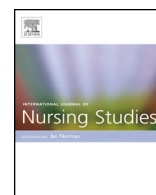




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Seeing or not seeing: Taiwan's parents' experiences during stillbirth

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ABSTRACT

Background: The findings of most quantitative studies and the clinical guidelines for encouraging or discouraging parents to see their stillborn babies remain diverse depending on country and culture of residence. There is still a lack of research comprehensively exploring the situational or cultural meanings of parents' decisions to face their stillborn infants.

Objectives: Understanding the essence and structure of decision-making and seeing phenomena that parents go through during stillbirth of their child adds to the body of nursing knowledge and provides insight into how to care for this group of clients.

Design: A descriptive phenomenological approach with multi-setting, multistage, and paired design was used.

Setting: The study was conducted in maternity units in Taoyuan, Taiwan.

Participants: A purposive sample of 12 couples (total = 24 subjects) who experienced stillbirth deliveries following a diagnosis of fetal death participated in this study.

Methods: The participants' observations and in-depth interviews were recorded and analyzed according to Giorgi's methods.

Results: Most parents expressed a sense of deep upset, of never anticipating seeing their deceased babies while some had no fear of how their babies' bodies would look. Two constituted patterns with five themes each emerged from the study: 1.(a) "Deciding to see the stillborn baby" shows the seeing event as an experience of "believing", (b) "avoiding regret", (c) "an opportunity to say farewell", (d) "a chance for imprinting the stillborn infant in one's memory", and (e) "shock of seeing". 2.(a) "Deciding not to see the stillborn baby" demonstrates the meaning of not seeing is "cutting the attachment to the stillborn baby," (b) "preventing memory imprinting," (c) "avoiding guilt and suffering", (d) "pretending event closure", and (e) "the act of following a cultural taboo".

Conclusions: Participants experienced acts of seeing and not seeing throughout their denial or facing of ongoing bereavement, which was influenced by their personal beliefs, readiness for the event, and social values. Health professionals need to understand the powerful interpretation of the "visual" meaning of the stillbirth experience and learn to be sensitive, empathetic and keep communication lines open in order to create and maintain a compassionate and caring environment.

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What is already known about the topic?

- Prior to the 1970s, avoiding contact with a stillborn infant was believed to minimize parental distress worldwide.
- Later guidelines began recommending that parents be encouraged to see and/or hold their stillborn based on the belief that not doing so could make mourning and recovery from grief difficult.
- The latest guidelines in the UK were issued by the National Institute for Health and Clinical Excellence on antenatal and postnatal mental health in April 2007 and suggest “mothers whose infants are stillborn or die shortly after birth should not be routinely encouraged to see and hold the dead infant....” and they also clarify their intent is not to discourage parent-child interaction, but to consider the individual’s needs and preferences.
- Care administered after a stillbirth in the hospital influences how the parents cope with this loss and determines the extent of recovery of their psycho-socio-cultural well-being.

What this paper adds

- The results provide the structural essence about the inner life world of Taiwanese parents who experience seeing or not seeing their stillborn infant.
- This study provides an example for individual and cultural precision pertaining to the decision making process of Taiwanese parents in the context of stillbirth.
- The findings of seeing stillborn baby’s phenomenon add to the body of nursing knowledge, which reveals the significant value of the visual meaning in clinical care.
- Personal meaning and cultural background are both essential in constructing an understanding of the decisional and visual meaning of seeing stillborn baby for parents, and thus improve culturally competent nursing care in clinics and in academics.

1. Introduction

Prior to the 1970s, avoiding contact with a stillborn child was believed to reduce parental distress worldwide. Care administered after a stillbirth is one of the factors influencing whether the parents cope with this loss and recover psychologically, or whether the stillbirth results in mental health problems (Cacciatore, 2010). Nonetheless, the standard of psychosocial care after stillbirth has changed over time and is still evolving. Caring routines began to change in Sweden, the UK, and then more broadly from the late 1970s to the 1990s (Lasker and Toedter, 1994; Leon, 1992; Lewis, 1979). Care guidelines began recommending that health care professionals encourage parents to hold their stillborn babies based on the belief that not doing so could make mourning and recovery from grief difficult (Radestad et al., 1996; Radestad, 2001; Weiss, 1987). Nevertheless, the most recent UK guidelines recommend that “mothers whose infants are stillborn or die shortly after birth should not be routinely encouraged to see and hold the dead infant” (National Institute for Health and Clinical Excellence, 2007). The institute further

issued a clarification statement indicating that the intention was not to discourage parent-infant interaction, but to consider the individual’s needs and preferences.

Notably, research findings related to this practice are inconsistent and controversial. Most studies demonstrated that seeing and holding the dead baby facilitated the recovery of the parents and helped them avoid pathological sequelae (DeFrain et al., 1990; Radestad et al., 1996). Radestad (2001) found better long-term outcomes for mothers who had seen and held their stillborn babies than mothers who did not experience this contact. Some studies had indicated that, when facing a stillbirth, medical and nursing professionals should encourage parents to have contact with the stillborn child, including seeing, touching and hugging the infant, and keeping personal belongings, such as pictures and footprints, which help parents in working through their sorrow (Haas, 2003; Trulsson and Radestad, 2004). However, a recent study challenged the assumption that contact with the stillborn infant improved the mental health outcomes of these mothers (Hughes et al., 2002; Hughes and Riches, 2003). Different studies postulate the opposite position regarding seeing or holding a stillborn infant (Hughes et al., 2002; National Institute for Health and Clinical Excellence, 2007). Seeing and holding the dead baby could enhance parents’ attachment and intensify their grief (Hughes et al., 2002; Hughes and Riches, 2003).

Hutti (2005) suggested that clinicians avoid recommending that parents see and hold their dead baby until more information is available. Instead, nurses should explain the potential positive and negative effects of seeing the stillborn baby and encourage parents to make their own decisions. Awareness of the significant challenges for late-term fetal death poses to parents is increasing. This crisis involves the grieving process for couples to cope with the dream of having a baby and their shattered dream of the sociocultural responsibility of carrying on the ancestral line (Hsu et al., 2004), which are especially important for Asian parents. Whilst there is also some research on women’s adaptation experiences after stillbirth in Asia (Hsu et al., 2002, 2004; Sun et al., 2011), there is little, if any, research exploring the situational meanings of parents’ decisions to face their stillborn infant worldwide.

Husserl emphasized that understanding a phenomenon involves examining personal experiences and the implications that an individual attributes to his or her experiences (Polit and Beck, 2006). The object does not passively take on meaning under the gaze of the subject, but becomes an active part of the meaning-making process by returning the gaze and guiding the beholder in their look. The work of Merleau-Ponty reminds us to shift our focus from the structure of the visual sign to the event and meaning of the visual experience as our everyday engagement with the surrounding world (Belova, 2006). Thus, seeing is a personal, emotional, and deeply embodied experience. The meaning of the visual experience originates in the object of seeing and the subject who looks (Kavanagh, 2004). Nevertheless, contemporary knowledge of parents’ decisions regarding whether or not to see their babies after stillbirth and meaning of seeing itself are lacking.

Therefore, this study applied a qualitative, phenomenological approach to examine, describe, interpret, and

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