



# Taiwanese Parents' Perceptions of Their Very Low-Birth-Weight Infant With Developmental Disabilities

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## ABSTRACT

This study explores the perceptions and experiences of Taiwanese parents in coping with the unfolding evidence of a disability, their response to the official diagnosis, and their views about their child's developmental disability. This descriptive qualitative study is a partial analysis of data from a larger study including 19 Taiwanese parents of very low-birth-weight infants with developmental disability at 6 and 12 months of corrected age. Four themes were generated: uncertainty and worry about developmental progress, search for meaning and supernatural will, desire for normality and attitude toward services, and finding a balance point in family life and relationships. The parents of very low-birth-weight infants face uncertainty about developmental and other potential problems in the infant's early age. Adequate information related to infant development needs to be integrated into follow-up clinic and early intervention services. Early intervention programs should not only focus on the needs of these infants but also provide support and care to the whole family. Understanding parental beliefs and values toward developmental

disabilities can help neonatal and pediatric professionals to provide optimal early intervention to these families.

**Key Words:** developmental disability, infant, parent, Taiwan, very low-birth-weight

Advanced medical management has increased the rate of survival of very low-birth-weight (VLBW) infants (birth weight <1500 gm) in many developed countries including Taiwan. However, these infants remain at risk for developmental disabilities.<sup>1,2</sup> Possible developmental disabilities include cognitive, motor, and language delays; perceptual impairment; behavioral problems; difficulty learning; and cerebral palsy.<sup>3–5</sup> Very low-birth-weight infants who also experience health problems such as bronchopulmonary dysplasia, intraventricular hemorrhage, and periventricular leukomalacia (PVL) are at even higher risk of developmental disabilities. For example, infants with severe bronchopulmonary dysplasia exhibited significantly higher incidences of cognitive and motor delays than those without bronchopulmonary dysplasia throughout infancy.<sup>4</sup> Mechanical ventilation and intraventricular hemorrhage during the neonatal period were related to poorer cognitive function and reduced reading skill in adolescence,<sup>6</sup> and PVL was highly correlated with cerebral palsy and cognitive and behavioral deficits.<sup>5</sup> As for perceptual impairments, retinopathy as a result of prematurity makes VLBW infants at risk for visual disturbances.<sup>7</sup>

Although many risk factors have been identified that predict adverse developmental and clinical outcomes in VLBW infants, various developmental disabilities of VLBW infants might not be confirmed until the second half of the first year of life or later.<sup>6,8</sup> In addition, not every VLBW infant has poor neurodevelopmental prognosis.<sup>9</sup> Wang et al<sup>9</sup> point out that talking with parents about these potential future problems during the

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first few months of their infant's life is difficult and complex. As a result, parents are often inadequately prepared for these developmental and health complications after their infant's discharge from hospital and face additional stress associated with the morbidity of premature birth.<sup>10</sup>

An important service to identify and help these infants is early intervention, a global trend in developed countries.<sup>11,12</sup> In Taiwan, any child suspected of having a developmental disability must be assessed and the developmental disability confirmed by an accredited medical institution. If the child is younger than 6 years, early intervention must be provided.<sup>13</sup>

Once a disability is confirmed, parents' understanding of their child's disability can impact how they face the challenges of caring for the child and how they access supports and services.<sup>14</sup> The impact of the child's birth and illness as well as cultural beliefs and values can also influence parental health-seeking behaviors and determine the expected nature of caring and curing.<sup>15</sup> Parents may view the infant as vulnerable and, therefore, seek health and developmental services. A study in the United States found that high parental perception of child's vulnerability, regardless of the severity of the infant's medical condition, was associated with a worse developmental outcome among premature infants at 1-year corrected age and disproportionately high healthcare utilization.<sup>16</sup> Parents may also deny problems and avoid further contact with healthcare provider to reinforce their child's normalcy.<sup>17</sup> In a study of mothers of 3-year-old prematurely born children, Miles and Holditch-Davis<sup>17</sup> identified a concept they called *compensatory parenting*. The mothers paradoxically viewed their children as both special because of having suffered and survived and, at the same time, normal. Mothers of children with obvious delays or health problems often denied problems and avoided diagnosis or needed treatments or viewed their child as doing much better than expected.

Currently, most studies have focused on the VLBW infant's prognosis<sup>8,18,19</sup> and families of children with developmental disabilities at an older age.<sup>20</sup> Less is known about how parents in an Eastern society like that of Taiwan perceive and respond to a confirmation of developmental disability in their VLBW infant. Therefore, the purpose of this study was to explore the perceptions and experiences of parents of VLBW infants in coping with the unfolding evidence of a disability, their response to the diagnosis, and their views about their child's developmental disability. Healthcare professionals involved in such interventions can help optimize the care of families of VLBW infants with improved understanding of how parents perceive and respond to a diagnosis of developmental disability.

## METHODS

This descriptive qualitative study<sup>21</sup> is a partial analysis of data from a larger longitudinal study of Developmental Trajectories of the Parental Role in the Family with a VLBW Infant, focused on understanding how parents of VLBW infants ( $N = 55$ ) perceived their parental role in the first year. Data were collected during hospitalization, 2 months after discharge, and when the infants were 6 and 12 months of corrected age. Mothers' breastfeeding experience in the infants' first 6-month corrected age was published elsewhere.<sup>22</sup> This analysis includes interviews at 6 and 12 months of corrected ages for a subgroup of parents.

Participants were recruited from medical centers in Northern Taiwan. Participants for this analysis were a subgroup of VLBW infants who had developmental disabilities after 6 months of corrected age and were referred to an early intervention program. This included 19 parents (11 mothers and 8 fathers) including 8 couples who had completed interviews at 6 and 12 months of corrected ages. Three fathers refused to participate because of difficulties with time arrangements. All parents were married and none had a previous child with developmental disabilities. Five couples were first-time parents. Mothers ranged in age from 28 to 40 years and their education ranged from a high school degree to a bachelor's degree. Fathers ranged in age from 29 to 45 years and their education ranged from a high school degree to a master's degree. Infant birth weights ranged from 620 to 1470 g. At the time of the second interview (12 months), every infant needed at least 1 early intervention service.

## Data collection

After approval of the study by the ethics committees at the university and hospitals, a package explaining the study and the participant's rights was provided to the parents at discharge. Telephone consent and, later, signed consent from both parents were obtained. Interviews with parents were conducted in their homes. In-depth open-ended interviews were conducted with the parents separately at each data point. To maintain consistency, 1 researcher (first author) conducted all of the interviews. A relationship with the parents was maintained between the interview visits through phone or mail contacts and greeting cards. During the interviews, the parents were asked to tell the story about how they came to realize their infant's developmental problem, how they responded, and how they felt about the infant's condition. The interview was guided by the parents' responses. Parents were not interrupted until they had completely responded to a question. Probes were used where necessary to elicit deeper expressions.

The interviews lasted 60 to 90 minutes, were audio-taped, and later transcribed verbatim. The interviewer also asked the parents about demographics such as their age, education, and the infants' health. These data were recorded on the demographic and health history sheet.

### Data analysis

Data were analyzed using content analysis, a systematic and objective means to analyze qualitative data.<sup>23</sup> The process of analysis followed 3 major phases: preparation, organization, and reporting as suggested by Elo and Kyngäs.<sup>24</sup> In the preparation phase, every transcript was read line-by-line several times by the 2 authors in order to become immersed in the content and to make sense of the data as a whole. Then, open coding was performed with notes and headings written in the margins by each individual author describing all aspects of these parents' experiences. Through discussions to reach consensus, codes with similar meanings were organized and grouped to elucidate the themes of these parents' perceptions and responses to their infants' health problems. Four themes were named using content-characteristic words and reported in the findings. New interview data were continuously fit into the categories ending with the 19th parent interview.

### FINDINGS

Four themes were identified on review of extracted data: uncertainty and worry about developmental progress, the search for meaning and supernatural will, desire for normality and attitudes toward services, and finding a balance point in family life.

### UNCERTAINTY AND WORRY ABOUT DEVELOPMENTAL PROGRESS

While most parents knew that their children were at high risk for developmental disabilities, inconsistent and unclear explanations about the infant's risk, type and severity of disability, and prognosis caused most parents to feel uncertain and worry about their child's future. Information about the infant came from many sources: neonatal physicians, developmental specialists, and local medical practitioners.

Neonatal physicians usually explained to parents of VLBW infants who had PVL or intraventricular hemorrhage at discharge that their infants had mild, moderate, or severe developmental disabilities depending on cranial ultrasound results. These descriptions were not consistent. Some would directly tell the parents that there were *cysts* or *bleeding* in the infant's brain that could cause cerebral palsy. Other physicians told parents that the affected area might persist, decrease, or

disappear as the infant grew older. One father said that he was told to wait about 2 years to know the developmental consequences of PVL on his daughter, leaving the parents unsure how much the infant's brain was damaged. As a result, parents worried and became vigilant about observing developmental milestones and behavior, especially related to motor function.

In the first year of life of the infants, disabilities such as motor problems were gradually noticed and they were referred by neonatologists to a hospital rehabilitation center for specialty care such as speech and physical therapy. Physicians and others conducting follow-up developmental evaluations gave parents classifications of their infant's disabilities, depending on the results of developmental assessment (mainly the Bayley Scale of Infant Development II) at the 6- and 12-month follow-up visits. Findings and developmental implications for the infant were often not made clear. For instance, one mother mentioned her emotional discomfort when she took her daughter to have a developmental evaluation: "The hardest part was you did not know if the result was good or bad." Another first-time mother expressed her confusion:

I didn't know whether her failure to reach milestone behaviors was because of immaturity or because of having impairment. If the behaviors were because of immaturity, they would develop later and you gave her more time to catch up.

Besides a developmental disability such as a deficit in motor functioning, other concomitant physical conditions would result in parents worrying. For example, 1 VLBW baby's physical condition gradually deteriorated with a severe developmental disability. The family spent 10 months visiting many doctors in different hospitals to determine the infant's exact diagnosis (a rare disease). Because there was no adequate medical treatment or available information, the parents felt uncertain about what they could do next to help their infant or how long their infant could live.

### THE SEARCH FOR MEANING AND SUPERNATURAL WILL

Parents would search for the *meaning* of having an infant with developmental disabilities. Depending upon the parents' beliefs, they attributed the reason for having an infant with developmental disabilities to fate, which was handled by *lao-tien* (a general term for all deities in the heavens) or by a deity they believed in and worshipped. Believing in supernatural will and knowing that there were things beyond their control could seemingly reduce their tension. One mother felt sad about her older twin having severe developmental

disabilities but was comforted by her friends. She said: "My friends told me it was *lao-tien's* will. The child had his fate [being severely delayed] and it was also my fate [having a severely delayed child]. I thought it was a trial which *lao-tien* gave me."

Another mother, whose infant had moderate PVL and was 3 to 4 months developmentally delayed at 12 months of corrected age, thought that it was Buddha's blessing that the infant had a mild disability and just needed a little physical therapy to catch up. On the contrary, another mother expressed that her family worshiped *san-tai-tzu* (a young deity in Taiwanese folk religion) and believed that *san-tai-tzu* would bless her daughter who had a mild motor disability, so there was no need to get therapies. These parents of infants with mild or moderate disabilities felt their own situation "fell short of the best but was better than the worst" when they saw other VLBW infants with more severe disabilities.

Only 1 father in this study was a Christian and contemplated the meaning of his son's developmental disability. He described the moment he learned from the doctor of his son having a moderate handicap:

I was very disappointed at first because I planned to teach him to play tennis when he was older. I am very athletic and a quick learner in any sport. I could not imagine how people could not do well. . . . Now I consider my son's condition [possible permanent disability] as a tough trial God gave me . . . . Ever since I knew the possible prognosis related to his physical functioning, I have more empathy when seeing other handicapped children. I think God is fair. I appreciate that my son's current condition is not as severe as the one shown on TV.

## DESIRE FOR NORMALITY AND ATTITUDES TOWARD SERVICES

Regardless of the severity of the prognosis, parents hoped and even expected their infants to be normal. In a parent's attempt to confirm the normality of his or her infant, he or she would compare the infant's development with other children such as his or her neighbor's child, other preterm infants, or an older sibling's development at an early age.

All parents in this study reported the hope and even expectation that their infant would have optimal development because of fear of the child being labeled. They rejected terms such as cerebral palsy, mental retardation, or handicapped. Based on the results of follow-up evaluation, the doctor would determine the level of an infant's disability so that the parents could apply for social welfare programs. Most mothers were hesitant to apply, however, because they were afraid that

their infant would be permanently labeled. One mother described how she persuaded herself to apply:

I could not accept he was "severely handicapped" at first, especially when I saw the doctor write down the term on his report . . . . He needs to be evaluated after three years. So I told myself if we worked harder [at rehabilitation], maybe he would be normal or become mildly disabled.

This concern for normalcy and fear of labeling often affected follow-up care. One mother shared her feelings as to why she at first refused to take her infant to a rehabilitation center. She said: "I thought the word *rehabilitation* was for adults who got strokes. I did not understand why my baby needed to go there. I felt offended and feared hearing the word."

For parents who accepted early intervention, they expected not only that the program would stop deterioration of the infant's functions but also that the impairment would disappear or become less obvious. One mother described this situation:

I saw a boy who was very obviously crippled . . . . I related this situation to my daughter and feared she would walk like that boy when she grew up . . . . I believed if she continued her physical therapy, then one day she would walk like a normal child. No one would know she had been a premature baby with impairment.

Many expected the early intervention to quickly produce therapeutic effects. Six couples concurrently took their infant to different rehabilitation programs, hoping to speed up the infant's development. While most fathers did not agree with the infant receiving multiple therapies, they escorted the mother and the infant to clinics. These fathers often adopted a flexible attitude toward the care of their infant. One father set a goal for his daughter: "I think her motor function will improve in three years, but we will prepare the rehabilitation device or corrective shoes for her if necessary and accompany her to the rehabilitation center."

In addition to participating in the hospital's rehabilitation programs, many parents employed other strategies and engaged in alternative therapies as ways to help their infant. These included giving their infants dietary supplements and participating in alternative therapies such as acupuncture, herbal baths, massage, and swimming.

Some parents, especially those with milder disabilities, treated their infant like a normal full-term child allowing the infant to grow naturally according to their beliefs regarding developmental disabilities and their impressions of early intervention services. These parents often neglected to follow through with services such as home physical therapy. Grandparents were influential with some. They believed that the infant would

naturally grow out of his or her delayed development if the infant ate and slept well. Grandparents might also suggest refusing physical therapy because they thought the therapy would cause discomfort or pain.

### FINDING A BALANCE POINT IN FAMILY LIFE AND RELATIONSHIPS

Because the infant had many medical appointments with different therapists, parents needed to reorganize family life and adjusted family relationships. For example, couples decided who should stay home on the basis of either the one who earned less or had a less stable job. Only 1 couple, living with paternal grandparents who took care of the twin boys in the daytime, remained working. At night, the mother took over the care of the twin boys. The older boy of the twins, who had a severe developmental delay, required considerable care. This mother mentioned how her life style had changed:

I often went out with my friends before I had them [the twins]. Now I have to rush back after work so my in-laws can take a break. I feel guilty if I go out with my friends and come back late.

Parents also changed their priority toward their lives in general because of uncertainty about how caring for their infant would affect their lives. One father, long before the birth of his VLBW infant, had plans for a family trip. Later, when he found out that his daughter had developmental and medical problems, he decided to take his wife and elder daughter abroad right away. This father said:

You can't plan for all contingencies. I decided to ask my sister-in-law to take care of her [the infant] for a few days. If you plan to do something, just do it now because you never know what [her condition] will happen next.

Some parents also planned to save money to pay for the infant's future health expenses or long-term care after the parents passed away.

Couples needed to communicate, negotiate, and reach agreement on childrearing. Because of no previous experience, the couple might disagree and argue over their infant's care issues. One mother described her feelings related to the argument with her spouse, "I knew everyone in the family cared about the baby. You should not take things personal, but you felt hurt. We needed to find a balance point when dealing with the kid's issues."

Another issue was time for the other children, as more than half of the studied infants had siblings. As many of the study infants needed home care or had

numerous follow-up appointments and might require special attention at home, parents were in a constant search for a balance point with other healthy siblings in the family. For instance, one mother said, "We try to find ways to distribute time to both of them. We feel sorry for the big [healthy] sister because we are no longer able to read bedside stories and take her out."

Parents often had feelings of guilt because they planned to have a second child to be the elder sibling's playmate. Instead, the VLBW infant with developmental disability became the healthy sibling's later "burden." One father was told in the follow-up clinic that his infant had a severe eye problem, and he described how he felt when he first heard this: "This was the baby's new problem and we felt shocked. I immediately thought she would be blind and would not see forever. What a big burden it would be on her older sister's entire life."

On the contrary, parents hoped that the healthy sibling would understand and assist them in taking care of the sibling with developmental disability. They expected the healthy sibling to protect the younger one, who might be rejected by peers in the future. One father thought that having a VLBW infant with a developmental disability was not all negative because his elder daughter became more mature.

### DISCUSSION

Our findings indicate that the parents of VLBW infants with developmental disabilities experience a variety of challenges related to their child's risk for and diagnosis of a developmental disability. Because of inconsistent and unclear explanations from many professionals about risk for sequelae such as developmental disabilities and the diagnoses when they were made, parents lived with uncertainty, worry, and confusion. Uncertainty about outcome is commonly found in parents of children with a chronic illness such as cancer.<sup>25,26</sup> For parents in this study, uncertainty arose from the often ambiguous prognoses and the possibility of occurrence of unknown disabilities for their VLBW infants at an early age. Previous reports have described increased fear and arousal among mothers of high-risk premature infants at 6 months of corrected age,<sup>27</sup> and they had psychological distress at 1 year postdischarge.<sup>28</sup> Thus, explanations need to be easy to understand and consistent from various professionals to reduce emotional stress and confusion.<sup>29</sup>

Asian families with children who have developmental disabilities commonly have negative perceptions about disability and concerns about labeling.<sup>29</sup> All the parents in this study reported such concerns, frequently following the identification of a diagnosis, such as

cerebral palsy or mental retardation, that was used to describe the child's developmental delays. Having negative responses toward terms that related to developmental disability and a fear of being labeled were possibly due to the emphasis that many Chinese parents place on a child's learning and development and their tendency to judge the efficacy of parenting by the educational achievement of the child.<sup>30</sup> A developmental disability would hinder parental expectations toward the child and might threaten family face ('mien-zi'), a prominent cultural value in Chinese society. Mien-zi is maintaining self-image in front of others.<sup>31</sup>

Once parents were informed of their infant's disability, many parents in our study were concerned about the prognosis and how people would regard their infants and families. These parents had hope for normalcy with high expectations for treatment outcomes. All parents cared deeply about their infant's prognosis, and some elected to arrange concurrent rehabilitation programs, doing their best for the infant in terms of fostering development. These parental behaviors were similar to reported compensatory parenting of prematurely born children of 3 years of age.<sup>17</sup> Overuse of medical resources not only made parents' lives chaotic but also affected the availability of limited resources to other children with disabilities.

Folk beliefs and religion strongly influence Taiwanese people's way of living and thinking about health and healthcare.<sup>32</sup> Parental views about diagnosis and decisions regarding healthcare are strongly influenced by Asian cultural beliefs and religious messages toward the developmental disabilities.<sup>15,33</sup> For example, in Taiwan, there is a saying that "big roosters call late," meaning that a great person will take time to shape and mature. This saying is often used to comfort parents whose infant reaches a milestone later than the average.<sup>34</sup> In this study, some parents were told by grandparents that the infant would naturally grow out of the developmental delay if the infant ate and slept well. A consequence of this attitude could be that if infants were considered as simply late bloomers, the necessity of early intervention could be ignored and the critical period to receive early intervention might be missed.<sup>34</sup>

When Taiwanese people are facing a crisis, they tend to incorporate their needs into their religious practices to achieve settlement and consolation and believe that they will subsequently be blessed by the deity they worship.<sup>35,36</sup> Religious beliefs are associated with how the family reacts to the disability and copes with a child with disability.<sup>37,38</sup> In this study, the responses of parents with strong religious beliefs to the early intervention services ranged widely. For example, some parents believed that the deity was in control of the infant's health and, therefore, there was no need for early inter-

vention. Other parents resigned to fate, considering the infant's health beyond their control. In the latter case, parents believed that they could only try their best to assist their infant by providing good care.

Living with a child with disability can have profound effects on the entire family including parents, siblings, and extended family members and can affect all aspects of family functioning.<sup>39</sup> Parents need to find balance in relationships with the affected child, spouse, and with their other children. Tension between couples might occur because they were novice learners in the care of the VLBW infant with a developmental disability.<sup>40</sup> Their thoughts related to childrearing issues, and the time distribution toward each family member needed to be mutually disclosed and discussed.

Previous research found that "normal" school-aged siblings experienced an increased burden and a sense of responsibility to assist with the care of the sibling with disability.<sup>41</sup> Positive attributes such as a caring and compassionate nature and increased maturity compared with their peers were also found among some of the "normal" siblings.<sup>42</sup> In this study, 7 families had older child between 2 and 5 years of age; the parents observed an increased maturity in those children at an early age. Although parents felt sorry that the older children did not have a normal sibling to play with, they hoped that the older sibling could act as a protector of the child with a developmental disability and hoped that he or she would share the care of that child in the future. In addition, these parents also foresaw future problems and the necessity to make adjustments to take care of each of the children appropriately. Therefore, parental counseling about sibling support issues should be provided early.

Limitations of this study are the relatively small sample size and findings that are culturally linked to Taiwanese parents. However, a study strength is the focus on this largely unstudied population. Another strength was studying VLBW infants with developmental delay longitudinally from discharge to later infancy. Findings can guide health professionals in designing effective family interventions prior to and continuing after discharge.

### Implications for practice

Early intervention programs using a family-centered approach to support the family have been proposed in many studies.<sup>43-45</sup> Through assessing the impact on the whole family, helping parents learn positive ways to manage care of the child and also by helping families maintain normalized family functioning, nurses can promote the family members' well-being and the child's development.

While reinforcing the importance of early intervention, nurses who encounter Taiwanese parents should assess the parents' religious thinking and cultural beliefs and also help them accept the disability and recommended intervention program through the lens of their beliefs. Nurses should also provide teaching and support to foster realistic expectations and appropriate developmental goals for infants.

## CONCLUSION

Although the survival rate of VLBW infants has increased, developmental disabilities are gradually identified throughout infancy. The need for adequate information integration for parents is necessary during the infant's early age. A diagnosis of developmental disability often creates fear of labeling and judgment in the Asian culture. Thus, positive attitudes and realistic expectations toward these infants should be fostered and reinforced among the parents. Nurses should collaborate with physicians in follow-up clinics and with therapists in early intervention programs to support the infant's optimal development and family life. Practice guidelines in early intervention services should consider cultural and family-centered care for these subsets of the population of infants.

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