

Title page

Descriptive title: Cerebral palsy: experiences of mothers after learning their child's diagnosis

Short title: learning child's diagnosis

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Abstract

Aim. This paper is a report of a study describing mothers' experience of learning that their child has been diagnosed with cerebral palsy.

Background. Learning a child's diagnosis of disability is a crisis for parents. Their reactions include shock, refusal to accept the diagnosis, anger, fear, and uncertainty about the extent of disability and associated impairment. Knowledge about parental reactions is based on studies conducted in western countries, many of which do not apply to Taiwan where Confucianism strongly influences cultural perspectives of family and disability.

Method. In this phenomenological study, data were collected in 2005-06 using in-depth interviews and journaling with 15 Taiwanese mothers of children diagnosed with cerebral palsy. Hermeneutic analysis was undertaken of interview transcripts and journal notes.

Findings. Four shared meanings associated with learning of their child's diagnosis were revealed: feeling out of control and powerless, mistrusting healthcare professionals, release and confirmation, and feeling blamed for not following traditional practices. Mothers experienced a loss of their 'ideal' child when their child was diagnosed with cerebral palsy. Expectations of 'normal' motherhood and fulfilling societal anticipation of giving birth to a healthy child were lost. Maintaining their husband's family honour and prosperity, as well as saving face in their community were threatened. Mixed feelings of disbelief, rejection, self-blame and sadness were compounded by uncertainty about their child's future.

Conclusion. To promote better understanding of the child's condition, emotional support and information should be provided to the mother and family, both when informing them of the diagnosis and in the period after diagnosis.

Keywords: culture, cerebral palsy, Chinese, diagnosis, mothers, phenomenology, Taiwan, nursing

Summary Statement

What is already known about this topic

- Mothers' dreams of having a healthy child are shattered when their child is diagnosed with a disability.
- Mothers feel uncertain about their future when physicians' disclosure of their child's prognosis is poor.
- Paradoxically, mothers may feel relief when a diagnosis verifies long-term suspicions about their child's developmental delay, and this offers directions for managing care.

What this paper adds

- Mothers experienced a loss of their 'ideal' child when their child was diagnosed with cerebral palsy, and their expectations of 'normal' motherhood and fulfilling societal anticipation of giving birth to a healthy child were lost.
- Mothers feelings of loss of face, self-blame or being blamed by their husband's family where there was a belief that the child's disability were linked to carelessness, violating the fetus god, or breaking traditional Chinese taboos.
- Mothers felt out of control, powerless and living with no hope of their child being cured of cerebral palsy.

Implications for practice and/or policy

- To promote better understanding of the child's condition, emotional support and information should be provided to the mother and family, both when informing them of the diagnosis and in the period after diagnosis.
- Home visits should follow diagnosis to assess the mother's and family's responses to the diagnosis, with particular consideration given to cultural background influences on beliefs about disability.

INTRODUCTION

Learning of a child's diagnosis of disability has long been regarded as a crisis for parents (Hatton et al. 2003). Their reactions include shock due to loss of their expectations of a healthy baby, denial and refusal to accept the diagnosis, anger and blaming the medical system for poor quality treatment, fear and uncertainty about the extent or degree of disability and associated impairment (Ho & Keiley 2003, Graungaard & Skov 2006, George et al. 2007), and feeling disempowered and overwhelmed by an unpredictable future (Graungaard & Skov 2006). These findings are based on studies conducted with parents in western countries. Although some common experiences apply to parents in Asian countries, the unique influence of culture and the traditional Chinese family are not well understood. As countries such as the United States of America (U.S.A) and the United Kingdom (U.K.) have become more multicultural, with large and growing Asian populations (Hatton et al. 2003, Hayes et al. 2008), it is important for healthcare professionals in many countries to understand better how Asian parents experience a child's diagnosis of disability, influenced by family and culture.

BACKGROUND

Chinese culture has been deeply influenced by Confucianism (Lang 1968), which argues that social context defines and gives meaning to the self. Thus, relationships or interactions with others are crucial to an individual's identity and roles (Lau 1996). In Confucianism, several relationships are associated with the family, such as father/son, elder brother/younger brother, and husband/wife relationships. Each role in a relationship has a status of superiority or inferiority in a hierarchy that guides every family member in their personal position, duty, and obligation to regulate their behaviour. Such guidance is deemed important in maintaining family harmony and meeting social expectations (Baker 1979, Lee 1999, Lam et al. 2006).

In Chinese society, giving birth to a child is a fundamental and significant event for the family since it signifies that the family clan and ancestral lines will be continued, ensuring the traditional kinship structure and the family's future prosperity. This is called *chuanzong jiedai* (傳宗接代) (Baker 1979, Lau 1996). In Chinese culture, children are expected to satisfy their parents' wishes by becoming a 'dragon' (for a boy) or a 'phoenix' (for a girl) (望子成龍/望女成鳳). This translates into a child becoming a successful and significant person who contributes to mainstream society. Parents hope that their child will grow up healthy, with good morality, intelligence, physical health and beauty (Lau 1996). Since parents have high expectations for their child, they do not expect that their child will have physical impairments or could be born with a disability. In Confucian terms, having 'good' offspring honours ancestors and descendants in terms of family reputation (Li et al. 2004). The significance of a woman's ability to give birth to a healthy child is demonstrated by her husband's acceptance (Baker 1979).

As a deviation from the hierarchical structure of human relationships, disability is viewed in Chinese society as a condition of disharmony. Accepting disability is difficult, because it threatens social harmony (Lam 2006). For example, Chinese families believe in the concept of reciprocity and mutual responsibility. Parents have obligations to take care of their children when they are young, and children will attend to their parents when they are too old to work (Baker 1979, Hwang 1987). Parents or grandparents of a person with a disability may be unable to expect that their children will be able to reciprocate by caring for them. People with disabilities, according to Chinese cultural beliefs, are viewed as a social burden due to their uselessness (McCabe 2007). It is within this cultural context that mothers are told of their child's diagnosis.

An anticipated 'healthy' baby is the greatest hope for a pregnant Taiwanese woman. Following traditional Chinese customs and superstitions, it is deemed important to prevent imperfections in the newborn and prevent miscarriage, stillbirth and death of the mother. These old practices include avoiding bad language, arguments and disputes, because they will put a curse on the unborn baby and disturb its development. According to these beliefs, pregnant women should restrain their daily activities, not move things around, not lift and not use scissors, all of which could lead to miscarriage, abortion or a deformed child by offending the fetus god. For example, using scissors or knives is believed to cause the infant to be born with a cleft palate or lip. Any heavy work or lifting during pregnancy can cause miscarriage. Therefore, some Chinese people will blame the mother for a child's disability or imperfection (168 Destiny Class 2005, British Born Chinese 2008).

Living up to personal role expectations is crucial to 'save face' in Chinese culture. In losing face, a mother can experience shame, a sense of inferiority, self-debasement and social rejection. Furthermore, families and ancestors are also involved in losing face and can be treated in the same way as the mother. Having or saving face is generally viewed as important by Chinese people, and so they can be sensitive to judgment or evaluation from others. According to an old Chinese saying, 'family scandals should not be made public', which often results in families covering up things they perceive as shameful to avoid losing face (Li et al. 2004).

In this paper we focus on mothers' experiences of learning of their child's diagnosis of cerebral palsy (CP), as they have been shown to bear the primary caregiving responsibility in Taiwan. Liao (1995) conducted a survey in Northern Taiwan and found that 72% of primary caregivers of children with CP were their mothers, which is consistent with findings from other countries (Lin 2000, Pritchard et al. 2005).

THE STUDY

Aim

The aim the part of the study reported here was to describe mothers' experience of learning that their child has been diagnosed with CP.

Design

In this study, which formed part of a larger hermeneutic phenomenological study, the philosophical world views of Heidegger (1962) and Gadamer (1975) provided theoretical guidance in revealing and interpreting mothers' experiences.

Hermeneutic phenomenological research focuses on how people come to understand, aiming to discover meaning and achieve better understanding of phenomena. First, mothers as human beings possess the capacity to reflect on the nature of their existence and experience in such a way that personal meanings are uncovered and rendered publicly visible (Kellett 1997). Second, the essence of how mothers exist in the world as they learn of their child's diagnosis of CP is influenced by their background, shaped by a particular period in historical time, culture, language and family. Third, the ways in which mothers engage in activities and relationships serve to illuminate the significance of their child being diagnosed with CP. Fourth, understanding personal concerns offers access to the ways in which existence as a mother of a child diagnosed with CP is deemed meaningful. Finally, seizing possibilities for meaningful existence is possible as mothers are temporal beings capable of attributing meaning to their child being diagnosed with CP as influenced by the past, and anticipated in the future (Kellett 1997).

Participants

In seeking to understand the nature of the experience of caring for a child with CP, a purposeful sample was adopted to recruit participants who met a number of criteria. As

mothers have been shown to be the primary caregivers for children with CP, this study purposefully sought out mothers who had experience of the phenomenon under investigation. Mothers who were primary caregivers for children with CP ($n=15$) and who met the following inclusion criteria were included in the study: primary caregiver for a child aged 0-18 years with a diagnosis of CP, ability to speak Mandarin or Taiwanese as a primary language, and willingness to share experiences with the researcher. Mothers were recruited by three methods: a poster in the hospital's Paediatric Rehabilitation Department, an advertisement in a Taiwanese CP magazine, and direct approach to mothers in an out-patient clinic. The first author introduced herself after mothers had finished their consultations. They were invited to a nearby private room to discuss the study and their possible participation. The rationale for adopting this method was to get to know each potential participant, discuss the purpose, research process, potential risks and benefits of the study, and to be aware of how both the researcher and each participant were responding to and defining the situation. Following such discussion, participants signed a consent.

Data collection

Data were collected from December 2005 to June 2006 by two 1-2 hour in-depth interviews with each mother conducted by the first author, who speaks Mandarin and Taiwanese and is an experienced Registered Nurse in the field of child disability. First interviews were accomplished with broad open-ended questions, for example "Can you tell me about the experience of finding out your child's diagnosis of CP?" Immediately after each interview, the researcher recorded journal notes to describe the context, personal responses and thoughts (Rodgers & Cowles 1993).

Follow-up interviews were an opportunity to share and validate developing interpretations of mothers' experiences and to probe specific areas that had been highlighted as significant

during the first interview: for example, “Could you tell me about that experience in more detail?” (Rubin & Rubin 2005). All interviews were audiotaped. Pseudonyms were used to protect the identity of participants, family members and institutions. Data collection ceased after 15 participants, because the data were saturated, that is, no new information, topics or themes were emerging from further participant interviews. There was repetition of information after interviewing the fifth participant.

Ethical considerations

The study received ethics approval from the participating hospital and university

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Data analysis

The audiotaped interviews were transcribed verbatim into Chinese to ensure that subtle meanings were not lost in translation (Twinn 1997, Neubert 2003). Selected transcripts were translated into English to enable input from the research team. The transcripts and journal notes provided the text for analysis, presenting a complete picture and allowing deep understanding of the relationship between context and the experience of being a Taiwanese mother who has learned that her child has CP.

The hermeneutic circle, a metaphor for moving between the whole and its parts (Palmer 1969), was used to capture the nature of how mothers as human beings attempt to make sense of their everyday existence when they learn of their child’s diagnosis. Thus, analysis moved between the focused experience of learning the diagnosis to the whole experience of having a child with a developmental disability in a Taiwanese context.

Rigour

Rigour was achieved by inviting an interpretive phenomenological research expert to validate emerging findings; checking the findings with participants, taking detailed journal notes, transcribing data verbatim, keeping an audit trail, and prolonged engagement with participants (Lincoln & Guba 1985). Although Mandarin and Taiwanese are different languages used in Taiwan, they are both generally called Chinese language and use the same Chinese characters. The Chinese language transcripts, themes and selected quotes were translated into English and translations were checked for meaning accuracy by a translator who was fluent in Chinese and English.

FINDINGS

The mothers' ages ranged from 27 to 42 years and their educational level from junior high school to college. Most ($n=12$) were not employed, two worked full-time and one worked part-time. The children's ages ranged from 8 months to 14 years, and their educational level varied from preschool to junior high school. Their type of CP ranged from monoplegia to severe quadriplegia. Eight families in this research were extended, meaning that they lived with their parents-in-law, and the other seven belonged to nuclear families.

The analysis revealed four aspects related to the experience of learning that their child had CP: feeling out of control and powerless, mistrusting healthcare professionals, release and confirmation, and feeling blamed for not following traditional practices.

Feeling out of control and powerless

Mothers were told of their child's diagnosis in two main situations. Some went to physicians for medical help after realising that their child was delayed in reaching developmental milestones. The second group was told of the diagnosis before their child was discharged

from a neonatal intensive care unit, usually after a difficult delivery. Before knowing the diagnosis, the first group focused on the normal aspects of their child's development, which gave them hope that their child could still be healthy despite their fears. To maintain hope, mothers often denied the diagnosis, because it contradicted their image of having a healthy child and they had difficulty connecting CP with their child. Some visited various hospitals for further tests to confirm the diagnosis. One mother described her experience:

She was very cute when she was little... I felt her legs were fine. But she stood on her toes and her legs would shake when she stood up... We went to [name] hospital first, and the doctor told me my daughter had CP. I didn't believe them when the results came back. So I took her to the [name], [name], and [name] hospitals.

Another mother said: "My image of people with CP was they had severe mental retardation and were paralysed in bed their whole lives... My heart was bleeding when the doctor told me the diagnosis."

A diagnosis of CP announced to a mother that her child was disabled. This information destroyed hope for having a healthy child, and meant that the situation was out of their control. Permanent brain damage from CP meant that there was no hope of being cured, which gave mothers a sense of foreboding for their child's future. One described her profound shock, sorrow, sadness, and even contemplated suicide:

I thought it [the diagnosis] was curtains. What would we do for our future and the rest of our life? I really had a disabled child ... my child's whole life. ... Why was I the mother of a special needs child? ... I asked why the gods treated me so unfairly. I imagined my child

would end up like some very severely disabled children ... at an institution. ... and her whole life might be like this.

Some mothers felt hopeless because the diagnosis of CP felt like 'the end of the world'. Giving birth to a disabled child prevented them from living up to their own and others' social expectations of having a healthy baby. One woman could not feel joy in the motherhood role when her physician revealed the diagnosis of CP shortly after her prolonged delivery. The loss of a healthy child forced her to modify her ideal role of motherhood:

I felt that was the end of the world. ... I felt I had dropped from heaven to hell, so I wasn't able to feel joyful and be happy about giving birth to my son. It was sad and miserable to face a problem like this. People's expectations are always of a healthy, happy, vigorous baby. But my son didn't meet these expectations.

Mothers' feelings of powerlessness and hopelessness were made worse because of the attitudes of healthcare professionals. Physicians usually revealed the child's diagnosis and condition as very severe, and gave no hope of anticipating future possibilities. One mother described feelings of being out of control when professionals did not offer sufficient hope or empathy:

I just couldn't help but burst into tears and cried loudly on the spot [upon hearing the diagnosis]. ... [I] just felt very sad. ... because he explained that our child's condition was very serious. He said my son's condition was severe and he had mental retardation ...four limbs would be paralysed.

Family members rejected the child, felt ashamed and that they had lost face due to the child's disability, which further contributed to the mother's hopelessness. Such rejection meant poor family support and failure to bond with the child. Some mothers felt that their parents-in-law thought they were not 'good' daughters-in-law, because they did not have a healthy baby. Such interactions prevented mothers from feeling a sense of identity, belonging and caring during this stressful time, leading to hopelessness and powerlessness in family relationships:

She [the mother-in-law] called my mum and said, 'How could my lovely son [the husband] have a son [child with CP] like that? If his IQ is affected after brain surgery and he is lame and cannot walk steadily on the road, people will say whose son is that? Then my lovely son [the husband] would lose face [stops and sobs]. She even said it to me when we were face-to-face, that I gave birth to a silly boy and a monster, and I had placed a burden on her son.

Mistrusting healthcare professionals

For some participants diagnosis of their child's condition was delayed, either because in the mother's opinion healthcare professionals did not perform thorough and careful physical examinations or did not suggest seeking further opinions. Mothers often felt that healthcare professionals were careless or lacked sufficient knowledge about CP to ensure that their child received optimal medical assessment and diagnosis. For example, one mother described her disappointment:

I took her [child with CP] to the regional health service to have her vaccinations when she was about 6 months old. Some nursing students said they would like to check my daughter's health. But they didn't check her head circumference. ... Her milestone of rolling over was later than for other children. ... They didn't assess my child's development very well.

Mothers felt angry, overwhelmingly shocked and helpless when healthcare professionals did not take their suspicions seriously or gave false hope that their child was healthy, which contributed to delays in diagnosis and lost opportunities for early treatment. Where children suffered from mistaken diagnosis and treatments, mothers felt angry and powerless:

She was at her corrected age of three months. She was unable to lift her head and her whole body was just too floppy. I told the doctor. ... The doctor answered, 'Oh, premature babies are usually slower in achieving their developmental milestones. That will be fine.' ...the doctor kept saying it was okay when she was six months old. One day the Premature Association Foundation ... came to do developmental tests on my daughter. ... Wow, you know the outcome of the test. My daughter had problems with developmental delay in many areas. It was just like a thunderbolt hit my head.

Optimal medical care was considered vital for finding opportunities to improve their child's condition. When appropriate referrals were not made by the healthcare system, mothers lost hope. Mistaken diagnosis and treatments left them feeling angry and powerless. They refused to accept a diagnosis of development delay where a clinician's poor professional performance, lack of communication skills, and impatience with their child led them to mistrust the outcome report. This mistrust could result in a delay of treatment:

My kid was too little and he feared strangers so he just kept crying and crying when the examiner asked him to do something [developmental tests]. He [the examiner] never tried to comfort him [the child] or give him a chance to warm up. He just wrote down 'developmental delay'. How could I accept this report? I just felt very angry about this, which also delayed me seeking treatment.

Release and confirmation

Mothers had paradoxical feelings about the diagnosis. They had feared that there was something wrong with their child, yet felt a sense of release after learning the diagnosis of CP. The diagnosis confirmed long-held suspicions about their child's developmental delay. However, it was hard to accept the diagnosis at that moment, because it destroyed their hope of being a mother of a healthy child:

To be honest, I felt relief after I took time to contemplate and reflect on it [diagnosis], because at least I knew the reason. ... Before, I just felt there was something a little odd with my daughter, but now I have the answer. Knowing the answer was better than not knowing. ... At that moment, I wasn't able to accept it ... After experiencing a period of time of profound sadness, I just felt relief due to knowing the reason.

Feeling blamed for not following traditional cultural practices

All of the mothers felt guilt. They blamed themselves for causing their child physical harm by not following traditional Chinese practices and sufficiently nurturing their bodies during pregnancy. They felt that, as a dutiful mother, they should have protected their child from any possible harm and danger. This experience damaged their self-concept as a mother and their relationships with their family. For example, a woman who lived with her parents-in-law could not develop a harmonious relationship with her mother-in-law:

When I was given the diagnosis of CP... I blamed myself. I thought it had been caused by my emotional problems. Why couldn't I be open with my mother-in-law during that time [pregnancy]! Maybe he [child with CP] would not be in this situation. ... Also I was taking

care of my elder son. I didn't regard doing housework as a taboo so I did it as usual. ... I think this [doing housework] was the reason for my preterm labour.

Some mothers were blamed by their families, especially parents-in-law, for not giving birth to healthy children. These mothers had deep feelings of guilt, poor self-esteem and negative images of themselves as mothers:

My mother-in-law told me that I might have eaten the wrong food to cause my son's problems and I wasn't careful enough during my pregnancy. My parents-in-law's relatives also thought that way. We moved during my pregnancy. ... They might have thought that such movement violated the fetus god.

Another participant said: 'At the time [child with CP stayed in the intensive care unit], my mother-in-law told me that the healthy unborn baby in my abdomen ended up unhealthy because of me'.

DISCUSSION

This study is limited to the experiences of mothers. However, the findings revealed that a diagnosis of CP has an impact not only on mothers, but also on other family members. To gain a better understanding of the phenomenon, future research is needed to explore this experience in a family context by including the voices of significant others, particularly the father, grandparents and siblings.

All mothers in this study demonstrated deep despair and negative feelings when they realised that their child was disabled. These findings are consistent with previous research on parents' experiences at diagnosis of a child's chronic illness or disability (Gordeuk 1976,

Mardiros 1982, Graungaard & Skov 2006, George et al. 2007), suggesting that women's dreams of having a healthy child are shattered and their future becomes uncertain, out of control and hopeless. Inability to give birth to a healthy child further threatens the mother's maternal identity and self-esteem (Gordeuk 1976), since they regard the child as part of themselves, a perception they have developed throughout pregnancy.

Mothers in our study felt hopeless when physicians disclosed their child's diagnosis and prognosis as very severe, without giving any positive information. George et al. (2007) pointed out that disclosure without positive information leads to dissatisfaction with a physician's insensitive attitude, caring, and support (George et al. 2007). Hope is an important motivating factor for parents in seeking treatment for their child and helping them to overcome their negative emotions (Graungaard & Skov 2006).

Our mothers experienced aggravated grief, anger and/or frustration when healthcare professionals failed to be thorough, empathetic, offer any hope or deal with parents' emotions and stress during the diagnostic disclosure. Not only were children dehumanised, but mothers' feelings and concerns were also ignored. These findings are echoed in the literature on the experiences of parents with a disabled and chronically ill child (Dagenais et al. 2006, Graungaard & Skov 2006, Tattersall & Young 2006).

A difficult or prolonged diagnostic process can be like 'fighting for the child' to push physicians for more detailed examinations in a timely manner to gain an accurate diagnosis (Graungaard & Skov 2006). In this study, mistrust of healthcare professionals was compounded by repeated wrong diagnoses, failing to address parents' suspicions and concerns, and prescription of treatments that either exacerbated a child's condition or delayed appropriate treatment. Delay in effective treatment not only increased mothers' mistrust and dissatisfaction with physicians' knowledge and skills, but fuelled their hopelessness about

receiving a better prognosis. These findings echo previous research relating to a loss of trust in healthcare professionals and the resulting loss of hope for future treatment and possibilities for their child (Baird et al. 2000, Rannard et al. 2005, Graungaard & Skov 2006, Tattersall & Young 2006, Fitzpatrick et al. 2007).

The relief felt by some mothers on learning about their child's diagnosis suggests that they needed some certainty, a possible picture of the future, and direction for starting treatments and management (Graungaard & Skov 2006, Fitzpatrick et al. 2007, George et al. 2007). Graungaard and Skov (2006) argued that knowing a diagnosis creates new images rather than uncertainty about the future and identifies possibilities for action.

A unique finding of our study was that family members can blame the mother for the child's disability, resulting in dysfunctional family relations and poor support for the grieving parent. Culturally, disability in Taiwan may cause loss of face and stigma. Having a child with a disability can bring stress and anxiety to the whole family, since people in Chinese society may still hold traditional beliefs that a child's parents, family members, or ancestors may have done some "misdeed" to cause a child's impairment. This kind of social stigma can lead to social discrimination or rejection, especially from a husband or in-laws who blame the mother for placing the family in this shameful situation (Holroyd 2003, Pun et al. 2004). Hence, the issue of losing face in society or being judged by others can have a profound effect on Chinese families, unconsciously or consciously.

Our findings highlight that where parents-in-law either apportion blame to the mother or are perceived to do so, this has a great impact in determining acceptance of the child into the family and the self-concept of the mother. King (1971) argued that, in order to provide holistic care, personal, interpersonal and social systems interactions should be addressed.

Moreover, King's interpersonal system could be used to guide care provision focused on the interactions, communications and transactions between mothers and other family members, since there is an impact on all family members when a child is diagnosed with CP (Fawcett 2005; King 1971).

CONCLUSION

Nurses can assist mothers, fathers and families to understand CP, work through their problems and refer them to other healthcare professionals if necessary. Mothers may need an opportunity to discuss their feelings of shock and shame. Better understanding of CP may enable other family members to accept the disabled child as part of the family, to be involved, and to support to the mother. Nurses can act as advocates by communicating parents' concerns and wishes to other healthcare professionals, helping to reach a consensus on expectations, and reducing the communication gap, misunderstandings and conflicts between parents and healthcare professionals.

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