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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

discuss the meaning and essential structure of Taiwanese parents seeing or not seeing their stillborn babies. Although the specific cultural and religious influences may be limited to the Taiwanese (or greater Asian) culture, religious and cultural influences exist everywhere. Understanding the beliefs of Asian parents is necessary and has increasing clinical importance in western countries, as many societies become global and multicultural in nature.

2. Methods

In this study, we investigated the decisional meaning of parents seeing or not seeing their stillborn infant based mainly on the theoretical framework of Husserlian phenomenology (Polit and Beck, 2006). According to Crotty (1996), becoming aware of a phenomenon through the method is referred to as 'what is known is in the knower', which is aligned with Husserl's assertion that he referred to as the intentionality of consciousness. Therefore, the researcher must examine phenomena in a practical context, as how it is experienced in real life (Husserl, 1970; Stewart and Mickunas, 1990).

2.1. Recruitment and participants

The study protocol was approved by the Ethics Committee of the institutional review board of the participating teaching hospital in Linkou, Taiwan. Following a diagnosis of fetal death, we engaged a purposive sample of paired parents who terminated their pregnancies in maternity units at a medical center teaching hospital in Taoyuan, Taiwan from January 2009 through December 2010. Additional criteria for inclusion in the study were: (1) parental age of 20 years or more, without restriction on the number of pregnancies, (2) the married, pregnant woman and her spouse accepted labor induction for stillbirth, (3) the study participants were able to communicate in Mandarin or Taiwanese, and (4) parents agreed to audio recordings of personal interviews for data collection. Because the topic of stillbirth is a taboo in Taiwan, talking about the dead infant is a highly sensitive and emotional burden for parents. Therefore, the study purpose and procedures were explained for "gaining better understanding of the needs for caring upon delivery of a stillborn infant," and informed consent was obtained from all participants. To build a trusting and caring relationship, the primary researcher would not only play a role of a clinical nurse researcher, but also accompany the couples through the whole process in the hospital.

2.2. Data collection

The principal researcher was a Ph.D. candidate, who was also a clinical instructor with a long-term, good relationship with clinical nursing staff. The multi-setting, multistage, and paired design was adopted for this study to examine the couples' stillbirth delivery experiences. The study obtained field data through both participant observation and in-depth interviews in maternity unit, including in the delivery room and postpartum units at the medical center teaching hospital. When the pregnant woman was induced to deliver her baby in the delivery room, the researcher assisted and provided individualized nursing care and primarily functioned as a participant observer. The further observation was also conducted after the stillbirth delivery. The researcher recorded most of the postpartum nursing guidance provided and clients' reactions to it, including verbal and non-verbal actions in the postpartum unit. After the women had physically recovered, the researcher asked the couples to join her in the conference room of the postpartum unit to present some information on the researcher's observations and to ask the couples questions such as, "Could both of you describe how you decided whether or not to see your infant after the pregnancy was terminated?" "How did both of you feel and think while making that decision?" "What factors did you consider in making that decision?" "What is the value or meaning of this event to you?" and "Did I get the correct context and meaning for the preceding question?" The interview continued until the participants stated that they had expressed all they want to express. Interviews lasted about 60–120 min. Following the interview, the researcher answered the couples' questions and provided or transferred related nursing consultation in the hospital. Every parent was contacted 4–6 times in different situations. Through observation and note-taking, most of the nonverbal behaviors studied were clarified by verbal communication, through in-depth interviews with audiotaped recordings. All data were documented and summarized.

2.3. Data analysis

Data analysis was based on Giorgi's phenomenological method in which all transcripts were read and reread to gain a holistic view of the participants' experiences (Camic et al., 2003). The significant meaning units of the phenomena were extracted (Giorgi, 2009), converted into language that highlighted the key understandings of the participants' experiences, and finally synthesized into consistent statements regarding their experiences (Giorgi, 2009).

Several strategies were employed to enhance the rigor or trustworthiness of the study, such as the credibility, fittingness, dependability, and confirmability (Lincoln and Guba, 1985; Madows and Morse, 2001; Morse et al., 2002). Credibility was maximized by spending time with the participants to build a trusting relationship. Every parent had been contacted multiple times before the interview. Observation in the natural setting, interviews with open-ended questions, verification of the participants' responses, and asking participants to validate findings were also employed to establish the credibility and fittingness of the data. Dependability was ensured by a clear audit trail with documented reflective notes and self-awareness memos, which were taken to examine the relevance of research methods and personal biases. This study was not initially limited to the issue of seeing, but also included care actions and observations on the delivery process; thus ample data were collected, which achieved natural bracketing for the pre-concept of the decision to see the stillborn baby. The analyses also included bracketing to control for research bias and the

researchers' impressions associated with exposure to the participants. Faithfully transcribed and similar themes were categorized and recategorized using a peer-review coding process and constant re-encoding of the transcripts to allow readers afterward to grasp the meaning of the data. Confirmability was established through recruiting of couples who were willing to share their experiences and by gaining their agreement on data interpretation.

3. Results

Twelve couples met the inclusion criteria and consented to take part in the study. Nearly 60% of the couples approached refused to take part in the survey. This high refusal rate most likely reflects Taiwanese adherence to the long-held cultural taboo against talking about and seeing death, including the viewing of corpses and coffins and writing wills before one is considered 'old' (Hsu et al., 2002).

Among the 12 couples that joined the study, five chose to see their stillborn infants while four couples chose not to see theirs; one mother chose to see her stillborn infant while her husband did not; two mothers chose not to see their stillborn infants, while the fathers did. The characteristics of participating families are provided in Table 1. The 12 couples interpreted, decided, and acted on seeing their stillborn infants in different ways. Fathers played a dominant role in the decision to see their stillborn infant ($n = 7/12$, 58%); few parents decided jointly ($n = 3/12$, 25%), and only two mothers played a primary role in deciding whether or not to see their stillborn baby ($n = 2/12$, 17%) (Table 2).

Table 2
Couples' decision modes of seeing stillborn baby.

Decision-maker	Decision mode	*n* (12)
Father decided ($n = 7$)	Face together	3
	Avoid together	3
	Father face and mother avoid	1
Mother decided ($n = 2$)	Face together	0
	Avoid together	1
	Father face and mother avoid	1
Joint decided ($n = 3$)	Face together	2
	Avoid together	0
	Father face and mother avoid	1

3.1. Decision patterns

The two constituted decision patterns were: (1) "deciding to see the stillborn baby," and (2) "deciding not to see the stillborn baby." Five themes were distilled from each pattern.

3.1.1. Pattern 1: deciding to see the stillborn baby

The parents seldom thought about witnessing their child's death, let alone accepting it, which was a totally unimaginable situation. Some parents decided to see their stillborn infant to confirm the death.

(i) *Seeing is believing*. Seeing their stillborn infant was parents' opportunity to come to terms with the infant's death and validate the baby's status, thus achieving a certain degree of reassurance through the visual experience.

Table 1
Participant characteristics.

Pair number	Seeing infant (interviewee)		Age (years)	Education	Religion	Decision-maker	Parity	Previous abortion (<20weeks)	Gestational weeks at delivery	Stillbirth sex	Other living children
1	Mother	Yes	30	Junior college	Buddhist	Mother	2	0	22	Male	One
	Father	No	31	Junior college	None						
2	Mother	Yes	28	Junior college	Tao	Joint	1	0	28	Female	None
	Father	Yes	28	Junior college	Tao						
3	Mother	Yes	23	University	Buddhist	Father	1	0	30	Female	None
	Father	Yes	26	University	Buddhist						
4	Mother	No	27	Senior high school	Tao	Father	1	0	26	Male	None
	Father	No	28	University	Buddhist						
5	Mother	Yes	41	Junior high school Senior high school	Tao	Father	2	0	25	Male	One
	Father	Yes	42		Tao						
6	Mother	No	32	University	Buddhist	Father	1	1	23	Male	None
	Father	No	33	University	Buddhist						
7	Mother	Yes	30	Senior high school	Buddhist	Father	1	0	33	Female	None
	Father	Yes	32	Senior high school	Tao						
8	Mother	No	40	Junior high school	Buddhist	Mother	2	1	31	Male	One
	Father	No	41	Senior high school	Buddhist						
9	Mother	No	33	Junior college	None	Father	2	0	28	Male	One
	Father	No	34	University	Tao						
10	Mother	Yes	38	Senior high school	None	Joint	2	0	35	Male	One
	Father	Yes	38	University	None						
11	Mother	No	29	University	Christian	Joint	1	1	30	Female	None
	Father	Yes	31	University	Christian						
12	Mother	No	28	Junior college	Buddhist	Father	1	0	24	Female	None
	Father	Yes	30	Junior college	Tao						

> "My husband did not want me to see the infant because doing so would make things much more painful. However, I wanted to check and see if anything was wrong with my baby. He appeared normal, but his life was taken away before he was born" (weeping) (Mother 1).

(ii) *Seeing is to avoid regret*. Some parents said they would regret it if they lost this chance to see their stillborn infant.

> "She is our first child. We discussed this. If we had decided not to see her, we would always have imagined what she looked like and would have regretted not knowing. We wanted to see her" (Father 3).

(iii) *Seeing is an opportunity to say farewell*. Seeing was to bear witness to the infant's death and was the parents' only opportunity to bid sad farewell to their baby.

> "We burst into tears upon seeing the infant. We were speechless. We looked at her and said, 'It is our fate to lose you. In your next life, please come back to become our child again'" (Mother 3).

(iv) *Seeing is imprinting the stillborn infant in one's memory*. Seeing the infant validated his or her existence, providing a meaningful image that enabled the parents to maintain memories of the baby.

> "We could not stop crying when we saw him. My husband comforted me and asked me not to think of it too much. How can I not think? After seeing him, I swore that I would never forget that he is the second son in our family" (Mother 10).

(v) *Seeing is a shock*. Seeing their stillborn babies forced parents to deal with the pain of reconciling the real and imagined appearance, size, and skin color of their infants. The infant's appearance profoundly impacted the parents and some had negative reactions, especially parents who had little, if any, prior psychological preparation.

> "The nurse asked if we would like to see the baby, and we were taken aback since we had never encountered such a situation. We agreed. I was frightened as the nurse uncovered the baby. The baby was entirely different from what we had imagined. She was so small, purplish, and swollen. I could not accept that she looked so much different than what we had imagined." (Father 2).

3.1.2. Pattern 2: deciding not to see the stillborn baby

Stillbirth is a paradox of facing the joy of life and then unexpectedly being struck by the sadness of death. Under this circumstance, some parents chose to avoid or isolate the event of stillbirth or follow their cultural taboo of not seeing their babies.

(i) *Not seeing is cutting the attachment to the stillborn baby*. Some parents chose not to see their stillborn babies because they were fearful of greater emotional attachments to their infants and less willingness to let go after seeing them.

> "It is similar to the past, when poor families gave up their children to other families; they would not look at their baby after the birth, out of fear of becoming attached to him or her. I thought I would feel conflicted if I saw our stillborn baby because his appearance would always be in my mind, so we chose not to see him" (Mother 4).

(ii) *Not seeing as preventing memory imprinting*. Some parents were afraid that their babies could be abnormal, emaciated, or deformed; thus, they chose not to see them to avoid bad memories.

> "I didn't want to see him after he was born because I was afraid he was abnormal, swollen, or dark in appearance. If I saw him, I would never forget his face. I chose not to see my baby" (Mother 9).

(iii) *Not seeing is to avoid guilt and suffering*. Most mothers worried that they were responsible for their babies' deaths, and they felt guilty. They feared that seeing their babies would create more guilt, and thus, chose not to see them.

> "The nurse asked if I would like to see my baby and also if I would like to deal with her or leave it to the hospital. I did not know what to do. I was unprepared. I felt that I would have more pain and would fail to let go if I had seen the baby. I did not want to see the baby. So I let my husband see her" (Mother 12).

(iv) *Not seeing is to pretend event closure*. After the stillbirth, some mothers chose to escape and block out all issues regarding the stillborn infant.

> "I did not want to see the stillborn baby. I wanted to leave the hospital immediately after the delivery and try to forget it. I wanted someone to bury him and never to think of him again" (Mother 8).

(v) *Not seeing as the act of following the cultural taboo*. In Taiwanese culture, stillborn infants have no funerals or religious ceremonies. Buddhists and Taoists believe that this will allow the spirit to reincarnate, rather than "lingering as a lonely ghost." Parents feared violating this taboo would affect the survivors and the dead, so they chose not to see their stillborn babies.

> "I did not know whether I should see the baby, so my husband called my mother-in-law who said it would not be good for the baby if we saw him. I wanted to see him, but the cultural taboo prohibited us from seeing him. If we saw him, he would be attached to us and reluctant to leave the world, resulting in failure to reincarnate" (Mother 6). "As parents, if the decision benefits the baby, then we feel comforted" (Father 6).

4. Discussion

Parents of stillborn babies must decide whether or not to see their babies, have an autopsy performed, and handle of the remains of the baby, all within a short time in the hospital (Radestad and Christoffersen, 2008). Health professionals face difficult choices about what issues

should be raised with parents at this sensitive time and the optimal timing to inform them of the decisions they will face. Amongst the 12 couples, four expressed that they tried to look on the internet for information about labor induction for stillbirth so that they could anticipate the impending decision of seeing their stillborn baby. Eight couples exclaimed that they were not prepared and were not informed about making a decision on whether or not to see their stillborn baby. Enabling parents to understand the decisions they must face in advance of the stillbirth process would help parents feel prepared when facing these issues (Badenhorst et al., 2006; Hunt et al., 2009). Health professionals should give advice in advance of the decisions parents will need to make, so that parents have enough time to consider calmly what they might do. The details may include when and how they would prefer to see their stillborn baby: immediately after delivery or later and in what situation.

In this study, only three couples presented shared decision making and achieved consensus for facing the event; fathers ($n = 7$) played more dominant roles than mothers ($n = 2$) in the decision-making process of seeing or not seeing their stillborn infants. Only two mothers showed more determination to see their infants than did their husbands. Although the spousal relationship appeared to be governed mainly by male protectionism in this study, many decisions that several fathers faced were upsetting because they were not anticipated. Therefore, health care staff should be mindful of and overcome the stereotypical image of the male partner carrying the overwhelming responsibility or task of seeing the stillborn infant.

Almost a half of parents chose to avoid or isolate the event of stillbirth ($n = 11$). Cultural taboos played a leading role in the decision not to see a stillborn infant. In Taiwan, children who die before 12 years of age are considered to have died an early death. It is taboo for the elderly to touch the body of the young. If the taboo is violated, the dead are reluctant to leave the world, and their ghosts stay with the families. Additionally, it is believed that the dead would fail to achieve reincarnation (Hsu et al., 2002; Wang, 2006). Most Taiwanese people still abide by traditional religious customs and societal taboos. Rituals such as ancestor worship and ghost beliefs are a publically acceptable reason for not seeing a stillborn baby, which might be a way to help parents implicitly deal with the grief and guilt of the stillbirth and their loss. From another perspective, many Taiwanese parents may be reluctant to talk about or view the deceased infant due to the taboo, which prevent them from accessing strategies that are considered helpful in western countries, including seeing, baptizing, and naming the deceased baby as a means of acknowledging its existence and possibly preventing the onset of pathological grief (Hsu et al., 2002). However, some western studies showed that parents who had seen their deceased baby had considerably increased grief (Hughes et al., 2002; Hughes and Riches, 2003; Warland et al., 2011).

Some parents perceived visual recognition of the baby as a key stage in their coming to terms with the reality that the baby had passed away or ever existed and in the growth of their self-identity as the baby's parents (Sandelowski and Black, 1994); parents showed different interests of seeing their stillborn infants in our study. Therefore, it is significant to know the individual's meaning and readiness of seeing the stillborn infant, but not following a generalized rule or interpretation for anticipating the event of seeing the stillborn infant. The parents might be afraid of or become shocked on seeing how their babies' bodies appear. This visual image has a lasting and strong impact. Nurses of stillborn infants should take into account the visual impact on mothers and fathers. The information implied in the stillborn infants' appearance, size, facial expression, and color, as well as the environment is perceived and responded to by the parents who internalize it into cognition and memory. Nurses need to clean the stillborn infants' bodies, dress or wrap them, and appropriately cover them with a blanket. A proper environment should be created to avoid any external interference. A quiet, comfortable, and private environment should be arranged for the parents the viewing. The parents' expected companions should also be confirmed in advance. The parents should have sufficient, continuous time to approach the stillborn infant so that they may freely express their feelings (Saflund et al., 2004; Warland et al., 2011).

5. Conclusions and implications for practice

We recommend that clinical care personnel accommodate parents' choices and cultural customs at an appropriate time and place. Health professionals should orient parents to the circumstances and assist in the additional decisions parents may face in advance of the stillbirth. Parents should have sufficient time and information to consider the implications of seeing or not seeing their stillborn infant, express their feelings, share their experiences, and discuss what to do following the stillbirth. Following these discussions, parents' decisions of whether or not to see their stillborn infant should be respected and supported. With a better understanding of parents' belief systems and timely advice and environmental arrangements on what parents can expect of the stillbirth process, health professionals can provide quality, culturally adept nursing care.

This qualitative study provides individual and cultural interpretation of parents' decisional meaning for seeing stillborn infant in Taiwan, which aims not to generalize the results to other populations, but to prompt deeper concern and better understanding for Taiwanese people regardless of what country they live. The timing of this study focused on the period of hospitalization, thus investigation of a community sample to see if parents would make the same decision they took in the hospital would provide yet deeper understanding of the decisional process of whether or not to see or not see their stillborn infants.

Conflict of interest

None declared.

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Ethical approval

This study was approved by the Ethics Review Board of the Chang Gung Memorial Hospital, Linkou, Taiwan.

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