

Views of Chinese women with perinatal loss on seeing and holding the baby

Kit-Ying WONG, RN, RM, BNurs, MNurs

Ngan-Chi NG, RN, RM, BNurs, MSNurs

Department of Obstetrics and Gynaecology, Pamela Youde Nethersole Eastern Hospital, Hong Kong

Objective: To explore the views of Hong Kong Chinese women who experienced perinatal loss on seeing and holding the baby and on commemoration.

Methods: Chinese women who had experienced second-trimester miscarriage, termination of pregnancy for fetal anomaly (TOPFA), stillbirth, or neonatal death within 5 years and had been under the care of the Grief Counselling and Support Team in a regional hospital in Hong Kong were recruited to complete a questionnaire through telephone interview or self-administration between May and December 2019.

Results: Of 56 women recruited, 51 (91%) with a mean age of 35 years completed the questionnaire through self administration (n=26) or telephone interview (n=25). The cause of perinatal loss included second trimester miscarriage (n=14), TOPFA (n=23), stillbirth (n=7), and neonatal death (n=7). The mean gestation was 22 (range, 14-38) weeks. The mean time from perinatal loss to survey was about 30 (range, 1-47) weeks. 52.9% of the participants were primiparous, and 45.1% had a living child. 33.3% of participants had a history of perinatal loss. 36 (70.6%) participants reported to have seen and 30 (58.8%) reported to have held, touched, or kissed the baby. Six themes were identified from the experience of seeing and holding the baby: natural experience: inborn parenthood, positive feeling in the traumatic life event, negative emotions, sense of relief, avoiding regret, and psychological preparation matters. All participants who had seen and held her baby did not regret their choice. However, among the 21 participants who did not see and/or hold the baby, five (23.8%) regretted. 44 (86.3%) participants had commemorated the baby; 54.5% of them were guided by midwives/nurses.

Conclusion: The current study helps healthcare providers to better understand Hong Kong Chinese women's views and experience on seeing and holding the baby, and to guide them to provide better bereavement care in a more culturally sensitive manner.

Keywords: Bereavement; Fetal death; Stillbirth

Introduction

Perinatal death represents multiple losses to parents, including the loss of a significant person, some aspects of the self, and a dream¹. Parents with perinatal loss have seven times higher risk of developing post-traumatic stress disorder symptoms and four times higher risk of developing depressive symptoms².

Bereaved parents often have difficulty in articulating their preference on whether to see and hold the baby and to keep any mementoes of the baby. Thus, guidance and support by healthcare providers are important. However, healthcare professionals may not be able to provide effective bereavement care owing to emotional, knowledge, and system-based barrier³. There is controversy on the management of seeing and holding the baby.

Some bereaved parents considered that contact with their stillborn baby validated the birth and life⁴. Seeing and holding the baby is associated with less depressive

and anxiety symptoms, better sleep, more satisfaction with hospital care, and less regret⁵⁻⁸. Parents may express regret for the missed opportunity to see the baby and make tangible memories⁹. In contrast, some bereaved women who have seen and held the stillborn baby have more anxiety and post-traumatic stress disorder symptoms¹⁰. Thus, healthcare providers used to not routinely encourage mothers to see and hold the baby. This raises concerns in many bereaved parents, midwives/nurses, and bereaved parent support groups, leading to public campaigns and proliferation in research^{8,11}, and then the National Institute for Health and Care Excellence (NICE) guideline¹² recommends that experienced healthcare professionals are encouraged to discuss with women and her family about the option of seeing or holding the baby, having mementoes, or seeing photographs of the baby.

Correspondence to: Kit-Ying WONG

Email: wongkymw@gmail.com

Since 1995, the Grief Counselling and Support Team (the Bereavement Team) has been established in the Department of Obstetrics and Gynaecology, Pamela Youde Nethersole Eastern Hospital in Hong Kong. The Bereavement Team comprises midwives, nurses, obstetricians, gynaecologists, social worker, clinical psychologist, and peer support volunteers. Women who experienced perinatal loss after the second trimester or beyond caused by miscarriage, termination of pregnancy due to fetal anomaly (TOPFA), stillbirth, or neonatal death (NND) are referred to the Bereavement Team. A dedicated midwife or nurse provides bereavement care for the grieving mother and accompanies the bereaved parents to see and hold the baby if the parents choose to do so. The practice may vary owing to various reasons such as personal belief and experience.

Talking about death is a taboo in Chinese culture, especially when the death is at a young age. However, in recent years, bereaved Chinese parents in Hong Kong are more willing to share their views and recognise the perinatal loss, especially for those under 24 gestational weeks^{13,14}. This study aimed to explore the views of Hong Kong Chinese women who experienced perinatal loss on seeing and holding the baby and on commemorating the baby.

Methods

The study was approved by the Hong Kong East Cluster Research Ethics Committee (reference: HKECREC-2019-022). Written informed consent was obtained from each participant. Confidentiality and anonymity were affirmed. Chinese women who experienced the loss of a baby or fetus (caused by miscarriage, TOPFA, stillbirth, or NND) perinatally (from second trimester [12 gestational weeks] to 28 days of life after birth) within 5 years and had been under the care of the Bereavement Team were purposively recruited. A cross-sectional and

qualitative phenomenological research design was used. Qualitative phenomenological design aids investigation of the in-depth meaning of participants’ lived experience¹⁵, facilitating exploration on grieving mothers’ view.

Participants were asked to complete a questionnaire in Chinese through telephone interview or self-administration between May and December 2019. The questionnaire comprises four structured open-ended questions about the experience of seeing and holding the baby and commemoration activities for the baby. Probing questions and examples were given to aid reflection and expression following the main questions (Table 1). During telephone interview (lasting about 15 to 20 minutes), attentive listening was used. The participants’ exact words were recorded, together with non-verbal expressions (pause and emotional change such as weeping), and the telephone interview was transcribed in Chinese and then translated to English for analysis. To increase study credibility and confirmability, participants were asked to verify whether the transcript truly and completely reflected their views and experience. The interview notes and field notes were completed right after each telephone interview to ensure accuracy and minimise memory loss. Personal belief and bias were avoided through continuous application of reflexivity and bracketing to maintain openness and non-judgment to participants’ views and experience. The Bereavement Team is good at establishing a trusting relationship with participants to enable participants to express their views and experiences in comfort, and is sensitive to participants’ verbal and non-verbal expression.

Data were categorised and coded, and themes were identified. To increase study confirmability and dependability, thematic analysis was performed by two authors independently. Differences and similarities in the codes and themes were compared and discussed, and a consensus was reached. Recruitment of participants was

Table 1. Structured open-ended questions with follow-up probing questions and examples

Q1	Did you see your baby? Why or why not? What happened? (eg, initiated by you? Under nurse’s encouragement? Saw the baby naturally? Who accompanied you to see?) Did the nurse give you psychological preparation beforehand? (eg, described what the baby looks like first) How did you feel? (eg, fear, touched, natural, sad, annoyed, relieved, positive, negative, painful but tolerable)
Q2	Did you hold/touch your baby? Why or why not? How did you feel?
Q3	Did you regret your choice? Why? If you could choose again, what would you choose?
Q4	Did you commemorate your baby? If yes, what did you do? How did you feel? (eg, treasured baby-related mementoes such as footprints, ultrasound photos; cleansed baby’s face; sent towel as gift to baby; wrote letter to baby; made commemoration booklet; named the baby; arranged rituals or religious ceremony; did good deeds under the name of the baby?) Did the healthcare providers offer any help? (eg, give advice, encouragement)

stopped when data saturation reached (when no new codes emerged and sufficient data collected in terms of thick and rich description). Psychological support and counselling would be provided by the Bereavement Nurse after the interview if needed.

Results

Of 56 women recruited, 51 (91%) with a mean age of 35 years completed the questionnaire through self administration (n=26) or telephone interview (n=25) [Table 2]. The cause of perinatal loss included second-trimester miscarriage (n=14), TOPFA (n=23), stillbirth (n=7), and NND (n=7). The mean gestation was 22 (range, 14-38) weeks. The mean time from perinatal loss to survey was about 30 (range, 1-47) weeks. 52.9% of participants were primiparous, and 45.1% had a living child. 33.3% of participants had a history of perinatal loss.

36 (70.6%) participants reported to have seen and 30 (58.8%) reported to have held, touched, or kissed the baby. Of the 36 who saw the baby, 13 (36.1%) initiated the request, 14 (38.9%) were asked or encouraged by midwives/nurses, five (13.9%) initially declined but later changed their mind, and four did not mention or just saw the baby naturally. Six themes were identified from the experience of seeing and holding the baby.

Theme 1 was 'natural experience: inborn parenthood'. Many participants affirmed the mother-and-child relationship and had a strong natural desire to see and touch/hold the baby. "*She is my daughter, my precious treasure. I want to see her very much! I will remember her face well with effort.*" (case 5, Stillbirth, 27 gestational weeks) "*It happened naturally.*" (case 18, TOPFA, 23 gestational weeks) "*[Seeing baby] as a remembrance. After seeing the baby, [I] touched and held the baby naturally.*" (case 26, miscarriage, 15 gestational weeks)

Theme 2 was 'positive feeling in the traumatic life event'. Despite experiencing a traumatic life event, many participants reported positive feelings in the process of seeing and holding the baby. Participants treasured this moment to have intimate contact with the baby. Some identified family traits from baby's appearance, whereas others remarked her baby as beautiful, adorable, and peaceful. This helped create a fond memory. "*We were emotionally calm. [We] also talked with the baby in a gentle voice.*" (case 47, TOPFA, 21 gestational weeks) "*I had held [and] touched the baby's hands and feet. Looking at her hands and feet... as [this was] the second pregnancy, [I] would compare [the baby] with [my] elder daughter.*

Table 2. Demographic characteristics of participants (n=51)

Characteristic	Value
Age, y	35.4±4.8 (23-46)
Cause of perinatal loss	
Miscarriage	14 (27.5)
Termination of pregnancy due to fetal anomaly	23 (45.1)
Stillbirth	7 (13.7)
Neonatal death	7 (13.7)
Gestation, weeks	21.7±5.5 (14-38)
Type of pregnancy	
Spontaneous	47 (92.2)
In vitro fertilisation / intrauterine insemination	4 (7.8)
No. of living children	
0	27 (52.9)
1	23 (45.1)
2	1 (2.0)
Education level	
Primary	1 (2.0)
Secondary	26 (51.0)
Tertiary	24 (47.1)
History of perinatal loss	
No	34 (66.7)
Yes	17 (33.3)
Time from perinatal loss to interview, weeks	30.3±11 (1-47)

* Data are presented as mean ± standard deviation (range) or No. (%) of participants

[She] had long hands and legs like her elder sister..." (case 51, TOPFA, 23 gestational weeks) "*I had held my baby. A nurse helped to place my baby into my arms. [I] felt she was very comfortable, without any pain. Also, [she was] warm and of considerable weight. [Her] lips were red. I thought the nurse had put some lipstick on her, but it was my baby's own colour.*" (case 52, stillbirth, 34 gestational weeks)

Theme 3 was 'negative emotions'. Some participants expressed sorrow, grief, and even guilty feeling in the process of seeing and holding the baby. "*...I felt miserable. Other [babies] were born with beating heart, but my [baby] was not. [I am] very depressed.*" (case 31, miscarriage, 14 gestational weeks) "*... being his parents, [we] want to see him. [I] felt miserable. [I] couldn't protect him. [I] felt guilty for him. (crying)...*" (case 33, miscarriage, 18 gestational weeks)

Theme 4 was ‘sense of relief’. Some participants reported that the negative emotions were bearable or even resolved during the process of seeing and holding the baby. Some even expressed a sense of relief. “[I] feel good [as I] can see the baby for the last time. Baby is being cleaned properly and [she is] even being tied with ribbon nicely. Baby is very peaceful. I feel good. [I can] see the baby is very comfortable.” (case 22, miscarriage, 14 gestational weeks) “[I] had held [my] baby. [I] felt heartbroken and sorrowful, but these feelings were resolved.” (case 39, miscarriage, 19 gestational weeks) “... When I saw my daughter, it was very touching and sorrowful. Seeing my daughter made me feel no regret. It was bearable.” (case 51, TOPFA, 23 gestational weeks)

Theme 5 was ‘avoiding regret’. Some participants worried that they might not have another chance to see the baby again, and this might induce regret. “Because she is also my daughter, although she is only 22 gestational weeks’ old, she is still a treasure in my heart. If I had not seen my daughter for the last time, I believe I must regret.” (case 54, TOPFA, 21 gestational weeks)

Theme 6 was ‘psychological preparation matters’. Some participants recalled positive feelings if they were psychologically prepared by midwives/nurses’ explanation before seeing and holding the baby. In contrast, some participants were fearful if they were not psychologically prepared beforehand. “The nurse had told me that as the baby was very premature, she did not look like [a] full-term [baby]. But [whose skin colour was] somewhat redder. This made me psychologically prepared.... [I] thought the baby was beautiful like an angel...” (case 42, TOPFA, 23 gestational weeks) “[I was] scared. She [the baby] was very red, unlike usual baby [whose skin colour] is very white. The nurse had not mentioned that before. It would be better if [the nurse] had told [me] and [I] was psychologically prepared.” (case 38, TOPFA, 18 gestational weeks)

15 (29.4%) participants did not see the baby and 20 (39.2%) participants did not hold/touch the baby, mostly owing to fear (non-specific fear, fear to be too mournful, lose emotional control, and fearful to have a stronger emotional attachment to the baby). Four participants did not know they could hold/ touch her baby.

All participants who saw and held the baby did not regret their choice. However, among the 21 participants who did not see and/or hold the baby, five (23.8%) regretted. One became ambivalent about the previous choice of not seeing and holding her baby. One who saw

but did not hold her baby reflected, “[I am] regretted. If [I] could choose once again, I would like to see and hold [my baby].” (case 13, miscarriage, 15 gestational weeks) One who did not see or hold her baby exclaimed, “[I am] regretted because it was the single last [chance].” (case 15, NND, 24 gestational weeks)

44 (86.3%) participants reported that they did something to commemorate her baby; 24 (54.5%) of them were under midwives/nurses’ guidance. 26 (59.1%) participants treasured tangible tokens for remembrance, including antenatal ultrasound photos, baby photos and footprints, and commemoration booklet given by the Bereavement Team. 18 (40.9%) participants wrote letters or cards to her baby. Some regarded this as a way to talk to her baby. Some felt relieved while writing a letter to her baby. 15 (34.1%) participants gave presents to her baby, including clothes, towels, toys, and sibling’s painting. 19 (43.2%) participants arranged rituals or religious ceremony for her baby. 11 (25%) participants named their babies. Three (6.8%) participants showed benevolence to others under the name of her baby such as sewing baby hats for other prematurely born babies. Some commented that without midwives/nurses’ suggestion, they did not know they could do such commemoration for her baby.

Discussion

This is the first qualitative study to date about the experience of Chinese women with perinatal loss in Hong Kong on seeing and holding the baby. Many participants affirmed the mother-and-child relationship and had a natural strong desire to see her baby. Mother-infant attachment started long before baby’s birth¹⁶. Maternal love has attached firmly to the growing infant since the earliest stages of pregnancy¹⁶.

For some participants, it might also be the last chance to see their beloved babies. Similar to a study on mothers’ experience about their contact with the stillborn baby¹⁷, our participants also expressed that it was a highly emotional and grief experience. However, many participants also reported positive feelings when they saw and held their baby. They treasured the precious moment to have intimate contact with their baby. They enjoyed the moment when they found family traits in their baby. The process of seeing and holding the baby directed the feeling of heartbreaking and intense sadness to fond memory and happiness¹⁷. Furthermore, many participants gained a sense of relief after seeing the baby who was peaceful and beautiful. A systematic review also reported that parents who had seen or held their baby had positive outcomes⁸.

Consistent with a study in Taiwan¹⁸, some participants chose to see and hold the baby to avoid regret. Our study showed that all participants who had seen and held the baby did not regret their choice. In contrast, among those who did not see and/or hold the baby, 23.8% regretted. Furthermore, five (13.9%) who initially did not want to see the baby changed their mind later and decided to see the baby. Bereaved parents felt psychologically incapacitated in absorbing information, making a decision, or expressing their preference. The bereaved parents value healthcare professionals' guidance and encouragement^{4,9,19}. A meta-synthesis reported that parents regretted if they missed the opportunity or had insufficient time to spend with their baby and they were left with a lack of memories⁹. Healthcare professionals should discuss actively with parents about their options and preference on seeing and holding the baby, and to provide these opportunities repeatedly in a sensitive way⁹.

Our study showed that psychological preparation before seeing and holding the baby was very important, especially when the baby was very premature. Participants reported positive feeling when they were psychologically prepared by midwives/nurses about the appearance of the baby. In contrast, they were fearful during the contact if they had not been psychologically prepared. This emphasised the crucial role of the healthcare providers, mainly midwives or nurses in clinical practice, in guiding and influencing the bereaved mothers to have a positive or negative experience of contact with the baby.

86.3% of our participants commemorated their babies and 54.5% of them did the commemoration under midwives/nurses' guidance. This indicated that commemorating the baby is well accepted in our participants and the importance of midwives/nurses' role in the process. Perceived professional support and opportunities to share the memory of the baby were associated with fewer post-traumatic stress disorder symptoms²⁰. Parents used tokens or performed rituals of remembrance to connect with the baby. These brought a sense of closure to mothers and social acknowledgement to the baby. This is a kind of adaptive coping strategies to help mothers to cope with the grief and other related responses after baby loss^{21,22}.

Some participants reported negative emotions such as sorrow, grief, and guilty when they saw and held their baby. These could be normal grief reactions after perinatal loss. It is also possible that seeing and holding the baby may not be good for some mothers. A meta-synthesis of qualitative studies reported that parents had different

preferences and needed different levels of guidance from healthcare providers for deciding on seeing and holding the baby, and so the support should be tailored⁴. It is important to discuss with bereaved parents sensitively about the option of seeing and holding the baby, and to allow time for them to decide. This shall include detailed explanations of possible emotional reactions elicited, including positive and negative ones, sense of regret, psychological preparation before seeing and holding the baby in a sensitive manner. Every bereaved parent may grief differently due to personal, cultural, and religious needs. Thus, healthcare providers shall provide tailored and individualised bereavement care, including memory making, seeing and holding the baby²³.

There are limitations to this study. All participants received hospital-based bereavement service, and such service may vary in different hospitals. Nonetheless, to increase the representativeness, purposive sampling was used to include participants with different types of perinatal loss. In addition, telephone interviews were not audiotaped owing to limitations of resources and technical issues. Telephone interviews were recorded by taking detailed interview notes with field notes. The interview notes might be incomplete owing to distraction or might be biased by the interviewer's memory. Thus, authors were reflexive throughout the study and adopted strategies to minimise biases. Future research may consider investigating the views and experience of bereaved fathers on seeing and holding the baby and compare those with the bereaved mothers', as well as investigating the bereaved parents' views and experience on other bereavement management such as discussion of postmortem.

Conclusion

Perinatal loss is a traumatic life event for women and their family. The current study helps the healthcare providers to understand more about Hong Kong Chinese women's views and experience about seeing and holding the baby and their preference in commemorating their baby. This guides healthcare providers to provide better bereavement care.

Acknowledgement

We are grateful to all women who shared their difficult life experience. We acknowledge Ms MY Yip, Ms WL Leung, and Dr KK Tang of the Department of Obstetrics and Gynaecology, Pamela Youde Nethersole Eastern Hospital for their comments and support.

Declaration

The authors have no conflict of interest to disclose.

References

1. Sonstegard L, Jennings B, Kowalski K. *Women's Health: Crisis and Illness in Childbearing*. Orlando: Grune & Stratton; 1987.
2. Gold KJ, Leon I, Boggs ME, Sen A. Depression and posttraumatic stress symptoms after perinatal loss in a population-based sample. *J Womens Health (Larchmt)* 2016;25:263-9. [Crossref](#)
3. Ellis A, Chebsey C, Storey C, et al. Systematic review to understand and improve care after stillbirth: a review of parents' and healthcare professionals' experiences. *BMC Pregnancy Childbirth* 2016;16:16. [Crossref](#)
4. Lisy K, Peters MD, Riitano D, Jordan Z, Aromataris E. Provision of meaningful care at diagnosis, birth, and after stillbirth: a qualitative synthesis of parents' experiences. *Birth* 2016;43:6-19. [Crossref](#)
5. Lasker JN, Toedter LJ. Satisfaction with hospital care and interventions after pregnancy loss. *Death Stud* 1994;18:41-64. [Crossref](#)
6. Cacciatore J, Rådestad I, Frederik Frøen J. Effects of contact with stillborn babies on maternal anxiety and depression. *Birth* 2008;35:313-20. [Crossref](#)
7. Rådestad I, Surkan PJ, Steineck G, Cnattingius S, Onelöv E, Dickman PW. Long-term outcomes for mothers who have or have not held their stillborn baby. *Midwifery* 2009;25:422-9. [Crossref](#)
8. Kingdon C, Givens JL, O'Donnell E, Turner M. Seeing and holding baby: systematic review of clinical management and parental outcomes after stillbirth. *Birth* 2015;42:206-18. [Crossref](#)
9. Kingdon C, O'Donnell E, Givens J, Turner M. The role of healthcare professionals in encouraging parents to see and hold their stillborn baby: a meta-synthesis of qualitative studies. *PLoS One* 2015;10:e0130059. [Crossref](#)
10. Hughes P, Turton P, Hopper E, Evans CD. Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study. *Lancet* 2002;360:114-8. [Crossref](#)
11. Stillbirth & Neonatal Death Charity (Sands). Sands position statement: Seeing and holding the baby after a pregnancy loss or the death of a baby before, during or shortly after birth. 2015. Available from: <https://www.sands.org.uk/sites/default/files/Position%20statement%20Seeing%20and%20holding%20a%20baby%20after%20death.pdf>. Accessed 8 August 2020.
12. National Institute for Health and Clinical Excellence. Antenatal and postnatal mental health. Clinical guideline 192. 2014. Available from: <https://www.nice.org.uk/guidance/cg192/chapter/Key-priorities-for-implementation>. Accessed 2 August 2020.
13. Su X. Nowhere to go on Ching Ming: Hong Kong parents struggle to mourn stillborn babies. *South China Morning Post*. 2018. Available from: <https://www.scmp.com/news/hong-kong/community/article/2140397/parents-struggle-find-final-resting-place-hong-kongs>. Accessed 8 August 2020.
14. Cheng C, Lau A. Complaints on abortuses handling: policy recommendations for Hong Kong. *Public Adm Policy* 2019;22:71-81. [Crossref](#)
15. Polit D, Beck C. *Nursing Research: Principles and Methods*. 7th ed. Philadelphia: Lippincott; 2004.
16. Peppers L, Knapp R. *Motherhood and Mourning: Perinatal Death*. New York: Praeger; 1980.
17. Ryninks K, Roberts-Collins C, McKenzie-McHarg K, Horsch A. Mothers' experience of their contact with their stillborn infant: an interpretative phenomenological analysis. *BMC Pregnancy Childbirth* 2014;14:203. [Crossref](#)
18. Sun JC, Rei W, Sheu SJ. Seeing or not seeing: Taiwan's parents' experiences during stillbirth. *Int J Nurs Stud* 2014;51:1153-9. [Crossref](#)
19. Downe S, Schmidt E, Kingdon C, Heazell AE. Bereaved parents' experience of stillbirth in UK hospitals: a qualitative interview study. *BMJ Open* 2013;3:e002237. [Crossref](#)
20. Crawley R, Lomax S, Ayers S. Recovering from stillbirth: the effects of making and sharing memories on maternal mental health. *J Reprod Infant Psychol* 2013;31:195-207. [Crossref](#)
21. Skinner EA, Edge K, Altman J, Sherwood H. Searching for the structure of coping: a review and critique of category systems for classifying ways of coping. *Psychol Bull* 2003;129:216-69. [Crossref](#)
22. Fernández-Basanta S, Coronado C, Movilla-Fernández MJ. Multicultural coping experiences of parents following perinatal loss: a meta-ethnographic synthesis. *J Adv Nurs* 2019;76:9-21. [Crossref](#)
23. Sands. The Sands Australian principles of care: miscarriage, stillbirth and newborn death. 2018. Available from: https://ranzcof.edu.au/RANZCOG_SITE/media/RANZCOG-MEDIA/Women%27s%20Health/Statement%20and%20guidelines/Clinical-Obstetrics/Sands-Australian-Principles-of-Bereavement-Care.pdf?ext=.pdf. Accessed 4 August 2020.