A Case Study on the Generation of Family Resilience in Preschool Children with Disabilities

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Abstract: Family resilience can help families in difficulty or risky situations realize their potential and support the active growth of family members. The study takes the family with a 6-year-old child with cerebral palsy as the research object, and based on Walsh's "Model of Family Resilience" theory, interprets the generation process of resilience in the family from three aspects: belief systems, organizational processes, and communication and problem-solving. It can provide experience for families with Preschool children with disabilities to explore advantageous resources on the basis of their existing conditions, and promote the healthy growth of such families.

1. Introduction

Resilience refers to an individual's good adaptation process when facing life adversity, trauma, tragedy, threat, or other major life stresses ^[1]. It is the ability to smoothly cope with and rebuild a new life against life stress and setbacks. At first, the research on resilience mainly focused on the exploration and application of individual resilience. With the deepening of research on resilience, researchers found that the perspective on individual alone cannot explain some phenomena and problems well, so family resilience was introduced. Family resilience as the capacity and a process of the family, withstands and recovers from stressful life challenges, and thus becomes stronger and more resourceful ^[2]. Walsh put forward a theoretical model of the family resilience process from belief systems, organizational processes, and communication/problem-solving. Each process includes three sub-processes, namely, family beliefs include making meaning of adversity, positive outlook, transcendence and spirituality; organizational processes include flexibility, connectedness, mobilize social and economic resources; communication and problem-solving involve three processes: clear and open emotional sharing, and collaboration and problem solving ^[3]. It emphasizes the interaction process and collaborative influence within the family and its social environment.

Raising children with disabilities can bring tremendous impact and sustained pressure on families. Research shows that parents of children with disabilities have higher parenting pressure than parents of normally developing children ^[4,5]. Many families may fall into functional disorders and even fall apart, causing secondary harm to the young children. However, some families adapt, recover, and grow in adversity, generating resilience and transforming stress into motivation to move forward ^[6]. The study attempts to use the family resilience process theory model proposed by American psychologist Walsh, by taking a family with a 6-year-old cerebral palsy child as a case study, to explain the generation process of family resilience in cerebral palsy children, reveal the key factors affecting family resilience, and provide a reference for self-healing for millions of families of preschool children with disabilities.

2. Method

2.1. Participants

The study case is Yiyi, 6 years old. At the age of two and a half, she was diagnosed with cerebral palsy with GMFCSIII and ataxia. The main cause is in the cerebellum, with the most obvious features being poor balance function, poor coordination, low muscle tone, delayed language and intellectual development, and strabismus ^[7]. Yiyi has been receiving treatment for more than three years since the diagnosis and has a surgery at a professional hospital in another city. She is now returning home for regular rehabilitation treatment, and her ability to take care of herself has gradually improved significantly. Yiyi's family is located in a remote area of County Z, with poor family conditions, low economic income, and low education among family members (see Table 1).

Family members	Code	Age	Education level	career
Father	В	43	Primary school	Construction worker
Mother	М	41	Primary school	Farmer
Brother	G	16	High school	Student
Grandmother	Ν	68	Primary school dropout	Farmer

Table 1 Basic information of Yiyi's family members.

2.2. Data collection methods

As a case study, the study uses participatory observation and in-depth interviews to collect data. To enhance mutual trust and conduct more in-depth research, researchers entered the family of the study subjects for three months and conducted participatory observation. In addition to using informal interviews to gain a scattered understanding of the research object's parenting experience, the complete process of generating family resilience is mainly achieved through comprehensive and in-depth formal interviews. Because of the sensitivity of the topic, in order to ensure a comfortable and relaxed interview atmosphere, the researchers chose to interview at Yiyi's home. Under the consent of her family, the entire interview with the main family members of the case, including Yiyi's father, mother, brother, and grandmother, is recorded. After completing the recording and transcribing, the researcher submitted the text to the interviewee for review, and through WeChat voice, inquired about some details of the interview, and finally compiled the formal interview manuscript.

3. Results

3.1. Family belief system

3.1.1. Stay optimistic: "As long as we persist, she will get better definitely"

Family belief is the core element for families to adapt to difficulties. Yiyi's family was not always optimistic from the beginning. When Yiyi was diagnosed with cerebral palsy, it was a mental torment unbearable for the entire family. Yiyi's mother thought that it was her fault and wanted to jump off a building together with Yiyi. When Yiyi fell ill, the whole family cried together, feeling hopeless and numb with pain. But the despair and pain of the family cannot make the child better. Yiyi's parents are reluctant to part with their child, worrying about their child's future education and work issues. Concerns about Yiyi's future prevent Yiyi's family from giving up.

"I came to see that the child's condition was very bad at the time. Her parents were crying at the beginning, and I told them not to be so pessimistic. If the child was sick, they would go for treatment. What if it could be cured? We absolutely cannot give up." Yiyi's mother also responded positively, saying, "We think as long as we persist in treating her, she will get better definitely." (20190108N2)

How families view problems and make choices determines whether they can cope with and control the future^[8]. As long as we persist, we will get better definitely. With this optimistic belief, families have shown great courage in facing these difficulties, and have also strengthened their

determination to treat their child's illness, becoming the main source of resilience for their families.

3.1.2. Set reasonable expectations for the young child: "Progress is enough."

Victor H. Vroom believes that when expectations are lower than reality, that is, when actual results are greater than expected, it helps to increase people's motivation, self-confidence, and motivation ^[9]. "We know this disease is difficult to cure, so we followed the doctor's advice. She could just take care of herself a bit and let her make progress slowly! She used to not eat on her own, but now she can eat with a spoon. There's nothing better than this, at least she won't starve in the future. The only thing we can do is take care of her to the best of our ability, and the rest is up to fate". (20190108M3)

If parents of children with disabilities eagerly hope that their child can make rapid progress after receiving treatment, high expectations will only lead to frustration. Low expectations can lead parents to ignore the special talents and potential of their children and hinder their development. Yiyi's mother's expectation for Yiyi is "progress is enough". Based on the professional guidance of a doctor, they set it as a rehabilitation goal not only reduces the child's stress, but also allows parents to have a reasonable understanding of their child's future ability level, thereby adjusting their mentality.

3.1.3. Positive affirmation of self-worth: "We are already excellent as parents"

Behind the upbeat beliefs that Yiyi's parents can build in their families is the positive affirmation of their self-worth. Affirming self-worth helps to improve self-efficacy, thus stimulating the confidence and courage of resistance.

"We have no education and earn money by labor. But as parents, we have done our best. Although we are not the wealthiest and most powerful, we must be the best. Her mother and I sold our car and borrowed money everywhere possible. Over the past three years, we have tried every means to help her recover, which is why we have made such a big improvement. As long as we see her progress, I see hope!" (20190108B3)

They demonstrate positive self-affirmation in thinking of their own value and ability assessment. This belief helps them overcome crises, and after success, it strengthens self-affirmation, forming a cycle of "self-affirmation -- overcoming crises -- strengthening self-affirmation", thus forming an important driving system in family resilience.

3.2. Family organizational process

3.2.1. Actively seeking mutual assistance within the family: "We need each other"

The family organizational process is considered as a buffer for coping with risk crises in the process of family resilience. A benign family organizational model can stabilize the structure and function of the family, and maintain its effective operation^[10]. Yiyi's parents chose to live with their grandmother and seek help from the original family, instead of the independent life mode of the nuclear family. The development of education, healthcare, and social services has reduced people's dependence on kinship networks. But when the family encounters long-term pressure of disease, the mutual assistance function of this family network is activated again, and the family network formed by intergenerational relationships becomes the last fortress for individuals to resist risks^[11]. Although there may be friction between parents of two generations due to differences in lifestyle and educational concepts in daily interactions, when it comes to the issue of Yiyi's treatment, families choose to downplay the conflict and focus on taking care of their child.

"When they got married, I told them that I didn't want to spend time with young people, which would be inconvenient. But later on, the child fell ill, and I couldn't watch them live such a miserable life. It's okay for me to ignore the child because it's time for me to enjoy my elderly life. But I can't bear this family to bear the pain alone. I don't trust handing over the child to the hospital, only if I take care of it myself can I feel at ease. I can help them take care of the child now. When I get old or sick, I still need them to take care of me." (20190108N2)

Parents need the material resources and manpower support of their parents, and grandparents

also need their support. Yiyi's grandmother's psychological needs for family affection and the practical needs of future retirement actively integrate into the family, forming an indispensable part of the family's resilience.

3.2.2. Rational division of labor and flexible adjustment: stable family structure

Maintaining the normal functioning of family life is the foundation of normal family function. Tasks are divided based on the abilities of family members: the father is responsible for economic income; the grandmother takes full-time care of Yiyi's living; the mother is responsible for providing rehabilitation training for Yiyi; the brother is responsible for collecting rehabilitation materials for cerebral palsy in his spare time and teaching other family members how to do rehabilitation training. Yiyi's father was injured on the construction site last year due to work and needs to rest at home for a month. Yiyi's mother took the initiative to take on the responsibility of supporting the family and went to work in the nearest brick factory. Yiyi's rehabilitation training and daily care were handled by her father and grandmother. It can be seen that when family life changes, family members will adjust their task scope, support each other, and present a stable family structure and strong family cohesion.

3.2.3. Learn rehabilitation knowledge together: "There is 'a Little Teacher' at home"

Tao Xingzhi proposed the "Little Teacher System", which allows children to be both students and teachers and pass on the knowledge they have learned to those around them at any time. Families of rural children with cerebral palsy are limited by conditions and lack opportunities to learn rehabilitation knowledge, urgently requiring relevant resources. In order to master rehabilitation knowledge and skills, as the most educated person in the family, Yiyi's brother took the initiative to take on the responsibility of being "a Little Teacher". Yiyi's brother helped take care of Yiyi when he came back in vacation, holding a medical record book to search for information online, and seeking guidance from a special school counselor. After he understood, he gave his family a "lesson" and asked them to follow the method on the pictures to do rehabilitation training for Yiyi. The approach of "the brother teaches his mother, his mother teaches his grandmother" not only strengthens the cohesion of the family but also to some extent alleviates the economic pressure on the family. For such a resource-poor rural impoverished family, "self-study rehabilitation and mutual teaching" is a courageous attempt and positive resilience strategy.

3.3. Family communication and problem-solving process

3.3.1. Honest communication: "It would be much better to say it directly"

The study suggests that family communication includes both internal and external communication. Internal communication refers to the communication between family members. External communication refers to the communication with relatives, friends, and others. When it comes to communication issues, Yiyi's mother repeatedly emphasizes "directness" and shows a frank, inclusive, and direct attitude in communication.

"Usually, her grandmother and I have disagreements when it comes to taking care of the child. We just speak up and try not to get angry. The older generation has outdated educational concepts and thinks that it's well enough if Yiyi has food and clothing, and if it's too painful for Yiyi, she can stop rehabilitation. I will explain to her. It's normal for the elderly not to understand, but as long as they slowly see the child's progress, she will understand. I am never afraid of conflicts, and the most difficult days have passed, there is nothing that cannot be passed." (20190108M5)

Children with disabilities often receive attention in public places due to their physical and behavioral differences from ordinary people, and sometimes they may receive strange glances from others. Yiyi's family lives in a remote mountain village, with many elderly people and children in their hometown. Most of the elderly people have a low level of education and conservative thinking and do not understand Yiyi's condition. They will provide some unreasonable explanations. At first, Yiyi's family had arguments with them, but later they chose to respond with a frank and tolerant attitude.

"When someone asks about our child's situation, whether it's relatives, friends, or empathetic people, I tell them directly. I don't act like some families who feel very shy and inferior if their children are sick, which makes others even more suspicious. Especially some elderly and uneducated neighbors think that our child is a fool or has an infectious disease. They have no malicious intent; they just don't understand. I tell them that our child had cerebral palsy and that they will understand it later. Many people who used to be unwilling to interact with us now sometimes bring their children to play with Yiyi." (20190108M6)

It can be seen that effective internal communication in families of children with cerebral palsy can help them timely and comprehensively grasp the situation of the child, release stress, and enhance emotions, which is beneficial for the treatment of young children. Effective communication outside the family can clarify the condition of young children and enable neighbors to provide assistance and support for Yiyi from the beginning to the present. Yiyi's family has received more social support and increased their confidence in facing difficulties.

3.3.2. Participate in social communication actively: "making jokes" to relieve stress

In the village where Yiyi lives, most people make a living by farming. They work hard during the day, and their neighbors visit each other after dinner at night, chatting, boasting, and joking with each other. They also give people nicknames and share their life experiences as humor. They often amuse themselves by mocking and dispraising each other. According to their words, the closer they get, the more they will mock each other. The "dispraising style" can enhance emotions, and mutual oral dispraising can train their "resilient ability".

"They all call me 'tired dog' and say that I work outside every day to earn money, which is very difficult. They think that Yiyi's mother should come with me to work and say that I am inflexible. That's easy for them to say. They say what they say, and there's nothing to get angry about. We curse each other, and it's joyful." (20190105B6)

Good communication can help alleviate stress. Perhaps the wording and tone of this "dispraising communication" are not elegant, but for families of cerebral palsy children struggling at the bottom of society, actively participating in social interaction is a way to release stress and promote the generation of individual resilience among family members.

3.3.3. Empathy and sharing: experiencing the fun of life for children with cerebral palsy

Empathy refers to the tendency of individuals to share and understand the emotional states of others in the process of interacting with others^[12]. It means that when young children share the joy of life with their parents, parents can understand their children's emotional states and produce similar social emotional reactions. The interaction can better meet the psychological needs of young children and achieve efficient parent-child communication, so that parents can also experience the joy of young children's lives.

"Yiyi must listen to music before she goes to bed, especially she enjoys listening to 'Woven Flower Basket', she waving her hands while listening. Her grandmother and I sang to her nearby, and when we sang the peonies, she would put her hands together forming the shape of a flower, incredibly happy. Sometimes when we were too tired to move, she would give us a performance and sing "Woven Flower Basket". Her grandmother couldn't even close her mouth when she smiled, and it was like having a concert with the three of us at home." (20190108M8)

Although children with cerebral palsy are different from healthy children, they also have strong sensitivity and the wish to express their thoughts. Only when parents understand their children's feelings can it be more beneficial for children's mental health. Some families are busy taking care of children with disabilities in their daily lives and neglect their hobbies. While Yiyi's family not only understands and accepts their listening to music behavior, but also engages in altruistic behavior, willing to participate in the world of Yiyi, experience the joy brought by music, and alleviate life pressure through this way. Caring for children with cerebral palsy can be stressful, but it brings more than just bitterness to the family. Following the perspective of the children will gradually calm down in the fast-paced life, feel the details of life, and understand and listen

attentively to experience the unique joy of life.

4. Conclusion

After encountering a crisis of cerebral palsy in a child, the family in the study utilized positive factors and actively sought resources, forming positive beliefs such as "as long as we persevere, she will get better definitely", "progress is enough", and "we are already excellent as parents". Under the influence of these beliefs, they actively fought against the crisis through honest communication, mutual assistance among family members, reasonable division of responsibilities, and shared learning; And in the process of interacting with young child, they empathize with her and experience the joy of life, gradually forming their resilience model (see Figure 1).

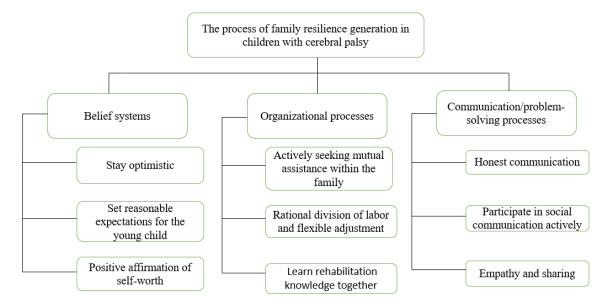


Figure 1 The generation process of family resilience of children with cerebral palsy.

Each family has different cultural backgrounds, social resources, family models, and social environments, resulting in different positive factors. It leads to a diversification of resilience generation strategies for each household. According to Walsh's resilience process, other families of preschool children with disabilities can explore their resilience paths in belief systems, family organizational processes, and family communication and problem-solving by tapping into their strengths and resources based on their situation.

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References

[1] LI Donghui, TIAN Guoxiu. (2018). Growing in Adversity: A Case Study on the Family Resilience of Family with an Autistic Child. Journal of East China University of Science and Technology (Social Science Edition),33(1),42-50.

[2] Walsh F. (1996). The concept of family resilience: crisis and challenge. Family Process, 35(3), 261-281.

[3] Walsh F. (2016). Family resilience: a developmental systems framework. European Journal of

Developmental Psychology.

[4] LI Jing, WANG Yan. (2015). The Parenting Stress of Disabled Preschool Children's Parents: The Roles and Nature of Social Support and Coping Styles. Chinese Journal of Special Education, (5),3-8+14.

[5] YAN Tingrui, HOU Yujia.(2022). The Effects of Maternal Parenting Stress on Social Dysfunction of Children with Autism Spectrum Disorder: The Model of Moderated Mediator. Chinese Journal of Special Education,(3),63-71.

[6] LIU Ying, XIAO Fei. (2018). A Case Study of the Formation of the Family Resilience in a Family with a Hearing-Impaired Child. Chinese Journal of Special Education,2018(4),26-31.

[7] LI Haili. (2013). Analysis of rehabilitation efficacy and influencing factor of children with spastic cerebral palsy.[Master's thesis, Jilin University], CNKI, URL.

[8] Walsh F. (2013). Family Resilience (ZHU Meihua, Trans.). Shanghai: East China University of Science and Technology Press.

[9] BI Jiao. (1988). Victor H. Vroom and Expectancy Theory. Modernization of Management, (2), 46-47.

[10] XIAO Jiayi, LUO Guoao. (2022). Strategies in the Dilemma: A Study on Family Resilience of Children with Acute Leukemia ——Taking P Hospital in Kunming City as an Example. Journal of Jinzhou Medical College: Social Science Edition,20(1),52-56.

[11] SHI JIngqun. (2016). The Evolvement of Family Intergenerational Relationship in Transition: Mechanism, logic and tension. Sociological Studies,(6),191-213.

[12] CHEN Wuying, LU Jiamei, LIU Lianqi, LIN Wenyi. (2014). Gender Differences of Empathy. Advances in Psychological Science, 22(9), 1423-1434.