applies to sensory, bodily, and interpersonal experiences.] 3 = acknowledges trait	? 1 2 3	88
ALREADY CODED ON ITEM (8) FOR SCHIZOTYPAL PERSONALITY DISORDER	(5) lacks close friends or confidants other than first-degree relatives	? 1 2 3	89
64. You've said that it doesn't *[Does it NOT]* matter to you what people think of you. How do you feel when people praise you or criticize you?	(6) appears indifferent to the praise or criticism of others 3 = claims indifference to praise or criticism	? 1 2 3	90
65. You've said that *[Do]* you find that nothing makes you very happy or very sad. Tell me more about that. (ALSO CONSIDER BEHAVIOR DURING INTERVIEW)	(7) shows emotional coldness, detachment, or flattened affectivity 3 = occurring not exclusively during a Mood Disorder	? 1 2 3	91
	AT LEAST FOUR ITEMS ARE CODED "3"	1 3 ↓ **SCHIZOID PERSONALITY DISORDER**	92

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

HISTRIONIC PERSONALITY DISORDER	**HISTRIONIC PERSONALITY DISORDER CRITERIA**		
	A pervasive pattern of excessive emotionality and attention seeking, beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:		
66. You've said that *[Do]* you like to be the center of attention. How do you feel when you're not?	(1) is uncomfortable in situations in which he or she is not the center of attention 3 = feels uncomfortable when not the center of attention	? 1 2 3	93
67. You've said that *[Do]* you flirt a lot. Has anyone complained about this? (ALSO CONSIDER BEHAVIOR DURING INTERVIEW)	(2) interaction with others is often characterized by inappropriate sexually seductive or provocative behavior 3 = acknowledges complaints, describes inappropriate behavior, or observed to be inappropriately seductive	? 1 2 3	94
68. You've said that you *[Do you]* often find yourself "coming on" to people. Tell me about it. (ALSO CONSIDER BEHAVIOR DURING INTERVIEW)			
OBSERVED DURING INTERVIEW	(3) displays rapidly shifting and shallow expression of emotions	? 1 2 3	95

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

69. You've said that you *[Do you]* try to draw attention to yourself by the way you dress or look.

How do you do that?

Do you do that all the time?

(4) consistently uses physical appearance to draw attention to self

3 = gives example and acknowledges that behavior occurs all the time

? 1 2 3 | 96

OBSERVED DURING INTERVIEW

(5) has a style of speech that is excessively impressionistic and lacking in detail

? 1 2 3 | 97

70. You've said that you *[Do you]* often make a point of being dramatic and colorful.

Tell me about that. (ALSO CONSIDER BEHAVIOR DURING INTERVIEW)

(Do you like to show your emotions—for example, hugging people even if you don't know them very well or crying very easily?)

(6) shows self-dramatization, theatricality, and exaggerated expression of emotion

3 = acknowledges trait and at least one example

? 1 2 3 | 98

71. You've said that you *[Do you]* often change your mind about things depending on the people you're with or what you have just read or seen on TV.

Tell me more about that.

(7) is suggestible (i.e., easily influenced by others or circumstances)

3 = acknowledges trait and at least one example

? 1 2 3 | 99

72. You've said that you *[Do you]* have lots of friends that you are very close to.

How many? Who are they?

(8) considers relationships to be more intimate than they actually are

3 = claims to have many more "close" relationships than is believable

? 1 2 3 | 100

AT LEAST FIVE ITEMS ARE CODED "3"

1 3 ↓ | 101

HISTRIONIC PERSONALITY DISORDER

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

NARCISSISTIC PERSONALITY DISORDER

NARCISSISTIC PERSONALITY DISORDER CRITERIA

A pervasive pattern of grandiosity (in fantasy or behavior), need for admiration, and lack of empathy, beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:

73. You've said that *[Do]* people often fail to appreciate your very special talents or accomplishments.

Give me an example.

74. You've said that people have *[Have people]* told you that you have too high an opinion of yourself.

Give me some examples of this.

(1) has a grandiose sense of self-importance (e.g., exaggerates achievements and talents, expects to be recognized as superior without commensurate achievements)

3 = at least one example of grandiosity

? 1 2 3 | 102

75. You've said that *[Do]* you think a lot about the power, fame, or recognition that will be yours someday.

Tell me more about this.

(How much time do you spend thinking about these things?)

(2) is preoccupied with fantasies of unlimited success, power, brilliance, beauty, or ideal love

3 = much of time spent daydreaming or in pursuit of unrealistic goals

? 1 2 3 | 103

76. You've said that *[Do]* you think a lot about the perfect romance that will be yours someday.

Tell me more about this.

(How much time do you spend thinking about this?)

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

77. You've said that when you have a problem *[When you have a problem, do]* you almost always insist on seeing the top person.

    Give me some examples.

    (Why do you have to see the top person?)

(3) believes that he or she is "special" and unique and can only be understood by, or should associate with, other special or high-status people (or institutions)

3 = acknowledges trait and at least one example

? 1 2 3 104

78. You've said that *[Do]* you feel it is important to spend time with people who are special or influential.

    Why is that?

79. You've said that it is *[Is it]* very important to you that people pay attention to you or admire you in some way.

    Tell me more about this.

(4) requires excessive admiration

3 = acknowledges trait and at least one example

? 1 2 3 105

80. You've said that *[Do]* you think that it's not necessary to follow certain rules or social conventions when they get in your way.

    Give me some examples.

    Why do you feel that way?

(5) has a sense of entitlement (i.e., unreasonable expectations of especially favorable treatment or automatic compliance with his or her expectations)

3 = several examples

? 1 2 3 106

81. You've said that *[Do]* you feel that you are the kind of person who deserves special treatment.

    Tell me more about this.

82. You've said that *[Do]* you often find it necessary to step on a few toes to get what you want.

    Tell me some instances of that. (Does that happen often?)

(6) is interpersonally exploitative (i.e., takes advantage of others to achieve his or her own ends)

3 = several examples in which another person is exploited

? 1 2 3 107

83. You've said that *[Do]* you often have to put your needs above other people's.

    Give me some examples of when that happens.

84. You've said that *[Do]* you often expect other people to do what you ask without question because of who you are.

    (Does this happen often?)

85. You've said that you're *[Are you]* NOT really interested in other people's problems or feelings.

    Tell me about that.

(7) lacks empathy: is unwilling to recognize or identify with the feelings and needs of others

3 = acknowledges trait OR several examples

? 1 2 3 108

86. You've said that people have *[Have people]* complained to you that you don't listen to them or care about their feelings.

    Tell me about that.

87. You've said that you are *[Are you]* often envious of others.

    Tell me about it. (How often do you feel that way?)

(8) is often envious of others or believes that others are envious of him or her

3 = acknowledges trait and at least one example

? 1 2 3 109

88. You've said that *[Do]* you feel that others are often envious of you.

    What do they envy about you?

89. You've said that you *[Do you]* find that there are very few people that are worth your time and attention.

Tell me about that.

(ALSO CONSIDER BEHAVIOR DURING INTERVIEW)

(9) shows arrogant, haughty behaviors or attitudes

3 = acknowledges trait or observed during interview

? 1 2 3 110

AT LEAST FIVE ITEMS ARE CODED "3"

1 3 111

NARCISSISTIC PERSONALITY DISORDER

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

BORDERLINE PERSONALITY DISORDER

BORDERLINE PERSONALITY DISORDER CRITERIA

A pervasive pattern of instability of interpersonal relationships, self-image, and affects and marked impulsivity, beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:

90. You've said that you have *[Have you]* often become frantic when you thought that someone you really cared about was going to leave you.

What have you done?

(Have you threatened or pleaded with him/her?)

(1) frantic efforts to avoid real or imagined abandonment (**Note:** Do not include suicidal or self-mutilating behavior covered in item (5).)

3 = several examples

? 1 2 3 112

91. You've said that *[Do]* your relationships with people you really care about have lots of extreme ups and downs.

Tell me about them.

(Were there times when you thought they were everything you wanted and other times when you thought they were terrible? How many relationships were like this?)

(2) a pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation

3 = either one prolonged relationship or several briefer relationships in which the alternating pattern occurs at least twice

? 1 2 3 113

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

92. You've said that you have *[Have you]* all of a sudden changed your sense of who you are and where you are headed.

Give me some examples of this.

(3) identity disturbance: markedly and persistently unstable self-image or sense of self

[Note: Do not include normal adolescent uncertainty.]

3 = acknowledges trait

? 1 2 3 | 114

93. You've said that your sense of who you are often changes *[Does your sense of who you are often change]* dramatically.

Tell me more about that.

94. You've said that you are *[Are you]* different with different people or in different situations so that you sometimes don't know who you really are.

Give me some examples of this. (Do you feel this way a lot?)

95. You've said that there have been *[Have there been]* lots of sudden changes in your goals, career plans, religious beliefs, and so on.

Tell me more about that.

96. You've said that you've *[Have you]* often done things impulsively.

What kinds of things?

(How about . . .
. . . buying things you really couldn't afford?
. . . having sex with people you hardly know, or "unsafe sex"?
. . . drinking too much or taking drugs?
. . . driving recklessly?
. . . uncontrollable eating?)

(4) impulsivity in at least two areas that are potentially self-damaging (e.g., spending, sex, substance abuse, reckless driving, binge eating). (**Note:** Do not include suicidal or self-mutilating behavior covered in item (5).)

3 = several examples indicating a pattern of impulsive behavior (not necessarily limited to examples given above)

? 1 2 3 | 115

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

IF YES TO ANY OF ABOVE:
Tell me about that. How often does it happen? What kinds of problems has it caused?

97. You've said that you have *[Have you]* tried to hurt or kill yourself or threatened to do so.

98. You've said that you have *[Have you ever]* cut, burned, or scratched yourself on purpose.

Tell me about that.

(5) recurrent suicidal behavior, gestures, or threats, or self-mutilating behavior

3 = two or more events (when not in a Major Depressive Episode)

? 1 2 3 | 116

99. You've said that *[Do]* you have a lot of sudden mood changes.

Tell me about that.

(How long do your "bad" moods last? How often do these mood changes happen? How suddenly do your moods change?)

(6) affective instability due to a marked reactivity of mood (e.g., intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days)

3 = acknowledges trait

? 1 2 3 | 117

100. You've said that *[Do]* you often feel empty inside.

Tell me more about this.

(7) chronic feelings of emptiness

3 = acknowledges trait

? 1 2 3 | 118

101. You've said that *[Do]* you often have temper outbursts or get so angry that you lose control.

Tell me about this.

(8) inappropriate, intense anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights)

3 = acknowledges trait and at least one example

? 1 2 3 | 119

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

102. You've said that *[Do]* you hit people or throw things when you get angry.

Tell me about this.

(Does this happen often?)

103. You've said that *[Do]* even little things get you very angry.

When does this happen?

(Does this happen often?)

104. You've said that when you are under a lot of stress, you *[When you are under a lot of stress, do you]* get suspicious of other people or feel especially spaced out.

Tell me about that.

(9) transient, stress-related paranoid ideation or severe dissociative symptoms

3 = several examples that do not occur exclusively during a Psychotic Disorder or a Mood Disorder With Psychotic Features

? 1 2 3 120

AT LEAST FIVE ITEMS ARE CODED "3"

1 3 121

BORDERLINE PERSONALITY DISORDER

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

ANTISOCIAL PERSONALITY DISORDER

Note: Behavior should NOT be considered characteristic of Antisocial Personality Disorder if it occurs exclusively during the course of Schizophrenia or a Manic Episode.

ANTISOCIAL PERSONALITY DISORDER CRITERIA

B. The individual is at least age 18 years.

C. There is evidence of Conduct Disorder with onset before age 15 years [as evidenced by at least two of the following:]

105. You've said that before you were 15, you would *[Before you were 15, would you]* bully or threaten other kids.

Tell me about that.

(1) (Before the age of 15) often bullied, threatened, or intimidated others ? 1 2 3 123

106. You've said that before you were 15, you would *[Before you were 15, would you]* start fights.

How often?

(2) (Before the age of 15) often initiated physical fights ? 1 2 3 124

107. You've said that before you were 15, you hurt or threatened someone *[Before you were 15, did you hurt or threaten someone]* with a weapon, like a bat, brick, broken bottle, knife, or gun.

Tell me about that.

(3) (Before the age of 15) used a weapon that can cause serious physical harm to others (e.g., a bat, brick, broken bottle, knife, gun) ? 1 2 3 125

108. You've said that before you were 15, you deliberately tortured someone or caused someone physical pain and suffering. *[Before you were 15, did you deliberately torture someone or cause someone physical pain and suffering?]*

What did you do?

(4) (Before the age of 15) was physically cruel to people ? 1 2 3 126

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

109. You've said that before you were 15 you tortured or hurt animals on purpose. *[Before you were 15, did you torture or hurt animals on purpose?]* What did you do?	(5) (Before the age of 15) was physically cruel to animals	? 1 2 3	127
110. You've said that before you were 15, you robbed, mugged, or forcibly took *[Before you were 15, did you rob, mug, or forcibly take]* something from someone by threatening him or her. Tell me about that.	(6) (Before the age of 15) stole while confronting a victim (e.g., mugging, purse snatching, extortion, armed robbery)	? 1 2 3	128
111. You've said that before you were 15, you forced someone *[Before you were 15, did you force someone]* to have sex with you, to get undressed in front of you, or to touch you sexually. Tell me about it.	(7) (Before the age of 15) forced someone into sexual activity	? 1 2 3	129
112. You've said that before you were 15 you *[Before you were 15, did you]* set fires. Tell me about that.	(8) (Before the age of 15) deliberately engaged in fire setting with the intention of causing serious damage	? 1 2 3	130
113. You've said that before you were 15, you deliberately destroyed *[Before you were 15, did you deliberately destroy]* things that weren't yours. What did you do?	(9) (Before the age of 15) deliberately destroyed others' property (other than by fire setting)	? 1 2 3	131
114. You've said that before you were 15, you broke *[Before you were 15, did you break]* into houses, other buildings, or cars. Tell me about that.	(10) (Before the age of 15) broke into someone else's house, building, or car	? 1 2 3	132

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

115. You've said that before you were 15, you lied a lot or "conned" *[Before you were 15, did you lie a lot or "con"]* other people. What would you lie about?	(11) (Before the age of 15) often lied to obtain goods or favors or to avoid obligations (i.e., "cons" others)	? 1 2 3	133
116. You've said that before you were 15, you sometimes stole or shoplifted things or forged someone's signature. *[Before you were 15, did you sometimes steal or shoplift things or forge someone's signature?]* Tell me about it.	(12) (Before the age of 15) stole items of nontrivial value without confronting a victim (e.g., shoplifting, stealing but without breaking and entering, forgery)	? 1 2 3	134
117. You've said that before you were 15, you ran away from home and stayed *[Before you were 15, did you run away and stay]* away overnight. Was that more than once? (With whom were you living at the time?)	(13) (Before the age of 15) ran away from home overnight at least twice while living in parental or parental surrogate home (or once without returning for a lengthy period)	? 1 2 3	135
118. You've said that before you were 13, you would *[Before you were 13, did you]* often stay out very late, long after the time you were supposed to be home. How often?	(14) (Before the age of 13) often stayed out at night despite parental prohibitions	? 1 2 3	136

? = inadequate information 1 = absent or false 2 = subthreshold 3 = threshold or true

119. You've said that before you were 13, you often skipped *[Before you were 13, did you often skip]* school. How often?	(15) (Before the age of 13) often truant from school	? 1 2 3	137
	AT LEAST TWO ITEMS ARE CODED "3" (i.e., "some" evidence of Conduct Disorder)	1 3	138

CRITERION C OF ANTISOCIAL PERSONALITY DISORDER MET; CONTINUE ON NEXT PAGE

GO TO PERSONALITY DISORDER NOT OTHERWISE SPECIFIED, PAGE 41

Now, since you were 15. . .	A. There is a pervasive pattern of disregard for and violation of the rights of others occurring since age 15 years, as indicated by three (or more) of the following:		
Have you done things that are against the law—even if you weren't caught—like stealing, using or selling drugs, writing bad checks, or having sex for money? IF NO: Have you ever been arrested for anything?	(1) failure to conform to social norms with respect to lawful behaviors as indicated by repeatedly performing acts that are grounds for arrest 3 = several examples	? 1 2 3	139
Do you often find that you have to lie to get what you want? (Have you ever used an alias or pretended you were someone else?) (Have you often "conned" others to get what you want?)	(2) deceitfulness, as indicated by repeated lying, use of aliases, or "conning" others for personal profit or pleasure 3 = several examples	? 1 2 3	140
Do you often do things on the spur of the moment without thinking about how it will affect you or other people? What kinds of things? Was there ever a time when you had no regular place to live? (For how long?)	(3) impulsivity or failure to plan ahead 3 = several examples	? 1 2 3	141

(Since you were 15) have you been in any fights?

(How often?)

Have you ever hit or thrown things at your spouse or partner?

(How often?)

Have you ever hit a child, yours or someone else's—so hard that he or she had bruises or had to stay in bed or see a doctor?

Tell me about that.

Have you physically threatened or hurt anyone else?

Tell me about that. (How often?)

(4) irritability and aggressiveness, as indicated by repeated physical fights or assaults

3 = several examples

? 1 2 3 142

Did you ever drive a car when you were drunk or high?

How many speeding tickets have you gotten or car accidents have you been in?

Do you always use protection if you have sex with someone you don't know well?

(Has anyone ever said that you allowed a child that you were taking care of to be in a dangerous situation?)

(5) reckless disregard for safety of self or others

3 = several examples

? 1 2 3 143

How much of the time in the last 5 years were you not working?

IF FOR A PROLONGED PERIOD: Why? (Was there work available?)

When you were working, did you miss a lot of work?

IF YES: Why?

Did you ever walk off a job without having another one to go to?

IF YES: How many times did this happen?

Have you ever owed people money and not paid them back? (How often?)

What about not paying child support, or not giving money to children or someone else who depended on you?

(6) consistent irresponsibility, as indicated by repeated failure to sustain consistent work behavior or honor financial obligations

3 = several examples

? 1 2 3 144

IF THERE IS EVIDENCE OF ANTISOCIAL ACTS AND IT IS UNCLEAR WHETHER THERE IS ANY REMORSE: How do you feel about [LIST ANTISOCIAL ACTS]?

(Do you think what you did was wrong in any way?)

(7) lacks remorse, as indicated by being indifferent to or rationalizing having hurt, mistreated, or stolen from another

3 = lacks remorse about several antisocial acts

? 1 2 3 145

Appendix H: Barwon Health and Deakin University Ethics Approval

Corporate Office
Ryrie Street
Geelong, 3220
PO Box 281
Geelong, 3220
T 03 5226 7111
F 03 5221 3429
ABN 65 877 249 165

A/Prof Julie Pasco
Barwon Epidemiology & Biostatistics Unit
Barwon Health/Deakin University
PO Box 281
Geelong VIC 3220

11 February 2013 (Re-released 6 March 2013)

Dear A/Prof Julie Pasco

Study title: Maternal Vitamin D in Pregnancy and Childhood Growth
Barwon Health Reference: 01/43_E2

Thank you for submitting the above for our consideration. Your project was considered in relation to the National Statement on Ethical Conduct in Human Research (2007) at the meeting of 12th September 2012 and I am pleased to advise that you have been granted approval by the Barwon Health Human Research Ethics Committee (HREC) from the date of this letter.

This approval pertains to participants recruited through Barwon Health, however we note that some measures will be taken at the Royal Melbourne Hospital.
If you wish to use this approval at another site, please apply for an amendment of this approval.

Your obligations under this approval include notifying the Committee of any intent to deviate from the approved protocol and of the occurrence of any untoward events.

It is now your responsibility to undertake the following:

1. To inform any personnel who should be aware of this project of this approval
2. To ensure, if applicable, that accurate documentation of the consent process is recorded in the participant's hospital history and that a copy of the participant information and consent form is also placed in the hospital history.
3. To advise the Committee, in writing, of any changes you wish to make to the running of the project, including extending beyond the anticipated completion date or any discontinuation prior to the expected date. Please supply reasons.
4. To advise the Committee, in writing, of any adverse events that impact upon the site
5. To supply written annual reports on the anniversary of your approval advising of the progress of the project and a final report advising of completion
6. Please note: Research projects to be undertaken at private institutions are not covered by the Barwon Health Medical Malpractice Policy.

In the case of medical research undertaken in the private sector, care should be taken to ensure that the investigator's medical insurance policy is current and the institute in which the research is conducted is adequately insured. It is the responsibility of the investigator to ensure adequate coverage in the event of litigation.

Please note that template forms for reporting changes to the project may be obtained from the Barwon Health website http://www.barwonhealth.org.au/research/default.aspx

Barwon Health may conduct an audit of your project at any time.

Should you require any further information concerning the Committee's approval of your research or have any concerns regarding the reporting requirement, please contact the Office for Research on 03 4215 3372.

Site Specific Assessment (SSA)
Please accept this letter as site authorisation in addition to the HREC approval.

Finally, in all future correspondence regarding your study, please quote the Barwon Health reference number and full title of your research project. On behalf of the Committee, best wishes for your project.

Yours sincerely

SIMON FRENCH
CHAIR
Human Research Ethics Committee

BERNICE DAVIES
Research Governance Officer, Barwon Health
Office for Research
Ph: (03) 4215 3372
Email: bernice.davies@barwonhealth.org.au

Documents at Approval

Protocol Version 1D dated 05/02/2013
NEAF
Participant Information and Consent Form Version 1C dated 05/02/2013
Radiation Assessment
Questionnaire Version 1D dated 05/02/2013
Letter of Invitation Version 1D dated 05/02/2013

Human Research Ethics

Deakin Research Integrity
70 Elgar Road Burwood Victoria
Postal: 221 Burwood Highway
Burwood Victoria 3125 Australia
Telephone 03 9251 7123 Facsimile 03 9244 6581
research-ethics@deakin.edu.au

Memorandum

To: A/Prof Julie Pasco
School of Medicine

cc: Ms Natalie Hyde

From: Deakin University Human Research Ethics Committee (DUHREC)

Date: 17 May, 2013

Subject: 2013-116
Maternal vitamin D in pregnancy and childhood growth

Please quote this project number in all future communications

Approval granted by Barwon Health HREC for this project will be noted at the DUHREC meeting to be held on 17th June 2013.

It will be noted that approval has been granted for A/Prof Julie Pasco, School of Medicine, to undertake this project as stipulated in Barwon Health HREC approval documentation.

The approval noted by the Deakin University Human Research Ethics Committee is given only for the project and for the period as stated in the memo. It is your responsibility to contact the Human Research Ethics Unit immediately should any of the following occur:

- Serious or unexpected adverse effects on the participants
- Any proposed changes in the protocol, including extensions of time.
- Any events which might affect the continuing ethical acceptability of the project.
- The project is discontinued before the expected date of completion.
- Modifications are requested by other HRECs.

In addition you will be required to report on the progress of your project at least once every year and at the conclusion of the project. Failure to report as required will result in suspension of your approval to proceed with the project.

DUHREC may need to audit this project as part of the requirements for monitoring set out in the National Statement on Ethical Conduct in Human Research (2007).

Human Research Ethics Unit
research-ethics@deakin.edu.au
Telephone: 03 9251 7123

Appendix I: Notification of Ethics Approval to Victoria University

Lisa Burke
[redacted]

Ethics Secretary
Office for Research
Victoria University
PO Box 14428
MELBOURNE VIC 8001

Dear Secretary,

I write to inform you of my research progress as a candidate in the Doctor of Psychology (Clinical) program at Victoria University. My student number is [redacted].

For the research component of my degree, I am undertaking my research externally as part of the project entitled "Maternal vitamin D in pregnancy and childhood growth". This research is being conducted with Deakin University and Barwon Health. Ethics approval has been granted by the Deakin University Human Research Ethics Committee (DUHREC) and Barwon Health Human Research Ethics Committee (HREC) respectively; please see enclosed copies of approvals.

My research was previously supervised by Dr Karen Hallam, however as Karen is no longer employed at Victoria University, I am now supervised by Dr Carolyn Deans.

I understand that as this is an external research project involving me as a VU student as investigator, with no involvement of VU participants, I am not required to seek ethics approval from the Victoria University Human Research Ethics Committee (VUHREC). I understand this from the following passage on the VUHREC website:

> ***External research projects involving VU student as investigator but not involving VU participants***
> *VU staff and students listed as investigators on those external research projects which do not involve a cohort of VU participants and have been approved by another appropriately constituted ethics committee do not need to notify the VUHREC of their involvement. However, it is a National Health and Medical Research Council (NHMRC) and National Research Statement requirement that all research projects involving human participants be approved by an appropriate HREC. The Office for Research reminds all VU staff and students to ensure that they have ethics approval from an appropriate HREC (VUHREC or an external HREC) prior to commencing their research.*

As I read this, I do not need to formally notify the VUHREC of my research involvement; however I do so now as a courtesy. If any further documentation is required, please contact me on [redacted].

Regards,

Lisa Burke.

Appendix J: Participant Consent and Information Form

MATERNAL VITAMIN D IN PREGNANCY AND CHILDHOOD GROWTH STUDY
Epi-UMMD
School of Medicine, Deakin University
PO BOX 281, GEELONG, VIC 3220
TELEPHONE (+61 3) 421 53333/3331
FACSIMILE: (+61 3) 421 53491

Participant Information and Consent Form

Full Project Title: 01/43_E2 Maternal vitamin D in pregnancy and childhood growth
Principal Investigators: Prof Julie A Pasco and Prof John D Wark
Associate Investigators: Dr Sharon L Brennan, Dr Peter Vuillermin, and Dr Lana Williams

1. Introduction

You and your child are invited to take part in this research project, which is an extension of the Vitamin D in Pregnancy Study, for which you have previously consented.

This Participant Information and Consent Form contain detailed information about this research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not you and your child will take part in it.

Please read this Participant Information and Consent Form carefully. Feel free to ask questions about any information in this form.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form you indicate that you understand the information and that you give your consent to you and your child participating in the research project. You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. What is the purpose of this research project?

This study is designed to provide information about maternal vitamin D levels during pregnancy and growth and wellbeing in the offspring at ages between 9 and 11 years. In this study we will determine the following in the mother-child pairs:

- bone and muscle development
- body shape, size and composition
- wheeze and lung function (child only)
- behavior
- physical and psychological symptoms/illnesses.

Approximately 400 child-mother pairs will participate in this phase of the project.

3. What does participation in this research project involve?

The child-mother participation in this project will involve completion of questionnaires and clinical measurements as follows:

- questionnaires will seek information concerning the child's diet, physical activity, bone fractures, wheezing illnesses, food allergies, skin rash, immunisations, sun exposure, medication and supplement use, behaviour, physical and psychological symptoms/illnesses
- the child will self-rate physical maturity by matching the appearance of their bodies to Tanner charts
- a clinical assessment will include measurement of the child's blood pressure, height, weight, circumference (waist, hip, head, limb), skinfold thicknesses, naevi (mole) counts, eczema
- the child's muscle strength will be measured by grasping a hand-held meter (hand strength), resisting pressure on the legs using a manual muscle tester, and by asking them to complete some jumping and balance tests using a special plate on the floor (Ground Reaction Force Platform)
- a scan will be which measures the child's bone mass in the spine, hip, forearm and total body to measure the calcium content of the bones, and the amount of fat and lean tissue in your child's body, using a dual energy x-ray densitometer. The painless procedure takes approximately half an hour while your child is lying on an x-ray table
- a more detailed scan which will measure your child's bone structure in the lower leg and forearm, and the size and mass of muscles, using peripheral quantitative computed tomography (pQCT). This is a painless procedure performed while your child is lying on an x-ray table. The pQCT scans and use of the Ground Reaction Force Platform will be performed at the Royal Melbourne Hospital, in Melbourne. This is the only part of the project not conducted at Barwon Health in Geelong. This part of the project is optional, should you and your child not wish to travel to Melbourne. Travel expenses from Geelong to Melbourne (return) will be available upon request.
- an ultrasound measurement for both yourself and your child at the heel. During this procedure your child will be required to place one foot in the ultrasound machine for a few minutes
- a lung function test which involves your child breathing into a device that can measure the amount of gas they are able to breathe out in one second
- mother's diet, mental health and measured weight, height and waist circumference.

Data from this study may be used as reference data to identify risk factors for other diseases. Parts of this study may also be used for the purposes of obtaining an academic qualification. In the event that we establish collaborations (partnerships) with other researchers and/or commercial partners, your child's and your information may be used for further research into health disorders. For such partnerships to work, it is important that you assign ownership of all the

information to the research team. If you wish, you may decline to have the information used by collaborators.

4. What are the possible benefits?

We cannot guarantee or promise that you will receive any benefits from this project but the information from the study may benefit people in the future.

5. What are the possible risks?

As part of your inclusion in this research the child will undergo DXA and pQCT scans that he/she would not normally receive and is therefore considered to be in addition to standard care. These DXA, pQCT and x-rays of your child's body involve exposure to a very small amount of radiation. As part of everyday living, everyone is exposed to naturally occurring background radiation and receives a dose of about 2 millisieverts (mSv) each year. The effective dose from all these x-rays is about 0.032 mSv. At this dose level, no harmful effects of radiation have been demonstrated, as any effect is too small to measure. The risk is believed to be minimal. As your child is under the age of 18 years, you (or your child) should inform us of any other studies that he/she has participated in that involves the use of radiation. The ultrasound measurement is a rapid, painless procedure, not involving x-rays. The lung function test is neither painful nor distressful. The use of the Ground Reaction Force Platform is neither painful nor distressful, and does not involve any radiation.

6. Do I and my child have to take part in this research project?

Participation in this research project is voluntary. If you do not wish your child to take part, he/she does not have to. Similarly, if you, as a parent do not wish to take part, you do not have to. If you and/or your child decide to take part and later change your mind, you are free to withdraw from the project at a later stage. If you decide that your child will leave the project, the researchers would like to keep the personal and/or health information about you and your child that has been collected. This is to help make sure that the results of the research are accurate. Similarly, if your child provides body scans as part of this project, the researchers would like to retain these. However, if you do not wish for your child's and your information to be retained, you must tell a researcher before withdrawing from the project. Your decision whether your child will take part or not, or to take part and then withdraw, will not affect your child's or your routine treatment, your or your child's relationship with those treating you or your and your child's relationship with Barwon Health or Deakin University.

Before deciding whether or not to take part, you may wish to discuss the project with a relative or friend or your local health worker, and also with your child. Similarly, before you make your decision, a member of the research team will be available so that you can ask any questions you or your child may have about the research project. Once you feel confident that you have all the required information, you may then sign the Consent Form.

7. How will I be informed of the final results of this research project?

Periodically you will be sent newsletters summarising research findings and informing you of the progress of the project. Bone mineral density (DXA) results will be routinely sent to you and your doctor if you request it.

8. What will happen to information about me and my child?

Any information obtained in connection with this research project that can identify you or your child will remain confidential and will only be used for the purpose of this research project. Use of any information obtained in connection with this research project for future studies can only be used upon further approval from the Human Research Ethics Committee. The information will be retained for a minimum of 7 years after the completion of the study, in accordance with the Australian Code for the Responsible Conduct of Research (2007). After this period, all hard copies of data will be shredded and destroyed, and all data files will be permanently deleted.

Data will be de-identified prior to data analysis thereby preserving the privacy of all participants. Data will be collated into group findings for publication and at no time will any individual be identifiable.

The information will be stored in a locked archive room based at Barwon Health. This is a secure facility with limited access to staff members. Electronic data will be stored in databases password protected and accessible only to research staff.

9. Can I access research information kept about me and my child?

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to access the information collected and stored by the researchers about you and your child. Please contact one of the researchers named at the end of this document if you would like to access your information.

In addition, in accordance with regulatory guidelines, the information collected in this research project will be kept for a minimum of 7 years. Access to information about you and your child after this point will not be possible.

10. Is this research project approved?

This study has been approved by the Human Research Ethics Committee, Barwon Health. This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

11. Whom can I contact?

If you want any further information concerning this project, please contact the Principal Investigator, Professor Julie Pasco on (03) 4215 3331 or the research centre on (03) 4215 3333.

If you have any complaints about any aspect of this project, please contact Bernice Davies, RGO/HREC Manager, (03) 4215 3372 or The Manager, Office of Research Integrity, Deakin University, (03) 9251 7129.

CONSENT FORM

01/43_E2: Maternal vitamin D in pregnancy and childhood growth.

Principal and Associate Researcher(s):
Julie A Pasco, John D Wark, Sharon L Brennan, Peter Vuillermin, Lana J Williams

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I have read, or have had read to me in my first language, and I understand the Participant Information and Informed Consent Form Version 1C, Date: 5 Feb 2013.

The researcher has agreed not to reveal my child's or my identity and personal details if information about this project is published or presented in any public form.

I **freely agree / do not agree** *(strike out non-applicable)* to my and my child's participation in this project according to the conditions in the Participant Information and Informed Consent Form.

I **freely agree / do not agree** (strike out non-applicable) to answer questions to determine the presence of psychological symptoms/disorders.

I **freely agree / do not agree** *(strike out non-applicable)* to allow members of the research team access to my and my child's medical records.

I **freely agree / do not agree** *(strike out non-applicable)* to transfer ownership of my and my child's questionnaire and clinical data to the research team.

I **freely agree / do not agree** *(strike out non-applicable)* to allow transfer of my and my child's de-identified questionnaire and clinical data to collaborators.

I **freely agree / do not agree** *(strike out non-applicable)* to allow transfer of my and my child's de-identified questionnaire and clinical data to commercial partners.

I **freely agree / do not agree** (strike out non-applicable) to agree to be contacted in the future if there is a further follow-up study.

Parent/Guardian Name (printed) ……

Signature Date

Declaration by researcher: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher's name (printed) ……

Signature Date

Note: All parties signing the consent section must date their own signature.

Assent (optional)

Child's Name (printed) ……

Signature Date