

## Grief, guilt and emptiness: emotional experiences of bereaved mothers after perinatal loss

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### Abstract

**Introduction:** This review gives the wonderful scope for improved coping strategies, identifying the various factors that affecting the grief process and obtaining the opinions of bereaved mothers regarding hospital staff.

**Objective:** To explore the emotional experiences of bereaved mothers after perinatal loss.

**Materials and Method:** Keyword searched in PubMed, EBSCO, online journals by using the keywords of 'perinatal loss', 'perinatal grief', 'abortion', 'stillbirth', 'neonatal death' and 'emotional experience of bereaved mothers'. Total 10 articles are selected according to eligibility criteria and removing articles are rejected because they did not match the eligibility criteria and some are duplicates.

**Result:** The review identified two types of qualitative studies on perinatal loss, they are focused on coping with grief, guilt and emptiness after perinatal loss and emotional experiences of bereaved mothers after perinatal loss. This review identified the significant emotional experiences like grief, guilt, anxiety, emptiness and self-blame. By developing the self-help coping strategies the women's are able to cope up with the situation and accept the changes.

**Conclusion:** This review explores the emotional experiences of bereaved mothers after perinatal loss. Women's do not only feel the loss of pregnancy, but also the dreamed and anticipated child, their mothership and their self-esteem along with experiences of the grief, guilt and emptiness.

**Keywords:** Grief, Guilty, Emptiness, Emotional experience, Bereaved mothers, Perinatal loss

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### Introduction

According to the World Health Organization (WHO), "the perinatal period extends from the 22<sup>nd</sup> gestational week through one-week post birth."<sup>(1)</sup> Perinatal loss is defined as deaths among fetuses weighing 1000gm or more at birth that die before or during delivery or within the first 7 days after delivery.<sup>(2)</sup> Perinatal loss includes stillbirths and neonatal death. The stillbirths have decreased by 19.4% from 2000 to 2015 throughout the world with annual rate reduction of 2%. Worldwide 2.6 million stillbirths occurred in 2015 and 7178 stillbirths per day. Globally, the number of perinatal mortality rate has declined to 40% in 2011 (WHO). In India, Karnataka state has the highest perinatal loss (stillbirth) rate that accounts for 12 deaths per 1000 births in the country according to the Sample Registration Survey (SRS, 2013).<sup>(3)</sup> The current perinatal mortality rate (PNMR) in India is 49 per 1000 births as per National Family Health Survey (NFHS, 2015 to 2016).<sup>(4)</sup>

Women sorrow might be accompanied by the unconcerned reaction of family members and friends on perinatal loss (DeFrain, Millsbaugh, & Xiaolin, 1996; Woods & Woods, 1997).<sup>(5)</sup> During new pregnancy, women need family, friends and health care support (Annsophie Adolfsson, Cecilia Johansson and Emma N, 2012).<sup>(6)</sup> Since the psychological aspects of mothers who had undergone perinatal loss is most often

neglected, there is a need to synthesize the qualitative aspect of studies undertaken in this area, this will help to address the psychological needs of such mothers.

These reviews give the marvelous scope to acquire the views of bereaved mothers about the benefits of perinatal loss support services from hospital staff and to identify the various factors those are affecting the grieving process.

### Materials and Method

The primary focus of this review was about to identify the experience of pregnant mothers after perinatal loss and to identify the various factors influencing grief. An electronic search of 110 articles published in the PubMed, EBSCO and online journals by using the keywords of "perinatal loss", 'perinatal grief', 'abortion', 'stillbirth', 'neonatal death' and 'emotional experience of bereaved mothers'. All the studies are based on qualitative approach. By using, the electronic sources total 110 articles identified through the database and any additional articles are not identified through the other sources. In total 110 articles, only two articles are duplicates and these two articles are removed. Total 108 articles are there after removing the duplicates and these articles are screened. After screening of total 108 articles 92 articles (full-text) are excluded because these articles are not relevant

to my review. Then 16 full-text articles are assessed for eligibility.

The eligibility criteria are selected only those studies will be included in which

1. Women with more than 20 weeks of gestation who had an experience perinatal loss.
2. Women in the history of perinatal loss one to two years ago.
3. Hospital support services role in the grief recovery of women after perinatal loss.
4. Women who had experience of perinatal loss through stillbirth, death of the neonate and miscarriage.

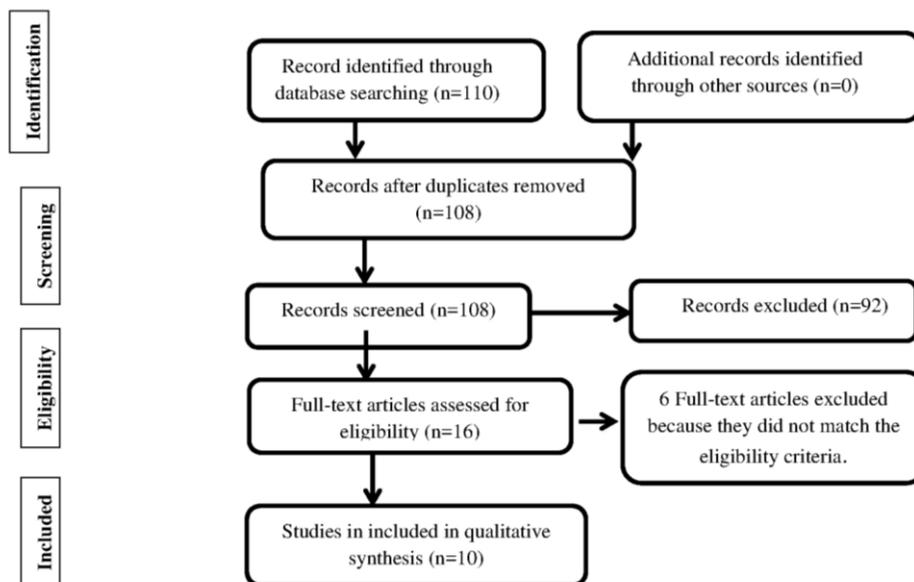


Fig. 1: Prisma chart

In 16 articles, six full-text articles are excluded because they did not match the eligibility criteria. Then 10 full-text articles or studies are included because these are related to qualitative review. All studies collected the data through the in-depth interview or semi-structured interviews either face to face or the telephone. In conducting the interviews they are using the open ended questionnaires. The duration of the interviews should be 45 minutes to one hour in all studies. The majority of studies conducted the interviews with the maintenance of confidentiality and privacy. In many of the studies, interviews were recorded (with permission from the participants) and transcribed verbatim. Most of the studies recruited participants from the clinical sites with the help of health professionals. Sometimes letters, emails and telephones are used to inform the family members regarding the research and to call them for participation. Non-probability purposive sampling techniques are used in most of the studies. Only one study, were used for non-probability sampling a technique that was convenient and snowball sampling technique for recruitment of participants. After data collection, most of the study's data should be analyzed by the thematic analysis. A qualitative data, software (NVIVO 9, MAXQDA) also used in many of the studies. All the studies were ethically approved.

## Results and Discussion

The women expressed that their loss of an expected or awaited child was usually with the feeling of sadness, anxiety, anger, disorientation and self-blame. The loss of baby not only indicate the end of a relationship between the developing baby and parents, but it also indicates the loss of dreams, hopes and an elemental part of the pregnancy. Women are sensing guilt, blankness, fear, and disapproval after perinatal loss. This review identified the emotional experience of bereaved mothers and emotional support from family as well as from health professionals also. The review identified two types of qualitative studies on perinatal loss, these are:

1. Studies focused on coping with grief, guilt and emptiness after perinatal loss (n=3). These three studies conducted in the Western United states, Southwest Sweden and Northern Ireland. The findings of these studies are coping with sorrow, guilt and emptiness. In these, personal reactions after perinatal loss, in one study participant illustrates her thought that if she talk to someone who had undergone perinatal loss, then she can feel that person will understand her feeling and she can ventilate her feeling and she can feel relaxed (Paulina, V., and Afaf, I. M. 2003).<sup>(7)</sup> And reaction of others after perinatal loss, in one study participant dealt with insensitive comments from

society and family and they lose their confidence than they develop unsupportive behaviors that no one can understand their feelings and thoughts (Paulina, V., and Afaf, I. M. 2003).<sup>(7)</sup> Women feeling guilt and emptiness after perinatal loss and the experience of perinatal loss, giving the negative impact on the woman’s mind so by developing the self-help coping strategies the women’s are coping with the situation and accept the changes.

2. Studies focused on the emotional experiences of bereaved mothers after perinatal loss, in one study the mother expressed that she felt incredible rush of love when she saw her baby for the first time. The studies highlighted the significant emotional experiences of grief, shock and denial, anger and self-blame. More than half of the women described shock when they are realizing that they lost their babies. During this period the women’s are feeling numb, complete exhaustion, loneliness, weakness and longing. Perinatal loss support services from hospital help the mothers in recovery from grief and other emotional problems.

This review identified a large number of themes related to the emotional experiences of bereaved mothers after perinatal loss and definite need of mothers for emotional support from family members and health care team members. The themes were emerged from the narration of bereaved parents interviewed in the case of a perinatal loss and this also includes the parents, their family members and health care professionals. This review emerged three major themes, these are coping with grief, guilt and emptiness, memories of the baby and perinatal loss support services.

Mothers feeling grief, guilt and emptiness after perinatal loss. These experiences of perinatal loss through the stillbirth or neonatal death up to seven days of life give the negative impact in the mother's mind. Mothers show their emotional problems through the grief, denial, anger, and self-blame. The mothers explained about the loss of child by describing their future thoughts of motherhood and anticipated child. During these times some mothers get family support and some mothers are not getting family support. By the help of the family, mothers easily cope up with the grief reactions and emotional problems. Educate mothers to identify grievance reaction after perinatal

loss and managing those responses efficiently would arrest negative effects on their body and mind (Paulina Van, Afaf I. Meleis., 2003).<sup>(7)</sup> Grief defined related to experience of significance of attachment not in the term of length of pregnancy (Gensch and Midland, 2000).<sup>(8)</sup> Mother explained that they felt same level of sorrow who had lost a single or more than one baby (Swanson et al 2009 and Cuisinier et al., 1996).<sup>(9,10)</sup> Women and their husbands expressed grief differently that can be result of conflict in their relationship (Berry, 1999; Swanson, 1999).<sup>(11)</sup>

Memories of the baby play a very important role especially in the perinatal loss mother’s life. Some memories (e.g., pictures, toys, cloths) help the mothers in recovery from their grief. All the mothers were told that through the memories they are connected with their babies and they are gradually getting relief from the grief through the memories. Funeral of stillbirth babies also help mothers in recovery from the grief and emptiness. Parents are motivated to keep the memories of lost baby such as photographs, foot and handprints (McCreight, S.B., 2007).<sup>(12)</sup> Those mothers lost their babies should not be placed with other mothers and their new born babies as that could unbearable for them (Conry, j., and Prinsloo, c., 2008).<sup>(13)</sup>

Now days, the hospitals are organizing the perinatal loss support services for the mothers. These services provide the emotional support and psychological support to the mothers through the counseling. Timing of support is also one of the important factors in these themes. In many studies, mothers disclose their feeling regarding staffs’ timely support to mother for encountering the incident of perinatal loss. Mothers feel supportive when the staff given more time to hold the baby and encouraged the mother to cope up with the changes. Other side most of the mothers feel unsupportive because the staff members was not handling the babies in a proper way because the baby was dying. Hospital staffs were sincerely concerned about the emotion of mothers and supported them and the loss their babies (Conry, j., and Prinsloo, c., 2008).<sup>(13)</sup>

By contrast, the review identified most of the mothers were feeling uncomfortable in the hospitals due to unsupportive behaviors from staffs, and provided less opportunities to make memories of their babies.

**Table 1: Study characteristics: “emotional experiences of bereaved mothers after perinatal loss”**

Sl No	Problem statement/ Author	Place of research & year	Variables	Tools	Time duration	Outcomes	Remarks
1	Coping with grief after involuntary pregnancy loss: perspectives of African	The urban community based sites in the Western United states	Coping with grief after involuntary pregnancy loss.	Semi-structured interview	45 to 60 min interview for each participan.	In this study the major findings were, women were coped with four areas that was reactions, reaction of others and memories of baby. The women	This study was helpful to create the self-help strategies to handle with responses after involuntary

	American Women. Paulina Van and Afaf I. Melesis	2003				coped and managed with grief reactions and responses by keeping some memories of lost baby like pictures and warm cloth and it helps the women to feel connected with their babies.	pregnancy losses by using the inner resources and improving the personal relationship by decreasing the grief intensity.
2.	Guilt and emptiness: women experiences of miscarriage <sup>(14)</sup> Annsophie Adolfsson P. G. Larsson Barbra Wijma	Southwest Sweden. 15 <sup>th</sup> January 2001	Women experience guilt and emptiness after miscarriage	General interview-guide.	45 to 100 minutes interview for each participant	In the study one main theme and five subthemes were emerged. The main theme was guilt and emptiness of women who had miscarriages. They feel guilty and blamed on themselves. Whether empathy and debriefing will decrease the feeling of weariness and disgrace among the women need to be identified.	In this research the women expressed they not only loss of an pregnancy but also loss their motherhood, self-confidence and expected baby.
3.	Mothers' perspectives on the perinatal loss of a co-twin: a qualitative study. <sup>(15)</sup> Judy Richards Ruth Graham Nicholas D Emblazon Claire Campbell and Judith Rankin	Neonatal Intensive Care Unit and Fetal Medicine department of tertiary hospitals of UK.  2014	Mothers' perception on the perinatal loss of a co-twin.	In-depth and semi structured interview	Minimum 1 hour interview	In this study identified three themes by the data analysis and the themes was the status of special encompasses three subthemes were feeling special, acknowledging bereavement and twin-ship and coping with trauma and grief on hold. Trust included three sub-themes were emotion work, continuity of information and continuity of staffing and trust. These three themes help to describe the mothers experience and the emotional support of health professionals in a crucial stage.	This study helps to figure out the different needs of the bereaved women and development of care packages by exploring the views of bereaved mothers.
4.	Bereaved parents' experience of stillbirth in UK hospitals: a qualitative interview study. <sup>(16)</sup> So Downe Ellie Schmidt Carol Kingdon Alexander E P Heazell	The American College of Obstetricians and Gynecologists and the Perinatal Society of Australia and New Zealand. 2011	Bereaved parents' experience of stillbirth.	In-depth direct or telephonic interview	Interviews lasted between 42 min and 1hour.	The data generated three key themes: enduring and multiple losses, Making irretrievable moments precious. The first concept related to a passive gap in resources, skills, attitudes and behaviors. The second concepts related to active practices that disrupted or damaged the recovery of	This study was given importance into the staff behaviors and support with the perinatal loss parents. Positive outcomes and memories help the mothers to recovery from the grief and guilty feeling.

						parents. The overall findings are stated as meta-theme 'One chance to get it right.'	Staffs meeting parents in such state should provide adequate support.
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Sl No	Problem statement/ Author	Place of research & year	Variables	Tools	Time duration	Outcomes	Remarks
5	Mothers' Perceptions of Benefits of Perinatal Loss Support Offered at a Major University Hospital. <sup>(17)</sup> Nancy Anne Sanchez	California 2001	Mothers Perceptions of Benefits of Perinatal Loss Support	Face to face in-depth semi-structured interview	The interviews lasted between 45 to 90 minutes for each participant	The spontaneous hospital's support in the loss experience occurred in 11 of the 12 interviews. Several themes were identified related to the hospital's support and the themes are the timing of support or the lack of good timing appeared to be important factors in a mother's perception of an experience as positive or negative. Nurturance was another important theme in the interviewee's assessment of the support of perinatal loss grief. Partner involvement was another important theme of the hospital support of the loss.	This study identified that most of the women prefer medical abortion than surgical abortion due to its ease, spontaneous and inexpensiveness. This study helps to, educating the mothers about coping strategies.
6	Exploring pregnancy termination experiences and needs among Malaysian women: A qualitative study. <sup>(18)</sup> Wen Ting Tong Wahl Yun Low Yet Lin Wong Sims Poey Chong and Ravindran Jegasothy	Urban family planning clinic in Penang, Malaysia. 2011	Pregnancy termination experiences and needs among Malaysian women	Face to face Semi structured interview.	Data collection was conducted during the period May In June, 2011.	The main findings of the study related to themes are these are personal abortion experiences, towards accessing abortion services and information, fear about abortion and its side effects, feelings and emotions post-abortion, abortion decision making and support, and needs of women to cope with abortion. This study also	From this study found that most of the women seemed to favor medical abortion due to its convenience, naturalness and cheaper cost compared to surgical abortion.

						highlighted the need to increase their reproductive knowledge pertaining to abortion.	
7	Seeing or not seeing: Taiwan's parents experiences during stillbirth. <sup>(19)</sup> Jui-Chiung Sun Wenmay Rei Shuh-Jen Sheu	Maternity units in Taoyuan, Taiwan.  2009	Parents' experiences during stillbirth.	In-depth interviews with open ended questions	Data collection was done between May and June, 2011.	The main findings of the study were: 1) Deciding to see the stillborn baby and 2) Deciding not to see the stillborn baby. According to these findings five themes were emerging from this study. Seeing was believing, the participant's husband doesn't want to see the baby, but mothers want to confirm about the baby's condition (death or not). Seeing was an opportunity to give the farewell to the baby and recover from grief gradually. Seeing the infant's baby for the last time that was helpful to maintain the memories of the baby.	This study mainly gives the importance on the experience of seeing or not seeing the stillbirth baby. The mothers need to see their babies for gradually recover from grief.

Sl No	Problem statement/ Author	Place of research & year	Variables	Tools	Time duration	Outcomes	Remarks
8	Parental needs in infant's end-of-life and bereavement in NICU: A qualitative study. <sup>(20)</sup> Marzieh Hasanpour Narges Sadeghi Mohammad Heidarzadeh	Iran 2016	Parental needs in infant's end of life and bereavement in NICU	Semi-structured interview	Interviews lasted between 35 to 75 minutes	This study was emerged two important themes and these are family preparatory needs and family support needs after infant death. Delivering the bad news and inform to the mothers that should be maintained by the family and husbands, so they were playing an important role. In only one case find out the mother accept the infant's death better than the fathers.	This study was helpful to find out the needs of family support into the emotional problems like grief, guilt and anxiety etc.

9	Mothers' access to supportive hospital services after the loss of a baby through stillbirth or neonatal death. J Conry and Dr C Prinsloo	South Africa 2008	Supportive hospital services after the loss of a Baby through stillbirth or neonatal death	Semi-structured interview by using an open ended questionnaire.	Interviews lasted between 35 to 95 minutes.	This study mainly focused on hospital support services after perinatal loss. There are three themes were emerging and these are supportive, compassionate and understanding or conversely. The theme of support was playing a very important role because supportive staff members encouraged the mother to accept the situation. Hospital support services should be improved by giving the training to the nurses.	This study was helpful to identify the needs of mothers about hospital support services.
10	Perinatal Loss: A Qualitative Study In Northern Ireland Bernadette Susan McCreight	Northern Ireland Stillbirth and Neonatal Death Society, Remember Our Child, and Miscarriage Support Group 2007	Women experiences of Perinatal loss	In-depth interviews	The data were collected between three years	This study is focused on the emotional reaction of mothers to loss, need to recover and reconstruct their capability to express emotion as a valid form of grief. Hospital practices encouraged the parents or mothers to grieve openly and to be involved in the funeral arrangements for their stillborn baby, which was helpful for the mother to accept the changes. In this study give the main focus on the women's need to recover their capability to express their emotions and grief.	This study gives the main importance on women's need after pregnancy loss. Medical personnel support also needed after the loss. So by this study to increasing the capability of the women's to express their emotions and grief with others

### Recommendations

- Develop the self-help strategies to cope with reactions following involuntary pregnancy losses by using the inner resources.
- Development of care packages by exploring the views of bereaved mothers.
- Women's do not only feel the loss of pregnancy, but also feel the loss of anticipated child, their motherhood and their self-esteem.

### Conclusion

In this review, each woman's experience is unique. This review provides the precious information about emotional experiences of bereaved mothers after perinatal loss. Bereaved mothers express their emotional experiences through the grief, guilt and emptiness. During the new pregnancy after perinatal loss the bereaved mothers want more support from husband and family members as well as from the

healthcare professionals. Memories of lost baby help the mothers in recovery from the grief and guilty.

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