



Original Article

Mothers' experiences after single-event multilevel orthopedic surgery in cerebral palsy: A descriptive qualitative studyGulsah Kose^{1*}, Arzu Aydoğan², Sevinc Tastan³, Cemil Yıldız²¹ Department of Nursing, Faculty of Health Sciences, Mugla Sıtkı Kocman University, Mugla, Turkey² Department of Orthopedics and Traumatology, Gulhane Education and Research Hospital, Ankara, Turkey³ Department of Nursing, Faculty of Health Sciences, Eastern Mediterranean University, Via Mersin 10, Famagusta, North Cyprus, Turkey

ARTICLE INFO

Received 16 October 2019
Accepted 17 December 2019
Published 01 April 2020

Available online at:
<http://npt.tums.ac.ir>

Key words:

cerebral palsy;
mothers;
experiences;
qualitative research;
orthopedic surgery

ABSTRACT

Background & Aim: Mothers with children with cerebral palsy experience various problems during the care process, especially after surgery. Since these problems of parents directly affect the care provided to the child, it is essential to evaluate the problems that families experience in this process. This study aims to explore the experiences of mothers of children with cerebral palsy and to find out how these mothers care for their children that underwent single-event multilevel orthopedic surgery due to cerebral palsy.

Methods & Materials: A descriptive phenomenological study was used to explore the life experiences of 24 participants who had children with CP. This study was performed in the Department of Orthopedics at a Training and Research Hospital in Turkey, between March and July 2015. The study was completed with the participation of 24 mothers who had children with cerebral palsy. A qualitative, face-to-face and in-depth interview technique were used for data collection. Colaizzi's method and Professional Software for Qualitative and Mixed Methods Research 11 software were used for analysis.

Results: The mean age was 37.29±6.86. Based on the mothers' care experiences data, three main themes were identified, namely "Be concern about the process," "Facing the Difficulties and Coping," "Adaptations the changing family lifestyle."

Conclusion: The findings demonstrated that CP affects intra-family relations and functions, and contributes to various physical and mental health problems, and financial statement. We believe that the findings may help healthcare professionals to provide and plan education in the field of healthcare services in a way that helps families cope with the process successfully.

Introduction

The prevalence of cerebral palsy (CP) ranges from 1.5 to 4.0 per 1,000 live births around the world (1) and is 4.4 per 1,000 live births in Turkey (2). Unlike other diseases that cause loss of functions, problems related to CP, including spasticity, contractures, joint dislocations, and bony deformities, are accentuated with age (3,4). Change in the ratio of body mass to strength leads to limitations in physical functions. Full treatment of CP, which is a chronic disease that leads to disabilities, is not possible (4,5). Therefore, parents of children with CP suffer from new problems in each developmental stage of their children (6).

Various surgical treatment methods have been used to prevent or correct developmental problems related to CP (7,8). Single-event multilevel surgery, which is the most common surgical method today, corrects deformities of the musculoskeletal system in a single surgical session by using multiple procedures (3,7). During the period, motor dysfunction in children with CP may be accompanied by sensory and speech disorders as well as auditory, visual, behavioral, and educational problems. These problems limit the self-care ability of the children and increase their need for specialized care (6,9). Besides, a postoperative hospital stay is shortened and homecare is encouraged for diseases, such as CP, which require special care and complex treatment due to high hospital costs, an increasing number of patients and adverse effects of prolonged hospital stay on healthy

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DOI: <https://doi.org/10.18502/npt.v7i2.2737>

child development and family health (10). As the number and severity of the problems increase, self-sufficiency and functions of the children with CP decrease, which, in turn, may result in the need for lifelong special care (9,11). In such cases, mothers, who are mostly responsible for caring for children with CP face various difficulties that may have a direct impact on the quality of care. Therefore, examining the problems faced by mothers while caring for their children with CP is important to explore how taking care of children with CP affects the family life of these mothers (5,6).

World Health Organization (WHO) underlines the need for studies on the demands of children that need special care due to diseases, such as CP, and the problems faced by their families (12,13). Existing studies on the experiences of children with CP and their families focus on postoperative pain, rehabilitation problems, quality of life, walking, and physiological problems (7,14). However, only one study is concerned with the expectations of parents from the surgical operation and their children's quality of life (8). Besides, only one study deals with the postoperative experiences of the parents, whose children underwent surgical operation due to CP. This study primarily focused on the difficulties and experiences that parents had at the hospital but did not deal with the home care experiences of the parents (15). Our study aims to explore the experiences of mothers of children with cerebral palsy and to find out how these mothers care for their children who underwent single-event multilevel orthopedic surgery due to cerebral palsy.

Methods

Study design

This study was conducted between March and July 2015 at the Orthopedics and Traumatology Department of a Training and Research Hospital. We used descriptive qualitative design in order to explore the

experiences of the mothers of children with CP.

Setting & participants

This qualitative study, which used a phenomenological approach, has used the widely used sampling method to contribute to the clarity of the theoretical framework and to provide relevant information that is commonly used in qualitative research and cannot be obtained otherwise. This method does not require the calculation of specific sample size; instead, participants who provided sufficient information were included in the study until data saturation was reached (16,17). Therefore, in our study, 24 participant mothers were included in the study.

The mothers who came to the hospital for control were informed. The aim of the study and the conditions of being a participant were explained in advance. Voluntary mothers, whose children underwent a surgical operation in the hospital where the study was conducted, and who have actively taken care of their children, were included in the study. Children with CP that underwent surgical operation start physiotherapy in the early postoperative period. However, the recovery period may take up to two months for tendon transfer surgery. Improvements in the functions of children with CP may be evaluated after the use of orthosis, which is used two months after surgical operation. Therefore, we waited for at least two months after the intervention in order to gather data so that the experiences of the parents with the interventions may be evaluated. The study was conducted with 24 mothers who meet these criteria. All the participants were Turkish speaking, aged between 26–52 years, and all participants were female. Ten mothers who did not want to talk about their experiences refused to participate.

Data collection

Qualitative, face-to-face and in-depth interview techniques were used for data collection. Interviews lasting between 45

and 60 minutes were held in a private room with each participant once interviewed. Two researchers recorded interviews by using a tape recorder. The interviews were organized according to the convenience of the participants and clinical follow-up, so they did not take place within the same day or week. In some cases, more than one participant came to the interviews at the same time. In such cases, interviews were conducted by two different researchers in separate rooms.

Qualitative studies using purposive sampling evaluate all aspects of the research phenomenon in order to gain an in-depth understanding of the research subject. Participants who share similar characteristics or experiences focus on revealing similarities and their relationship to the phenomenon being investigated. Purposeful sampling methods place primary emphasis on saturation. Saturation is achieved when no additional information is available or when new information duplicates existing ones (17). For this reason, interviews continue until a time that no further new information could be obtained. Data saturation is evaluated independently by two researchers during the data collection process and considered to be reached after consensus between the researchers (18).

The data collection form consisted of two main parts. The first part included descriptive questions about the mothers and their children with CP (age, profession, type of CP.). The second part consisted of semi-structured questions (Table 1). Participants were encouraged to express their experiences in their own words.

Table 1. Semi-structured questions

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| <ol style="list-style-type: none">1. Can you explain your experiences during the period that you decided to consent to a surgical operation for your child?2. Can you explain your experiences about the care of your child during the period that the child underwent a surgical operation?3. Can you explain your experiences with the health personnel during the period that your child underwent a surgical operation?4. Can you explain the things that changed in you and your child's lives after your child underwent a surgical operation? |
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Data analysis

Descriptive data were analyzed by using SPSS 15.00 software (SPSS Inc., Chicago, IL, USA). Professional Software for Qualitative and Mixed Methods Research (MAXQDA) 11 (VERBI GmbH, Berlin, Germany) program was used for qualitative data analysis. Transcribed texts were stored on computers, with data subsequently analyzed using Colaizzi's method of data analysis. In Colaizzi's seven-stage process, each step is close to the data and offers a rigorous analysis (Table 2) (19).

Two researchers, who had experience in phenomenological studies, were closely collaborated in cross analysis to achieve consistency and agreement at each step of data analysis. Researchers and the participants were native Turkish speakers. Consequently, interviews and data analysis were conducted in Turkish. After the study was completed, an academician with fluent English and Turkish translated the study into English.

Ethical consideration

All procedures were performed per the ethical standards of the Declaration of Helsinki and approved by the Gulhane Military Medical Academy Clinic and Ethics Committee (Ethics Approval Number: 294-15/1648.4-775). The goals of the study were explained to the participants during an introductory session. The participants were verbally informed of the research, and their written permission was obtained.

Rigour

The principles of qualitative rigor were maintained to ensure the trustworthiness of the findings. The credibility of the data was ensured using robust methods of data analysis. Firstly, two field experts first defined and classified transcribed data on the researched phenomenon. Next, statements that reflect the phenomenon were determined and organized. After grasping the meaning of the whole text, the

researchers reread the text by focusing on the researched phenomenon and started coding. Expressions that reflected the researched phenomenon were selected and grouped. Researchers paid particular attention to the extent to which the selected expressions reflected the whole text. Dependability was confirmed by cross-checking the themes and statements were categorized into significant entities according to their similarities. All similar concepts were grouped under themes and categories. In case of disagreements about themes and categories, the authors discussed until a final agreement was reached. Transferability was created by generating detailed descriptions of participants' experiences. Confirmability was obtained by establishing a clear and adequate "decision trail" throughout the research process.

Two researchers that conducted the interviews were female and had prior experience in face-to-face interviews. One of the researchers was an academician whereas

the other was the chief nurse of the orthopedics clinic. Both researchers had clinical experience in healthcare provided to CP patients. However, the researchers did not take part in healthcare provided to the children of the participant mothers. Before the study, participant mothers were assured that their decisions regarding participation or their statements during the interviews would not affect their children's care. Appointment for interviews was arranged, and interviews took place after the children with CP were discharged. The researchers could easily communicate with the participants due to their experience with the healthcare of CP patients. Besides, since the researchers did not play a primary role in healthcare provided to the children of the participants, no interaction between the participants and the researchers that could influence data reliability took place. This situation enabled the researchers to objectively evaluate the experiences of the participant mothers and contributed to the reliability of the research.

Table 2. Colaizzi's special seven-stage process for phenomenological data analysis

1. Writing and reading the statements of all participants. After the interviews were completed, two of the researchers carefully transcribed the recorded interviews. The verbatim transcriptions of all of the interviews were transferred to the MAXQDA 11. After the transcription process, the voice records were destroyed to protect the privacy of the participants. After transcribing the statements of all participants, each transcript was read several times.
2. Determination of essential expressions. For each transcript, essential expressions of mothers' experiences were extracted and numbered. Expressions directly related to mothers' experiences were considered significant.
3. Formulate meaning. The meanings of each important expression extracted from the expression of the mothers were formulated carefully.
4. Collect the meaning of formulated into the theme sets. Formulated meanings divided into the theme sets. Return the original statements for validity the generated theme sets
5. Improve a comprehensive definition. A full and comprehensive description of all themes produced from mothers' experiences.
6. Determination of the basic structure of the phenomenon. At this stage, a rigorous analysis of mothers' experiences was made. The detailed descriptions of the mothers were reduced to a short, intense expression that captured the aspects required for the structure of the phenomenon.
7. Return to participants for final verification. Return the mothers, to determine if the findings based on the mother's experience were expressing the experiences of the mothers and to confirm the accuracy of the data. At this stage, any changes can be made according to the participant feedback in order to ensure the transfer of the intended meaning in the basic structure of the phenomenon investigated. Addition of additional information from participants to the final definition of the phenomenon and integration of information takes place at this stage (19, 30).

Results

Three main themes and nine subthemes were identified according to the statements of the participants on postoperative care experiences provided to their children with CP. Table 3 summarizes the explanatory excerpts from the participant's statements (Table 3).

Table 3. Main themes and themes related to views and perception of mothers

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| Main theme 1. Be Concern about the process |
| Theme 1.1. <i>Uncertainty about surgery</i> Theme 1.2. <i>Worries of what is to come</i> |
| Main theme 2. Facing the difficulties and coping |
| Theme 2.1. <i>Physical and mental health problems</i> Theme 2.2. <i>Hope for future</i> Theme 2.3. <i>The high cost of care</i> Theme 4: <i>Limitation of social life</i> Theme 2.5. <i>Coping With Problems</i> |
| Main theme 3. Adaptations the changing family lifestyle |
| Theme 3.1. <i>Accepted the responsibility</i> Theme 3.2. <i>Support expectation</i> |

Main Theme 1: Be Concern about the process

Subtheme 1.1. Uncertainty about surgery

The participant mothers stated that they hesitated before the surgery due to their concerns about uncertainty and possible complications related to surgery. Twelve mothers stated that they had difficulty in deciding on the surgery since they were not sure whether undergoing surgery would be beneficial or harmful to their children's physical status.

"It was hard to decide. We were afraid of possible death. But in the end, we agreed on her wellbeing." (Mother 12)

Six participants, whose children had a higher functional limitation, believed that their children would get better after the surgery, so they had no doubts about the decision to operate.

"It was not so hard for us to make a decision. We searched a lot before the surgery and talked with the physician in detail. The physician told us what we should do; we believed in him and agreed to do so." (Mother 2)

Subtheme 1.2. Worries of what is to come

This theme is related to the experiences of the participants during the postoperative period and the changes in the wellbeing of the children with CP. During this process, the mothers mostly expressed about the problems associated with CP, such as movement restrictions and hearing loss.

"My daughter could not speak because of CP. Therefore, I experienced great difficulties after surgery. She could not tell the place that hurt or the thing that happened. I had to explain everything to everyone else." (Mother 12)

Half of the participant mothers expressed their satisfaction from the improvements in the physical condition of their children, whereas the remaining participants stated that they were disappointed since no progress was evident in their children.

"I saw that her hand got bigger after the surgery and that she was trying to hold a pencil or a glass. Before, she inclined towards the left, but now she stands upright and tries to walk smoothly." (Mother 2)

Eight of the participant mothers stated that their burden of care decreased due to the improvements in the physical wellbeing of their children.

"Since she started to do most of the things on her own, my burden lessened." (Mother 11)

Main Theme 2: Facing the difficulties and coping

Subtheme 2.1. Physical and mental health problems

Under this theme, the participant expressed the physical and psychosocial problems related to the movement restrictions of their children during the

postoperative period. They expressed that their children could not walk, so they had to carry them, which resulted in some physical problems for the participants, such as lumbago, brachialgia, and low back pain as a result of caring for their children. Additionally, they expressed that they felt under psychosocial pressure since they always had to carry their children. All of the participant mothers stated that they could not care about their health problems since they had to care for their children all the time.

“My husband and I have herniated disks because we have to lift and carry our child. We have pains, but we have not visited a physician. We use muscle relaxants.” (Mother 15)

“We are exhausted psychologically. Now, we get angry at the slightest pretense. Our anger management is a little bit poor, in fact, impoverished.” (Mother 10)

Subtheme 2.2. Hope for future

Because the complete treatment of children with CP is not achievable and new problems arose as their children grew older, participants expressed concerns about the future of their children with CP. As well, all of the participants expressed their hopes for improvement in the condition of their children soon.

“I am anxious about the future. I always think what my child will do without us, and get upset.” (Mother 24)

“My child cannot say when she gets hungry, thirsty, or when she feels pain; she can only cry to explain her problem. The only thing I want for her is that she can talk a little or walk when I hold her hand. I hope she will be able to talk to explain her problems in the future.” (Mother 4)

Subtheme 2.3. The high cost of care

Under this theme, all of the participant mothers expressed their financial problems due to their children's health problems,

surgical operations, equipment used, treatment processes, postoperative rehabilitation, and daily needs. The participants expressed that they had financial difficulties due to the costs related to transportation, extraordinary rehabilitation sessions, and postoperative equipment that are necessary for postoperative care.

“Caring requires special treatment. We pay extra money for each session of physical treatment. Moreover, our house is outside the city, and we pay for transportation to come here. For these reasons, we had serious financial difficulties.” (Mother 1)

Subtheme 2.4. Limitation of social life

This theme is related to the isolation and the difficulties that the mothers of children with CP face in their daily lives. Participants mostly expressed their concerns about the reactions of the outsiders to their children's disease and medical equipment. They complained about their inability to set aside time since they had to spend most of their time taking care of their children. Ten participants expressed that they arranged their daily life according to the needs and care of their children and restricted their own social lives.

“Since the mother has the whole burden, everything happens to the mother. Taking care of the child, doing the household work, and taking care of the other children exhausted me in physical and mental terms.” (Mother 11)

Thirteen participants noted a change in the wellbeing of their children due to the surgery and medical equipment. They also noted that other people, including the children in the same age group, noticed this change, and started to ask questions. Five participants said that they suffered from the adverse reactions of other people and felt isolated. Eight participants expressed their discomfort about the lack of social awareness and knowledge about CP.

Mothers' experiences with cerebral palsy

"My child cannot play with my friends' children. They say to my child, "You cannot use your hand; you cannot run." Since I must take care of my child all the time, I cannot talk to my friends. Because of this, my friends did not tell me about or call me on their children's day. I was agitated." (Mother 15)

"I am tired of the questions of the people around us. Everyone around me thought that my son would walk after the operation. Although I told that the operation would improve my child's condition, rather than enabling him to walk, no one understood. I am tired of the suggestions about physicians, medicines, or shrines." (Mother 9)

On the other hand, four participants stated that they were satisfied with the positive reactions of their friends.

"She is a very social child; since she is very easygoing, the other children like her. Because of this, she did not have difficulty with other children." (Mother 3)

Subtheme 2.5. Coping with problems

This theme is related to the ways that the participant mothers used to cope with the difficulties and stress due to having and taking care of children with CP. An increase in care costs leads to negative feelings and makes coping a problematic task. Coping strategies of the participants varied. Seven participants stated that they adhered to religion, and their experiences were a part of their fate. Four participant mothers said that they counted their blessing when they saw children with worse problems.

"I believe in God; due to this, I think that this is our fate. I never asked why we had these problems." (Mother 13)

"When I see children with worse problems, I count my blessings for my child's situation. I am Pollyannaish." (Mother 10)

Main Theme 3: Adaptations the changing family life style

Subtheme 3.1. Accepted the responsibility

This theme is related to the effects of permanent movement and posture problems associated with CP on the intra-family relations of the participant mothers. All of the participants expressed that they held the responsibility of taking care of their children. Consequently, they developed a close relationship with their children. However, the participants stated that their relations with their husbands and other children worsened since they could not pay attention to them.

"Meanwhile, we neglected our other child and have problems with her. She does not directly tell us, but we understand from her behaviors that she is angry at us." (Mother 10)

"Naturally, my husband expects attention. Sometimes, I feel as if I am going mad. I have been living an unhappy and embittered life for 17 years; I live so." (Mother 24)

Subtheme 3.2. Support expectation

Under this theme, the participant mothers expressed the attitudes of their husbands, other children, and those in their immediate environment and the difficulties that these mothers faced. Twelve participants expressed that family members supported them, but twelve participant mothers expressed their demands for support from their relatives due to a high burden of care.

"Everyone was very supportive during the period. I have no problems with my elder daughter or my husband. Both my family and the family of my husband were very supportive." (Mother 16)

"I take my child to the school; I take care of her; I have the whole burden. I did not receive the support of my husband or our families. I needed a lot, but I could not receive it." (Mother 24)

Discussion

This study aimed to investigate the experiences of mothers who underwent single-event multilevel orthopedic surgery for CP and to find out how these mothers care for children. The study showed that the treatment process and repeated surgeries lead to further difficulties and created physical and mental health problems, financial difficulties, and problems within their families.

Recently, scholars and professionals have paid particular attention to the importance of the sustainability of the functionality of children with CP. Due to this reason, surgical procedures are performed to normalize the behavior of these children, to reduce the development of neurological symptoms and secondary disorders, and to minimize movement restrictions. The participants in our study had doubts about the uncertainties concerning the surgical operation and the post-operation period and found it hard to decide on surgical operation. In a study by Milbrath et al. (2012), the parents of children with CP also expressed their concerns and anxiety about the care of their children during the post-operative period (20). Similarly, Iversen et al. (2009) found that parents find it challenging to decide on surgical operation for CP (15). In this sense, our findings are parallel to the literature.

Taking care of patients with special needs, such as children with CP, is a hard task. In addition to the existing movement restrictions, the children suffer from further restrictions due to the surgery and medical equipment used. Children with CP may suffer from motor dysfunction, sensory and speech disorders, and auditory, visual, behavioral, and educational problems (6,9). Primarily auditory and speech disorders create particular problems since they prevent health professionals from explaining the treatment process to the children (15). These

problems increase the burden of care on caregivers.

Regarding caregiving, the participant mothers in our study mostly complained about the postoperative movement restrictions as well as poor communication with their children. Similarly, Iversen et al. (2009) found that speech impediments constituted an obstacle in the communication between the children with CP and their families (15). Therefore, cooperation with the mothers of children with CP is essential in order to help these mothers to cope with difficulties related to caregiving and to control their stress levels.

The children with CP have special needs related to their health condition and treatment, that influence the health of their families (11). The severity of the disease, problems associated with the disease and the age of patients limit the self-care abilities of children and increases their dependence on caregivers (6,9,11). Mothers are mostly responsible for carrying their children with CP. However, with the increase in their weight, carrying the children to meet their daily needs becomes harder (21,22). This, in turn, increases stress and puts an additional burden on the mothers, which ends up with various physical and psychological problems (11,23,24). Most of the participant mothers in our study expressed that they suffered from physical and psychosocial problems related to caregiving. Besides, most of these mothers prioritized caregiving to their children over their own health. Similarly, prior studies on children with CP found that the mothers of these children suffered from physical problems, such as backache due to carrying their children (5,22,25).

Self-sufficiency and functions of children with CP decrease as the number and severity of the problems increase (26). This situation enhances the dependency of the children on their mothers. Increased dependence on mothers creates new problems for these mothers and harms their expectations, emotions, and feelings (5,23,27). In our study, participants expressed their concerns about the future. They were anxious about their ability to care for their children with the

CP in the future since the full treatment of CP is not possible and new problems may arise as the children age. Similar concerns about the future of the children with CP were expressed in other studies (5,11,27,28).

This study found that most of the mothers faced problems related to the financial costs of healthcare, physiotherapy, treatment(s), and special treatment needs of their children. Medical equipment is used for functional limitations for diseases, such as the CP, that require specialized healthcare. This requirement increases the financial burden on families and decreases their quality of life. Existing studies also state that families of children with CP suffer from financial problems (5,21,25). Taking care of children with CP requires additional financial costs since the disease that requires special treatment is chronic. Special healthcare equipment used in the postoperative period and the costs of rehabilitation sessions, medical treatment, and transportation create additional financial problems. In order to solve these problems faced by families of children with CP, we believe that the politicians and administrations that develop health policies should also consider the special needs of these families.

Since diseases requiring special care, such as CP, are time-consuming, caregiver mothers may have less time to perform other roles and duties, including personal care, professional life, or social life (27). Participants of our study expressed that they organized their daily life according to the needs and care of their children, which, in turn, limited their participation in social life. Previous works have also noted similar findings (6,11,27). Besides, participants of our study expressed their discomfort about the adverse reactions in their social environment due to the medical equipment used and the changes in the appearance of their children. Similarly, caregivers in other studies complained about the reactions of the other people towards their children (6) and expressed that they felt anxious since they could not cope with a social stigma that they faced (13). A report published by the United Nations International Children's Emergency

Fund (UNICEF) stated that children that need special care are under the threats posed by social stigma, negative traditions, and beliefs and ignorance. According to the report, families of these children are isolated due to lack of social support and low level of social participation, which, in turn, leads to stress and new problems (29).

Traditional societies, such as the Turkish society, assign the responsibility of taking care of family members to the mother (26). In addition to caregiving, mothers in Turkish society are expected to perform their family roles. Taking care of children with CP, who have mental and sensory problems and physical limitations, becomes harder after these children undergo a surgical operation. During this period, the mothers of these children take the responsibility to care for their children on the one hand and continue to fulfill their other responsibilities related to their families, on the other hand (5,22,23). This, in turn, increases the stress levels of the mothers and creates family problems (5,24). Our study found that the participant mothers spent most of their time on their children with CP and less on their husbands and their other children, which created problems within the family. Similar findings have also been noted by other studies (5,11,22-24). Although the mothers are the most affected, having a child with CP hurts all family members and intra-family relationships. Difficulties in caregiving and the high burden of care negatively influence the family functions and daily activities of the family members. Even nuclear families need the support of relatives, such as family elders, during the process.

Limitations

This phenomenological study has no limitations.

Conclusion

Although CP is not a disease that progresses, it is a chronic disease that causes various musculoskeletal problems with increasing age. Therefore, mothers of

children with CP experience constant problems. Surgical operations that include these problems and increase the quality of life offer partial solutions. Hence, children with CP become consecutively different surgical operations, as they grow older. This study found that mothers who care for their children with CP suffer from various physical (low back pain, brachialgia, etc.) and mental (emotional, social, etc.) health problems. Besides, they faced financial difficulties and problems in their family functions (daily activities, relations with family members). Finally, participants expressed their concern about the future, the burden of care, limitations in their social lives, and a shift to religion as a way of coping with difficulties. Investigating experiences and difficulties during these processes may increase the awareness of health professionals about the seriousness of the process and may help them to adopt proper attitudes toward caregiving families.

Acknowledgment

We are grateful to mothers for the realization of this study.

Conflict of Interest

The authors report no declarations of interest.

Funding: This research received no specific grant from any funding agency in public, commercial, or not-for-profit sectors.

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