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Clinical Experiences of Perinatal Palliative Care After a Stillbirth: A Narrative Therapy for Grief

Yanhua Liu, M.M[1], Xiaolin Yang, Ph.D[2], Xiaoxiong Zhu, M.M[1], Xiaoling Tian, M.M[3], and Zhifen Yang, M.D[1]

Abstract

Narrative care for families suffering from perinatal loss is rarely provided by medical institutions in China Mainland. However, with the advancement of the Chinese narrative medicine theory and practice, the clinical significance of narrative care has been increasingly recognized. Based on the principles of Chinese narrative medicine, this narrative case study described traumatic narrative foreclosures occuring in a family suffering from stillbirth, and highlighted the multidisciplinary collaboration for practising narrative care in the process of supporting the bereaved in our hospital. Meanwhile, we advocate the establishment of a narrative care ecology by training more obsteticians and nurses with good narrative competence in purpose of helping the family experiencing perinatal losses to overcome their tramatic narrative foreclosures, increasing the chances of another successful pregnancy and childbirth as well as enhancing their quality of life.

Keywords

narrative care, traumatic narrative foreclosure, perinatal loss, narrative adjustment

Introduction

The incidence of fetal congenital malformations and chromosomal abnormalities is on the rise due to the increased number of high-risk pregnant woman in an elder age and the progress in prenatal diagnostic technologies like the fetal imaging and genetic screening.[1] As a result, the screening rate of life-limiting fetal condition (LLFC) and the incidence of perinatal loss by stillbirth (≥20 weeks gestation) or neonatal death (newborn through 28 days of life) have elevated.[2] It is reported that there are 2.60 million stillbirths annually.[3] Stillbirth remains to be the main cause of perinatal loss, which is a devastating and tragic event that mentally harms bereaved mothers and their families. They may suffer from negative emotions such as sadness, self-blame, shock, nervousness, anxiety, loneliness and shame, which further severely influence their work, daily life, marital relations and the next pregnancy. However, public health does not pay enough attention to stillbirths, compared with maternal deaths and deaths of children under 5 years of age.[4-6]

Perinatal palliative care has been vigorously advocated by the World Health Organization (WHO) since 2016. It is a comprehensive and multidisciplinary care strategy for both the newborns and their family members, including the physical, psychological, social and spiritual care.[7] Nevertheless, various challenges exist in conducting perinatal palliative care in Chinese medical institutions. As a team to practise the family-centered holistic care strategy, the medical staff who provide perinatal palliative care are required to be equipped with new conception of narrative medicine which contains the key points of narrative connectedness, narrative adjustment and narrative empowerment. They not only focus on the physical care, but also provide the guidance for overcoming the severe traumatic narratives. A narrative care for grief is also optional to families suffering from perinatal loss, aiming to help them regain and reconstruct the identity and bring new hopes and rebuild the capacity of resuming the normal life.

[1]Obstetrical Department, The Fourth Hospital of Hebei Medical University, Shijiazhuang, China
[2]Research Center of Narrative Medicine, Shunde Hospital, Southern Medical University, Shijiazhuang, China
[3]Dean's office, The Fourth Hospital of Hebei Medical University, Shijiazhuang, China

Corresponding Author:
Zhifen Yang, Obstetrical Department, the Fourth Hospital of Hebei Medical University, 169 Tianshan Street, Shijiazhuang 050000, China.
Email: cxsxfy@126.com

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At present, most medical institutions in China rarely or never provide narrative care for bereaved mothers and their families with perinatal loss. In 2001, Rita Charon for the first time proposed the concept of narrative medicine.[8] This new conception landed in China in the year of 2011.[9] Chinese narrative medicine scholars, represented by Professor Yang Xiaolin of Southern Medical University, further localized and developed the western narrative medicine theory based on a decade of medical education and clinical practice.[10,11] In the context of Chinese narrative medicine, narrative can play an active and dynamic role in such aspects as hospital management, professional development of medical staff, disease diagnosis and holistic treatment, interpersonal communication and crisis resolution, psychosomatic adjustment and health management, as well as palliative care and grief counselling.[10,12] Starting from the publication of Expert Consensus of Chinese Narrative Medicine System in November, 2023, the next 12 years will witness the development and gradual perfection of narrative palliative care, narrative oncology, narrative gerontology, narrative gynecology and so on.[11]

Cicely Saunders, the founder of modern hospice, established the core concept of hospice care through the storytelling records of more than 1000 patients. She was the pioneer for creating a deep integration of narrative medicine and hospice care.[13] Obviously, "narrative care for the dying and for the bereaved" is 1 of the most important dimensions of Chinese narrative medicine practice.[12] Just like the newly emerging practice of narrative death doula for the dying patient and the bereaved family,[14] Chinese narrative medcine also encourages the perinatal deaths family to share their stories and feelings, to recreat the painful journey and advocates the whole society create a good narrative ecology on the theme of families experiencing perinatal deaths.

Chinese narrative medicine provides an ideal approach to face death and overcome the fear of the unknown to people experiencing a severe trauma and suffering from traumatic narrative foreclosures.[15] In the present article, we will report a narrative case of full-term born dead, and describe her needs for narrative care. Using the framework of Chinese narrative medicine, we expounded the process and significance of narrative adjustments and narrative support for families suffering from perinatal loss. In addition, we hope that more obstetricians and nurses can be trained to acquire professional narrative competencies[10] and simultaneously advocate the whole society to create a more harmonious narrative ecology[10,11] on perinatal narrative care for mothers and families who suffer from stillbirth.

Case Presentation

A 44-year-old female at 38 weeks of gestation presented with abnormal fetal movement for 3 days and stillbirth for half a day. Prenatal examinations were regularly performed without abnormal findings. She felt excessive fetal movements with a larger amplitude 3 days ago, and decreased fetal movements on the other day, although she did not ask for a medical visit. On the day of admission, she did not feel any fetal movements. No fetal heartbeat was heard, and she was finally diagnosed as stillbirth by ultrasonography.

The patient experienced 1 cesarean section in 2007 and two artificial abortions. She denied bad habits like smoking, drug abuse and alcoholism, and abnormal family history and past history. She was remarried in 2020 and lived in a harmonious family. After admission, the bereaved woman was sorrowful and poorly cooperated. We immediately organized a multidisciplinary team of narrative care including obstetricians, maternity nurses, midwives, genetic experts, and narrative medicine experts.

Briefly, the patient and her families were managed by an entire process of medical services before delivery, during delivery, after delivery, and after discharge (see Table 1). The psychological, social, cultural, and family conditions of the patient were thoroughly assessed by a designated attending physician through observation, interviews, medical history collection, and physical examinations.

Catastrophic Self-Blame and Regret

Catastrophic self-blame and regret were attributed to the sudden intrauterine unexplained death. The patient was remarried, and the couple did not plan to have a baby due to the elder age. After considering the potential maternal and fetal risks, she and her spouse decided to continue the unplanned pregnancy. Prenatal examinations were regularly performed without abnormal findings, and she was filled with anticipation to embrace her new baby. At 38 weeks of gestation, she did not timely ask for medical treatment of fetal movement abnormalities.

As a result, the patient was deeply remorseful and regretful. She said, "I was at fault for not coming to the hospital immediately after feeling excessive fetal movements, and I should be blamed for the loss of my baby." All the efforts were taken to minimize ongoing parental trauma, which included a separate birthing suite, staff members dedicated to the post-birth care of mother and baby, and inclusion of the family for post-mortem care.

Caregiver Stress

Stillbirth is also a severe blow to the spouse, who feels unacceptable and difficulty in comforting his/her partner. "We have been regularly examined during the pregnancy and planned for a cesarean section next week", the patient's spouse said, "we would never have had our own baby in our lives and how my wife could accept the devastating loss?"

Table 1. Narrative Grief Counseling Process.

Process of narrativecounseling	Details
Before delivery	
Assembly of a multidisciplinary team of narrative therapy for grief	Team members The multidisciplinary team of narrative therapy for grief is composed of chiefs of the obstetrics, chief nurses, attending physicians, charge nurses, midwives, pediatricians (if necessary), perinatal psychologists, narrative medicine experts and other assisting staff Responsibilities • Chiefs and chief nurses of the obstetrics are responsible for coordinating, supervising, and guiding the narrative counseling and program formulation of the narrative therapy for grief • Attending physicians are responsible for explaining the fetal condition and medical management of the induced labor • Charge nurses, midwives, and narrative medicine experts are responsible for providing narrative counseling, identifying the needs of bereaved mothers and their family members, offering narrative therapy for grief during and after delivery, and conducting postpartum follow-up • Perinatal psychologists are responsible for prenatal screening and assessment, coping with sudden psychological problems, and conducting postpartum follow-up • Community support for bereaved mothers is provided as the follow-up service of narrative therapy based on the local situation
Identification of the psychological problems	• Assess the baseline characteristics of the puerperae (e.g., age, marriage, work and financial status), maternal and childbirth history, and course of this pregnancy • Assess the negative emotions of grief, anxiety and depression using the relevant scales like the perinatal grief scale (PGS) and the Edinburgh Postnatal depression scale (EPDS), and those with a poor psychological statue are transferred to perinatal psychologists • Assess the religious beliefs, nationality, and local funeral customs • Assess the specific wishes of the bereaved families regarding the management of stillbirth
Program formulation of the narrative therapy for grief	• Inform the fetal conditions (e.g., size, weight, appearance, abnormality), help the bereaved families choose an appropriate program of narrative grief counseling, recommend narrative books, and guide them to express grief • Introduce the various services of narrative counseling, and dynamically adjust the counseling contents based on the psychological changes of the bereaved families • Introduce the medical procedures of induced labor, and the environments of the labor room, delivery room and family waiting area
During delivery	
• Care provided by assigned midwives	• A series of measures to alleviate the physical and mental pain caused by the induced labor, including accompanying by assigned medical staff and providing a separate room • Prepare an ID card for the baby, including the name, birth time, weight and gender, or orally communicate with the above information
• Preparation of a farewell ceremony	• Midwives are responsible for cleaning the body appearance of the stillborn baby, assisting the bereaved family to dress the baby, take baby footprints, and preserve clinical data of the baby, and leaving them alone for farewell • Encourage the bereaved family to storytelling or write down their experiences, thus achieving the identity conversion from the passive bereaved parents experiencing perinatal loss to the active participants involved in the narrative writing
After delivery	
Follow-up visits	• After discharge: Encourage the bereaved family to write down their experiences or tell their experiences to family members and friends • 1 month after delivery: Psychological screening plus online guidance for postpartum recovery • 3 months after delivery: Psychological screening plus online guidance for postpartum recovery, and an additional support provided by perinatal psychological experts to those with a poor psychological state • 6 months after delivery: The abovementioned supports and guidance for the next pregnancy if necessary

Narrative interventions are as follows. The spouse is also hard hit by acknowledging a stillbirth, and he/she also needs an emotional support. A reasonable management of stillbirth strengthens the emotional connection in a couple; otherwise, it may greatly affect the conjugal relationship. The patient's spouse was guided for consoling touch to mentally support his wife, strengthen the narrative connection and cope with the devastating loss of their baby. We recommended him to accompany, walk and chat with his wife, and to honestly communicate with her about the stillbirth, rather than avoiding it.

Perinatal Grief

After admission, a preliminary grief counseling was given to the mother. She and her families were informed of the questionnaire survey using the PGS, aiming to assess the problems of narrative foreclosure and provide an individualized narrative intervention. After discharge, on-line follow-up and guidance of physical and mental recovery of the mother were performed by designated midwives, which were dynamically adjusted based on their demands. We encouraged the bereaved mother and her family members to tell their story and express the grief.

Emotional and foreclosure problems experienced following the stillbirth were measured using the Perinatal Grief Scale (PGS), grading from 33 to 165 points. It is a 33-item scale that consists of 3 subscales measuring active grief, difficulty coping and despair, with 11 items per subscale. A higher PGS score indicates a higher level of grief, and PGS score above 91 points represents a potential psychiatric morbidity.[16] The PGS score of this woman is 86. The patient and her family members were psychologically assessed as catastrophic self-blame and regret, caregiver stress, and perinatal grief. The PGS score on admission, at 1 week, 1 month and 3 months after discharge was 115 points, 96 points, 83 points and 61 points, respectively. It is suggested that the bereaved mother has been psychologically, inwardly free of miseries, anxieties and grief and prepared to embrace a new life.

Face up to the Patient's Needs for Perinatal Palliative Care

Frick et al[17] reported that the risk of stillbirth in female people over 40 years of age is significantly higher than that those aged 35–39 years, which increases with aging. In recent years, the number of women of advanced maternal age is remarkably enhanced with the initiation of the 3-child policy in China. The incidence of LLFC and perinatal loss is also on the rise. At present, women suffering from perinatal loss have been well intervened by clinical treatment, but an individualized narrative care is largely insufficient.[18]

Perinatal loss is a huge stress event that brings a great crisis to the mother and her family members from the inform of the unacceptable diagnosis to the delivery of a stillborn baby.[18] It not only poses economic burden, but also mental suffering, long-term influences on the next pregnancy and the life.[18] In this case, the sudden perinatal loss heavily traumatizes the couple of advanced maternal age, who may never have their own baby in the future. Perinatal palliative care offers a comprehensive, multidisciplinary management involving the physical, mental, emotional, and social needs of the mothers and their family members who experience the grief for perinatal loss.[19]

Generally, a series of examinations of the stillborn baby are performed after perinatal loss, including fetal autopsy, gross and histological examinations of the placenta, umbilical cord and fetal membranes, and genetic testing. However, a large proportion of stillbirths remains unexplained.[20] Families suffering unexplained stillbirths, especially those without any warning, are mentally catastrophic.[21] The World Health Organization (WHO) has suggested the perinatal mental health from pregnancy to 12 months of postpartum coverage as a global health issue.[22]

Referral to a bereavement counselor, peer support group, or mental health professional is an advisable choice for overcoming grief and depression.[23] Post spontaneous abortion care is currently the major program of the perinatal narrative care in China targeting the stillbirths and neonatal deaths, which has been less concerned. According to the experiences in narrative death doula for the terminal patients,[14] we believed that narrative care strategy proposed in the Chinese narrative medicine theory is the best method to consolate and empower the bereaved. Accordingly, we recommended to establish a thorough narrative care strategy for such specific life events in accordance with the Chinese national conditions.

Narrative Care Strategies for the Bereaved of Perinatal Loss

In order to offer holistic support for the bereaved, medical staff should be equipped with the new conception of narrative medicine. The bereaved family usually have no awareness of the risk of disenfranchised grief, resulting in a long-lasting painful emotion. Disenfranchised grief is defined as grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, socially sanctioned or publicly mourned.[24] This kind of complicated grief is often associated with perinatal loss.[14]

Focused on the formation of physician-patient empathetic relationship and interpersonal narrative community, narrative care is supported on 3 pillars, including narrative integration among family members and with medical staff or other people who have encountered similar loss, narrative reading

adjustment and narrative writing adjustment.[18,25] Through systematic and rigorous training like close reading and reflective writing, the narrative caregiver gained the abilities to offer medical help for alleviating physical concerns, pain, negative psychological feelings and socioeconomic problems.[26,27] Moreover, medical staff were trained to listen to the patient's suffering stories, and provide an individualized narrative intervention.

Comprehensiveness and Practicality of Narrative Care for the Bereaved

Grief intensity is correlated with pregnancy anxiety, depression, post-traumatic stress and intimate partner relationships.[28] An informed consent of induced labor program framed by a narrative setting is believed to reduce the grief of perinatal loss.[25] We fully respected the choice of the bereaved mother and her spouse, introduced the contents and approaches of the individualized narrative care for grief, and offered a comprehensive management from the admission until the follow-up visits.

First of all, we recommended a narrative book written by an expert who has been engaged in Goodwill counseling and promoting life and death education for many years. By a close reading of others' stories, the bereaved mother and her spouse obtained the capacity of acknowledging their loss, absorbing the sadness, and identifying their emotional link with the stillborn baby.

Secondly, we prepared a farewell ceremony for the lost baby, including a series of warm-hearted measures like dressing up the baby, gently placing the baby into a special box and writing the best wishes on the box. These details greatly warmed the bereaved parents, acknowledged and understood their grief, and supported them emotionally and spiritually.

Thirdly, we guided the bereaved parents to write down their stories and obtain the narrative initiative.[18] Narrative writing provides a tool to express the grief, self-blame and guilt buried in the heart. It is also a process of transforming physical connection into spiritual connection.[25]

Fourthly, the bereaved parents were encouraged to share their own stories, experiences and griefs, thus yielding the acceptance, understanding and inclusion from families and friends. Storytelling exerts a broad and far-reaching social influence to free the imprisoned parents suffering from perinatal loss and establish a narrative ecology of reproductive care.

In addition to the clinical treatment and care, it is important to identify the cause of a stillbirth. Targeted interventions based on the examination findings are expected to avoid the re-occurrence of such a catastrophic event. However, it is reported that 75% of bereaved parents refuse fetal autopsies due to the protection of their beloved babies from unnecessary harm. A professional narrative support is a good option to overcome psychological barriers of autopsies in bereaved parents.[23,29]

With the liberalization of the 3-child policy in China, women who suffering from LLFC or unexplained stillbirth are encouraged to regain their confidence in childbirth. Therefore, it is of paramount significance to perform professional skills of perinatal care, especially of the narrative care for perinatal loss. Narrative care offered by medical staff with professional narrative competence[10] proposed this article is expected to improve the fertility wishes of women of childbearing age.

Conclusions

Perinatal loss is a major stress event that brings a huge crisis to the affected family.[6] Perinatal palliative care requires medical staff to understand the urgent needs of narrative care and aware of the healing power of family narrative integration.[30] Understanding the multi-level needs of bereaved parents who have lost their beloved babies are the first but important step. Through narrative sharing, a physician-patient narrative community is then created to efficiently enhance the empathy of medical staff, and succesfully lead the parents to go out of the darkest moments and return to the normal life narrative procession.[25,31]

Narrative medicine is still an emerging concept in China. Through the present case of stillbirth, we believe that narrative care through the synergy of multidisciplinary teams for perinatal loss can bridge the communication gaps between physicians and patients, give empowerment to the bereaved and support families to face new life after perinatal loss. Meanwhile, this article also calls on the whole society to pay homage to the deceased, appease the souls of bereaved families and avoid recurrence of tragedies by enhancing the bio-health narrative awareness of the medical practitioners as well as ordinary people. [10] Only when we can pay attention to perinatal narrative ecology and consciously carry out narrative care, can we combat the social crisis of fertility rates decline.

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ORCID iDs

Yanhua Liu https://orcid.org/0009-0009-0483-0099
Zhifen Yang https://orcid.org/0000-0003-1464-0140

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