

Family Caregivers' Experiences of Caring for Children With Cerebral Palsy in China: A Qualitative Descriptive Study

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Abstract

This study aimed to investigate family caregivers' experiences of caring for children with cerebral palsy in China. This study used a descriptive qualitative design. We selected 18 family caregivers from 3 children's hospitals in Jiangsu Province, China, using a purposive sampling method. The following 5 themes emerged as needs of family caregivers' experiences of caring for children with cerebral palsy: overall responsibility, being alone, exhaustion from caring, being a prisoner of life, and uncertainty regarding the future. The findings of our research contribute to a better understanding of the life situation of family caregivers of children with cerebral palsy as we identify the difficulties they experience as well as their specific needs.

Keywords

nursing, caregiver, cerebral palsy, qualitative study

What do we already know about this topic?

Most children with cerebral palsy live with their parents and rely on their parents' care. Family caregivers of children with cerebral palsy have a higher prevalence of mental health difficulties than the general population.

How does your research contribute to the field?

In China, few studies have been conducted on the care experiences of family caregivers of children with cerebral palsy. In this study, the experiences of family caregivers of children with cerebral palsy were described. Their previous stable lives were broken, which reduced their happiness and health status.

What are your research's implications towards theory, practice, or policy?

This study provides a basis for understanding the needs of caregivers through their experiences of caring for their children with cerebral palsy. Healthcare providers should pay more attention to this group of people and contribute to improving their health and lives.

Introduction

Cerebral palsy (CP) is a non-progressive encephalopathy resulting from brain lesions. CP encompasses several types such as quadriplegia, spasticity, diplegia, and hemiplegia, and is the main cause of permanent disability in children.¹

The estimated prevalence of CP is 2.1 out of every 1000 births in the general population.² The average prevalence rate of children with CP aged 0 to 6 years in China is 1.86% to 4%. Currently, there are approximately 6 million cases in China.³ CP is associated with limitations in movement and posture as well as abnormalities in speech, vision, and intellectual abilities,⁴ which may inhibit the child's normal growth and development, as well as their participation in

age-related activities.⁵ The symptoms of motor disorders in children with CP include spasticity, muscle contracture, lack of coordination, loss of motor control, and poor voluntary movement.⁶ In addition, these patients often experience

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disturbances in sensation, perception, cognition, communication, and behavior.

Children with CP have difficulty with activities, which severely affects their quality of life.^{7,8} There is currently no cure for CP.⁹ The WHO considers limb movement function to be the main rehabilitation goal, and walking capacity training in children with CP needs to be taken seriously.¹⁰ The primary intervention includes the management of motor problems (physiotherapy, orthoses, and medical treatment).¹¹

Children with CP often require rehabilitation for several years. In most families, parents provide the primary care giving to children suffering from this disease.¹² Children with CP depend on their parents for care. As guardians and primary caregivers of children with CP, parents deal with a variety of stressors during their children's long treatment process, resulting in problems such as mental stress, bad mood, and decline in quality of life.¹³ Caregivers of children with CP report a higher prevalence of mental health problems such as depression and anxiety than those of the general population.¹⁴ In addition, caregivers usually show poor physical health and lack of energy, including difficulty sleeping, weight loss, and fatigue.¹⁵

It has been reported that 45% of family caregivers of children with CP in China experience depressive symptoms and 60% experience work and financial burdens.¹⁶ Significantly higher psychological and social burdens on family caregivers of children with CP than in the general population have also been reported.¹⁷ Most previous studies have not described the experiences and nursing needs of caregivers of children with CP. Our study aimed to explore the home care experiences of caregivers caring for children with CP. Professionals need to fully understand the feelings and nursing needs of these caregivers and provide them with timely help and support to prevent negative emotions.

The beneficial characteristics of the qualitative method for this current study include that it is effective in eliciting information about the experiences of care givers of children with CP. This method requires a sample size as much as necessary as saturation is a criterion for selecting the number of participants.¹⁸

This qualitative study, conducted in China, focused on the feedback gathered from family caregivers of children with CP through semi-structured interviews. Our findings suggest that healthcare providers need to pay more attention to this specific subgroup of individuals to try and assist them improve their health and quality of life.

Methods

Design

This study used a qualitative descriptive design to analyze the care experiences and nursing needs of caregivers of children with CP. All interviews were conducted between

January and June 2021 in 3 children's hospitals in Jiangsu Province, China, and purposive sampling was used to enroll the caregivers. We also included a convenience sample of children with CP who were treated in a rehabilitation center for CP between January and June 2021. The patients were treated by a multidisciplinary team that included pediatricians, nurses, rehabilitation trainers, and social workers.

Participants

A purposive sampling method was used to select the participants. The inclusion criteria for children with CP were as follows: (1) children diagnosed with CP in the hospital and (2) participation in rehabilitation exercises for more than 2 months. The exclusion criteria were as follows: complications from congenital heart disease, epilepsy, and other serious diseases.

The caregivers' inclusion criteria were as follows: (1) age ≥ 18 years, (2) child's parent, and (3) normal communication and expression skills. The caregivers' exclusion criterion was as follows: caregivers who had mental illness.

Data Collection

Interviews were conducted in a quiet consulting room at the hospital. The qualitative data collection methods included semi-structured, face-to-face interviews. A senior researcher (NZH) performed the interviews and trained less experienced co-workers. NZH is an experienced nurse whose highest credential is a PhD. All the researchers in this study experienced in performing qualitative research. To create the semi-structured interview, we consulted 5 child CP rehabilitation trainers and referred them to systematic reviews of related literature.^{19,20} Initially, a preliminary interview was conducted with the 5 caregivers. The data from the preliminary interviews were not included in this study but were used to modify the interview structure according to the preliminary outcomes. The final interview used in this study included the following items. The family caregivers were asked: "What did you think when your child diagnosed with cerebral palsy? What are your experiences and feelings when caring for your child? What is the impact of your child's illness on your life? What are the most difficult problems you experience in the process of taking care of your child?"

To capture the parents' real experiences of caring for children with CP, the interviewees and their children participated in rehabilitation exercises for more than 2 months, and we conducted one-on-one interviews with the primary caregivers of children with CP. Only the participants and interviewer were present during the interviews, and no other family members were allowed in the interview room. Each interview lasted 30 to 50 minutes. We continuously collected data until no new events occurred, thereby achieving data saturation.²¹ Audio recordings were used to collect data and field notes were created after each interview.

Data Analysis

For qualitative content analysis,²² the interviews were first transcribed word by word, and then interview notes were compiled. Data analysis was conducted using the NVIVO software (QST International, Cambridge, MA, USA). The investigators read the transcripts to familiarize themselves with the data and then extracted the most relevant words and phrases to describe caregivers' care experiences. The investigators read all transcripts and extracted sentences that conveyed the most meaningful information regarding the caregivers' experiences and needs. This was followed by the preparation of coding sheets, grouping of the data, and creation and abstraction of categories. Codes were used for the various descriptions, and data categorization was performed multiple times by the investigators, who worked closely together until the 5 main categories were identified. As a confirmatory test, the 5 categories were shown to caregivers who all agreed that the results accurately represented their experiences.²²

Rigor

Scientific trustworthiness was ensured through the principles of credibility, dependability, confirmability, and transferability.²³ Member checking to ensure that the views of participants were accurately captured was supported by concurrent content analysis by members of the research team. Three team members independently coded the data and the themes were later discussed and agreed upon by all the members of the team. These strategies were used to validate transcripts and interpretations made from the data, with follow-up one merging themes to ensure their full understanding. Moreover, a detailed audit trail of data collections and analysis processes was maintained to enable other researchers to replicate the study in similar contexts.

Ethical Considerations

The study protocol was approved by the ethics committee of Children's Hospital, Soochow University, Suzhou City, Jiangsu Province, China (approval no., #2021KS001). Ethical approval and study permissions were obtained. Informed consent was signed by each participant before being interviewed and was coded to maintain anonymity. Data results were stored in a locked cabinet and all electronic copies were password protected and could only be accessed by the team.

Results

General Information

After applying the selection criteria, 18 caregivers (13 mothers and 5 fathers) aged between 25 and 40 years were enrolled in this study. In addition, 10 boys and 8 girls with CP, aged 18 to 72 months, were included in the study. The general

Table 1. Demographic Data of the Cerebral Palsy Children.

Variable	N	F (%)
Gender		
Male	10	55.6
Female	8	44.4
Age (months)		
18-36	13	72.2
37-72	5	27.8
Diagnosis		
Quadriplegia	5	27.8
Spastic	3	16.7
Diplegia	6	33.3
Hemiplegia	4	22.2
Only child		
Yes	11	61.1
No	7	38.9

characteristics of children with CP and their caregivers are presented in Tables 1 and 2, respectively.

Theme 1: Overall Responsibility

Children with CP experience different situations within their families. Caregivers said that their responsibility include not only ensuring a fulfilled daily life activities but also caring for children with CP. They also stated that they are responsible for handling this new situation because no one else can undertake these tasks.

"I must take full responsibility. I must deal with everything myself. I cannot interfere with my husband's work. My family lives with my husband's salaries. He cannot lose his job."—Caregiver #12

Adapting to these changes and taking on more responsibilities have become significant challenges. After beginning to care for their children with CP, caregivers felt that their daily chores had increased.

"The child does not have the ability to take care of himself. He could not eat, dress, speak, go to the toilet, sit, or walk. I am responsible for all of his care in life."—Caregiver #4

Overload responsibilities include not only increasing daily activities and caring for children with CP but also feeling guilt toward other close family members, particularly when faced with their spouses and parents. Caregivers feel that they do not have sufficient time to care for their spouses and parents. This feeling sometimes leads to more responsibility from caregivers.

"My husband's work is very busy, but he has to help me take my child to the hospital. He took a laptop so that he could work in the hospital. However, despite the completion of his work, the company cut his wages. I feel guilty. I did not give him any

Table 2. Demographic Data of the Caregivers.

Variable	n	F (%)
Education		
Middle school	3	16.7
Junior college	10	55.5
University	5	27.8
Income (yuan)		
<4000	3	16.7
4000-6000	7	38.9
>6000	8	44.4
Occupation		
Unemployed	6	33.3
Company worker	3	16.7
Agricultural worker (poor)	4	22.2
Office clerk	5	27.8
Residence		
City	8	44.5
County	10	55.5
Caregiver		
Mother	13	72.2
Father	5	27.8

support, but this affected his career development. What else can I do?" (Yes, red)—Caregiver #1.

Theme 2: Being Alone

Caregivers showed different levels of loneliness and isolation when caring for children with CP. The sources of loneliness and isolation include lack of support and lack of understanding from family, friends, and society.

"When my child was first diagnosed with CP, my relatives and friends gave me some medical aid, but later, no one could help me. I have to take care of my child myself, so I cannot go to work, and I have no sarcopenia; the government should really consider how to help families with children with CP like us survive."—Caregiver #2

The lack of support also means it was difficult to gain understanding from others.

"A lot of people comfort me, but I know they haven't experienced the pain that I'm suffering. Only when it happens to them will they know that it's not a story—it's a disaster."—Caregiver #8

However, some caregivers reported that they were fully supported and assisted in the same situation by a wider range of family members, friends, health professionals, and other caregivers. This support enables caregivers to be more active in facing and accepting changes in their lives.

"In the hospital, the health professionals gave me a lot of information about the child's condition. In the ward, we have good relationships with other families of children with cerebral palsy. We help each other, we share food, and so on."—Caregiver #3

Theme 3: Exhausted by Caring

During the care process, caregivers realized that their health had deteriorated. Caregivers described in detail what they did daily for their children with CP, and they believed that it would lead to a decline in their own physical and mental health. They experienced pain in their wrists and shoulders, which resulted from carrying children with CP.

"Every time I go to the hospital with my child in my arms to do rehabilitation treatment, I take care of the child by myself, and I feel like I cannot hold them anymore; when I take care of the child for a long time, my shoulders and waist are very painful."—Caregiver #5

Children with CP have cognitive and language disorders and depend on their parents for food, clothing, shelter, and transportation. Parents' long-term care of their children affects their health.

"There is no suitable wheelchair and transportation, I have to carry my son everywhere. Now I feel pain with my waist."—Caregiver #9

"Taking care of the child leads to rapid weight loss and sleep difficulties. When he was in the hospital for one month, I lost 5 kg. I do not know how I lost weight."—Caregiver #7

In addition, their emotional state becomes unstable and sensitive because of a lack of support from their families and society. Some caregivers reported that they were more likely to be angry or sad than they were before their child's diagnosis. They also mentioned their emotional stress. For example, the diagnosis of a child suffering from CP provides disastrous information for parents and produces a very strong emotional response; the caregivers are thus suspicious and unaccepting.

"When the child was about a year old, I found that she could not turn over, could not raise her head, and could not grasp things. When the doctor diagnosed her with cerebral palsy, I did not believe it. At that time, I felt that the sky was falling."—Caregiver #11

"Now, I really understand what the family of a child with cerebral palsy once said. If the family has a child with cerebral palsy, the family caregiver is exhausted. And that's true. (Yes, turn red). I cannot stand it anymore. I am tired. Every day, I have no time to relax. I couldn't sleep. I was in pain again in the middle of the night." (tear fall)—Caregiver #14

Theme 4: Being a Prisoner for Life

Caregivers experience a situation similar to that of a prisoner, watching their lives slip away from them. They lost the opportunity to choose their own lives because they spent all their time caring for their children. They could not shop, travel, or spend time alone. They had no happiness in their lives.

"I used to work in the company, but now I quit my job at home to take care of my daughter. Now, I have given up on my hobbies. I can't go everywhere. I've been with him. I do not have the time and energy to do anything else."—Caregiver #13

The caregivers reported that they had lost their passion for life and personal development because of their care responsibilities.

"I really want to work to reduce my family's financial burden. My relatives encouraged me to work, but I could not leave my child."—Caregiver #6

"Sometimes I can't go to a friend's party. It is not convenient to take my child with me'. Now, I seldom associate with my friends."—Caregiver #17

Theme 5: Uncertainty Regarding the Future

Family caregivers raised uncertainty regarding the future. They often use negative language, such as helplessness and despair, to describe the future.

"Hope is useless. The more you dream, the less you get into reality. No expectations, no disappointment."—Caregiver #2

Family caregivers were worried about the future because they did not know when their children with CP would recover or how long they needed to take care of their children. Caregivers also reported their fear and anxiety over who would take care of their children with CP when they become old or weak.

"The child has no ability of self-care. He could not live without me for a moment. I cannot take care of him when I am old. I have not been at ease for so many years."—Caregiver #15

When the caregiver saw that the child did not improve rapidly after rehabilitation training, the caregiver felt desperate.

"My life has been wasted, what is the meaning of my life, I cannot see hope'."—Caregiver #18

"My child's cerebral palsy symptoms are very serious, and he recovered slowly. I see no hope. What should I do in my future life?" [Shake head]—Caregiver #16

Discussion

This study aimed to explore the experiences of Chinese family caregivers caring for children with CP. It describes the daily lives of family caregivers, for whom caregiving greatly affects their physical, psychological, and social lives. Overall responsibility, being alone, being exhausted by caring, being a prisoner in their own life, and feeling uncertain regarding the future describe the life of a family caregiver of a child with CP. The family caregivers in this study were fully

responsible for caring for children with CP. However, they also felt that this was what the people and society around them expected. Thus, family caregivers accepted the role of caring for children with CP as a part of their lives.²⁴

Family affection is an important aspect of Chinese culture. Family members are encouraged to act as caregivers in their families. In the interviews we conducted, caregivers stressed that a sense of family responsibility and obligation led them to assume their roles as primary caregivers. However, a high sense of responsibility may also have a negative impact on caregivers as they want to provide the best care for their children and this can lead to them feeling guilt and self-blame.²⁵

Full responsibility and lack of support led to the exhaustion of caregivers, who felt lonely and were prisoners in their own lives. Caregivers' roles are often characterized by reduced personal freedom and increased responsibility, as care consumes considerable time and energy.²⁶ Caring may lead to a series of negative experiences, including unstable emotions, health decline, anxiety, depression, despair, and a lack of support. This is especially true for those caregivers who are still working, and is essential for sustaining, recharging, and feeling relaxed. In this study, owing to family caregiver responsibilities, it was difficult for family caregivers to find work, which led to further economic pressure. They did not want to turn to others for help, which affected their employment.

Chinese family caregivers face economic pressure, medical expenses have been the main source of pressure for families of children with CP in China.²⁷ In this study, family caregivers encountered difficulties obtaining full help and support from a wider range of family members and society. Other Chinese family caregivers also described the balance between responsibility and freedom. This seems to be a general problem, as other studies have also described the difficulties faced by caregivers owing to their increased workload and substantial responsibilities.²⁸ This study highlights this conflict in the Chinese context. In this study, family caregivers experienced fear and anxiety regarding losing hope and feelings, which led to an uncertain future. They stressed the need for healthcare professionals in long-term care and to support them in finding continuity and significance in life and overcoming uncertainty about the future. In this study, caregivers used helplessness to describe their lives and future. This study described the fear of an uncertain future; this uncertainty is related to poor communication among healthcare providers and a lack of professional information about the disease.²⁹

Caregiving is viewed only under a negative light. Some family caregivers said that they were well-supported and helped by a wider range of family members, friends, medical professionals, and other caregivers in the same circumstances, particularly during their children's rehabilitation exercise period. However, the description of this experience is mainly somber in nature. In other words, when family

caregivers overburden, it prevents them from feeling meaningful and experiencing the positive aspects of caregiving. Caregivers should have the opportunity to express their pain to help them gradually understand their situations.³⁰ In most of the interviews, respondents were described as people who asked about and listened to the stories of their home caregivers. In addition, according to Moos and Schaefer,³¹ stress and coping models, coping resources, and processes affect how people solve and adapt to stressful living environments. Coping resources are relatively stable, personal, and social resources. This study identified the need for China to increase support for family caregivers by healthcare professionals and the community to reduce the burden and pressure on family caregivers.

Study Limitations

Our self-selected sample was not representative of all caregivers in families with children with CP. In addition, our findings cannot be generalized due to the lack of diversity among the participants' ethnicity, age, education, and economic status. There was also a lack of diversity amongst the characteristics of the children with CP. Most of these children were under the age of 6 years and this resulted in less information from caregivers on the challenges of parenting adolescents with CP.

Recommendations

Given the findings of the study, the researchers recommend that; Future research could include personal characteristics and demographic variables among the participants' ethnicity, age, education, and economic status. Future research could include the caregivers' experiences of caring for adolescents with CP.

Conclusion

This study explored family caregivers' experiences of caring for children with CP in the Jiangsu Province, China. Having overall responsibility, being alone, being exhausted from caring, being a prisoner of life, and uncertainty regarding the future, portrays a rather somber picture of family caregivers caring for their children with CP.

The information gained from research on the family caregivers' experiences of caring for children with CP. Healthcare authorities and professionals should recognize and understand the life situation of family caregivers of children with CP to identify their difficulties and needs in order to offer and implement appropriate and effective support such as peer support, economic support, and household or volunteer services.

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Authors' Contributions

All authors participated in the study design. NZH collected the clinical data, and data analysis was conducted by all the investigators. DS and WJH wrote and revised the draft and subsequent manuscripts. ZS and LCY assisted with drafting and revising the manuscript. All authors read and approved the final manuscript.

Declaration of Conflicting Interests

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