

Impacts of Perinatal Death on Women and Families: A Qualitative Systematic Review

Nedruetai Punaglom¹; Nadnapa Arayasinlapathon¹



Nedruetai Punaglom

¹ Nakhon Phanom University, Nakhon Phanom Province, Thailand.

* Address Correspondence to author:
Nedruetai Punaglom
Nakhon Phanom University,
Nakhon Phanom province, 48000, Thailand.
email: nedruetai@npu.ac.th

Received: February 22, 2022
Revision received: March 14, 2022
Accepted after revision: August 15, 2022
BKK Med J 2022;18(2): 141-150.
DOI: 10.31524/bkkmedj.2022.23.003
www.bangkokmedjournal.com

Abstract

Perinatal death is the death of unborn or newborn children that is perceived as the death of a non-person which affects not only women but also the whole family and may have a long-lasting negative impact on the living child. This review aimed to outline current evidence concerning focus on the impacts of perinatal death on women and families. A systematic review of literature focused on women and families facing perinatal death was undertaken using Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research. The search was limited to published studies from January 2012 to December 2021, and the relevant databases utilized to conduct the systematic search included CINAHL Complete, MEDLINE, PsycARTICLES, PsycINFO, SCOPUS, and Google Scholar. Over 1,000 titles were initially identified, which yielded 11 studies for evaluation and synthesis. Data extraction was conducted using the Joanna Briggs Institute data-extraction tool. Thematic synthesis was used to synthesize the data. Two core themes were identified: 1) impact on women (being overwhelmed with suffering, losing a sense of self-worth, risks of pathological grief); and 2) impact on families (subsequent pregnancy produces mixed emotions, neglecting a living child, marital disharmony, lacking support from a health professional).

In conclusion, further research is needed on the voices of men, existing children, and entire families. In particular, there is a need to develop an effective intervention for entire families experiencing perinatal death by focusing on individuals and different cultures.

Keywords: women, family, perinatal death, systematic review, qualitative systematic review

Globally, approximately 6,700 neonatal deaths occur daily, and nearly three-quarters occur within the first week of life. This equates to 1 in 72 total births resulting in a stillborn baby, or one every 16 seconds.¹ It means that many countries around the world are experiencing major public health problems caused by perinatal death (PD),^{2,3} which is the death of a fetus or neonate from 28 completed weeks (196 days) of gestation to seven completed days after birth.⁴ An associated risk for PD can be divided into two subgroups; easily preventable and treatable, such as from danger and injury during the birthing process, diseases or complications in pregnant women; and causes that are difficult to prevent and treat, such as congenital malformations, abnormalities of the placenta and umbilical cord, and asphyxia caused by placental abruption, etc.¹⁻⁴ Therefore, PD is the death of unborn or newborn children that is a traumatic event occurring in a sudden, violent, or traumatic way and is also considered the death of a non-person.⁵⁻⁶

Birth is perceived as a pleasant event followed by motherhood and fatherhood. Thus, birth symbolizes a perfect family.⁷ Many women around the world have been expected to perform feminine roles as wife and mother from generation to generation⁸ in the same way men are expected by wives, families, and society to be family leaders providing all family members with physical and mental comforts.⁹ Once PD had occurred, the devastation of PD is considered a life-long crisis event widely impacting not only women but also whole families. This is because the family is seen as a crucial support system for all family members, especially when faced with a devastating event caused by PD. In this regard, the family is a system

that reacts and adapts to a bereavement in diverse ways, which can be either normal adaptation or maladaptation depending on various influencing factors that the family system interacts with.¹⁰⁻¹¹ Previous studies have illustrated how PD impacts women and families suffering from intense feelings of grief, helplessness, self-blame, and stigmatization, and people remain unable to express grief openly because PD is perceived as disenfranchised grief.¹² In the systematic review and meta-analysis by Smythe et al.¹³ PD affect not only women but also their couples and may have a long-lasting negative impact on existing children.¹⁴⁻¹⁷

PD also impacts family functioning in parenting roles for existing children, who are usually ignored by grieving parents and not provided information regarding the death of their youngest sibling due to their young age or other reasons. Parents usually avoid communication about PD, leaving children to self-interpret and likely distort understanding of the event. Additionally, living children have little chance of encouragement to demonstrate their grief reaction, thereby putting them at risk for short- and long-term pathological guilt, fear and blame potentially leading to cognitive distortions.¹⁸

Identified Gap in the Literature

Although a lot of literature tries to understand the lives of women following PD, little is known regarding the impacts on families. It means that empirical evidence is still largely individualistic in focus. However, PD may cause significant debilitation for the family leading to a breakdown in structure and the dynamics of interaction. These can lead to existing care failing to address the complicated problems faced as little is known regarding the impacts of PD on women and families. This hinders the healthcare providers' competency in developing effective interventions to help women and families to overcome PD. Proper interventions for women and families should be based on a comprehensive understanding of the impacts of PD, meaning that comprehensive understanding in this area will create a body of knowledge promoting understanding among healthcare providers, which will be useful for further development of effective supportive interventions. Therefore, to comprehensively understand the impact of PD on women and their families and to raise awareness, interested parties can use this paper as a literature review guide to conduct further qualitative research; one of the reasons why this qualitative systematic review has been carried out.

Purpose of the Study

This review aims to outline current evidence concerning focus on the impacts of PD on women and families in order to develop an effective intervention for this group.

Method

This study used thematic synthesis of qualitative study in systematic reviews and enhancement of transparency in reporting the synthesis of qualitative study.^{19,20} Importantly, Preferred

Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) was used in collection, selection, and critical appraisal to assure the quality of selected studies before conducting articles analysis.²¹

Search Strategy and Data Sources

The PRISMA statement²¹ was employed to conduct this study. The search was limited to published studies from January 2012 to December 2021 including information about the impacts of PD on women and families. The relevant databases utilized to conduct the systematic search were CINAHL Complete, MEDLINE, PsycARTICLES, PsycINFO, SCOPUS, and Google Scholar in addition to reviewing reference lists of all relevant articles. The following five sets of search terms were used in each database:

1. "perinatal death", "stillbirth", "neonatal death", "early neonatal death", "pregnancy loss", "perinatal loss", or "death of a child"
2. "parent", "mother", "father", "man", "woman", "men", "women", "male", "female", "motherhood", or "fatherhood"
3. "impact", "effect", "affect", or "perinatal outcome"
4. "family", "families", or "relatives"
5. "living child/children", "existing child/children"
6. "women's background", "families' background"

Each search consisted of a combination of the six sets of search terms connected by "AND". Each database search was then combined using "OR" to account for duplication. The literature search tries to answer one question; how does PD impact women and families? To state the question in terms of PICO (Population, Interest, Context); the population was women and their families; the interest was the impact of PD; and the context was women's and families' background such as age, gestational ages at time of loss, time since loss, and different socioeconomic statuses etc.

Study Selection

The search was limited to any peer-reviewed studies published in English between January 2012 and December 2021 to capture all recent evidence. Inclusion criteria selected studies that:

1. Aimed to explore the impacts of PD on women and families in which PD refers to stillbirth and early neonatal death.
2. Focused on women and families or individual women or family voices.
3. Were a primary qualitative study.
4. Were a full text with sufficient information for critical appraisal.

However, any studies that were written in a language other than Thai or English, commentaries, narrative review, full-text unavailable, editorial, no concepts relating to, and insufficient information for critical appraisal were excluded.

The articles retrieved from the systematic search were evaluated using the PRISMA 2020 flow diagram. Search

selection strategies were conducted in a stepwise fashion with a team of two reviewers: two reviewers independently examined all titles against the inclusion criteria. Consensus was reached, all abstracts were considered independently by two reviewers, and full-text versions of studies meeting the inclusion criteria and presenting an original study on the topic were obtained and randomly assigned and examined by two reviewers. Eligible articles were included in the review through data extraction into evidence tables. The reference lists of all relevant articles were cross-checked to ensure that no relevant article was left unexamined.

Search Outcome

The literature review identified 946 papers. After removing 92 duplicates, 854 titles and abstracts were screened independently by two reviewers. After removing 667 studies that did not meet the eligibility criteria, 187 titles and abstracts were systematically screened with 145 not meeting the inclusion criteria. Forty-two full-text articles were retrieved for eligibility and thirty-three were excluded. A review of the reference list of included studies identified two additional articles meeting the inclusion criteria. A total of 11 qualitative primary papers were included in this study (see Figure 1 for the PRISMA flow diagram).

Quality Appraisal

Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research²² was used to conduct an assessment of qualitative studies selected regarding methodological validity prior to inclusion in the review by two independent reviewers. This appraisal tool comprising a 10-item checklist was used to assess the methodological quality of a study and to determine the extent to which a study has addressed the possibility of bias in its design, conduct, and analysis.²² Any disagreements were reconciled through discussion.

Data Extraction and Synthesis

Data from eligible studies were extracted into evidence tables using the JBI data-extraction tool.²³ The results of the included studies were synthesized using Thomas and Harden’s thematic synthesis¹⁹ comprising of three steps; the coding of text line-by-line, the development of descriptive themes, and the generation of analytical themes. The synthesis method used specifically for the review question and specific objective in this review.

Identified themes were grouped into similar concepts, and data were presented in a narrative synthesis. Discrepancies were discussed until consensus was reached.

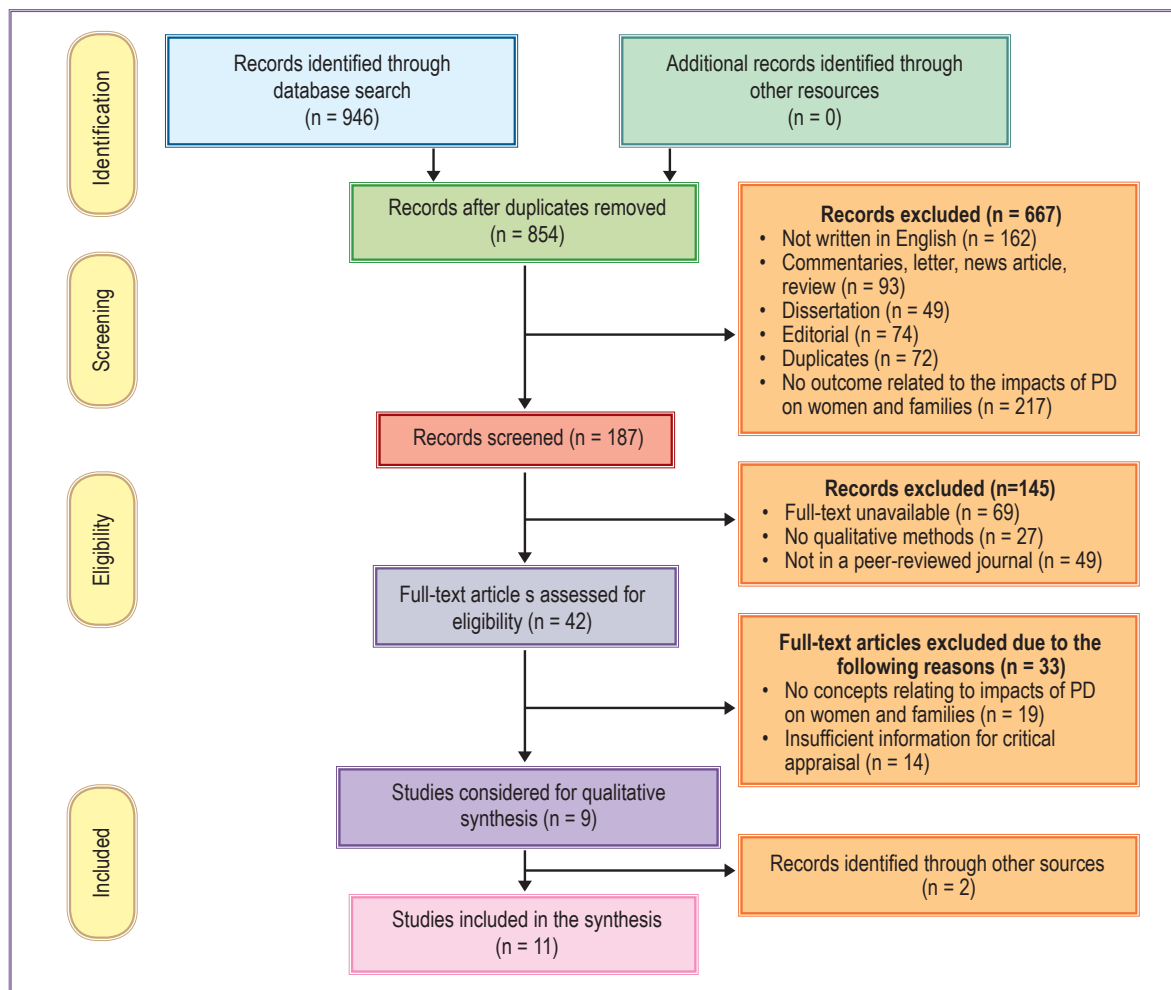


Figure 1: PRISMA flow diagram on the outcomes of search strategies

Results

Characteristics of Included Studies

Table 1 provides details of the key characteristics of the eleven qualitative studies. Four studies explored the impacts of PD on women and families;²⁴⁻²⁷ one study explored factors influencing the impacts of stillbirth and coping styles women used following stillbirth;²⁵ four studies described the experiences and perceptions of parents suffering a PD;^{26,28-30} three studies investigated women’s and family’s experiences with previous PD or stillbirth in relation to subsequent pregnancies and subsequent parenting and lastly,^{9,31-32} one study described parents’ reports of children’s responses to sibling death.³³ Eligible studies were conducted in different countries (each country n = 1): Malaysia, Miami, India, USA, and Australia.^{9,25,27,30,33} Other countries (n = 2) were Ireland,^{26,31} the United Kingdom, U.K.,^{29,32} and Spain.^{24,28}

Most participants were females (n =118), with males and families (n = 42, and 22) respectively. The women were between the ages of 18 and 48 years, with gestational age at the time of PD between 24 weeks and 6 days after birth, and the time since PD was between 3 months and 12 years. Most studies (n = 10) collected data through in-depth interviews. One study combined focus group discussions and in-depth unstructured interviews.²⁷ Another study³⁰ collected data by using semi-structured focus groups. Data analysis was done through different methods including descriptive analysis,²⁷ discourse analysis,³⁰ constant comparative technique,²⁹ thematic analysis,^{9,25} interpretative phenomenological analysis (IPA),^{26,31-32} content analysis,³³ and inductive analysis.^{24,28}

Table 1: Summary of included studies (n = 11)

Reference /Country	Aims	Sample and Study Population	Data Collection and Analysis	Findings
Sutan&Miskam ²⁷ Malaysia	• To explore psychosocial experiences and support in women after PD.	• 16 Muslim women experiencing PD. • Recruited women attending Universiti Kebangsaan Malaysia • Medical Centre by purposive sampling.	• Focus group discussion and in-depth unstructured interviews. • Descriptive analysis	• Analysis was grouped into 4 themes: 1. women's feelings following PD (confusion, emptiness, anger, guilt, anxiety over subsequent pregnancy), 2. women's perception on health care provider roles during grief (inadequate communication/ privacy), 3. support (family, friends, religion) 4. decision.
Gopichandran et al. ²⁵ India	• To explore psychosocial impact, aggravating factors, coping styles and health system response to stillbirths.	• 8 women experiencing stillbirth in the past 1 year and families who were identified with the help of community health workers.	• In-depth interviews. • Thematic analysis.	• Participants perceived negative experiences due to insensitive health care provider attitudes and poor health facility service quality, searching for causes of the death of their children and blaming other people.
Nuzum et al. ²⁶ Ireland	• To understand experiences and explore the impact of stillbirth on bereaved parents.	• 12 women and 5 men who experienced stillbirth. • Recruited from an Irish tertiary maternity hospital by purposive sampling.	• Semi-structured in-depth interviews. • Interpretative phenomenological analysis (IPA) for data analysis.	• Grief and guilt were major psychological consequences following stillbirth. Four themes emerged: hope (something went wrong, confusion, hope against hope), the importance of the personhood of the baby (real baby, name and identity, parenting their baby), protective care (postmortem, protective of self, fear, regrets), and relationships (partner, baby, staff).
Kelly & Trinidad ³⁰ USA.	• To understand in- depth accounts of parents' experiences following stillbirth.	• 18 women and 4 men who experienced stillbirth. • Participants were recruited through parent hospital guild groups and snowball recruitment through friends of guild members.	• Qualitative study used semi- structured focus groups; • Data analysis was performed through discourse analysis.	• The important themes emerging in this study were stillbirth as an unexpected event, confusion and shock, typical labor and delivery environments are not designed to support parents during stillbirth, clinician empathy and rituals to honor a baby's death are important to parents, grief following stillbirth is ambiguous, and parents struggle with silence and taboo surrounding stillbirth.

Impacts of Perinatal Death on Women and Families: A Qualitative Systematic Review

Reference /Country	Aims	Sample and Study Population	Data Collection and Analysis	Findings
Downe et al. ²⁹ UK.	<ul style="list-style-type: none"> To understand the perspectives of bereaved parents in interactions with professionals just before or during labor with PD. 	<ul style="list-style-type: none"> 22 families (n = 25) participated in the study. Participants were recruited from bereaved parents who had completed an e-questionnaire via the Sands website. 	<ul style="list-style-type: none"> In-depth interviews. Constant comparative technique. 	<ul style="list-style-type: none"> “One chance to get it right” was the meta-theme composed of three important themes underpinning this synthesis: parent experiences (enduring and multiple losses); parent needs (making irretrievable moments precious); and negligent care (best possible to worst imaginable).
Üstündağ-Budak et al. ³² UK.	<ul style="list-style-type: none"> To gain detailed accounts of first-time mothers experiencing stillbirth and going on to deliver a living child. 	<ul style="list-style-type: none"> Purposive sampling of 6 women experiencing stillbirth; recruitment on internet-based social support websites. 	<ul style="list-style-type: none"> Semi-structured interviews. Interpretive Phenomenological Analysis. 	<ul style="list-style-type: none"> The findings were presented through three themes: broken canopy, how did this happen? and a continuing bond.
Meredith et al. ⁹ Australia	<ul style="list-style-type: none"> To explore women's experiences with previous PD in relation to subsequent pregnancy-to-birth journeys. 	<ul style="list-style-type: none"> 10 women previously experiencing perinatal loss with subsequent live delivery and in a relationship with the father of the new baby. Recruited from women attending the Mater Mothers' a Pregnancy After Loss Clinic (PALC) during subsequent pregnancy in Brisbane, Australia with purposive sampling. 	<ul style="list-style-type: none"> Semi-structured interviews were conducted in hospital or by telephone. Data Analysis: thematic analysis. 	<ul style="list-style-type: none"> Six themes were identified: <ol style="list-style-type: none"> The overall experience The unique experience of pregnancy after loss Support Experiences of other services Need for appropriate alternative services Advice: mother-to-mother
Camacho-Ávila et al. ²⁸ Spain	<ul style="list-style-type: none"> To explore and explain the experiences and perceptions of mothers and fathers suffering PD. 	<ul style="list-style-type: none"> 13 mothers and 8 fathers participated. Recruited from parents who had suffered a PD in Torreveja Hospital and Vinalopó Hospital in Alicante, Spain. 	<ul style="list-style-type: none"> In-depth interviews. Inductive analysis. 	<ul style="list-style-type: none"> Three themes were identified: <ol style="list-style-type: none"> Perceiving threat and anticipating PD Emotional outpouring We've had a baby
Fernández-Sola et al. ²⁴ Spain	<ul style="list-style-type: none"> To explore, describe and understand the impacts of PD on parents' social and family life. 	<ul style="list-style-type: none"> 13 mothers and 8 fathers suffering PD; recruited from contact information for parents suffering PD in the last 5 years at Torreveja and Vinalopó Hospitals, Alicante, Spain 	<ul style="list-style-type: none"> In-depth interviews. Inductive analysis to find themes. 	<ul style="list-style-type: none"> PD effects on family dynamics was an important emerging theme comprising the following sub-themes: <ul style="list-style-type: none"> Fathers: struggle between conserving stereotypical protective roles and succumbing to pain; Elder Siblings: feeling over-protected or abandoned; new pregnancies dominated by fear: medicalization and avoidance, and strengthening and weakening the couple's link.
Meaney et al. ³¹ Ireland	<ul style="list-style-type: none"> To gain insight into consideration and planning of subsequent pregnancy by parents in the weeks following stillbirth. 	<ul style="list-style-type: none"> 15 parents with stillborn babies: ten were female and five were male. Recruitment strategy focused on the parents of ten stillborn babies. 	<ul style="list-style-type: none"> Semi-structured interviews. Interpretative phenomenological analysis. 	<ul style="list-style-type: none"> Two superordinate themes were identified: <ol style="list-style-type: none"> Aspirations for future pregnancy Expectations of future care.
Youngblut et al. ³³ Miami	<ul style="list-style-type: none"> To explore parents' reports of children's responses to a sibling's death in a neonatal or pediatric intensive care unit via qualitative interviews at 7 months after the death. 	<ul style="list-style-type: none"> 24 parents whose 24 deceased infants died in a pediatric/neonatal intensive care unit. Potential participants were identified by hospital collaborators and death records from the state's Office of Vital Statistics. 	<ul style="list-style-type: none"> Semi-structured interviews. Content analysis. 	<ul style="list-style-type: none"> Six themes illustrated child's response to sibling's death: changed behaviors, not understanding what was going on, maintaining connectedness with sibling, no time to be with sibling and/or say goodbye, believing the sibling is in a good place, and not believing the sibling would die.

Synthesis of the identified themes

Across the eleven studies, findings were presented through a disparate range of foci and study aims. Two core themes were identified by data synthesis: impacts on women (being overwhelmed with suffering, losing a sense of self-worth, risks of pathological grief), and impacts on families (subsequent pregnancy produces mixed emotions, neglecting a living child, marital disharmony, lacking support from a health professional). All findings fell within these categories.

Impacts on Women

Being overwhelmed with suffering

Being overwhelmed with suffering refers to a myriad of emotions and thoughts that the women were grappling with caused by PD. All studies in this review illustrated being overwhelmed with suffering women face due to PD. A study by Gopichandran et al.²⁵ found that women faced psychosocial suffering following PD such as feelings of frustration, guilt, and strained couple relationships. This finding corresponds with a study by Nuzum et al.,²⁶ Sutan and Miskam²⁷ revealing that women reported feelings of frustration and anger due to perceptions that they might do something wrong during pregnancy and eventually be the cause of the death of their children. The women were particularly frustrated and angry with healthcare providers since women could not know the cause of the death of their child, feeling that they received no explanation about the death of their child.^{30,32} These feelings persisted in their minds and influenced the emergence of guilt since they felt they had made the wrong decision in choosing health facilities without the competence to provide proper care. Also, the study by Gopichandran et al.²⁵ revealed grief and guilt as the major psychological consequences following stillbirth that caused them to face the feeling of being overwhelmed with suffering.

Losing a sense of self-worth

Losing a sense of self-worth refers to the women's feelings in terms of feeling they lost the sense of their own value or worth as a wife and of motherhood compared to those who give birth to healthy children and protected their children's lives in accordance with social expectations. This feeling resulted from the women perceiving themselves as the cause of the death of their children and their failure to perform spousal and maternal roles. These emotions stayed in their minds and influenced the emergence of self-blame and low self-esteem. This finding corresponded with a study by Nuzum et al.²⁶ stating that women tried to maintain hope that the diagnosis for their baby was wrong and that their baby might survive. Thus, the women tried to adopt the maternal role amidst panic, fear, and confusion, because they perceived their role as giving birth to a healthy child according to social expectations. However, once women received confirmation of the reality of their baby's death, they usually perceived themselves as worthless for being unable to protect their child's life.²⁹ Thus, PD was a devastating event producing losing a sense of self-worth.

Risk of Pathological Grief

PD is a tragedy producing intense grief for all women and increasing the risk of pathological grief.³⁴ A study by Sutan and Miskam²⁷ showed that women experiencing PD felt confusion, emptiness, blaming other and oneself. Parents may also be at risk for post-traumatic stress disorder (PTSD) due to PD. Gopichandran et al.²⁵ also found that women felt they had made the wrong decision in choosing a health facility without good quality care, perceived themselves a failure in motherhood and also blamed themselves for not making an independent decision about care. The study by Meredith et al.⁹ found that women who had previously experienced PD faced overwhelming psychosocial impacts, particularly during subsequent pregnancies marked by flashbacks of suffering caused by PD. Similarly, the study by Meaney et al.³¹ revealed that subsequent pregnancy was met with fears about potential loss of another child. PD was, therefore, an immense loss that was hard to endure and led to pathological grief.

Impacts on Families

Subsequent Pregnancy Produces Mixed Emotions

The studies revealed that women and their families faced social pressure to forget and leave the deceased child behind,³⁰ particularly women, who strongly desired to continually bond with the deceased child,³² which impacted any subsequent pregnancy since the previous loss might remain unacknowledged by the women and their families.^{30,32} In this regard, even once a woman becomes pregnant and realizes the significance of having another life in her body, the feeling of being a mother develops, and women are typically filled with feelings of excitement, joy, and high enthusiasm as their unborn children interact with their bodies.³⁵ The study by Meredith et al.⁹ showed that besides the excitement, subsequent pregnancy still triggered women to recall the previous suffering caused by PD. Women perceived themselves not as normal pregnant mothers, but as mothers approaching pregnancy with mixed emotions such as worries, anxieties, and fears. Similarly, the study by Fernández-Sola et al.²⁴ found that a new pregnancy not only brings happiness to the family, but also overwhelmed families with fear, stress, and anxiety regarding the potential loss of another baby as fears were rekindled instead of happiness for the family.

Neglecting a living child

The study of Fernández-Sola et al.²⁴ revealed that living children in the family were generally forgotten by the care system, received no support and suffered the consequences of their parents' grief. Nobody paid attention to them, and nobody noticed their support needs to help them understand the loss of a sibling. Living children are sometimes omitted or given incorrect information about PD, because parents are protective and feel living children are too young.⁹ Youngblut et al.³³ found that living children respond to sibling death in a way that changes behaviors, leads to no understanding, reveals a desire to stay connected with the sibling, non-belief that the sibling would die. Some parents reported being absent and neglectful of older children. Concerning prevention of recurrent loss, the

study by Meaney et al.³¹ found that some parents show excessive protection of other children.

Marital disharmony

After PD, most parents viewed marital relationships negatively, finding it hard to communicate or share feelings of grief due to differences in the way men and women responded to PD grief.³⁰ The study by Meredith et al.⁹ found that PD was a unique experience differing from other losses due to potential marital disharmony. The study illustrated that women felt that their husbands could not understand their feelings about the loss, so women found it hard to talk about their deceased child, while husbands tried to talk about positive aspects. The study by Meaney et al.³¹ stated that men felt that they had to be strong emotionally, at times putting aside their own grief to be able to successfully support their wives. Moreover, discordant opinions about subsequent pregnancy after PD caused marital disharmony. Although women wanted to be pregnant again, men did not due to fear of recurrent loss. Similarly, the study by Fernández-Sola et al.²⁴ revealed that a lack of sexual desire after PD was a common point in nearly all interviewees due to fear of a new pregnancy and recurrent PD, which made sexual intercourse null or minimal. Additionally, Nuzum et al.²⁶ stated that women usually sensed a lack of spousal support resulting in changed relationships after PD.

Lacking support from a health professional

Most studies illustrated that women perceived inadequate support for self and family following PD. Sutan and Miskam²⁷ stated that, after PD, women wanted counseling, advice, and assistance with discharge and burial, etc. However, most women perceived staff as complacent about the devastation of PD. Healthcare provider attitudes were described as avoidance of visits and support. Downe et al.²⁹ stated that women perceived healthcare providers as inattentive to their needs, or insensitive about loss by minimizing or ignoring complaints about uncomfortable symptoms after PD. The women felt that they had no social space to legitimize or express feelings about PD, which made them lonely.^{9,24,27} Moreover, women and their families fear recurrent loss due to a belief that previous PD was likely to be the result of healthcare provider errors. The study by Gopichandran et al.²⁵ revealed that women and families blamed the health system for poor service quality, no continuity of care and frequent changes in health care providers in shift work, leading to higher incidence of errors due to poor staff communication. The study by Meaney et al.³¹ found that women expected care in a future pregnancy to include reassurance of medical guidance and support with a need for consistent specialized care.

Discussion

Impacts on Women: PD is a catastrophic event for women and families. PD differs from other childhood deaths.³⁶ Some evidence indicates that PD is not recognized as worthy of mourning and is otherwise referred to as “invisible death”.⁶ Many women facing this tragedy are overlooked because of societal attitudes minimizing the personal value of a baby’s

life based on societal views that differ once a baby has died.³⁷⁻³⁸ Accordingly, society anticipates a milder emotional response from women in this circumstance than in the case of childhood death in almost any other circumstance. Women often maintain a strong desire to stay connected to their deceased children by commemorating anniversaries and conversations with family and friends.³⁹ Such incongruent perspectives between what grieving women feel and what others think they should feel can intensify the severity of grief since women are made to feel they have been devalued and isolated from families and society, resulting in women being overwhelmed with suffering causing deep pain and distress combined with immense grief amid complete silence.³⁰

Interestingly, PD is defined as causing the loss of a sense of self-worth, because women perceive the maternal role according to social expectations; giving birth to a healthy child and raising the child to be healthy. PD, therefore, is a death involving social stigmatization and intrapersonal feelings firmly tied with the loss of a sense of self-worth contributing to emerging feelings of guilt and low self-esteem in bereaved parents, especially women.^{34,39-40} Although grief is normally a human response occurring after PD that helps women to adjust through the grieving process,⁴¹ not everyone can deal with PD, particularly in the case of women who have abruptly terminated a pregnancy because their unborn child was diagnosed with a life-limiting condition or when loss occurs in early pregnancy. In these cases, women usually have no time to prepare for the impending death of their children.⁴² Normally, there is no funeral or other mourning rituals.⁴³ This condition produces a high level of grief and may complicate the process of grief, since their grief may remain unacknowledged by women who have suffered this loss. Similarly, women who have developed a strong relationship with their children through fetal movements, and by seeing and knowing the sex of their babies via ultrasound presentation usually feel that all is well.²⁶ Kersting and Wagner⁴² stated that the more women experienced or comprehended the reality of their babies, the higher the level of grief is likely to be. The impacts of PD, therefore, are profound and long-lasting, especially life-long psychological impacts.^{8,12,44}

Impacts on Families: Women in most societies around the world have cultivated social values and feminine roles based on maternity and motherhood with the goal of becoming nurturing mothers.⁴⁵ Whenever a woman cannot perform her duties as a mother according to social expectations, she is questioned, judged, and evaluated negatively by other people in her context.⁸ This unfair view is a trap that makes women lose identity, bargaining power, and freedom to think independently.⁴⁶ Thus, women and families might be overlooked and not receive effective support from society, which becomes an obstacle to overcoming grief. Additionally, when combined with marital disharmony due to the different ways couples respond to grief following PD,³⁰ women and their spouses cannot support each other.¹³ These impacts seem to carry over into any subsequent pregnancy with women, partners, and families who have difficulty trusting that things

will be alright. Healthcare providers, therefore, should provide the support interventions based on holistic care for the whole family to promote the ability to handle PD.²⁹ Finally, parents should be assessed for traumatic feelings, especially marital relationship problems, before proceeding to a subsequent pregnancy to lessen suffering. Hence, the family retains its role as a vital support source during the grief journey following PD.³²

Interestingly, the impact of PD on living children is a vital issue requiring appropriate care to promote them in overcoming the loss caused by sibling death. Although women and their families try to continue relationships with both deceased and living children as they integrate the trauma into their lives, they remain concerned and anxious about the future, with anxiety, worries, and fears translated into parenting experiences, which impacts living children. This reflects the way parents change parenting styles for living children who might either be neglected or over-protected. As a result, living children might lack the chance to be encouraged in demonstrating their grief reaction, which potentially leads to cognitive distortions for the children.

As highlighted and mentioned above, PD is a tragic event that leaves the family with overwhelming pain and grief, which is recognized as the most stressful life event faced by women and whole families. Thereby, PD widely and inevitably impacts on women and their families. However, the family is widely accepted as an important system that has been believed to play a vital role in caring for all family members. Therefore, this insightful understanding will guide healthcare providers to integrate this knowledge for the development of an effective intervention focusing on comprehensive support care involving all stakeholders impacted by PD. Doing so will promote the family's ability to reach their utmost capability in supporting each other to lessen the impacts they faced and to heal themselves eventually through the suffering caused by PD.

Limitation of the Study

Although this study emphasizes the particularly relevant topic of the voices of women and families, most studies mainly focused on women, while there are limited studies on men, living children, and entire families.

References

1. United Nations Inter-Agency Group for Child Mortality Estimation (UNIGME). Levels & trends in child mortality: report 2020, estimates developed by the UN inter-agency group for child mortality estimation. [Internet].2022 (Accessed January 15, 2022, at <https://www.unicef.org/media/79371/file/UN-IGME-child-mortality-report-2020.pdf>).
2. United Nations Inter-Agency Group for Child Mortality Estimation (UNIGME). Levels & trends in child mortality: report 2017, estimates developed by the UN inter-agency group for child mortality estimation. [Internet].2022 (Accessed January 15, 2022, at https://www.unicef.org/media/48871/file/Child_Mortality_Report_2017.pdf).
3. Gaurav S. Maternal, perinatal and neonatal mortality in South-East Asia region. *Asian J Epidemiol* 2012;(5(1):1-14. doi: 10.3923/aje.2012.1.14.
4. World Health Organization (WHO). Child health: health topic. Geneva: WHO, 2016.
5. de Montigny F, Verdon C, Meunier S, et al. Women's persistent depressive and perinatal grief symptoms following a miscarriage: the role of childlessness and satisfaction with healthcare services. *Arch Womens Ment Health* 2017;20(5): 655-62. doi:10.1007/s00737-017-0742-9.
6. Kelley M. Counting stillbirths: women's health and reproductive rights. *Lancet* 2011;377(9778):1636-7. doi:10.1016/S01406736(11)60279 1.

Conclusion

The devastating tragedy of PD widely and inevitably impacts women and families. In this regard, the family as a system reacts and adapts to PD in diverse ways. Most family members react with anxiety immediately after death happens. The heightened grief levels can damage the pattern of interactions and quality of relationships among the whole family, leading to any family member feeling alone, or depressed.

Furthermore, support interventions to increase capability for handling this suffering is limited in terms of accessibility and quality of care across countries. Nevertheless, even when the treatment is available, women and their families are reluctant to seek help because of a lack of knowledge about symptoms, fear of stigma, and feelings of guilt and shame. Particularly, in the case of women and their families who felt that PD resulted from healthcare provider errors, there was also a persistent lack of faith in healthcare professionals. Nowadays, women's and families' mental health has still so far received little attention from researchers and clinicians. It means that this concern should be called in perinatal research and practice. Doing so will give universal screening for perinatal mental health disorders that might be beneficial for women and their families in order to detect problems at the early stages.

Therefore, this study points out a guideline for the development of comprehensive support care that should overreach all stakeholders involved and impacted by PD. The essential contents applied for the construction of the support intervention should be clear and concise on certain impacts of PD concerning women and families. Importantly, the quality of care provided should include clinical skills, emotional intelligence, genuine care, and consistent care to lessen the impacts caused by the devastation of PD. Doing so will give women the best chance to replace tragedy with good memories from sensitive bereavement care provided by healthcare providers. This may become a resilience factor to help women and families to handle PD with feelings of better comfort and easier recovery.

7. Montero SMP, Sánchez JMR, Montoro CH, et al. Experiences with perinatal loss from the health professionals' perspective. *Rev Lat Am Enferm* 2011;19(6):1405-12. doi:10.1590/s0104-11692011000600018.
8. Frøen JF, Cacciatore J, McClure EM, et al. Stillbirths: why they matter. *Lancet* 2011;377(9774):1353-66. doi:10.1016/S0140-6736(10)62232-5.
9. Meredith P, Wilson T, Branjerdporn G, et al. "Not just a normal mum": a qualitative investigation of a support service for women who are pregnant subsequent to perinatal loss. *BMC Pregnancy Childbirth* 2017;17(1):6. doi:10.1186/s12884-016-1200-9.
10. Punaglom N, Kongvattananon P, Shu BC. Grief journey: perception and response based on cultural beliefs in Thai women experiencing perinatal death. *Pacific Rim Int J Nurs Res* 2022;26(2):327-40.
11. Punaglom N, Mangkarakere N. Integrative review for factors related to family functioning in the family living with the children with thalassemia. *BKK Med J* 2020;16(2):242-49. doi: 10.31524/bkkmedj.2020.23.003.
12. Burke LA, Neimeyer RA. Complicated spiritual grief I: relation to complicated grief symptomatology following violent death bereavement. *Death Stud* 2014;38(4):259-67. doi:10.1080/07481187.2013.829372.
13. Smythe KL, Petersen I, Schartau P. Prevalence of perinatal depression and anxiety in both parents: a systematic review and meta-analysis. *JAMA Netw Open* 2022;5(6):e2218969. doi:10.1001/jamanetworkopen.2022.18969.
14. Dias N, Docherty S, Brandon D. Parental bereavement: looking beyond grief. *Death Stud* 2017;41(5):318-27. doi:10.1080/07481187.2017.1279239.
15. Murphy S, Shevlin M. Psychological consequences of pregnancy loss and infant death in a sample of bereaved parents. *J Loss Trauma* 2014;19(1):56-69. doi:10.1080/15325024.2012.735531.
16. Buyukcan-Tetik A, Finkenauer C, Schut H, et al. The impact of bereaved parents' perceived grief similarity on relationship satisfaction. *J Fam Psychol* 2017;31(4):409-19. doi:10.1037/fam0000252.
17. Dyregrov A, Gjestad R. Sexuality following the loss of a child. *Death Stud* 2011;35(4):289-315. doi:10.1080/07481187.2010.527753.
18. Clossick E. The impact of perinatal loss on parents and the family. *J Fam Health* 2016;26(3):11-5.
19. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 2008;8(1):45. doi:10.1186/1471-2288-8-45.
20. Tong A, Flemming K, McInnes E, et al. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol* 2012;12(1):181. doi:10.1186/1471-2288-12-181.
21. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi:10.1136/bmj.n71.
22. Joanna Briggs Institute. Checklist for systematic reviews and research syntheses. [Internet].2022 (Accessed December 22, 2021, at <http://joannabriggs.org/research/critical-appraisal-tools.html>).
23. Evans C, Tweheyo R, McGarry J, et al. Improving care for women and girls who have undergone female genital mutilation/cutting: qualitative systematic reviews. *Health Serv Deliv Res* 2019;7(31). doi: 10.3310/hsdr07310.
24. Fernández-Sola C, Camacho-Ávila M, Hernández-Padilla JM, et al. Impact of perinatal death on the social and family context of the parents. *Int J Environ Res Public Health* 2020;17(10):3421. doi:10.3390/ijerph17103421.
25. Gopichandran V, Subramaniam S, Kalsingh MJ. Psycho-social impact of stillbirths on women and their families in Tamil Nadu, India – a qualitative study. *BMC Pregnancy Childbirth* 2018;18(109):1-13. doi:10.1186/s12884-018-1742-0.
26. Nuzum D, Meaney S, O'Donoghue K. The impact of stillbirth on bereaved parents: a qualitative study. *PLoS One* 2018;13(1):e0191635. doi:10.1371/journal.pone.0191635.
27. Sutan R, Miskam HM. Psychosocial impact of perinatal loss among Muslim women. *BMC Women's Health* 2012;12(15): 1-9. doi:10.1186/1472-6874-12-15.
28. Camacho-Ávila M, Fernández-Sola C, Jiménez-López FR, et al. Experience of parents who have suffered a perinatal death in two Spanish hospitals: a qualitative study. *BMC Pregnancy Childbirth* 2019;19(512):1-11. doi:10.1186/s12884-019-2666-z.
29. Downe S, Schmidt E, Kingdon C, et al. Bereaved parents' experience of stillbirth in UK hospitals: a qualitative interview study. *BMJ Open* 2013;3(2):e002237. doi:10.1136/bmjopen-2012-002237.
30. Kelley MC, Trinidad SB. Silent loss and the clinical encounter: parents' and physicians' experiences of stillbirth—a qualitative analysis. *BMC Pregnancy Childbirth* 2012;12(137):1-15. doi.org/10.1186/1471-2393-12-137.
31. Meaney S, Everard CM, Gallagher S, et al. Parents' concerns about future pregnancy after stillbirth: a qualitative study. *Health Expect* 2017;20(4):555-62. doi:10.1111/hex.12480.
32. Üstündağ-Budak AM, Larkin M, Harris G, et al. Mothers' accounts of their stillbirth experiences and of their subsequent relationships with their living infant: an interpretative phenomenological analysis. *BMC Pregnancy Childbirth* 2015;15(263):1-14. doi:10.1186/s12884-015-0700-3.
33. Youngblut JM, Brooten D. Parents' report of child's response to sibling's death in a neonatal or pediatric intensive care unit. *Am J Crit Care* 2013;22(6):474-81. doi:10.4037/ajcc2013790.
34. Duncan C, Cacciatore J. A systematic review of the peer-reviewed literature on self-blame, guilt, and shame. *Omega (Westport)* 2015;71(4):312-42. doi:10.1177/0030222815572604.
35. Lee L, McKenzie-McHarg K, Horsch A. The impact of miscarriage and stillbirth on maternal-fetal relationships: an integrative review. *J Reprod Infant Psychol* 2017;35(1):32-52. doi:10.1080/02646838.2016.1239249.
36. Heazell AEP, Siassakos D, Blencowe H, et al. Stillbirths: economic and psychosocial consequences. *Lancet* 2016;387(10018):604-16. doi: 10.1016/S0140-6736(15)00836-3.
37. Sisay MM, Yirgu R, Gobeze AG, et al. A qualitative study of attitudes and values surrounding stillbirth and neonatal mortality among grandmothers, mothers, and unmarried girls in rural Amhara and Oromiya regions, Ethiopia: unheard souls in the backyard. *J Midwifery Womens Health* 2014;59(Suppl):110-7. doi:10.1111/jmwh.12156.

38. Flenady V, Boyle F, Koopmans L, et al. Meeting the needs of parents after a stillbirth or neonatal death. *BJOG* 2014;121(4):137-40. doi:10.1111/1471-0528.13009.
39. Cacciatore J. Psychological effects of stillbirth. *Semin Fetal Neonatal Med* 2013;18(2):76-82. doi: 10.1016/j.siny.2012.09.001.
40. Cacciatore J, Frøen JF, Killian M. Condemning self, condemning other: blame and mental health in women suffering stillbirth. *J Ment Health Couns* 2013;35(4):342-59. doi:10.17744/mehc.35.4.15427g822442h11m.
41. Stroebe M, Schut H. The dual process model of coping with bereavement: rationale and description. *Death Stud* 1999;23(3):197-224. doi:10.1080/074811899201046.
42. Kersting A, Wagner B. Pathological grief after perinatal loss. *Dialogues Clin Neurosci* 2012;14(2):187-94. doi: 10.31887/DCNS.2012.14.2/akersting.
43. Ayebare E, Lavender T, Mweteise J, et al. The impact of cultural beliefs and practices on parents' experiences of bereavement following stillbirth: a qualitative study in Uganda and Kenya. *BMC Pregnancy Childbirth* 2021;21(443):1-10. doi:10.1186/s12884-021-03912-4.
44. Human M, Green S, Groenewald C, et al. Psychosocial implications of stillbirth for the mother and her family: a crisis-support approach. *Social Work (Stellenbosch)* 2014;50(4):563-80. doi:10.15270/50-4-392.
45. Rich A. *Of woman born: Motherhood as experience and institution*. New York, N.Y: Norton & Company, 1995.
46. Roach C. *Loving your mother: on the woman-nature relation*. In: Warren K, ed. *Ecological feminist philosophies*. Bloomington: Indiana University Press, 1996.