Leisure as a Means of Coping: The Experience of Taiwanese Parents of Adult Children with Disabilities

Pei-Chun Hsieh  
Department of Rehabilitation Sciences  
Temple University

Marieke Van Puymbroeck  
Department of Recreation, Park and Tourism Studies  
Indiana University

Acknowledgement: The research project was funded by Leisure Research Institute (LRI) at Indiana University.

Address all correspondence to:  
Pei-Chun Hsieh  
Department of Rehabilitation Sciences  
Temple University  
Email: pchsieh@temple.edu  
Phone: 215-204-0011
Abstract

The complexity of the caregiving phenomenon suggests a need to explore the diverse voices and perspectives of parental caregivers of children with disabilities concerning the meaning of caregiving within the cultural context. In this study, we used semi-structured interviews to investigate how Taiwanese parents of adult children with disabilities manage their caregiving stress on a daily basis. Through snowball sampling, ten participants were recruited from Southern Taiwan. We found that the parents in this study had gone through a stressful induction process to overcome their denial about having a child with a disability and learn how to manage social stigma. Despite these external stressors, over time the parents developed a variety coping techniques to maintain their health and well-being. Additionally, we found that these parents consciously and deliberately used leisure activities to relieve their stress. Implications for practice and research are discussed.

Keywords: Caregiving, Coping and adaptation, Stress, Stigma, Leisure
Leisure as a Means of Coping: Experience of Taiwanese Parents of Adult Children with Disabilities

Of the 23 million people living in Taiwan, people with disabilities represent 4.45% (1,023,500 people) of the total population (Department of Statistics Ministry of the Interior, 2008). Similar to Western societies, people with chronic illnesses or disabilities in Taiwan have a significantly lower rate of employment and often rely on family members, typically their parents, to look after them (Chou, Lin, Chang, & Schalock, 2007; Chou, Pu, Lee, Lin, & Kröger, 2009; Lin, Yen, Li, & Wu, 2005). The care of children with disabilities is seen almost entirely as the individual family’s responsibility, thus the needs of caregivers are often overlooked by policy makers in Taiwan (Ao et al., 2007; Ho & Huang, 2007). Lacking sufficient formal support, parental caregivers of children with disabilities in Taiwan experience higher levels of physical, psychological, and societal stress and a lower overall quality of life than the general population in Taiwan (Chou, Lee, Lin, Chang, & Huang, 2008; Chou et al., 2007).

Currently, most of the research concerning families of children with disabilities has been conducted in Western countries, with a paucity of research in Asian societies (Chang & McConkey, 2008). Although parental caregivers in Taiwan and in Western countries may share some similar caregiving experiences and outcomes (e.g., higher levels of negative emotions), researchers have suggested that Chinese cultural, religious, and philosophical ideas may exacerbate the negative impact of having a child with disabilities in the family (Chou & Palley, 1998). The present study proposed to explore how Taiwanese parental caregivers view their caregiving experiences as this is an area that has little empirical data. We believe understanding the cultural context when interpreting various situations, such as parental stress, helps capture an integrated picture of the caregiving phenomena.

Literature Review

The Taiwanese lifestyle has changed dramatically over the past 40 years, moving from an agricultural society to a modern industrial society. The traditional philosophical beliefs of Confucianism, Taoism, and Buddhism, however, are still considered essential in Taiwanese culture (Chang & McConkey, 2008; Chiu et al., 1998). The concept of karma, stemming from Buddhism, promotes the idea that everything happens for a reason—cause and effect. A belief in karma suggests that good deeds bring rewards in the future, while violations of moral axioms result in punishment. This traditional belief breeds a social stigma against people with disabilities and their family members because it invokes the idea that a disability represents punishment resulting from evil conduct in a previous life (Chang & McConkey, 2008). With this traditional belief, providing care to the child with a disability is often considered a way to reconcile the sin; therefore, parents may be reluctant to accept help from extended family and friends.

Furthermore, under the beliefs of Confucianism, the Taiwanese focus heavily on social expectations and the reactions of others; an unsuccessful social performance not only brings shame to the individual, but also dishonors the whole family (Holroyd, 2003). Children with developmental disabilities may have behavioral problems or express inappropriate behaviors which violate social expectations and thereby increase the parents’ feelings of a perceived stigma. In Shu and colleagues’ (2001) study, mothers of children with autism in Taiwan reported feeling as though they were a cause of embarrassment to their family and also perceived rejection from
Leisure Coping in Taiwanese Caregivers

A participant in their study said, “My relatives could not accept him until now. They were afraid to see him due to his strange behaviors” (Shu et al., 2001, 208). Additionally, the feeling of dishonoring the family may limit parental caregivers’ interaction with others, causing them to become socially isolated. In Chang and McConkey’s (2008) study, the mother of a child with an intellectual disability reported, “my husband is a doctor, he probably loves him, but… he doesn’t let his colleagues or friends know he has a special child” (p. 35). The additional pressures of not being accepted by society negatively affect parental quality of life, which makes the need for a leisure-based outlet even more important for this population.

The benefits of leisure on quality of life and its ability to moderate stress have been well-documented (Gump, 2000; Strauss-Blasche, Muhry, Lehofer, Moser, & Marktl, 2004). For instance, the literature on caregivers for older adults supports leisure as a beneficial coping strategy for informal caregivers (Bedini & Bilbro, 1991; Bedini & Guinan, 1996; Keller & Hughes, 1991). Researchers have also found that leisure can promote family quality of life (e.g., family unity and bonding) for families of members with disabilities reference? However, previous leisure literature concerning Western countries has shown that caregivers tend to decrease or give up leisure participation due to their caregiving responsibilities (Brattain Rogers, 1997; Stevens et al., 2004). Moreover, families of children with disabilities experience inequities in their leisure participation and have limited leisure choices (Dowling & Dolan, 2001; Jiyeon, Turnbull, & Turnbull III, 2002). Reviewing the existing literature on Taiwanese parental caregivers, it seems that the traditional Taiwanese beliefs may influence the health-promoting behaviors of family caregivers in Taiwan, but the impact of these beliefs has not been explored in terms of the leisure participation of Taiwanese parental caregivers. For that reason, in the present study, we were interested in exploring the following research questions:

1. How do Taiwanese caregivers view leisure?
2. Is leisure participation influenced by providing care?
3. What are the leisure-related needs of Taiwanese caregivers?

Method

We used an interpretive approach with in-depth individual interviews to investigate Taiwanese parental caregivers’ views of, and experiences with, providing care to an adult child with a disability and leisure participation. This approach best reflects the details and nuances of the caregiving experience from the perspective of the respondents, as the meanings of a social event are constructed through the dynamic interaction between individuals and are influenced by the context of the situation (e.g., one’s experience, values and social environment) (Daly, 2007).

Procedures

We utilized snowball sampling to recruit participants from the Kaohsiung region of Southern Taiwan. This recruitment strategy began with key informants who provided the first author with names of individuals who were known to provide at-home care to an adult child with a disease or
disability. The first author, a native Mandarin speaker, served as the data collector and contacted each potential participant to screen for eligibility and willingness to participate in the study. Then, after each interview, the interviewee was asked to provide the name of another individual who also provided care for an adult child with a disability. Inclusion criteria for participation in this study required that an individual be a parent who provides care to an adult child with a disability who required care at least 3 hours per day, 5 days per week.

Data Collection

We used semi-structured interviews that helped participants reflect on their caregiving experience and leisure participation. The following are examples of the interview questions: (1) How do you spend your days since you’ve begun providing care for your loved one? (2) What does leisure mean to you? and (3) What do you enjoy about these leisure activities? When the study was conducted, there were no ethical standards committees operating in Taiwan. Hence, the study was approved by a local Institutional Review Board in the Midwestern United States. A set of questions and probes was developed in English and later translated into Mandarin by the first author who is fluent in both English and Mandarin. The interview questions were then provisionally tested with three Taiwanese individuals to ensure cultural appropriateness.

Prior to the commencement of the interviews, all of the participants signed informed consent forms which addressed the procedure of confidentiality protection and specified the right to refuse to answer any interview questions. Each interviewee was asked to complete the demographic questionnaire, which included questions about age, gender, marital status, education level, employment status, hours of care provided per day, self-rated health, and the use of respite or other care services. The interviews were tape-recorded after the interviewer received consent for taping the interview.

Following a suggestion from the work of Lincoln and Guba (1985), the researchers discontinued data collection when saturation of the data occurred. In other words, we continued data collection until no new information and themes emerged from the interviews. We conducted ten interviews, with four face-to-face interviews and six telephone interviews. Participant preference determined the format of the interviews. Interviewees who opted for the phone interview often explained that their selection of that format was based on their reluctance to conduct the interview in their home combined with the difficulty in meeting the interviewer elsewhere, given their caregiving responsibilities. Each interview lasted between 25 and 75 minutes. The interview recordings were transcribed verbatim in Mandarin and then translated into English by a professional. In order to ensure the accuracy of the translation, the first author reviewed all of the translated documents. A member check was conducted with three of the ten participants. That is, a Mandarin transcript of the interview was given to each participant so that he or she could check it for accuracy and consistency. All three participants reported the transcription accurately reflected the interview.

Data Analysis

We used constant comparison techniques to generate recurring trends in the data (Glaser & Strauss, 1967). During the coding process, we read, reread, and coded each incident in the translated transcriptions to determine the themes and patterns in the data. We compared the
meanings of each category to ensure that no sentences with different meanings were labeled with the same tag. Additionally, we compared similarities and differences between individuals and groups of individuals for attaining maximum credibility. The multiple levels of comparison allowed us to reveal both individual perceptions of caregiving and the experiences shaped by social characteristics. After both authors identified the primary themes independently, we then discussed those individual interpretations of the data to explore each theme in more detail. All subjects were assigned a pseudonym.

**Participant Description**

Ten Taiwanese parental caregivers participated in this study. Of the respondents, 90% were female, 80% were married, 80% were unemployed, and 70% had a self-rated health description of “good.” The average age of the participants was 52 (ranging from 41 to 62) and, on average, these parental caregivers provided 15 hours of care per day. Most of the participants (70%) were providing care to one care recipient (their adult child), while three of the participants were taking care of more than one care recipient (one mother provided care to two children with spinal muscle atrophy, another mother provided care to three children with muscular dystrophy, and yet another provided care to one child with a severe intellectual disability in addition to taking care of her husband who had Parkinson’s disease). The conditions of the adult children, as reported by the parents, varied widely and included intellectual disabilities, cerebral palsy, Down syndrome, muscular dystrophy, spinal muscle atrophy, paraplegia, autism, and blindness with chronic illness. The levels of disability of the care recipients ranged from moderate to severe. Seven caregivers reported that the care recipients needed help for most activities of daily living (e.g., eating, dressing, taking shower, etc.) and all instrumental activities of daily living (IADL). Three caregivers reported that they assisted their children with some activities of daily living (e.g., moving them from their wheelchairs and preparing their meals) and most IADLs.

**Findings and Discussion**

As indicated previously, the purpose of the study was to understand the impacts of having a child with a disability for Taiwanese parental caregivers and the role of leisure in their lives. Through the interviews, we found that these caregivers were aware of the negative impacts of caregiving on their well-being, and had negotiated their caregiving stresses via a variety of coping strategies. The three most salient themes—health and well-being, leisure constraints, and coping strategies—appeared to reflect how parents react to the impact of having a child with a disability.

**Health and Well-being**

The first major theme that arose to answer the research questions was the influence of the caregiving experience on health and well-being. Consistent with previous studies, most caregivers in this study reported that they experienced emotional and/or physical strain due to their caregiving responsibilities (Chang & McConkey, 2008; Ong, Chandran, & Peng, 1999). However, an innovative finding derived from the data suggested that providing care to a child with a disability may motivate the parents to stay healthy in order to provide a higher quality of care to their loved one.
The participants with children who require intensive physical assistance often reported that they experienced body aches, muscle fatigue, and long-term physical illnesses, such as carpal tunnel syndrome and sciatica, as a result of providing care. These findings are similar to others who have shown that caregiving demands have a direct impact on the parental caregiver’s physical health (Brehaut et al., 2004; Raina et al., 2005), and that parental caregivers are more likely to report a greater number of chronic physical conditions, compared to parents of children without any disabilities (Brehaut et al., 2004).

Besides the impact on physical well-being, much of the literature has documented that providing care to a child with a disability can also have negative emotional outcomes for the parents (Baum, 2004; Brehaut et al., 2004). During the interviews, the majority of the participants reported that they experience periodic sadness because of their children’s conditions. Mrs. Peng cares for her son-in-law who suffers from blindness and chronic health conditions, and described her caregiving experience in this way: “To be happy is impossible for me now. Though we laugh, we cry inside. How can you be happy if you have a problem that can’t be solved?” Peng’s daughter works two low-paying jobs in order to support her husband, while Peng stays at home and watches over the care recipient. During the interview with Peng, she expressed that she experiences emotional pain because she does not see any hope for her daughter’s future. She said,

“My daughter is already in her 30s. How can she still have a future? She attended medical school, but didn’t get a license. Originally, she planned to go back to school and take the licensing exam a few years after getting married; however, now she doesn’t have the mood anymore. After a few years, she’ll become 40. And there is no hope left [for my daughter].”

Olshansky (1962) first used the term “chronic sorrow” in describing the recurrent emotional pain experienced by parental caregivers of children with disabilities. He proposed that critical moments in a child’s development, such as learning to walk or graduating from high school, often trigger a feeling of sadness because these parents are reminded of the disparity between their children and others. In Peng’s case, her daughter’s age reminds Peng that, due to her son-in-law’s condition, her daughter’s life has deviated from the one Peng had hoped she would have. Even the appearance of the first author, who is close in age to Peng’s daughter, seemed to have evoked those feelings of sadness, as during the interview she made comparisons between her daughter and the first author: “We pampered our daughter before she married. Her hands were as pretty as yours.”

Despite the aforementioned negative physical and emotional impacts of providing care to an adult child with a disability, interestingly, some participants implied that providing care to their child motivated and encouraged them to stay healthy. With regard to the state of their own health, several caregivers made comments like, “How can I take care of him [the care recipient] if I’m not healthy?” (Ms. Hsu, the single mother of a child with Down syndrome). The majority of the participants in this study rated their health as good or better. Mrs. Tsao, the mother of a child with severe intellectual disabilities, explained the need for her to be involved in health promotion activities:

“I told myself to maintain an exercise habit in order to stay healthy. It’s better for her [the care recipient] if I’m healthy. Otherwise, it would be terrible for both of us. . . . So I keep telling myself that I need to stay healthy.”
Many, if not all, of the participants expressed the idea that their health is crucial in quality caregiving. They worried that no one would be able to take care of their children if their own health became a concern. For many of the parents in this study, this concern becomes a motivating factor for participating in health promotion activities. This is an innovative finding, as previous studies mainly focused on the negative impacts of caregiving (Brehaut et al., 2004). It is worth noting, though, that while participants recognized the benefits of health promotion activities, such as leisure or physical activities, they also experienced some constraints to their leisure participation.

**Leisure Constraints**

Leisure time is generally thought to be filled with enjoyable activities which provide opportunities for relaxation and refreshment from daily fatigue. Ms. Yu, a single mother of three children with muscular dystrophy, explained what leisure meant to her:

> Leisure is time for me to restore energy from my caregiving duties. I take care of my three children all by myself. Even when I feel exhausted, I have to do it because no one else could help. Leisure would be nice. It also would be good if I can go out sometimes.

During the interview, all participants acknowledged the benefits of leisure, such as relaxation, relationship-building, enjoyment, self-development, and rejuvenation from the rigors of caregiving duties. Mrs. Wang, whose two children (a son and a daughter) have spinal muscle atrophy, provides another example concerning how leisure can help one to cope with maternal stress in early years when:

> I took my sons to the Cheng-Ching Lake [a park nearby] by scooter. I had a small chair in the front platform for my eldest son [who has spinal muscle atrophy] to sit in and second son on my back. We went to see the sunset and the night scene. I let my second son walk around and watch other children skate. We were happy at that moment. Otherwise, when life got too hard, I felt like committing suicide.

From the examples above, we found that these caregivers perceived the benefits of, and have a desire for, leisure time; however, they experienced various barriers that potentially kept them from participating in leisure activities as frequently as they wished. There were three main leisure constraints reported by these parents: social stigma, time restriction, and ethic of care.

**Social stigma**

Many parental caregivers in this study reported that they experienced prejudice, social barriers, and poor service during their leisure participation. Mrs. Tsao stated, “If I take her [a 38-year-old female with severe intellectual disabilities] out with her classmates and their family members, then it’s fine. But if I take her out with other able people, we have to bear their judgment.” This experience was repeatedly expressed by participants in this study, supporting previous studies that suggested the perception of stigma can affect parental caregivers’ quality of life by increasing their subjective burden (e.g., embarrassment, guilt, shame, resentment, worry or other emotional upset) and social isolation (Green, 2003).
Some caregivers internalized the negative attitudes of others about their children and reported that they felt ashamed of being seen in public. The feeling of a perceived stigma became a barrier that prevented them from leisure participation and increased their social isolation. Mrs. Tsao, the mother of a child with severe intellectual disabilities, shared her experience:

It’s hard to step out at the very beginning. I felt shame to have this kind of child. In the first few years, I was afraid of others’ malicious gaze. It felt so unfair and I wondered why they stared at me like that. . . . Sometimes people passed by and turned back to look at us. I don’t know what they are looking at.

Although these parents experienced emotional turmoil due to the perception of negative attitudes toward their children, they developed different strategies against the stigmatizing reactions of others in order to participate in leisure. For example, some caregivers chose to do outdoor activities in remote areas with fewer visitors around or participated in activities held specifically for people with disabilities. For example, Mrs. Wang explained that she felt embarrassed to bring her son, who has spinal muscle atrophy, out in the beginning due to the fear of being “stared” at. She said,

There was a time when my first son [a 32-year-old male with spinal muscle atrophy] was just born, I felt really depressed. I never dared to bring him out. I was afraid about how people would stare at me, what people would gossip about me.

When I asked how she overcame the feeling of a perceived stigma, she said:

I entered the association [Taiwan SMA? Families] for 4 years only. . . . We started to go out and join group activities only for these few years. Before, my husband and I, we had our children in hands, and we usually went to remote areas and had fun in the corner to avoid other people. We did not dare have activities with other people, in public. We were afraid that people would ask us [about the child’s condition].

Many caregivers have similar experiences and find group activities held by associations for people with special needs beneficial for both parents and children. Mrs. Yu explained, “We all need friends after all. And friends care for one another. I feel better to talk to them and we can share some experiences in taking care of our children.” Through talking with other parents who have children with disabilities or taking educational sessions provided by professional organizations, these parents were able to empower themselves. They reported that they changed their attitudes about having a child with a disability and that, in turn, changed their responses to the negative attitudes or reactions of others. When asked about how she now deals with the stigmatizing reactions of others, Mrs. Yeh—who earlier lamented, “I felt shameful to have this kind of child. . . .”—reported, “it’s a matter of how I think about it. I have to be positive first otherwise no one can help me.”

Through the voices of these caregivers, we found it to be clear that these parents received a variety of benefits during their leisure participation. However, they first had to deal with a harrowing induction process to overcome the feeling of a perceived stigma. In addition to the perception of a stigma, we found that these parents experienced other leisure constraints.
Time restriction

The need for physical assistance in the activities of daily life can be time consuming for the parents of a child with a disability. Many parents in this study reported that they did not have time for themselves. For example, when Mr. Chou, the father of a child with autism and severe intellectual disabilities, was asked about the impact of having a child with a disability on his life, he noted, “I am restricted. My time is restricted, because of him.” Time was the major leisure constraint reported by the participants, although, interestingly, we found that participants have limited their leisure participation due to a feeling of restriction in time, or a perceived constraint, as they often reported, “I am not free.”

Ms. Hsu, a single mother whose child has Down syndrome, commented about the impact of caregiving on her leisure life and said, “I could still go out. But if the activity does not fit in my time schedule, then I do not like to attend. Because if I attend the activity, sometimes the time does not allow [me to be back in time], then I don’t feel like going anymore.” During the interview, Ms. Hsu reported feelings of time pressure and restriction because of the need to be at home at certain times in order to prepare meals for her son. The real and perceived time restrictions of their caregiving duties caused these parents to select leisure activities that required less of a time commitment. Finally, we found that even when these parents participated in leisure activities, they still worried about their child’s condition constantly. They reported that they decreased or ceased their leisure participation because they could not fully enjoy the activity. In the following section, we continue to discuss how the ethic of care became one of the major leisure constraints for these caregivers.

Ethic of care

The ethic of care was one of the major constraints these caregivers experienced during leisure participation. Due to this ethic of care, many of the parents in this study reported that they placed their care recipient’s needs before their own and considered leisure participation as being “selfish”. Mrs. Wang reported, “I would like to travel abroad, but I still think that my children are my first priority. There will still be chances [for me to travel abroad] in the future.” Like Mrs. Wang, all but one of the participants in this study abandoned their desire to travel abroad due to their caregiving role. These caregivers also ceased participation in overnight trips, often changing the schedule or duration of the leisure activity to accommodate their caregiving duties. Mrs. Hou, the mother of a child with paraplegia, explained a change in her leisure participation after her daughter’s motor accident:

My daughter can move around [the house] by her wheelchair so I can leave the house if I want. However, I won’t leave for too long. I usually get back as soon as possible, because I’m worried about her alone at home.

Although these parents could use formal services provided by the government, including day care and respite care, most parents commented that they will not use the respite service to fulfill their leisure needs. Mrs. Cheng provided an explanation as to why she will not use the respite care service: “I want to, but [pause] I can’t. I can’t just go out to have fun myself and leave my child to others. I feel worried about my child. I won’t go out to have fun myself.” The feelings of constant worry not only prevent these caregivers from participating in some activities, but they
may also hinder them in the enjoyment of the activity once they do participate. Mrs. Peng commented about the ways having a family member with a disability impacts her leisure:

Leisure… it depends on your mood. If you don’t have the mood, you can’t concentrate and calm your heart down even if you do exercises. It’s the same thing, if you are not happy, even if you see nice scenery, you won’t feel happy. If you are happy, even the scenery is not that good, you still feel great. It’s the same for leisure and physical activities, you have to have a peaceful mind. I don’t really have any leisure.

In sum, we found that their leisure participation changed in terms of schedule and frequency depending on their perception of their caregiving roles and responsibilities, as well as the feeling of a perceived stigma. Over time, these caregivers developed a variety of strategies to cope with social stigma of having a child with a disability during their leisure participation; however they seemed to cease their leisure participation due to time constraints and ethics of care. Previous research has suggested that parental caregivers often experience increased feelings of isolation (Gravelle, 1997). As one known benefit of leisure participation is to develop a larger social network, many participants actually reduced or gave up their leisure participation and that further limited their opportunities for social involvement. More importantly, though many participants in this study reported that they desired leisure, they appeared reluctant to negotiate with their leisure constraints. They tended to give up or decrease their leisure participation due to their caregiving duties. All participants explained that their child’s needs were their first priority.

**Coping Strategies**

As we discussed above, participants in this study reported experiencing emotional and/or physical strain due to their caregiving responsibilities. We also found, however, that caregivers in this study utilized various strategies to manage their caregiving stress. Four common coping strategies reported by these caregivers were social support, social comparison, religion, and acceptance.

**Social support**

Many caregivers reported that the social support they received from family, particularly spouses, was the most important factor in easing anxiety. The participants who received support from family did not take it for granted. They (often mothers) expressed their gratitude to their spouse for being supportive and not blaming them for the child’s condition. For example, Mrs. Wang, the mother of two children with spinal muscle atrophy, explained how she coped with her caregiving stress,

I rely on a kind of emotional support [from my husband]. My husband doesn’t give me any pressure. . . . When he gets back [from work], he helps to take care of them. He doesn’t complain that it’s because of me that my two children have the disease and never gives me any pressure. So I feel thankful.

The gratitude for her spouse performing his role as father is indicative of the feelings of shame and guilt stemming from having a child with a disability that are rooted in Taiwanese social values. Many participants in this study considered themselves responsible for their children’s
illnesses and the emotional support of their family proved to be vital in relieving this guilt. This finding is consistent with a previous parental caregiver study conducted by Baum (2004) which found that family, particularly one’s spouse, was the most important source of emotional support for parental caregivers of children with special needs.

In addition, the emotional support of family members may have a significant impact on Taiwanese caregivers’ well-being. Participants also reported that they received financial and physical support from their family. For example, Mrs. Cheng reported that she is able to attend a Buddhism course once a week because her husband watches the care recipient while she is gone. Some caregivers in this study, however, perceived rejection from the family. Yu, the mother of three children with muscular dystrophy, reported that she did not receive any support from her parents-in-law because “they all blamed me for the children’s condition.” Studies have shown that levels of social support were the most powerful predictors of depression and anxiety in mothers (Doering, Moser, & Dracup, 2000; Speechley & Noh, 1992). This finding echoes a hypothesis proposed by Chou and Palley (1998) which suggests that the lack of supportive systems may evoke in parental caregivers those feelings of shame and guilt which are rooted in social values and societal reactions, thereby becoming the major stressor for Taiwanese families who have children with disabilities.

Interestingly, though all of the participants received some forms of support from the government (all of the participants received financial subsidies and eight participants have used respite care or have hourly at-home care nurses provided by the government), none of the participants noted the formal services as an aid in relieving their caregiving stress. Quite the opposite - many of the participants felt frustrated when discussing the formal support from the government.

**Social comparison**

Social comparison theory suggests that people have an urge to evaluate self-abilities based on comparisons to other people (Festinger, 1954). Based on Festinger’s social comparison theory, developing an activity with a group of people with similar abilities may increase their feelings of belonging and their ability to associate with other group members. This study’s findings support this theory; parental caregivers in this study found satisfaction through associations with other parental caregivers in a group activity. Group activities with adult children who have similar disabilities provide both parents and children an opportunity to relate to one another and share their experience. Mrs. Wang explained why she enjoyed participating in the group activity and said, “I wanted to let my children get in touch with other people like them, make them realize that they are not the only children like this, and there are more children whose illness is more serious than theirs.” Mrs. Wang expressed her desire to help her children feel less “different” through interacting with other people with similar disabilities.

Later, Mrs. Wang also expressed that she validated her feelings about having children with disabilities through discussions with other families experiencing similar issues. She reported,

> When we join the association, we see other families that live an even more difficult life than us. . . . We often talked about our moods, family issues, financial problems or relationship with spouses. Some wives were deserted by their husband. I felt fortunate that my husband is willing to take care of us and work hard to support us financially.
Similar to Mrs. Wang, we found that other caregivers in this study also perceived some benefits from comparing themselves with others who are experiencing similar issues. Mrs. Yen, the mother of a child with autism and severe intellectual disabilities, provided another example. She shared how she felt about having a child with a disability and said,

> When I was in a hospital for my knee rehabilitation, I saw a child who has cerebral palsy. His hands and feet are twisted. . . . I saw that child doing rehabilitation. I feel myself was fortunate enough that my son can walk. When I saw his condition, I wondered why his mother didn’t give him up. But if you gave birth to a child, he is yours, so you have to take care of him without complaint.

Wills (1981) proposed that individuals who experience a threatening experience can bolster their negative emotions through comparison with someone who is less fortunate than themselves. We do not suggest that these parents gloated over someone else’s misery. In fact, they often expressed how they sympathized with the unfortunate situations of others. However, the comments from the caregivers in this study provided some support to Wills's theory of downward comparison. Many parents compared their condition to others who are less fortunate than themselves and reported that it helped them feel better about their own situation.

**Religion**

When the participants were asked how they coped with their caregiving stress, reading Buddhist scriptures and prayer were the most commonly reported coping strategies. Mrs. Wang explained how she managed her caregiving stress:

> I read Buddhist scriptures in the morning and in the evening. I also handwrite the copy of “Ksitigarbha Mantra” to kill time every day. People say that if you read “Ksitigarbha Mantra”, your sin will be eliminated soon. I feel really good, because . . . In “Ksitigarbha Mantra”, everything about life is explained, then you’ll realize gradually how life and things work. Sometimes you come to understand the cause and effect of things happened in your life from one or two lines of the scripture.

Yen and Lundeen (2006) found that Taiwanese caregivers with a religious affiliation perceive caregiving more positively than those who do not have religious beliefs. Many caregivers in this study reported that reading religious scriptures and prayer are ways to release their stress because they can shift their attention from caregiving to larger life issues or focus on unburdening themselves of sin.

Moreover, we found that their religious beliefs also influenced their view of caregiving. Many parents in this study used the word “indebted” when they described how they viewed their caregiving responsibilities. Ms. Yu explained how she felt about providing care to her three children with muscular dystrophy and said, “I think it’s my fate. Probably it’s because I owed them [the care recipients] in my previous life so that I have to pay them back now.” The comment from Yu reflected the traditional belief in karma - they need to take care of their ill children now because they were indebted to their care recipients or they violated moral axioms in a previous life. In other words, providing care to others is a way to repent or pay off the moral debt of a past life. This belief provides them a sense of inner-calm and allows them to imagine
that their next life will be better. The findings of this study echo Chao and Roth’s (2000) ideas that the caregivers’ beliefs were reflected in how they cope with the strain of caregiving and that a perceived sense of spiritual rewards encourages them to continue providing care.

Acceptance

All parents in this study reported that it was initially difficult to accept or understand why their child was born with or acquired a disability or chronic illness; however, over time, they accepted and learned to manage their child’s condition. Mrs. Yuan, whose son became a paraplegic at age ten due to a motor accident, explained how she felt about her son’s condition in the beginning:

When he was injured, my initial thought was why this happened to him. . . . Then I changed my thought. I accepted the fact that he has a disability and needs my assistance. After I grew acceptance about his condition, I felt better.

Copley and Bodensteiner (1987) reviewed the concept of chronic sorrow in families who have a child with a disability and posited a two-phase model of the bereavement process as experienced by parents of children with disabilities. They proposed that within the first phase, parents experience an emotional roller-coaster ride by moving circularly in the stages of impact-denial-grief. Only parents who learn to accept their child’s disability can break the cycle and move from Phase I to Phase II, in which parents successfully integrate the child into their life and experience emotional eruptions that are less frequent and less intense. The findings of this study seem to echo Copley and Bodensteiner’s hypothesis in that the parents in this study did experience a period of denial-grief, but over time they gradually accepted the child’s condition. We also found that interacting with other parents who have similar experiences may facilitate the transition from Phase I to Phase II. For example, Mrs. Cheng, who has a son with severe intellectual disabilities, expressed how she felt after finding out about her son’s condition:

I couldn’t accept it at the beginning, I couldn’t understand it. But gradually, I learned to accept the fact. Because I realized that I can’t change the fact, so I have to accept it. And it’s helpful to join some group activities, talk with other people then I feel better. I talk with other parents who have the same problems, then I realize that there are people who suffer like me and then we share our experiences. I became more understanding.

Apparently, learning to accept the fact of having a child with a disability was a turning point for these parents; their emotional well-being was influenced by how well they accept or adapt to their child’s condition.

Conclusion

This study provides the first data that examines the leisure participation and needs of Taiwanese parental caregivers; thus, this study represents an exciting venture into a previously unexplored area. First, caregiving experiences provided by the participants in this study seemed consistent with the findings from other cultures in terms of negative emotions or physical strain. However, the finding that having a child with a disability may become a motivating factor for health promoting behavior is new and, therefore, needs further investigation. It is worth noting, though, that while the caregivers in this study commented on the crucial role of their health on their
caregiving responsibilities, they also decreased or ceased their leisure participation due to their caregiving role. The complex findings on this issue require further study.

Based on the findings, it is clear that participants in this study experience some benefits--such as social support, friendships, and social acceptance--when they participated in leisure activities with other parental caregivers. They also reported that these activities helped them feel relaxed and disengaged from stress in that they were able to be away from the caregiving environment. The findings, then, show that parental caregivers desire leisure and that leisure does ease their stress and enrich their lives. Although previous studies on family and disability have suggested the importance of social support in a caregiver’s well-being, the previous literature did not make the connection that caregivers could develop feelings of support through leisure participation.

Coleman and Iso-Ahola (1993) examined the relationship between leisure and health and concluded that leisure can buffer people against the negative outcomes of life stress through leisure-based social support and leisure-generated self-determination. The findings of this study may provide partial support to the views of Coleman and Iso-Ahola, as many caregivers in this study did report feelings of perceived support from other parents who share similar experiences. More importantly, though, we found that attending activities with other parental caregivers provided an outlet for these caregivers to share their caregiving experiences and to “normalize” their life, which may help reduce the feelings of perceived stigma. Future research is encouraged to investigate the relationship between group activities including families with similar experiences and feelings of a perceived stigma.

Next, previous studies have largely focused on the negative impacts of providing care to a child with a disability. Some studies have revealed that over the course of years, parents of children with a disability develop some strategies to fight against their stress (Abbott & Meredith, 1986; Luescher, Dede, Gitten, Fennell, & Maria, 1999). This perspective was supported by the findings of this study. Parents in this study used a wide variety of strategies to cope with their stress and provided some potential explanations as to how Taiwanese parental caregivers fight the strain of caregiving. According to the study by Luescher and colleagues (1999), the degree of the caregiving burden depends more on the parent’s coping ability and the family’s functioning, than on the demands of the child’s condition. Four coping strategies revealed from the findings in this study were social support, acceptance, social comparison, and religious beliefs. Some of their coping strategies may be unique to the Taiwanese culture, such as the beliefs in karma; while despite the different cultures, parental caregivers in both Eastern and Western countries may utilize some similar strategies in managing their caregiving stress. Parental caregivers in Abbott and Meredith’s study (1986) also reported acceptance, family support, and religious beliefs as major coping strategies. The findings may help further investigations as to why some parental caregivers are resilient and thrive despite their negative life circumstances.

Although the findings of this study are not generalizable, the rich description may provide some directions for future research related to parental caregivers and may provide practitioners with some insight into working with this population. As Prezant and Marshak (2006) reported, American parents of children with disabilities do not perceive all of the professional services they receive as helpful. Recently, researchers in Taiwan have urged a reformation of social welfare policies by extending the focus from solely the needs of individuals with disabilities to the inclusion of the needs of parents as well (Chou, Tzou, Pu, Kroger, & Lee, 2008; Ho & Huang,
The findings of this study could provide practitioners with insight concerning how to facilitate and promote leisure participation as beneficial for parental caregivers.

Second, though previous studies have investigated the travel patterns of families with a member with a disability (Jo, Huh, Kosciulek, & Holecèk, 2004; Mactavish, McKay, Iwasaki, & Betteridge, 2007), the role of leisure in the daily lives of parental caregivers has not previously been studied. The findings of this study might reveal elements of leisure that can contribute to these parental caregivers’ well-being in terms of coping with caregiving stress, and support large-scale development in the continuing investigation of the relationship between leisure and stress in this population. Finally, Blacher and Hatton (2001) suggested, “the impact of disability on the family is clearly reflective of the political and economic climate, and as these change, so too will the level of burden” (p. 480). In the United States, families of children with disabilities receive a wide range of professional services. It is interesting to find that in a different culture with different societal organizational services, parental caregivers in Taiwan demonstrated behaviors and experiences similar to those of parental caregivers in Western literature, particularly in terms of coping mechanisms and caregiving strain.

Nevertheless, several limitations of the present study need to be acknowledged. First, due to the small sample size, the findings cannot claim to wholly represent the Taiwanese parental caregiver population. Additionally, the participants in this study were mainly recruited from an urban area; therefore, the study may not represent the diversity of the population. Chou and Palley (1998) suggested that families in rural settings who have a member with a disability often have limited access to social resources and are also under greater traditional cultural influences, compared to those in an urban setting. Therefore, caregivers from rural and urban areas may experience very different stressors. Future research using more diverse samples is recommended, for instance, using broader geographic regions and different disability types in examining the needs of leisure participation for Taiwanese parental caregivers of children with a disability. Second, the researchers were aware that their knowledge of the relative caregiving literature may have increased the risk of misleading participants’ responses, and tried not to impose their perception on the participants. To ensure the objectivity of the data analysis, two authors analyzed the data separately and reached agreements on the major themes generated. Finally, we understood that the format of the telephone interview would miss opportunities to observe the participants’ facial expressions, which may have been delivered with considerable emotion. However, to respect the participant’s choice, six interviews were conducted by telephone.

In sum, this study provided initial information on what leisure means to these Taiwanese parental caregivers and how their caregiving duties affect their health and quality of life. First, previous literature found that providing care to a child with a disability may have negative impacts on parental caregivers’ well-being (Haveman, van Berkum, Reijnders, & Heller, 1997; Plant & Sanders, 2007). Recently, a few studies have supported the idea that parental caregivers may receive psychological benefits from their caregiving responsibilities, such as feelings of gratitude and closeness to their child with a disability (Green, 2007; Hastings & Taunt, 2002). The findings of this study further supported the view? that having a child with a disability may be a motivational factor in helping parental caregivers stay healthy, as it allows them to provide a better quality of care to their loved one. This finding suggests to practitioners that, when working with parental caregivers, they should not overlook the positive impact of caregiving on parental well-being. In addition, when providing leisure education or health promotion programs, it might
Second, participants in this study experienced several leisure constraints, including social stigma, time constraints, and ethic of care. These constraints are not unique for Taiwanese caregivers; in fact, they are commonly experienced by caregivers in Western countries. Previous studies conducted with parental caregivers in Western countries have found that parents of children with a disability experience stigma and that perceived stigma has a negative impact on parents’ well-being (Green, 2007). In addition, Havemen et al. (1997) found that parental caregivers experience increased feelings of social isolation due to limited time available for themselves. For practitioners, however, it is worth noting that in Taiwan, social stigma toward people with disabilities might be exacerbated by Chinese traditional culture and religious beliefs and that families with a member with a disability may therefore experience higher levels of stigma and social isolation. Previous studies compared attitudes toward people with disabilities in various ethnic groups and found that Chinese people who were born in East Asia are more likely to distance themselves from people with disabilities and have more negative views toward people with disabilities compared with other people born in America and Europe (Saetermoe, Scattone, & Kim, 2001). In collective societies, families might want to hide the member who has a disability from the public eye to prevent the stigma against people with disability from spreading to the whole clan (Westbrook, Legge, & Pennay, 1993) and therefore, as supported in the findings of this study, they may hesitate to participate in outdoor leisure activities with their loved one who has a disability. More studies are required to examine if Asian people who were born in America and Europe still hold the same beliefs as those born in Asian countries.

Finally, parental caregivers in this study developed several strategies to cope with their caregiving burden, including social support, social comparison, religion, and acceptance. Practitioners in the leisure field should understand that, for this population, limited leisure participation may increase their feelings of isolation. In addition, parental caregivers can develop the above listed coping strategies through leisure participation. Therefore, a program of leisure education or counseling is needed to help these parents recognize the need for pursuing leisure activities. Additionally, the findings suggest that group activities for families with adult special needs children can provide an outlet for both caregivers and care recipients to share their experience and enlarge their social network in a leisure setting.
References


Green, S. E. (2007). 'We’re tired, not sad': Benefits and burdens of mothering a child with a disability. *Social Science & Medicine, 64*(1), 150-163. doi: 10.1016/j.socscimed.2006.08.025


