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Liu Shenglin
Faculty of Education Science, Sichuan Normal University
Chengdu, Sichuan, China

Miloň Potměšil
Institute of Special Education, Faculty of Education, Palacký University
Olomouc, Czech Republic

Chinese families' adaptation to childhood deafness: implications for psychoeducational support for families with deaf children in China

Introduction

It was the family, not the child that was in turmoil when a child was diagnosed with a disability (Gregory and Knight, 1998). For most parents, our children are everything to us: our hopes, our ambitions, our future (Department for Education and Skills, UK, 2003). For the overwhelming majority of families, the birth of a child with any disability can create severe stress, which parents find difficult to manage. Numerous studies have documented the impact of a childhood disability on family life. For example, Singer and Farkas (1989) used the Impact-on-Family Scales to examine the maternal perceptions of the impact of infant disability on various components of family life. The results showed that a high degree of maternal stress was related to caring for their young children with developmental disabilities. Thirty-two respondents reported that the child's disability affected all aspects of family life. Problems with family social interactions and with finances were cited by the majority of mothers in this sample. Other researchers proposed that the responses of parents to the diagnosis of a serious disability in their child had many parallels with reactions to bereavement. The main difference was that the child's disability was a permanent source of sorrow, whereas death marked a crisis point beyond which readjustment could begin (Hall and Hill, 1996). According to Barnett et al. (2003), some common parental reactions to a child's disability were as follows: (1) feeling devastated, overwhelmed, and traumatized by the news; (2) shock, denial, numbness, and disbelief; (3) a sense of loss for the "hoped for child"; (4) feelings of guilt, responsibility, and shame; (5) marital and other family relationships becoming severely strained, etc.

Childhood deafness, especially deafness beginning at birth and in early childhood, can constitute a disability with serious ramifications for the rest of the family, especially when the parents are hearing because of the significant developmental gap between hearing impaired children and hearing children. A number of studies have investigated the negative impacts of childhood deafness on family life. For example, Meadow-Orlans (1995) investigated the stress of hearing mothers and fathers of 20 deaf or hard of hearing (D/HH) and 20 hearing nine-month-old babies using the Parenting Stress Inventory and a questionnaire tapping the Stress of Life Events and found that mothers whose infants were D/HH reported greater life stress compared to mothers of hearing babies. Calderon et al. (1999) proposed that the stress and challenges of raising a deaf child were most often associated with the diagnosis of hearing loss, learning new communication methods, being more involved in educational decision making, increasing contact with professionals in a number of disciplines, and purchasing and using technological supports, as well as the everyday experience of having a child who is different and communicates in a different manner. Jackson et al. (2008) used a qualitative method to collect a detailed description of parents' experiences from nine parents of eight children who were deaf. The results showed that hearing mothers all expressed feelings of intense emotion such as shock, fear and uncertainty of the future, etc. when the child was diagnosed with deafness. Most of the hearing parents in the study emphasized their relationship with their children as influenced often by the child's deafness and communication difficulties.

However, childhood deafness is not a barrier that is insurmountable for every family. While many researchers draw attention to the impact of childhood deafness on families, other researchers shed light on how families adapt to this crisis. Calderon et al. (1999) recruited 36 families with deaf children to examine the factors affecting mother and child adjustment. Results indicated the following: (a) social support emerged as an important predicator of maternal adjustment as well as a buffer between current life stress and maternal adjustment, and (b) maternal problem--solving skills, such as finding someone to talk to, finding appropriate resources for the child and arranging the child's educational programme emerged as a significant predicator of a child's adjustment. Hintermair (2000) reported stressful experiences of parents with hearing-impaired children in Germany. The results suggested that parents who frequently met with other parents showed evidence of a warm, accepting, trusting relationship with their child. Also, the findings of this study demonstrated that parents who had many contacts with hearing-impaired adults showed evidence of a strong sense of competence in regard to their child's upbringing. Štěrbová (2007) studied the coping behaviour of families with hearing impaired children in the Czech Republic. As a result of this study, she was able to list a large amount of coping behaviours which were indicated by mothers as very beneficial and useful, such as having active contact with children, endeavouring to maintain family stability, guiding children with a health disability to greater independence, maintaining calm and balance, speaking with doctors and specialists about matters relating to the child's health disability, and building a closer relationship with one's partner (2007, p. 129).

Nonetheless, disability, especially deafness, is a term that is culturally, historically, and philosophically relative in its interpretation. According to the World Health Organization (2001), a person's functioning and disability is conceived as a dynamic interaction between health conditions (e.g., disease, disorders, injuries, traumas, etc.) and contextual factors. Contextual factors represent the complete background of an individual's life and living conditions. Among them the environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. These factors are external to individuals and can have a positive and negative influence on the individual's performance as a member of society, on the individual's capacity to execute actions or tasks, or on the individual's body function or structure (WHO, 2001, p.16). As for childhood deafness, there are three models of deafness: the medical model, the social model and the linguistic model, and each looks at deafness differently. As a result, the impact of childhood deafness on a family and the family's adaptation is complex and contextual and depends on factors such as social attitudes toward deafness and social support for deaf children and their families.

Further, despite the numerous studies that had been conducted to investigate the impact of childhood deafness on family adaptation, those studies primarily used white, middle-class families in western countries as samples. Less attention has been given to families with diversified cultures and social contexts, such as China. China is a large developing country with a social and cultural background that is unique from other countries across the world. It is a country with a population of more than 1.3 billion, nearly one-fifth of the world's population and, consequently, a country of rigorous competition for education and employment. Additionally, China has a large population of disabled people – 82,960,000, and among them 3,890,000 are disabled children under the age of 14 years according to the statistics of the Second National Disabled Persons Sample Survey conducted in China in 2006 (National Bureau of Statistics of China, 2007). These children are the most vulnerable when competition for education and work is concerned. At the same time, China is deep rooted in Confucianism, which stresses the importance of offspring and the importance of a child's education. As a result, Chinese families show strong passion and motivation for providing a better education for their children (Lee et al., 2009). However, it is well-documented in the field of deaf education that the majority of deaf children achieve lower educational attainment than their same-age hearing peers (Marschark, 1993). Without a doubt, having a deaf child will violate every Chinese parents' deep-rooted expectations associated with having a completely healthy and promising child and will have far-reaching effects on the Chinese family's life. In these circumstances, it is important to evaluate how Chinese families adapt to the stress of having a deaf child in the family. This question is critical to researchers in the fields of disability and intervention research across the world.

Theoretically, the family as a functional unit adapts to stressful conditions through the process of restoring balance between their capabilities and demands while still facing their challenges (Patterson, 2002). During the past decades, several conceptual frameworks had been developed to explain the process of family stress adaptation, namely Hill's ABC-X model (1958), Patterson's FAAR model (1983), McCubbin and McCubbin's Resilience Model of family stress, adjustment, and adaptation (1989) (Weber, 2010). This study adopted the ABC-X model, one of the earliest theoretical explanations of how families vary in their responses to stress, as its theoretical framework due to the fact that it had been widely used as a useful tool for identifying the components that determine how successfully a family manages stressful events (Wilmoth and Smyer, 2009). The ABC-X framework involves the following: Factor A is the stressor event that has the potential to change the family system; Factor B is the family's resources that assist the family in solving the problem mainly stemming from the individual members, the collective family, and the community; Factor C is the meaning a family assigns to an event; Factor X is outcomes that occur on a continuum from maladaptation to bonadaptation[1] depending on the interaction of the event, the family's resources, and the meaning the family ascribes to the event (Wilmoth and Smyer, 2009). With ABC-X as the conceptual framework, this study sharpened its focuses on the following specific questions: 1) What are the impacts of childhood deafness on Chinese families? 2) How do Chinese families perceive childhood deafness? 3) What resources do Chinese families use to buffer the impact of childhood deafness? And 4) what are the general outcomes of how Chinese families adapt to childhood deafness?

Method

Questionnaire

To investigate the questions mentioned above, a questionnaire consisting of four parts was developed. The first part concerned information about the informant's background, including the relationship between the informant and the participant child, residence, educational level, and the duration of taking care of the participant child. The second part collected background information about the participant child, including the child's age, gender, if the child's parents were married, if the parents were hearing, the family's social economic level, the number of children in the family , the degree of the child's hearing loss, the diagnosis time of hearing loss, the onset of hearing loss, the amount of time the child wore hearing aids, who paid for the hearing aids, the time the child had been using cochlear implants, the payer of the cochlear implants, the child's communication mode, the types of therapy the child received, the payer of the therapy, the child's educational placement, and the payer of the special education. The third part was the main body of the questionnaire, which consisted of 29 items. These items were designed to examine the impact of childhood deafness on family life, the family's perception of childhood deafness, family collective resources, and community resources to buffer the impact of both childhood deafness and the level of family adaptation, the parent's subjective appraisal of parenting a deaf child, and other themes relevant to family adaptation. These items were marked on a five-point Likert scale. Every sentence contained only one complete thought with five possible responses as follows: not true at all (1), rarely true (2), sometimes true (3), often true (4), and true nearly all of the time (5). The fourth part of the questionnaire involved three open-ended questions to examine any difficulties the family encountered in parenting, the main way in which the family communicated with the child, and the most effective help the family received in parenting.

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[1] Bonadaptation is defined as „meeting the needs of the individual family member to enable them to achieve their maximum potential and also the functioning of the family system and its transactions with the community (work place, school, health care system)" (McCubbin, M.A. (1993). Family Stress Theory and the Development of Nursing Knowledge About Family Adaptation. [In:] S. L. Feetham; S. B. Meister; J. M. Bell & C. L. Gillis (Eds.) *The Nursing of Families*. New Bury Park: Sage, 46–58, p. 50).

Participants

One hundred and seven main caregivers of deaf children between the ages of 31 and 220 months, with severe or profound hearing loss from three special schools and the Chengdu Disabled Children's Early Rehabilitation Centre in Sichuan province, a western and relatively underdeveloped area in China, were invited to participate in the questionnaire survey. Considering the diverse family systems and the fact that the parents were not always the persons who knew the child best and were not always the main caregiver of the deaf child, the main caregivers for this study were defined as those caregivers who had been with a child more than one year and consequently knew the child best. In some cases, this was a parent, and in others it was not. This caregiver was invited to represent the family of the deaf child and present their responses on behalf of the whole family. Among the participants, the overwhelming majority of caregivers were parents and both had normal hearing. Other participants were grandparents or other relatives. More families lived in rural areas rather than urban areas; more families were from a lower income group than a middle income group, while no family was with a higher economic status; and the majority were married. Generally, these families can be viewed as representative of typical Chinese families with deaf children. Detailed data regarding the participants are listed in Table 1.

Given that child-related factors and relevant intervention services were often regarded as significant important factors which affected family adaptation to childhood deafness (Calderon et al., 1999), this study also collected information concerning the children's demographics, hearing-loss-related characteristics, and the nature

Variable	N (n=107)	%
Main caregiver		
Father	20	18.69%
Mother	62	57.94%
Grandparent or others	25	23.36%
Parental hearing		
Both hearing	100	93.46%
Both deaf	2	1.87%
Mixed	5	4.67%
Family residence		
Urban	35	32.71%
Rural	72	67.29%
Family income status		
Lower	61	57.01%
Middle	46	42.99%
Parental education		

Illiterate	2	1.87%
Primary education	16	14.95%
Secondary education	77	71.96%
Higher education	13	12.16%
Parental marriage		
Married	97	90.65%
Separated	6	5.61%
Divorced	4	3.74%

Tab. 1. Key characteristics of participant families

of intervention services the children received. One point that needs to be mentioned is that despite the national one-child policy that has been implemented in China since the 1980s, 41.12% of the participant children were not the only-child in the family. This phenomenon can probably be attributed to supplementary regulations of the one-child policy in China, which state that if the first child in the family has a certificated but not genetic disability, the family is entitled to give birth to a second child. As a whole, it was found that most of the Chinese deaf children didn't have access to adequate intervention services. Specifically, their hearing loss was diagnosed later than 24.5 months, a considerable number of the children did not use

Variable	Percentage
Gender	
Boy	61.68%
Girl	38.32%
Only-child	
Yes	58.88%
No	41.12%
Average age (months)	101.6
Age range (months)	31–220
Average age at diagnosis (months)	24.5
Rate of using Hearing aids	71.96%
Average age for using Hearing aids (months)	43.8
Rate of using Cochlear implants	14.95%
Average age for using Cochlear implants (months)	33.19
Receiving Sign language training	
Yes	74.77%

No	25.23%
Communication mode	
Natural gesture	12.15%
Sign language	31.78%
Spoken language	11.21%
Mixed approach	44.86%

Tab. 2. Key demographic and clinical characteristics of participant children

hearing aids or cochlear implants and if they did, they did not receive them early, and most did not receive sign language training. More detailed information about the participant children's characteristics are shown in Table 2.

Results and Discussion

A. The impact of childhood deafness on Chinese family life

As a stressor, childhood deafness considerably impacts Chinese family life**.** In this study the impact of childhood deafness was estimated from the items regarding the caregiver's communication with the deaf child, their feeling of fatigue, changes in the family economic situation, and the level of mutual communication between family members due to the child's deafness. On average, the participant families scored above 3 points – the boundary point between disagreement and agreement with the statements in Items 10, 11, 12 on the 5-point scale. It means that childhood deafness considerably impacts communication with the child, as well as feelings of fatigue and the family's economic condition.

Item	Mean score
Item 10: When parenting my child, I often feel difficulty in communicating with my child	3.48
Item 11: Parenting my child makes me have a feeling of great fatigue	3.50
Item 12: Because of the child's hearing loss, the economic status of our family has deteriorated	3.51
Item 22: The mutual communication of the family members has been affected by the child's hearing loss	2.29

Tab. 3. The impact of childhood deafness on family life

However, mutual communication between family members seemed not to be affected in the same way by childhood deafness, with a mean score of 2.29. The questions from the questionnaire and the mean scores are listed in Table 3.

Childhood deafness resulted in a series of family parenting difficulties. The data collected from the responses to one of the open-ended questions, "Please write about the biggest difficulty that you have experienced while parenting your deaf child," validated the influence of childhood deafness on Chinese family life. One hundred and four Chinese families responded to this question. Some families provided more than one response while others did not responded to this question. When there were multiple responses, only the first response was used to analyze the results. The caregivers' responses provided an array of difficulties, including increased financial demands, increased time demands, worry about the future, fear of their child being teased by others, a feeling of fatigue, difficulty in communicating with the child, not understanding the child and difficulty in being understood by the child, and difficulty in dealing with the child's behavioural problems. Sorting and categorizing all the responses, the study found that the five top difficulties Chinese families experience (demonstrated in Table 4) are: economic burdens, communication difficulties, educational problems, worrying about the child's future, and the impact of the child's deafness on normal work. The number of families that responded this way is presented in brackets, and specific descriptions of the difficulties from the most representative families are presented as an example.

The five top responses from Chinese families concerning parenting difficulties
• Financial burden (37) *e.g.: "We can not afford his cochlear implant and one parent has to stop working in order to accompany his study."* (A16)
• Difficulty in Communication (30) *e.g.: "The biggest problem is we can not understand her when she communicates with us by sign and she can not understand what we say when we speak to her in spoken language." (B23)*
• Educational puzzle (18) *e.g.: "Sometimes we do not know how to educate him as we lack professional knowledge about the hearing impairment." (D16)*
• Worrying about the child' future (5) *e.g.: "He can not speak and understand well, what would happen if both his parent and grandparent die?" (A14)*
• Normal work being delayed (4) *e.g.: "I feel tired and can not work normally because every day I need to send him for speech therapy and take him back after work." (C6)*

Tab. 4. The five top responses from Chinese families concerning parenting difficulties

B. Chinese families' perception of childhood deafness

A large quantity of Chinese families experienced the social stigma associated with childhood deafness. This study collected families' perception of childhood deafness with two items. According to the responses to Item 2 (My family has always been teased by other people because of my child's disability) and Item 3 (My child's deafness means the child will not have a bright future), listed in Table 5, it was found that 69.8% and 67% of Chinese families with deaf children scored 3 points and above on these two items respectively. This meant that most of them tend to agree that a deaf child does not have a bright future and the families feel teased by others due to the child's disability. To some degree, these families' perceptions of childhood deafness are reflections of the Chinese social attitude toward deaf people. Compared with the understanding of the deaf culture in other parts of world and the growing success of deaf individuals in every walk of life, this is not common in China. This reality is worthy of attention since a considerable number of deaf children and their families still live with severe social stigma associated with childhood deafness.

Statement	Degree of agreement (n=106)				
	1	2	3	4	5
Item 2: My family has always been teased by other people because of my child's disability.	10.4%	20.8%	40.6%	19.8%	8.5%
Item 3: My child's deafness means the child will not have a bright future.	17.0%	16.0%	39.6%	9.4%	17.9%

Tab. 5. Chinese family's perception of childhood deafness

C. Family Resources

Family collective resources

Chinese families with deaf children were assisted by strong resources stemming from the family itself. Regarding the family as a functional unit, this study examined the families' resources from items dealing with family cohesion, family open communication, and family belief changes with stressful demands via Items 6, 13, 4, 7, 8, and 9. Only Item 4 was scored adversely. The statistics listed in Table 6 indicate that Chinese families benefit most from their strong cohesion, and childhood deafness makes Chinese families more optimistic about the future, more tolerant toward differences and more altruistic to others rather than forcing them to believe in 'destiny'. Also, open communication, such as sharing emotions and opinions, is probably useful in helping Chinese families coordinate resources and efforts to cope with the negative impacts imposed on them by childhood deafness. These results are consistent with other research on Chinese culture. For example, Ju and Chu (1996) have argued that for thousands of years, close family relations had been a major cornerstone of traditional Chinese culture. According to Xu et al. (2007), an outstanding expert in the Chinese family, one of the salient features of the Chinese family is cohesive family support while facing challenges and stressful events.

Variable	Item	Mean score
Cohesion	*Item 6: My family is characterized by close relationships and mutual support.*	4.16
Communication	*Item 13: To educate the deaf child we often share emotions and opinions in my family*	3.62
Fatalism	*Item 4: Facing the child's deafness, my family tends to be fatalistic.*	2.82
Altruism	*Item 7: While parenting my child, the degree of my altruism has increased.*	3.98
Tolerance	*Item 8: While parenting my child, the degree of my tolerance toward differences has increased.*	3.94

Optimism	*Item 9: While parenting my child, my degree of life optimism has increased.*	3.71

Tab. 6. Chinese families' collective resources

Community resources

Chinese families received only limited resources from individuals, organizations, and government agencies. Community resources from outside the family unit were found to be one of the important significant factors which predicted the outcomes of positive family adaptations (Margalit and Kleitman, 2006). This study examined the help families received from the extended family, professionals, other parents, and the social welfare agency. In general, Chinese families got extremely limited support from professionals, parental groups, and community or social welfare agencies. The main source of support for them came from the extended family and relatives. The descriptive statistics of community resources for the Chinese families are listed in Table 7.

Item	Mean score
Item 13: The support from my extended family and other relatives often help me greatly.	3.34
Item 17: My family can often get necessary information from professionals.	2.69
Item 18: My child can choose to attend specialized preschool or regular preschool, age-appropriately and freely.	1.30
Item 19: My family has access to a self-help group of parents.	1.91
Item 23: The financial support from welfare is high enough to meet the special needs of the child.	2.52

Tab. 7. Chinese families' community resources

D. Outcome of families' adaptation in general

Generally, Chinese families positively adapted to childhood deafness, accompanied by strong stress-filled feelings. The process of adaptation was an ongoing process, so it was difficult to judge whether the outcome of adaptation was good or bad at any particular point in time. This study inferred the outcome of Chinese families' adaptation from the combination of the level of family adaptation and the family's appraisal of their emotional experience toward parenting a deaf child. As a result of this dynamic process, the level of family adaptation was examined by four criteria: 1) accepting the past, 2) functioning in the present, 3) expectations for the future, and 4) general emotional experiences with raising the deaf child. Specifically, the level of adaptation was assessed by Items 25, 14, 24, 28, 27, and 29 on the questionnaire and was listed in Table 8. Among the items, only Item 14 was scored reversely. Based on the fact that scores were higher than 3 points on all items, one result was apparent – Chinese families have a good level of adaptation with an increase of acceptance over time, function normally, and have good expectations for the future. However, this satisfactory adaptation was also accompanied by long-term stressful experiences as Chinese families, in general, agreed with the statement that parenting a deaf child is linked to chronic sorrow and grief. The detailed statistics are presented in Table 8. Theoretically, the result of positive adaptation accompanied by stressful experiences is not a new thing. Masten et al (1994, in Luthar 2000) distinguished three groups of good adaptation: (1) at-risk individuals or families that show better-than-expected outcomes, (2) positive adaptation maintained despite the occurrence of stressful experiences, and (3) good recovery from trauma. As with other handicaps, childhood deafness is irreversible and has no recovery, consequently, for most of the families, a stressful experience is inevitable and bound to appear recurrently despite the fact that most of the families have come to terms with their child's disability.

Item	Mean score
Acceptance	
Item 25: Compared with the early days after the diagnosis of the hearing impairment, there is more acceptance and peace in my family at present.	4.52
Present functioning	
Item 14: Because of my child's deafness, my marital relationship has deteriorated	3.20
Item 24: Best efforts have been made to promote the child's communication and learning in my family.	4.62
Item 28: My relationship with my family has become closer in the course of parenting the deaf child.	4.16
Expectations	
Item 27: My child will have a bright future and be a beneficial member to society in the future.	4.03
Item 29: My family has the ability to deal with the child's difficulties and problems in the future.	3.70
Present emotional experience	
Item 1: Parenting a deaf child has been linked with chronic sorrow and grief.	3.59

Tab. 8. Overall outcomes of Chinese families' adaptation to childhood deafness

Conclusion

The purpose of this study was to examine how Chinese families adapt to childhood deafness in such significantly different cultural and economic conditions. This study adopted Hill's ABC-X model as the theoretical framework and developed a questionnaire to examine the influence of childhood deafness as a stressor on family life, family perception of childhood deafness, family resources from inside and outside the family unit, and the overall outcome of family adaptation. The findings of this study suggest that Chinese families adapted positively to childhood deafness according to the increase of acceptance over time, good functioning and good expectations for the future, despite strong stressful experiences and feelings that accompanied the process of adaptation. Further, the level of positive adaptation can probably be contributed to the Chinese family's resources from inside the family, such as family cohesion, open family communication and changes in family beliefs, namely altruism, optimism and tolerance toward the child's disability. Also, Chinese families benefited from the limited community support that came from extended family members and relatives. The strong stressful experiences related to family parenting may be caused by the changing social stigma associated with childhood deafness, such as the notion that childhood deafness means a child can not have a bright future and the lack of adequate educational supports, such as professional services and parent advocacy groups. However, these conclusions need to be further replicated by more descriptive studies with samples from other parts of China.

Implications for psychoeducational support

Because of the close relationship between family well-being and a child's healthy development, professionals are recognizing that improving the family's emotional life can serve as a pivotal focus when providing intervention services to empower families with deaf children. While the Chinese government is attempting to provide more financial support for handicapped children and their families, it has encountered many financial limitations. It is imperative that more attention be placed on psychoeducational support for these families to reduce their feelings of grief. Based on previous studies and in response to the identified difficulties that families experienced in this study, psychoeducational support should mainly include emotional, cognitive, and educational aspects, as proposed by the following:

Normalizing family grief. Little in life prepares someone for raising a child with a disability like deafness. Grief is a normal reaction to having a deaf child in China, a country where the Deaf Culture is not popular. The grief that families feel often comes from the loss of the hoped for child and not being able to control or change the situation. Not only should families be prepared for the strong emotional reactions after the diagnosis is accepted, but they should also be informed that some feelings of grief may always reappear and persist. They should be prepared for feelings of grief that emerge as a result of environmental triggers, such as contact with others with children of the same age who are developing normally.

Positively making sense of childhood deafness. As a result of some common Chinese myths and social stigma associated with deafness, such as, "deaf people have lower IQs than people with normal hearing", "deaf people are all underachievers", it is reasonable that many Chinese families worry about their children's future and experience strong sorrowful feelings when raising a deaf child. However, childhood deafness does not necessarily lead to delays in the child's development or lags in cognitive, language, and social areas. The many successful, intelligent, and socially well-adjusted examples of individuals in China and all over the world indicate that having a deaf child is not primarily a story of gloom and doom. Families with deaf children should be informed of these successful stories and should be given the opportunity to interact with other deaf adults. This approach has been successful, as evidenced by the findings of previous studies (e.g. Hintermair, 2000). These findings demonstrate that parents who had many contacts with hearing-impaired adults showed a strong sense of competence in regard to their child's upbringing. This approach may be the best way to help families build new hopes and dreams for their children and themselves.

Developing or taking part in a self-help parent group to share experiences and knowledge. Self-help or advocacy groups are formed by members who share a similar condition and understand each other. As a social support system, these groups help participants cope with risky conditions through supportive relationships among members. For instance, in groups, members can help validate the feelings and emotions of other members, establishing the universality of grief. Group members also pool and share information with one another. Meanwhile, group members can make comparisons, recognize, and benefit from other member's knowledge and coping strategies. However, in this study a number of Chinese families reported that they have no access to self-help groups. Consequently, at present when the Chinese government is taking steps to develop intervention service systems and improve the quality of services for children with special needs and their families, developing and organizing self-help family groups should be one of the cost-effective intervention services considered for families in these strained financial times.

Providing comprehensive information to address families' educational problems. In this study, a large number of Chinese families with deaf children reported that they did not get necessary information from professionals, and many wrote about difficulties in communicating with their children and their general dilemma regarding educating their children. To help families gain control over childhood deafness, intervention programs must have a systematic body of information, including knowledge from multiple disciplines, to provide these families or other families with similar experiences to help them make informed decisions. Specifically, this should include information on: (1) hearing and hearing loss; (2) sensory devices and relevant auxiliary equipments; (3) how children grow and develop; (4) the unique characteristics of the development of deaf children; (5) skills to communicate with deaf children and strategies to deal with children's behavioural problems; and (6) what services and educational options are available locally for specific children. With informational support, families will be helped to recognize that childhood deafness is only a risk that challenges the family rather than a barrier which is insurmountable.

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Chinese families' adaptation to childhood deafness: implications for psychoeducational support for families with deaf children in China

Abstract

Childhood deafness not only impacts children's development, but also affects all aspects of family life. This study used a sample of 107 families with deaf children from China to examine how Chinese families adapted to the stress of having a deaf child in the family. A questionnaire was developed to assess the impact of childhood deafness on family life, the family's perception of childhood deafness, the family's resources, and the overall outcome of adaptation. The results showed that childhood deafness, as a stressor, impacted Chinese family life considerably, leading to a series of parenting difficulties, such as additional financial burdens, difficulty in communicating with the child, and so on. However, in general, the surveyed Chinese families adapted to childhood deafness positively despite experiencing strong and long-term grief. The positive adaptation could probably be contributed to Chinese families' collective resources, such as family cohesion and open communication. Finally, implications for psychoeducational support for families with deaf children in China are discussed.

Adaptacja chińskich rodzin do głuchoty dziecka: implikacje dla psychoedukacyjnego wsparcia dla rodzin dzieci głuchych w Chinach

Streszczenie

Głuchota dziecka wpływa nie tylko na jego rozwój, ale także na życie rodziny. Badania, w których uczestniczyło 107 rodzin głuchych dzieci z Chin, miały na celu zbadanie sposobu radzenia sobie ze stresem uwarunkowanym posiadaniem głuchego dziecka. Opracowano kwestionariusz oceniający wpływ głuchoty dziecka na życie rodziny, rodzinną percepcję głuchoty dziecka, rodzinne zasoby i rezultaty procesu adaptacji. Wyniki ujawniają, że głuchota dziecka jako stresor wpływa na życie chińskich rodzin i jest przyczyną poważnych trudności związanych z dodatkowym obciążeniem finansowym, a także w zakresie komunikacji z dzieckiem. Rodziny chińskie dobrze się jednak adaptują do głuchoty dziecka dzięki zasobom społecznym, takim jak spójność rodziny i otwarta komunikacja. Omawiane są także implikacje dla psychoedukacyjnego wsparcia dla rodzin z dzieckiem głuchym.

Address for correspondence:
Liu Shenglin
Faculty of Education Science, Sichuan Normal University
Chengdu 610066, Sichuan Province, China
xiaoduo.liu@gmail.com;

Miloň Potměšil
Institute of Special Education, Faculty of Education
Palacký University, 771 40 Olomouc, Czech Republic
mvpotmesil@gmail.com