Preliminary Study: Taiwanese Mothers’ Experiences of Children With Sensory Processing Disorder

En-Chi Chiu

OTD, Doctoral Candidate, School of Occupational Therapy, College of Medicine, National Taiwan University.

ABSTRACT

Background: Different cultural backgrounds and parental experiences influence parenting styles and approaches to raising children with disabilities. Family-centered care should consider parental, especially main caregivers, experiences with their disabled children. In Taiwan, in most of homes, mothers are the main caregivers.

Purpose: The purpose of this study was to explore Taiwanese mothers’ experiences with their children who have sensory processing disorder.

Methods: This study used a qualitative ethnographic design and semistructured interview format. Transcripts were analyzed and synthesized into themes.

Results: Three mothers were interviewed. The following three themes emerged: (a) relationships within the shared worlds of disability and culture, (b) daily life challenges and expectations, and (c) opportunity to receive professional services. These Taiwanese mothers expressed that they experienced stress from being blamed for insufficient skills and from the shame of their children’s disabilities that reflected lack of teacher, friend, and other family members’ understanding of the cause of their children’s inappropriate behaviors. Their children experienced difficulties performing daily activities, which resulted in stresses on both the mother and her child. The interviewed mothers needed to receive timely, long-term services from healthcare professionals. However, hospitals are inadequately staffed with occupational therapists, which delays care for children with special needs.

Conclusion: Taiwanese mothers experience stresses from themselves, their child, and others. Healthcare professionals should apply a family-centered service approach to fulfill the needs of mothers and their disabled children. Moreover, healthcare professionals should promote greater awareness of sensory processing disorder symptoms and interventions to increase public awareness and acceptance of these children.

Key Words
sensory processing disorder, family-centered service approach, Taiwanese mothers, ethnographic research.

Introduction

Knowledge of disabilities, personal contact, types of disability, and ethnic background may affect a person’s perception of people with disabilities (Hampton & Xiao, 2007). Previous studies indicate that, when compared with other ethnic groups, Chinese people living in Australia, Hong Kong, Taiwan, and the United States are more apt to stigmatize people with disabilities and have more desire to disengage themselves from those with disabilities (Chan, Lee, Yuen, & Chan, 2002; Chen, Jo, & Donnell, 2004; Wang, Thomas, Chan, & Cheing, 2003; Westbrook, Legge, & Pennay, 1993). In general, the stigma of disabilities and the unfavorable thoughts that they evoke are common within the Chinese culture because of a cultural belief system that views disability as a form of punishment or the result of an evil spirit. From this perspective, people with disabilities can be wrongfully condemned and considered shameful, dangerous, and unpredictable (Lam, Tsang, Chan, & Corrigan, 2006; Lee, 1996).

Sensory processing involves receiving sensory information, transmitting this information to the nervous system, and organizing and comparing it with past experiences to confirm its meaning (Dunn, 2009). These processes are the foundation for learning, perception, and action in daily activities (Ahn, Miller, Milberger, & McIntosh, 2004; Koziol, Budding, & Chidekel, 2011). Children with sensory processing disorder (SPD) may exhibit disabilities such as decreased social skills, immature playing skills, impaired self-image, and decreased fine and gross motor skills. Although SPD may not be as visibly perceptible as disabilities that impair mental functions or cerebral palsy, which impairs physical body functions, this disease can affect the sufferer’s ability to accomplish daily activities and his or her physical coordination skills. Children with attention-deficit hyperactivity disorder (ADHD) and...
developmental delays may show signs of SPD (Miller, Nielsen, & Schoen, 2012; Parham & Mailloux, 2005). About 18% of children in elementary school in Taiwan are reported to have SPD (Jung & Yeh, 1990). Occupational therapists provide most services for children with SPD and their families in Taiwan. Parents’ responsibilities include nurturing and educating their children as well as seeking treatment for their children with disabilities. Different cultural backgrounds and parental experiences influence parenting styles and approaches to raising children with disabilities. In family-centered care, parents’ experiences with their child should be considered. This is especially so for mothers who are usually the main caregiver. However, the caring experience of Taiwanese mothers for children with SPD has not been explored. This limits the understanding of healthcare professionals and impairs their provision of appropriate care services. Therefore, this preliminary study aimed to explore the experiences of Taiwanese mothers of children with SPD.

Methods

Participants
The researcher recruited Taiwanese mothers living in Hsinchu County. This study was approved by the institutional review board (LLUIRB #58337). The inclusion criterion was that the total score on the Taiwan Sensory Integration Function Assessment (TSIFA; Lin et al., 2004) of their children was above the 95th percentile. Mothers of children diagnosed as mentally disabled or with moderate to severe autism were excluded.

Procedures
The researcher posted flyers in five elementary schools in Taiwan. Interested parents were requested to contact the researcher and complete the TSIFA to assess their children’s SPD diagnosis. Qualified mothers were asked to sign an informed consent form and subsequently interviewed. The TSIFA is a questionnaire widely used to evaluate a child’s level of sensory integration. A total score above the 95th percentile indicates SPD (Lin et al., 2004).

Data Collection and Analysis
This study used a qualitative ethnographic design and a semistructured interview format to explore the experiences of Taiwanese mothers with a child with SPD. Ethnography explores native points of view in a particular group to understand personal life experiences (Richards & Morse, 2007). To ensure study validity, the interview questions were developed based on a review of literature and reviewed by two pediatric experts. Examples of questions include the following: “How would you describe your child in comparison with other children his (her) age?” and “Describe the support you receive from your family, including your extended family.” To ensure study reliability, the participants were all asked the same questions in the same order, and one researcher did all the coding. The interviews were taped and held at the participants’ homes for approximately 1 hour. After the interview, the researcher transcribed the audiotapes verbatim and wrote field notes. The interview data were coded individually. The researcher read the transcriptions, condensed meaning units, developed the categories/subcategories, and identified the themes. The researcher discussed the codes, meaning units, categories/subcategories, and themes with two pediatric experts in qualitative research and refined the themes. The researcher and two pediatric experts then compared the themes in each interview, found commonalities and differences, and identified the overall themes that described the mother’s experiences with her child with SPD.

Results
Six mothers contacted the researcher. Three met the inclusion criterion. Each had a son of either 8 or 9 years old who had been diagnosed by physicians with ADHD or as developmentally delayed. The children all exhibited clumsy fine and gross motor skills, sought sensory stimulation by changing body posture, exhibited inappropriate emotions and behavior, and had poor muscle control. Further information about these mothers is provided in Table 1.

The following three themes related to the participants’ experiences with their children with SPD emerged during

<table>
<thead>
<tr>
<th>Participant (Child)</th>
<th>Age (Child’s Age), years</th>
<th>Mother’s Occupation</th>
<th>Education</th>
<th>Child’s Diagnosis</th>
<th>Husband’s Job</th>
<th>Number of Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>M1 (C1)</td>
<td>35 (8)</td>
<td>Real-estate agent</td>
<td>College</td>
<td>Developmental delay</td>
<td>F1 as business man</td>
<td>One son</td>
</tr>
<tr>
<td>M2 (C2)</td>
<td>45 (9)</td>
<td>Housewife</td>
<td>Technical school</td>
<td>Attention deficit hyperactivity disorder</td>
<td>F2 as business man</td>
<td>One son</td>
</tr>
<tr>
<td>M3 (C3)</td>
<td>38 (8)</td>
<td>Housewife</td>
<td>College</td>
<td>Developmental delay</td>
<td>F3 as engineer</td>
<td>Two sons (C3 is the oldest)</td>
</tr>
</tbody>
</table>

Note. M = mother; C = child; F = father.
the analysis: (a) relationships within the shared worlds of disability and culture, (b) daily life challenges and expectations, and (c) opportunity to receive professional services.

**Relationships Within the Shared Worlds of Disability and Culture**

This section describes how participants perceived disability and its impact on parent–child interactions and other relationships within the family and community. The Taiwanese family is considered a cohesive unit, and the behavior of children is considered a direct reflection of parenting skills. Thus, a child’s disability may be perceived as a result of insufficient parenting skills, potentially causing parents to believe their child’s shortcomings reflect their own inadequacies. M1 shared her husband’s reaction to their son’s disability:

> F1 feels so ashamed of the fact that others talk about his child. He can’t accept his child is different than others…. The teacher complains to F1. F1 feels ashamed about it, so he punishes C1.

When the teacher told F1 about his son’s violent behavior in school, F1 felt disgraced. He assumed that the teacher considered his son’s behavior a result of his lack of proper discipline. The teacher’s notification embarrassed F1 and increased his feelings of shame, making him angry and resulting in C1’s punishment. F1 was not aware that C1 is unable to react appropriately to sensory stimulations, which may have contributed to his inappropriate behavior at school.

Another mother, M2, explained her and her husband’s feelings about their son:

> I felt I was so humiliated. How could I raise a child like this?…. In fact, my husband…yep, his expectation is very high, but he does not know what his child is [inappropriate emotions and behaviors]. Sometimes, he cannot accept the fact.

The three participants shared the pressures they felt from other family members. M3 described the feedback from her family:

> I don’t think relatives give me any support. Sometimes, I talk to them about my children. They give some unhelpful advice…. They say I should go to see a fortuneteller or get help from a psychic.

In addition, M3 shared that her sister-in-law forbade her child from playing with C3 because this relative was afraid of her child copying C3’s inappropriate behaviors.

**Daily Life Challenges and Expectations**

Daily activities are actions people do regularly during a typical day. Children with disabilities experience difficulty engaging in daily activities because of sensory–motor function difficulties and inappropriate emotions and behaviors. This section describes the daily activity challenges that participants experienced with their children.

Academic performance was a primary concern of all three participants. Doing homework was the first responsibility of the children upon returning home from school. One of three children (i.e., C1) attended tutoring classes. C1 had difficulty with writing, which regularly caused fatigue. His behavior also distracted and disrupted other classmates. M1 transferred him to another tutoring class because of classmate complaints. She could not accompany C1 to do homework after school because she worked but checked his homework every night. If C1 did not write a word carefully and neatly, she would erase the word and ask him to write it again until he reached her expected standard. Doing homework occupied most of C1’s and M1’s time together.

M2 shared her experiences doing homework with her son every day:

> I ask him to do homework and he just says “No” everyday…. I am afraid of saying “do homework” out loud anymore…. I am more nervous than he is when I see his homework.

C2 could not sit upright, and he fidgeted all the time. M2 always asked him to sit upright and stop moving. C2 may feel uncomfortable when sitting upright and think his mother’s reproaches are unfair. When he became frustrated, he would begin shouting, use inappropriate language, and sometimes, hit his mother. Doing homework was the hardest daily activity for M2 and C2. M2 feared asking C2 to do homework every day, but she worried C2 would fall behind other classmates.

Play is an important daily activity for the physical, cognitive, emotional, and social development of all children. M3 stated that her child had uncoordinated gross motor skills and stumbled/fell down easily. She was afraid of her child getting hurt while participating in outdoor activities. In addition, the two other participants shared that their children were lonely and that classmates did not like to play with them. Their children with SPD had difficulty making friends and participating in social activities.

**Opportunity to Receive Professional Services**

Professional support is an important resource for parents. Occupational therapists assess a child’s ability in the physical, mental, and social domains as well as provide intervention for children with disabilities. A large number of children with disabilities require occupational therapy services. Hospitals in Taiwan are inadequately staffed with occupational therapists, resulting in delayed or sporadic care for disabled children. Participants shared that they typically waited 2–3 months to receive the intervention. M3 shared:

> An occupational therapist [in the hospital] had us on the waiting list for sensory integration treatment…. We saw many severe cases in the hospital.
Discussion
Participants in this study largely abided by traditional Chinese family and social values. Part of this value system is the cultural belief that disabilities infer a failure to conform to general social standards and that disabled children reflect a parent’s failings or wrongdoings (Lam et al., 2006). In this study, Taiwanese mothers expressed feelings of shame for themselves and their children with nonapparent disabilities because teachers, friends, and other family members did not understand the cause of their children’s inappropriate emotions and behaviors. Such emotions and behaviors may result in mothers experiencing isolation from others. Participants expressed lack of support from their husbands, especially when their husbands were made to feel like they had insufficient parenting skills. Moreover, participants experienced lack of social supports from relatives because of those relatives attributing illness and disability to demons/bad luck. This led to relatives suggesting participants to seek the help of a fortuneteller or a temple priest. Such difficulties faced by Taiwanese mothers reveal the need for a family-centered service approach, which provides family support services to help families cope with the stresses of parenting and family protection services to help families face serious problems, including home or out-of-home placement (McCroskey & Meezan, 1998). Healthcare professionals may apply a family-centered service approach to mothers of children with SPD to help relieve their stress and social isolation and provide social support.

Parents’ cultural beliefs affect their approach to parenting, including how they interact with and discipline their children (Harkness & Super, 1995; Rogoff, 1990). Children with disabilities are part of the family unit and must complete daily activities in accordance with parent requests and expectations. Many Taiwanese believe that a child’s success depends on how well parents perform their roles. The three participants in this study emphasized the importance of their children’s academic performances and checked their children’s homework carefully. Moreover, participants monitored their children’s daily activity performance in terms of seated posture, handwriting, and play skills. However, their children frequently failed to achieve their standards, which generated stress for both the mother and the child. Therefore, healthcare professionals should focus in clinical settings on improving the daily activities of children with SPD that are of most concern to mothers such as handwriting, seated posture, and play/social skills. Furthermore, healthcare professionals may teach mothers how to better interact with their children with SPD to reduce tensions and stresses.

Occupational therapists provide services to children with special needs. However, hospitals are severely understaffed by occupational therapists, with approximately three occupational therapists available per 100,000 population (Lo, Wu, & Chu, 2004). Therefore, children with special needs must often wait a long time to receive services. The current imbalance between care supply and demand is the increased prevalence of chronic childhood illnesses (e.g., autism and ADHD; Kelleher, McInerny, Gardner, Childs, & Wasserman, 2000; Wise, 2004). To better meet current needs, occupational therapists may adopt the three roles of consultant, organizer, and educator. As a consultant, occupational therapists may both teach parents in-home therapies that can facilitate improved quality of life and provide individual consultations to parents to help resolve problems encountered in implementing in-home therapy programs (Novak, 2011). As an organizer, occupational therapists may organize family support groups to facilitate the exchange of information and personal experiences among parents (Ho & Ulster, 2011; Holloway, 1994). As an educator, occupational therapists may promote awareness of SPD symptoms and interventions and encourage teachers and general healthcare professionals to include appropriate sensory-based activities in their services (Reeder, Arnold, Jeffries, & McEwen, 2011; Ripat & Becker, 2012).

There are two important limitations of this study. The first are its small sample size, lack of random sampling, and recruitment of participants from one Taiwan county only. Participant experiences and opinions may not represent the perspectives of other Taiwanese mothers of children with SPD. Further studies may explore the perceptions of other Taiwanese mothers and fathers of children with disability who have other/more varied regional and social/economic status demographics. Random sampling should also be employed to increase the validity and generalizability of findings. A second limitation of this study is that the study themes were not verified with the participants, which may reduce the validity of findings.

In summary, interviews with three Taiwanese mothers of children with SPD found that they experienced stress originating from others, themselves, and their children. In supporting mothers of children with SPD, healthcare professionals should use a family-centered service approach to address the needs of both the mother and her child in a manner appropriate to their cultural background and perceptions. Furthermore, healthcare professionals should promote greater awareness of SPD symptoms and interventions to increase public awareness and acceptance of those with SPD.

Acknowledgments
I thank Esther Huecker and Heather Javaherian-Dysinger for their research assistance.

References


初步探討台灣母親照顧覺統合失調孩童之經驗

邱恩琦

臺灣大學醫學院職能治療系博士班學生

背 景
對於養育失能孩童，不同的文化背景和家長經驗，會影響父母的教養方式和態度。以家庭為中心之服務模式下，家長照顧失能孩童的經驗應列入考量，特別是母親（為孩童的主要照顧者）。

目 的
探討台灣母親對感覺統合失調孩童的經驗。

方 法
使用質性民族誌研究設計，透過半結構訪談方法，收集台灣母親照顧感覺統合失調孩童的經驗，分析並統整其口述資料以歸納出主題。

結 果
共三位台灣母親參與訪談，於訪談結果中分析出三項主題：（一）失能與文化共享之間的關係；（二）日常生活中的挑戰與期望；（三）接受專業服務之機會。三位台灣母親表達出被責備教養技巧不足及對其孩童失能而感到羞恥之壓力，這些壓力源自老師、朋友、其他家庭成員不瞭解感覺統合失調孩童之適當行為。台灣母親對孩童應表現之行為和態度有所期待，當其孩童於日常事務中碰到困難時，此情況造成母親和孩童雙方之壓力。這些台灣母親需要立即及長期的醫療服務，但現實狀況為醫院之職能治療師人手不足，因此有特殊需求之孩童必須輪流以獲得治療服務。

結 論
台灣母親所體會之壓力源自於自身、孩童與他人。醫療人員應提供以家庭為中心之服務模式，以符合母親和孩童的需求。再者應推廣感覺統合失調及其治療方式的概，以增進社會大眾對這些孩童之接受度。

關鍵詞：感覺統合失調、以家庭為中心之服務模式、台灣母親、民族誌研究。