

# **The psychological impact of stillbirth on women: A systematic review.**

*Running head: Systematic review of the psychological impact of stillbirth on women.*

Louise Campbell-Jackson<sup>1</sup> and Antje Horsch<sup>2,3\*</sup>

<sup>1</sup>Oxford Institute of Clinical Psychology Training, University of Oxford, Isis Education Centre, Warneford Hospital, Oxford OX3 7JX, UK.

<sup>2</sup>Department of Child and Adolescent Psychiatry, University of Lausanne, Unité de recherche, Rue du Bugnon 25 A, CH-1011 Lausanne, Switzerland.

<sup>3</sup>Service of Neonatology, University of Lausanne, Unité de Développement, Maternité, CHUV, Avenue Pierre-Decker 2, 1011 Lausanne, Switzerland.

**\*Corresponding author:** Service Universitaire de Psychiatrie de l'Enfant et de l'Adolescent (SUPEA), Unité de recherche, Rue du Bugnon 25 A, CH-1011 Lausanne, Switzerland.

Email : antje.horsch@chuv.ch; Tel : 0041 21 314 74 80 ; Fax : 0041 21 314 74 81.

## **Biographical sketches**

Antje Horsch, D.Clin.Psych., is a clinical psychologist who currently is a research fellow at the Department of Child and Adolescent Psychiatry and the Department of Neonatology, University of Lausanne (Switzerland). She is also an adjunct faculty member at the Department of Psychology and Counseling, Webster University Geneva (Switzerland).

Louise Campbell-Jackson, D.Clin.Psych., completed her doctorate in clinical psychology at the Oxford Institute of Clinical Psychology (University of Oxford) in 2012. She is currently

working as a clinical psychologist for the Berkshire Healthcare NHS Trust both in the Adult Learning Disability Team and Child and the Adolescent Mental Health Service.

## Abstract

This systematic review explored the psychological impact of stillbirth (from 20 weeks gestation) on mothers. A search was conducted in the National Library for Health and Web of Science, Cochrane Review and Google Scholar. A secondary search based on results from the preliminary search was undertaken. A systematic search identified 26 articles (eight qualitative, 18 quantitative studies), which met criteria and were reviewed according to guidelines. The findings revealed that stillbirth is a distressing experience that can result in high levels of psychological symptoms including anxiety, depression, distress, and negative well-being. Symptoms appear to be highest in the first few months post loss although there is evidence to suggest that for some, symptoms may persist up to three years. The long-lasting impact of stillbirth on women was echoed in the qualitative research. Risk factors for higher levels of anxious and depressive symptoms included higher parity at the time of loss and not being married. Social support in particular was identified to be beneficial for women post loss. Longitudinal studies utilising designs, which permit causality to be determined are required to explore the specific experience of stillbirth. Further exploration of risk and protective factors, cultural beliefs and the impact on partner relationships is needed. Clinical implications of the findings are discussed in light of current guidance.

## Keywords

stillbirth; psychological; perinatal loss; systematic review; women's mental health

## **Introduction**

The current global estimate of stillbirths is 2.64 million, which is higher than the yearly total number of deaths for HIV/AIDS (Cousens et al., 2011). However, identifying global prevalence rates has been difficult due to variations in definition, which differ both internationally and across studies, and poor recording. For example, in the UK, stillbirth is defined as a baby born after 24 weeks completed gestation who does not show any signs of life (Hughes & Riches, 2003), the US and Australia most commonly define stillbirth as a foetus born after 20 completed weeks gestation (Goldenberg et al., 2004; Vance et al., 1991), the World Health Organisation (WHO) uses a definition of  $\geq 22$  weeks gestation (Lawn et al., 2010), and Sweden defines stillbirth as  $\geq 28$  weeks gestation (Surkan et al., 2009). A high number of stillbirths occur in pregnancies that have not had complications and in most cases the loss is very sudden, leaving parents feeling unprepared and in shock when they are told their baby has died (Horsch, 2009; Robinson, 2011).

Stillbirth is a unique bereavement as, unlike other losses, grieving parents have never known the lost child and, rather than a part of their past being lost, it is a part of their future that has changed significantly (Bennet et al., 2005). Many stillbirths occur at near or full term (Cacciatore, 2008) after parents have experienced months of preparation and eager anticipation for the arrival of their baby. These events magnify the devastating loss of giving birth to a baby who shows no signs of life (Mullan & Horton, 2011). Additionally, the birthing process in itself can be a traumatic experience (Silver, 2007).

The experience of stillbirth is complex, comprising many losses, including the loss of self-esteem, aspirations of parenthood, pregnancy and fear of the ability to create another life (Lamb, 2002). In comparison to other types of child loss, stillbirth is often treated differently in our society; it is seen as less significant, which can leave parents feeling isolated and as though their loss has not been validated (Froen et al., 2011; Vance et al., 1995). It may also

impede the grief process or intensify grief reactions in mothers and fathers (Badenhorst et al., 2006; Ney et al., 1994). Stillbirth may also affect the wider family system, including older children (Bennet et al., 2005), or impact on the attachment relationship to the baby born subsequently (Hughes et al., 2001). Additionally, stillbirth can have detrimental effects on couples' relationships (Turton et al., 2009).

Much of the literature to date has grouped together all forms of pregnancy or perinatal loss including miscarriage, stillbirth and neonatal death. Although it is recognised that women can form attachments early on in pregnancy (Gold et al., 2010), there is evidence to suggest that the further the pregnancy has progressed, the greater the attachment the mother has to the baby, leading to a more severe grief reaction (Goldbach et al., 1991). It has been argued that comparing early miscarriage with stillbirth will only serve to further confuse an understanding of the grief process (Brownlee & Oikonen, 2004). A comprehensive review of the psychological effects of miscarriage suggested that whether the psychological impact of stillbirth differs from early miscarriage requires further clarification (Klier et al., 2002). In addition, Cacciatore and Bushfield (2007) argue that psychological theories have not fully explored stillbirth as a unique loss independent from other losses.

Aspects of perinatal loss have been reviewed previously, such as care for women (Bennet et al., 2005) and the experiences of fathers (Badenhorst et al., 2006). However, there has been no systematic review focusing specifically on the psychological impact of stillbirth on women. This paper will review the research on mothers' psychological responses to stillbirth, including both quantitative and qualitative studies. Only results pertaining to mothers who experience a stillbirth after 20 weeks gestation will be included, as this definition has been used in other recent systematic reviews in the field (Badenhorst et al., 2006).

## **Methods**

### *Search strategy*

A systematic search was conducted using the following methods: (1) A key word search was conducted in PubMed, Web of Science, Cochrane Review and Google Scholar using the following keywords (truncation was used): stillbirth, stillborn, foetal death, foetal loss, pregnancy loss, intrauterine death, intrauterine loss, perinatal death, perinatal bereavement, perinatal loss, mothers, maternal, parents, family, psychological impact, psychological outcomes, psychological consequences, psychological sequelae, anxiety, depression, bereavement, grief, loss, post traumatic stress disorder, substance misuse, relationships, social support. (2) A manual search of relevant journals, as well as references in the articles obtained from searching was conducted to identify any further papers.

The following inclusion criteria were applied: papers that included a minimum of one psychological outcome experienced by women following a stillbirth (stillbirth defined as 20+ weeks of gestation); papers that only reported on mothers or that separated out the results for mothers from other family members; papers which provided a clear definition of stillbirth; peer reviewed articles. The following exclusion criteria were applied: papers that did not separate out results for stillbirth from other forms of perinatal loss; studies that considered interventions for women who had experienced a stillbirth rather than the effects of stillbirth on women; articles not in English; single case studies; unpublished articles.

### **Results**

The search yielded 26 articles, which met the aforementioned criteria. Eight of the papers used a qualitative methodology and the remaining 18 articles were quantitative (see Figure 1 for a flow diagram and Table 1 for characteristics of the studies). The results are structured in terms of outcome, listing the most frequently cited outcome first. For the quantitative studies, results are organised by complexity beginning with studies reporting

percentages of symptoms of psychological difficulties to studies that explore predictors. The qualitative studies are additionally structured according to a timeline, i.e. focusing on women's experiences prior to labour first.

**Insert Figure 1 about here**

**Insert Table 1 about here**

### *Anxious and depressive symptoms*

In a longitudinal study (Vance et al., 1991), mothers following stillbirth were significantly more likely to experience anxiety and depression than matched controls. Additionally, 28% of women following stillbirth had high levels of anxiety (five or more symptoms; would require clinical intervention) and 19% had high levels of depression compared to 7% and 3% of the control group. At eight months follow-up (Vance et al., 1995), there remained a significant difference in levels of anxiety compared to controls but not in levels of depression. At 15 months follow-up (Boyle et al., 1996), mothers following stillbirth showed similar but lower rates of anxiety compared to their scores at two and eight months. Rates of anxiety remained higher than controls at 15 months but not for depression. Scores for anxiety and depression at 30 months were no longer different from controls.

In a pilot study (n=17) by Radestad et al. (1996), nine women had anxiety symptoms above the median and five women had scores far above the median. In a questionnaire survey measuring depression in Nigerian women after stillbirth, 37% scored in the moderate to severe range for depressive symptoms compared to 6% of women who had a loss prior to 20 weeks. Two factors were significant predictors of high levels of depressive symptoms: loss after 20 weeks gestation and having no living children (Obi et al., 2009).

Only one study explored the impact of previous stillbirth on the experience of having a subsequent child. Hunfield et al. (1997) assessed anxiety, depression and general psychological distress in women (n=27) who had had a live birth subsequent to late pregnancy loss compared to women who had had a live birth with no loss history at four, eight and 16 weeks postpartum. Women with a history of pregnancy loss were significantly more anxious, depressed, and psychologically distressed than controls four weeks postpartum, more anxious and depressed at 16 weeks but at 16 weeks women with a history of loss did not differ significantly from controls. Fifty percent of participants with a loss history (at four weeks) and 25% (at 16 weeks) were above the norm score for anxiety. Seventy-five percent (at four weeks) and 33% (at 16 weeks) were in the clinically significant range for general psychological distress. Women with high trait anxiety, irrespective of a history of pregnancy loss, were more depressed, distressed and anxious at four and 16 weeks than women with low trait anxiety.

An internet questionnaire-based study (n=2,292) of women who had experienced a stillbirth up to three years previously (Cacciatore et al., 2008) explored the association of seeing and holding the stillborn baby with mother's reported anxiety and depression. The majority of women either saw (95%) or held (90%) their baby. Of the participants, 42% reported symptoms of anxiety and 62% of depression. Maternal characteristics associated with lower levels of anxiety included, older maternal age, a greater period of time since the loss, being married, births subsequent to the loss, lower parity and third trimester losses. Factors associated with lower depression scores included previous live births, being married, low parity, higher educational level, a longer time since the loss and births subsequent to the loss. Additionally, for women who were not pregnant at the time of the study seeing their baby was associated with lower levels of anxiety and depression. Women who were pregnant



at the time of responding however, had lower levels of depressive symptoms but higher levels of anxiety symptoms if they had seen or held their baby.

In their nationwide population-based study of 380 women who experienced a stillbirth and 379 controls, Radestad et al. (1996) assessed factors that might predict long-term anxious and depressive symptoms, using the same measures as in their pilot study. A cut-off for the anxiety and depression measures of above the 90<sup>th</sup> centile was used and modest differences between the two groups were found. For anxiety symptoms, 10% of subjects scored above the 90% centile compared with 5% of controls. Factors that were associated with anxiety symptoms included a delay of 25 hours or more before the start of the delivery, not having any tokens of remembrance of the baby, and not seeing the baby as long as women had wished.

Using the same data set, Surkan et al. (2008) found that factors associated with depressive symptoms three years later included not having contact with the baby for as long as they had wished, which resulted in a nearly seven-fold increased risk of depressive symptoms. Having no subsequent children resulted in nearly a threefold increase in risk compared to women who became pregnant within six months. Stillbirth occurring in the third pregnancy resulted in a 2.2 times higher risk of maternal depressive symptoms, increasing to 6.7 if the stillbirth occurred during the fourth or more subsequent pregnancy.

In a follow-up study, women who had experienced a stillbirth between 28-37 weeks were analysed separately from women who had experienced a stillbirth from 37 weeks of gestation (Radestad et al., 2009). In both groups, 68% of women had held their baby. For mothers whose stillbirth occurred at >37 weeks and who did not hold their stillborn babies compared with women who did, there was an increased risk of headaches and dissatisfaction with sleep.

### *Grief and the bereavement process*

Cuisinier et al. (1993) reported that women after stillbirth or miscarriage experienced grief, but women in the stillbirth group experienced significantly more intense grief reactions. Trulsson and Radestad (2004) interviewed 12 women 6-18 months after stillbirth about their experiences before, during and post stillbirth. The majority of women had a premonition that something was wrong before the diagnosis. Women described the time of receiving the diagnosis as frightening and shocking and experienced feelings of unreality and numbing. During the stage of delivery the women reported being focused on the task and some felt a sense of achievement for completing such a difficult task. After the birth, women reported being grateful for having pictures and mementos to remember their baby. All women stressed the importance of the time in hospital with the baby and 8/12 women felt this time had not been long enough.

Malm et al. (2011) interviewed 21 women, recruited via website, about their experiences of the time between diagnosis and labour. Utilising a qualitative content analysis, an overall theme of “waiting in no man's land” emerged with four subcategories. Women described a distressing and lonely time after diagnosis but said that amidst the pain they had had to focus on the next stage, delivery. They highlighted the realisation of loss and that focusing on the future was helpful at that difficult time.

Pilkington (1993) analysed the interviews of five women after stillbirth and described three core concepts. The first described the intense suffering experienced by the women with a loss of future hopes and dreams. The second highlighted the paradox of support, whereby women found support from friends and family beneficial but also wanted to distance themselves from others at times. The third concept discussed moving forward, faith and focus on the future, such as having another child.

Cacciatore and Bushfield (2007) interviewed women who had experienced stillbirth up to ten years previously. Bereavement was described as a transformative process changing

the way in which participants viewed themselves as well as others. Themes described the loss experienced by mothers as intense and profound, and the grief trajectory as long. Important steps in the bereavement process included altruism and eventually finding a sense of meaning and purpose in the loss.

In their follow-up article (Cacciatore, 2010), the majority of participants expressed feelings of self-blame and guilt. Regret was expressed, which particularly focused on rituals, e.g. not having included siblings in rituals. Mothers also reported blaming themselves for their baby's death and that this led to feelings of inadequacy and failure. A consistent theme was struggling to cope. Nearly half of the 47 mothers reported thoughts of self-harm, particularly soon after the stillbirth. The majority of mothers also described feelings of disenfranchisement and isolation and a need to talk about their difficulties. Important elements included having their loss validated and legitimised by others as well as themselves. Having mementos provided internal and external recognition of the child's identity.

Utilising an interpretative ethnographic methodology Hsu et al. (2002) explored the experience of Taiwanese mothers who had had a stillbirth up to two years previously. One of the main findings was the extent of guilt experienced by mothers. Important steps in the bereavement process included the importance of rituals and finding meaning in the loss, which was influenced by religious and cultural values. The impact of cultural beliefs, such as discouraging discussion of bereavement and the pressure to provide an heir, resulted in women having to attend to their loss in silence.

In their follow-up publication, Hsu et al. (2004) highlighted the many losses women experienced with a stillbirth. Firstly, a loss of control; women attributed causes of the stillbirth to fate and other supernatural reasons but at the same time continued to blame themselves for the loss. Loss of future plans was described and the loss of identity as a

woman and a mother. There was a sense of incompleteness and personal failure, which the authors linked to cultural expectations of a woman to marry and to produce a child.

Yamazaki (2010) used a grounded theory methodology to develop a model of the process of bereavement experienced by Japanese women after a stillbirth. They stated that the grieving process may take from one to several years and that the steps were not linear. The model described how women initially had to face the reality of their loss and emphasised the difficulties that can arise due to the differences in grieving styles between men and women. The authors discuss how the mothers "raise" and develop a relationship with the child that has died; the importance of daily routines, memories that provide "proof" of the birth and support groups, as well as an acceptance of the different ways their husbands managed the loss.

#### *Relationship difficulties*

Using the data from the longitudinal study by Vance et al. (1991), Najman et al. (1993) explored the impact of stillbirth on marital relationships at two and six to eight months post loss. At two months post loss, 12% of mothers following stillbirth reported conflict and disagreement in their relationship compared to 6.5% of control mothers. However, at six to eight months follow-up, there were no significant differences in the results between stillbirth mothers (14.7%) and controls (14.9%).

In a US-based national survey (Gold et al. 2010) including a face-to-face and computerised interviews, a survival analysis of relationships for 7770 pregnancies (6409 live births, 1225 miscarriages, 136 stillbirths) was conducted (details of measures were not provided). After controlling for risk factors known to affect relationship breakdown, women after miscarriages or stillbirths were found to be at a significantly greater risk of relationship breakdown than women after a live birth. For stillbirths, the impact on relationships continued until nine years post loss.

In contrast, higher rates of improved relationships with the baby's father at follow-up were reported for women after stillbirth (45%) compared to controls (25%) with a ratio of proportions of 1.8 by Radestad et al. (1997). Additionally, women after stillbirth reported higher levels of satisfaction with home life with 50% stating they were "entirely satisfied" compared to 38% of controls. There were no significant differences between the two groups with regards to wellbeing, rates of separation or divorce.

One questionnaire-based study of 22 couples found a significant difference between mothers' and fathers' well-being three months post loss (Saflund & Wredling, 2006). Mothers scored significantly higher on 'negative well-being', and lower on 'positive well-being' and 'general well-being', compared to fathers. In contrast, 18 couples reported that the loss had had a positive effect on their relationship by bringing them closer together.

### *Social support*

Cacciatore et al. (2009) assessed the effect of social support on anxiety and depression in 769 women who had experienced a stillbirth 18 months previously. They reported high levels of anxiety and depression in the sample. The most frequently cited form of support was from family members (97.7%) followed by nurses (90%), doctors (67.9%), and support groups (53.4%). Rates of depression were higher in women who were single, divorced or widowed. Perceived support from family, nurses and doctors was associated with lower maternal anxiety and depression scores. However, after controlling for individual factors, only family support was associated with significantly lower scores compared to women who did not report high levels of family support post stillbirth.

Surkan et al. (2009) found that unmarried women were at a ten times increased risk of depressive symptoms compared to married women three years post stillbirth. With regards to social support, fathers' refusal to talk was associated with an almost five times increased risk

of depressive symptoms. However, after adjusting for satisfaction with relationship with the father, this risk dropped to 2.1. Conversely, opportunity to talk with the father resulted in a 50% lower risk. Dissatisfaction with emotional support post stillbirth and with the relationship with the partner at the time of pregnancy was also associated with maternal depressive symptoms.

#### *Drug and alcohol use*

Vance et al. (1994) reported that mothers at two months following stillbirth did not differ significantly from controls regarding the amount of pain medication taken, how often they consumed alcohol, or their weekly alcohol intake. Significant differences, however, were found for the amount of prescribed tranquilizers taken and for rates of heavy drinking. Information about prior drug use, however, was not collected.

#### *Mother-infant adaptation*

Hunfield et al. (1997) explored mother-infant adaptation, requiring women to rate an ideal baby and their own baby on 13 qualities. Women with a previous stillbirth had greater difficulties with their babies' routine than controls four weeks post partum. These difficulties decreased over time and the differences between women with a history of stillbirth and controls were not significant 16 weeks post partum. Women with a history of pregnancy loss were, however, significantly more likely to perceive their child as less ideal than controls at 16 weeks.

### **Discussion**

This review included 18 quantitative and eight qualitative studies on the psychological impact of stillbirth on women. Some methodological issues need to be raised (CASP, 2012;

Moher et al., 2009). Several studies were completed by the same authors, who conducted further analyses on the original data set. Although this is detailed clearly in the articles it may appear as though the body of literature is larger than it is. The evidence base is thus dominated by a small number of research groups. Furthermore, a variety of definitions of stillbirth were used in the studies (20-28 weeks), thus creating difficulties in comparisons across studies.

The majority of studies were conducted using white European populations, women who were mainly of college education or higher, married, and of a higher socioeconomic status, and are therefore unlikely to be representative of all women who have experienced a stillbirth. Sample sizes for the quantitative studies ranged from 17 to 2,292 and most studies had no power calculations. Reported response rates ranged from 63.1% to 83%. Only two studies included characteristics of non-responders (Obi et al., 2009; Vance et al., 1991). The qualitative studies ranged significantly with regards to the time since stillbirth from two months up to 10 years and also within individual papers. Long time periods since the stillbirth may have increased the risk of recall bias. The majority of quantitative studies recruited women from hospitals or clinics using non-probability sampling, which may affect how representative the sample is and the generalisability of the results. Of the qualitative studies, three recruited women via bereavement support services, which may have excluded women who had not experienced difficulties since the stillbirth.

The differing methodologies make it difficult to compare studies and to draw firm conclusions. The majority of the quantitative studies used questionnaire survey designs, which has limited internal validity, as causation cannot be inferred. Many studies used measures that are validated with other groups but not with this population. This issue has been highlighted previously within the perinatal loss literature (Badenhorst et al., 2006). The majority of the quantitative studies utilised validated measures, although not all papers

included details of the psychometric properties of the measures used. Papers utilising population-based methodologies had the benefit of reducing the risk of selection bias and the longitudinal designs provided some evidence for the long-term impact of stillbirth on women. Few studies used a matched control, which goes some way to decrease the potential impact of confounding variables. For the studies that did not include a control group it is unclear whether the outcomes identified were uniquely linked to experiencing a stillbirth or not.

A range of qualitative methodologies was employed, including content analysis, grounded theory, phenomenology and Parse's theory of human becoming. All studies had clear aims, which were outlined, and provided a rationale for the methodology selected and all studies clearly described the form and methods of data collection. Although the majority of studies used interviews to obtain data, not all studies included details of the interview schedule, making replication difficult. Although all studies provided some description of the methods of analysis used, only two studies included tables showing how themes emerged from the data, raising questions about credibility. Half of the qualitative studies did not discuss reflexivity. All reviewed studies detailed the ethical approval obtained. Not all studies, however, reported obtaining informed consent. None of the papers discussed offering support, advice or signposting women who were identified as experiencing significant psychological difficulties.

Despite the methodological weaknesses outlined, the available evidence suggests that stillbirth is a distressing and difficult experience that can result in high levels of psychological symptoms including anxiety, depression, distress, and negative well-being. For the majority of women, these symptoms are highest in the first few months post stillbirth. For some women, symptoms may persist up to three years, although the percentage of women this may affect is unclear. There is some evidence to suggest that women may use alcohol or tranquilizers to cope with the distress. The intense grief and long-lasting impact of stillbirth



on women is echoed in the qualitative research. The impact can be far reaching and may affect initial adaption to a subsequent child. Risk factors for higher levels of anxiety and depression include higher parity at the time of loss and not being married.

From the evidence available, social support, particularly from family and partners, appears beneficial and may protect against later emotional difficulties. In contrast, a lack of perceived emotional support or opportunity to talk with partners about the loss may increase the risk of later depressive symptoms. This may be linked to the finding that being single is a risk factor for later anxious and depressive symptoms, as women may not have someone to talk to who shared the same experience (Radestad et al., 1997). There were conflicting findings with regard to the impact of stillbirth on relationship breakdown. Comparing the impact of stillbirth to earlier pregnancy loss, some studies found higher scores on measures of grief and depression for women who had experienced stillbirths. However, one study (Cacciatore et al., 2008) reported that third trimester losses (compared to second trimester losses) were associated with fewer symptoms of anxiety.

### *Clinical Implications*

Key healthcare professionals need to be aware of the possible early difficulties that women may experience, including not only anxiety, depression and grief but also feelings of guilt and self blame. For some women, these symptoms may require professional support, so signposting to local mental health services may be necessary. Professionals need to be aware that single women and women who have experienced a stillbirth at a higher parity may be at particularly high risk of developing psychological difficulties and may require additional support and signposting. Finally, professionals need to be mindful of cultural beliefs and the impact these beliefs may have on how women view and adapt to their loss and the support available to them (Bennet et al., 2005). For example, if discussing the loss outside of the

family is not encouraged women may not be able to access support groups, and therefore greater communication and support within the family may need to be facilitated. In addition, an awareness of the difficulties couples might have needs to be present. The research reviewed highlights the importance for some women of having the opportunity to spend time with their baby and create mementos. However, from the evidence available it is not possible to draw firm conclusion about whether contact with the stillborn baby has any long-term impact on maternal anxious or depressive symptoms.

### *Research Implications*

To date, the majority of research has grouped together all forms of perinatal loss and further research focusing exclusively on the impact of stillbirth is needed. Specifically, more longitudinal studies, and studies using measures validated in this population and representative samples are required. As it appears that not all women experience ongoing psychological difficulties following stillbirth, further exploration of the factors which may increase risk is needed (Bennet et al., 2005). Qualitative studies exploring the impact of stillbirth on relationships, the ways in which mothers and fathers grieve, and how couples make sense of the experience both separately and jointly as a couple, are needed. In addition, further quantitative research examining risk and protective factors that may influence relationship breakdown is called for (Gold et al., 2010). Most studies excluded women who had lost a twin to stillbirth, so future research exploring this experience is needed.

## References

- Badenhorst, W., Riches, S., Turton, P. & Hughes, P. (2006). The psychological effects of stillbirth and neonatal death on fathers: Systematic review. *Journal of Psychosomatics, Obstetrics and Gynaecology*, 27, 245–256.
- Bennet, S.M., Litz, B.T., Lee, B.S. & Maguen, S. (2005). The scope and impact of perinatal loss: Current status and future directions. *Professional Psychology-Research and Practice*, 36, 180-187.
- Boyle, F.M., Vance, J.C., Najmen, J.M. & Thearle, M.J. (1996). The mental health impact of stillbirth, neonatal death or SIDS: Prevalence and patterns of distress among mothers. *Social Science and Medicine*, 43, 1273-1282.
- Brownlee, K. & Oikonen, J. (2004). Towards a theoretical framework for perinatal bereavement. *British Journal of Social Work*, 34, 517-529.
- Cacciatore, J. & Bushfield, B. (2007). Stillbirth: The Mother's Experience and Implications for Improving Care. *Journal of Social Work in End-Of-Life & Palliative Care*, 3, 59-79.
- Cacciatore, J., DeFrain, J. & Jones, K. (2008). When a baby dies: Ambiguity and stillbirth. *Marriage and Family Review*, 44, 439-454.
- Cacciatore, J., Radestad, I. & Frøen, F. (2008). Effects of contact with stillborn babies on maternal anxiety and depression. *Birth*, 35, 313-320.
- Cacciatore, J., Schnebly, S., Froen, F. (2009). The effects of social support on maternal anxiety and depression after stillbirth. *Health and Social Care in the Community*, 17, 167–176.
- Cacciatore, J. (2010). The unique experiences of women and their families after the death of a baby. *Social Work and Health Care*, 49, 134-48.

Centre for Maternal and Child Enquiries (2008). Perinatal Mortality 2008.

<http://hqip.org.uk/assets/NCAPOP-Library/CMACE-Reports/36.-July-2010-Perinatal-Mortality-2008.pdf>. Accessed 4 April 2013.

Cousens, S., Blencowe, H., Stanton, C., Chou, D., Ahmed, S., Steinhardt, L., Creanga, A.A., Tunçalp, O., Balsara, Z., Gupta, S., Say, L. & Lawn, J.E. (2011). National, regional, and worldwide estimates of stillbirth rates in 2009 with trends since 1995: a systematic analysis. *Lancet*, 377, 1319-1330.

Critical Appraisal Skills Programme (2012). *Solutions for public health*.

<http://www.caspinternational.org/?o1020>. Accessed 04 April 2013

Cuisinier, M.C.J., Kuijpersb, J.C., Hoogduina, C.A.L., de Graauwc, C.P.H.M., Janssen, A. (1993). Miscarriage and stillbirth: time since the loss, grief intensity and satisfaction with care. *European Journal of Obstetrics, Gynecology and Reproductive Biology*, 52, 163–168.

Froen, F.J., Cacciatore, J., McClure, E.M., Kuti, O., Jokhio, A.H., Islam, M. & Shiffman, J. (2011). Stillbirths: why they matter. *Lancet*, 377, 1353-1366.

Gold, K.J., Sen, A. & Hayward, R.A. (2010). Marriage and cohabitation outcomes after pregnancy loss. *Paediatrics*, 125, 1202 -1207.

Goldbach, K.R.C., Dunn, D.S., Toedter, L.J. & Lasker, J.N. (1991). The effects of gestational age and gender on grief after pregnancy loss. *American Journal of Orthopsychiatry*, 61, 461-467.

Goldenberg, R.L., Kirby, R. & Culhane, J.F. (2004). Stillbirth: A review. *Journal of Maternal and Fetal Neonatal Medicine*, 16, 79-94.

Gosling, S.D., Vazire, S., Srivastava, S. & Oliver, J.P. (2004). Should we trust web-based studies? A comparative analysis of six preconceptions about internet questionnaires. *American Psychologist*, 59, 93-104.

- Horsch, A. (2009) Post traumatic stress disorder following childbirth and pregnancy loss. In: Beinart, H., Kennedy, P. & Llewelyn, S. (ed) *Clinical psychology in practice*. Oxford: Blackwell, pp 274-287.
- Hsu, M., Tseng, Y., Banks, J. & Kuo, L. (2004). Interpretations of stillbirth. *Journal of Advanced Nursing*, 47, 408–416.
- Hsu, M., Tseng, Y. & Kuo, L. (2002). Transforming loss: Taiwanese women's adaptation to stillbirth. *Journal of Advanced Nursing*, 40, 387–395.
- Hughes, P. & Riches, S. (2003). Psychological aspects of perinatal loss. *Current Opinions in Obstetrics and Gynecology*, 15, 107-111.
- Hughes, P., Turton, P., Hopper, E., McGauley, G.A. & Fonagy, P. (2001). Disorganised attachment behaviour among infants born subsequent to stillbirth. *Journal of Child Psychology and Psychiatry*, 42, 791-801.
- Hunfield, J.A.M., Taselaar-Kloos, A.K.G., Agterberg, G., Wladimiroff, J.W. & Passchier, J. (1997). Trait anxiety, negative emotions, and the mothers' adaptation to an infant born subsequent to late pregnancy loss: a case–control study. *Prenatal Diagnosis*, 17, 843–851.
- Klier, C.M., Geller, P.A. & Ritsher, J.B. (2002). Affective disorders in the aftermath of miscarriage: A comprehensive review. *Archives of Women's Mental Health*, 5, 129-149.
- Lamb, E.H. (2002). The impact of previous perinatal loss on subsequent pregnancy and parenting. *Journal of Perinatal Education*, 11, 33-40.
- Lawn, J.E., Gravett, M.G., Nunes, T.M., Rubens, C.E. & Straton, C. (2010). Global report on preterm birth and stillbirth: definitions, description of the burden and opportunities to improve data. *BMC Pregnancy and Childbirth*, 10, S1.

- Malm, M., Rådestad, I., Erlandsson, K. & Lindgren, H. (2011). Waiting in no-man's-land: Mothers' experiences before the induction of labour after their baby has died in utero. *Sexual & Reproductive Healthcare*, 2, 51–55.
- Moher, D., Liberati, A., Tetzlaff, J. & Altman, D.G. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Medicine*, 6, 1-6.
- Mullan, Z. & Horton, R. (2011). Bringing stillbirths out of the shadows. *Lancet*, 377, 1291-1292.
- Najman, J.M., Vance, J.C., Boyle, F., Embelton, G., Foster, B. & Thearle, J. (1993). The impact of a child death on marital adjustment. *Social Science and Medicine*, 37, 1005–1010.
- Ney, P.G., Fung, T., Wickett, A.R. & Beaman-Dodd, C. (1994). The effects of pregnancy loss on women's health. *Social Science and Medicine*, 38, 1193–1200.
- Obi, .SN., Onah, H.E. & Okafor, I.I. (2009). Depression among Nigerian women following pregnancy loss. *International Journal of Gynecology and Obstetrics*, 105, 60–62.
- Pilkington, B.F. (1993). The lived experience of grieving the loss of an important other. *Nursing Science Quarterly*, 6, 130-139.
- Radestad, I., Sjögren, B., Nordin, C. & Steineck, G. (1997). Stillbirth and maternal well-being. *Acta Obstetrica Gynecologica Scandinavica*, 76, 849–855.
- Radestad, I., Steineck, G., Nordin, C. & Sjogren, B. (1996). Psychological complications after stillbirth influence of memories and immediate management: population based study. *British Medical Journal*, 312, 1505-1509.
- Radestad, I., Steineck, G. & Nordin, C. (1996). Psychic and social consequences of women in relation to memories of a stillborn child: a pilot study. *Gynecological and Obstetric Investigations*, 4, 1194–1198.

- Radestad, I., Surkan, P.J., Steineck, G., Cnattingius, S., Onelo, D. & Dickman, P.W. (2009). Long-term outcomes for mothers who have or have not held their stillborn baby. *Midwifery*, 25, 422–429.
- Robinson, G.E. (2011). Dilemmas related to pregnancy loss. *Journal of Nervous Mental Diseases*, 199, 571-574.
- Saflund, K. & Wredling, R. (2006). Differences within couples' experience of their hospital care and well-being three months after experiencing a stillbirth. *Acta Obstetrica Gynecologica Scandinavica*, 85, 1193–1199.
- Silver, R. (2007). Fetal death. *Obstetrics and Gynecology*, 109, 153-165.
- Spielberger, C.D., Gorusch, R.L. & Lushene, R.E. (1970). *Manual for the state-trait anxiety inventory*. Consulting Psychologist Press, Palo Alto.
- Surkan, P., Radestad, I., Cnattingius, S., Steineck, G. & Dickman, P.W. (2009). Social support after stillbirth for prevention of maternal depression. *Acta Obstetrica Gynecologica Scandinavica*, 88, 1358–1364.
- Surkan, P.J., Rådestad, I., Cnattingius, S., Steineck, G. & Dickman, P.W. (2008). Events after stillbirth in relation to maternal depressive symptoms: A brief report. *Birth*, 35, 153–157.
- Trulsson, O. & Radestad, I. (2004). The silent child: Mother's experiences before, during and after stillbirth. *Birth*, 31, 189–195.
- Turton, P., Evans, C. & Hughes, P. (2009). Long-term psychosocial sequelae of stillbirth: Phase II of a nested case-control cohort study. *Archives of Women's Mental Health*, 12, 35-41.
- Vance, J.C., Foster, W.J., Najman, J.M., Embelton, G., Thearle, M.J. & Hodgen, F.M. (1991). Early parental responses to sudden infant death, stillbirth or neonatal death. *Medical Journal Australia*, 155, 292-297.

Vance, J.C., Najman, J.M., Boyle, F.M., Embelton, G., Foster, W.J. & Thearle, M.J. (1994).

Alcohol and drug usage in parents soon after stillbirth, neonatal death or SIDS.

*Journal of Paediatric and Child Health*, 30, 269–272.

Vance, J.C., Najman, J.M., Thearle, M.J., Embelton, G., Foster, W.J. & Boyle, F.M. (1995)

Psychological changes in parents eight months after the loss of an infant from stillbirth, neonatal death, or sudden infant death syndrome: a longitudinal study.

*Pediatrics*, 96, 933–938.

Yamazaki, A. (2010). Living with stillborn babies as family members: Japanese women who

experienced intrauterine fetal death after 28 weeks gestation. *Health Care Women*

*International*, 31, 921-937.



Table 1: Characteristics of studies exploring the psychological effects of stillbirth on women

Reference	Location	Study Design	Definition of SB	Participants	N	Measures	Psychological outcomes
Boyle et al. (1996)	Australia	Longitudinal Case control study	>20 weeks	Women only Women who had experienced SB, NND or SIDS in Queensland during 1985-1988	Loss group =194 (SB =78) Control Group = 203	DSSI	Anxiety & depression
Cacciatore & Bushfield (2007)	US	Qualitative; questionnaire survey	>20 weeks	Women only SB only Women accessing two bereavement organisations	47	Qualitative questionnaire	Grief
Cacciatore et al. (2008)	US UK Australia Canada	Questionnaire survey (MOMS)	>20 weeks	Women only SB only 3Women recruited through 37 organisations providing info about pregnancy including SB	2,292	HSCL	Anxiety & depression
Cacciatore et al. (2009)	US	Questionnaire survey (MOMS)	>20 weeks	Women only SB only As above	769	HSCL	Anxiety, depression & social support
Cacciatore (2010)	US	Qualitative; questionnaire survey	>20 weeks	Women only SB only Women accessing two bereavement organisations	47	Qualitative questionnaire	Grief
Cuisinier et al. (1993)	Netherlands	Case control study	>20 weeks	Women only SB or MC Out patients at one hospital	143 in total (SB =39)	PGS	Grief

Gold et al. (2010)	US	Retrospective population based survey (NSFG)	>20 weeks	Women only SB, MC or live birth	7770 (SB=136)	Survival analysis	Marriage & cohabitation outcome
Hsu et al. (2002)	Taiwan	Qualitative; Interpretative ethnographic	During the third trimester	Women only SB only	20	Interviews	Grief
Reference	Location	Study Design	Definition of SB	Participants	N	Measures	Psychological outcomes
Hsu et al. (2004)	Taiwan	Qualitative; Interpretative ethnographic approach	During the third trimester	Women only SB only	20	Interviews	Grief
Hunfeld et al. (1997)	Netherlands	Case control	>20 weeks	Women only. Women with a history of late pregnancy loss due to congenital abnormalities Control group = mothers with no history of pregnancy loss	56 (SB=27)	STAI; GHQ-28; EPDS; NPI; DIS & semi-structured interview	Anxiety, general distress, depression & mother-infant adaption
Malm et al. (2011)	Sweden	Qualitative; in-depth interviews	Earliest loss included 30 weeks gestation	Women only SB only	21	Two open ended questions were the framework of the interviews	Grief
Najman et al. (1993)	Australia	Longitudinal Case control	>20 weeks	Mothers & fathers Women who had experienced SB, NND or SIDS in Queensland during 1985-1988	Loss group = 260 (SB = 99) Control Group = 252	7 items from the Spanier Dyadic Adjustment Scale	Marriage & cohabitation outcome
Obi et al. (2009)	NG	Questionnaire survey	>20 weeks	Women only Losses <20 (MC, EP) Losses < 20 (FD, SB)	202 (SB=69)	Zung Self Rating Depression Scale	Depression

				Women who experienced an SB at 3 hospitals			
Pilkington (1993)	Canada	Qualitative; interviews	“Babies lost at birth”	Women only SB only Women who experienced a SB at one hospital	5	Interviews	Grief
Radestad et al. (1996b)	Sweden	Pilot study	>28 weeks	Women only SB only Women who had experienced a SB at 4 gynaecological depts	Subjects = 17 Controls = 17	STAI, CES-D & quality of life measure	Anxiety & depression
Reference	Location	Study Design	Definition of SB	Participants	N	Measures	Psychological outcomes
Radestad et al. (1996a)	Sweden	Nation-wide cohort study (NBHW)	>28 weeks	Women only SB only All women who had a SB in 1991 in SE using the medical birth register	Subjects = 380 Controls = 379	STAI, CES-D & quality of life measure	Anxiety & depression
Radestad et al. (1997)	Sweden	Nation-wide cohort study (NBHW)	>28 weeks	Women only SB only As above	Subjects = 380 Controls = 379	Quality of life measure	Satisfaction with relationship, Marriage & cohabitation outcome
Radestad et al. (2009)	Sweden	Nation-wide cohort study (NBHW)	>28 weeks	Women only SB only As above	Subjects = 314	STAI, CES-D & quality of life measure	Anxiety & depression
Saflund & Wredling (2006)	Sweden	Questionnaire survey	>22 weeks	Couples (Mothers & Fathers) SB only Women who experienced a SB at five hospitals	22	WBQ-12	Well-being
Surkan et al. (2008)	Sweden	Nation-wide cohort study (NBHW)	>28 weeks	Women only SB only	Subjects = 314	CES-D	Depression

Reference	Location	Study Design	Definition of SB	Participants	N	Measures	Psychological outcomes
Surkan et al. (2009)	Sweden	Nation-wide cohort study (NBHW)	>28 weeks	Women only SB only As above	Subjects = 298	CES-D	Depression & social support
Trulsson & Radestad, (2004)	Sweden	Qualitative; interviews	>24 weeks	Women only SB only Women who experienced a SB at one hospital	12	Interview schedule	Grief
Vance et al. (1991)	Australia	Case control study	>20 weeks	Mothers & fathers Women who had experienced SB, NND or SIDS in Queensland during 1985-1988	Loss group = 260 (SB = 99) Control Group = 252	DSSI	Anxiety & depression
Vance et al. (1994)	Australia	Case control study	>20 weeks	Mothers & fathers As above	Loss group = 260 (SB= 99 CG = 252)	Questionnaire	Drug & alcohol use
Vance et al. (1995)	Australia	Longitudinal Case control study	>20 weeks	Mothers & fathers As above	Loss group = 220 (SB = 82) Control Group = 226	DSSI	Anxiety & depression
Yamazaki (2010)	Japan	Qualitative; interviews	>28 weeks	Women only SB only Women accessing a SB support group	17	Interviews	Grief

*Note.* MC = Miscarriage; SB = Stillbirth, FD = Fetal death; NND = Neonatal Death; SID = Sudden Infant Death; EP = Ectopic Pregnancy; CES-D = Epidemiological Studies Depression Scale; STAI = State-Trait Anxiety Inventory; STAI –T DSSI = Delusions, Symptoms States Inventory; HSCL = Hopkins Symptom Checklist; PGS = Perinatal Grief Scale; NPI = Neonatal Perception Inventory; DIS = Discrepancy Scale; EPDS = Edinburgh Postnatal Depression Scale; GHQ-28 = General Health Questionnaire; WBQ 12 = Well Being Questionnaire; NSFG = National Survey of Family Growth; MOMS = Maternal Observations and Memories of Stillbirth; NBHW = National Board of Health and Welfare; SE = Sweden.



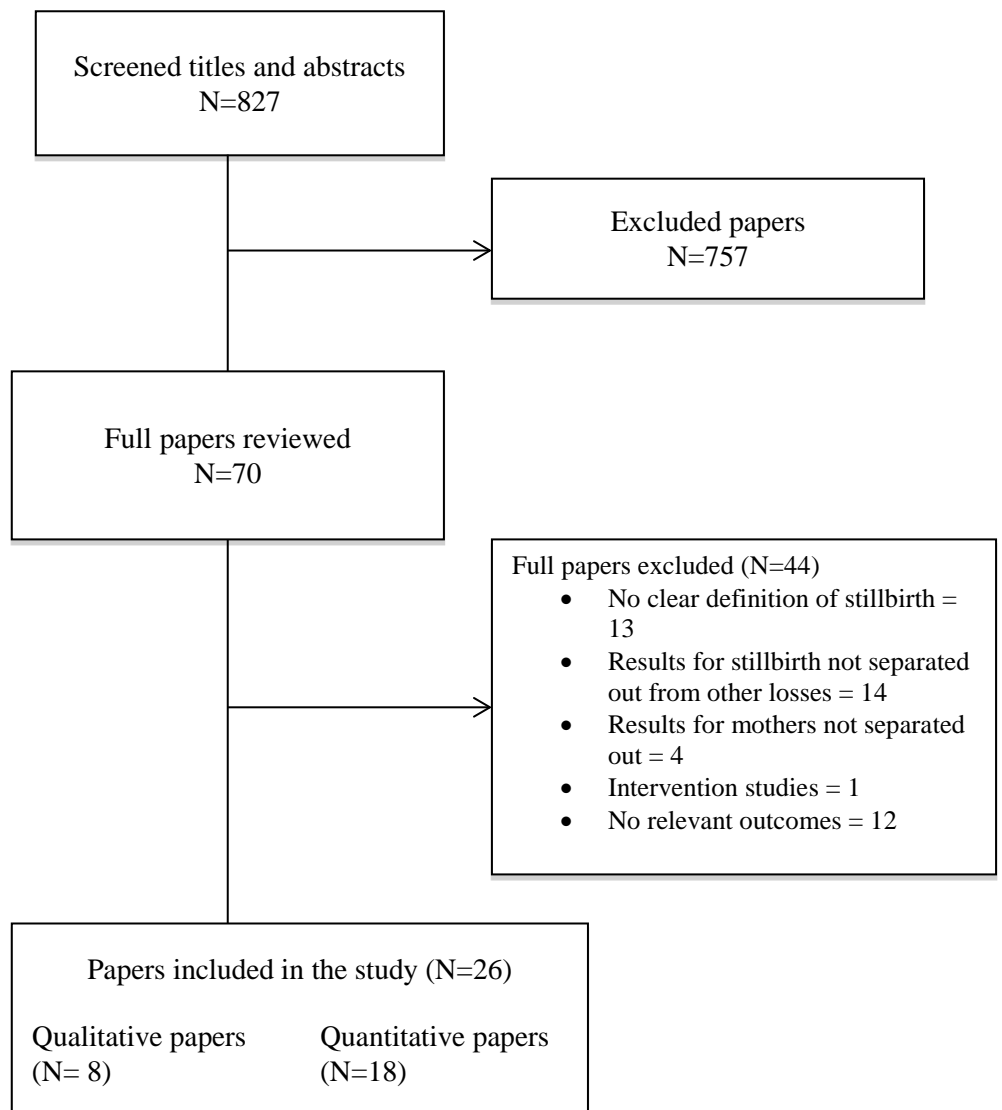


Figure 1: Flow diagram of studies included in the review