

Exploring the Process of Mothering Co-occupations in Caring of Children with Cerebral Palsy at Home

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Abstract

Background

Mothering co-occupations in caring for children with cerebral palsy (CP) are very challenging for mothers but play an important role in the daily life of children with CP. This study aimed to explore the mothering co-occupations process in caring for children with CP at home in an Iranian context.

Materials and Methods

A grounded theory approach was recruited using semi-structured interviews. The participants were 14 caregivers, 3 children with CP, 5 occupational therapists, 1 physiotherapist and 3 managers of rehabilitation centers. Participants selected through purposeful sampling followed by theoretical sampling and was continued until saturation. Trustworthiness of the study was examined throughout credibility, transferability, conformability and dependency. The Data were analyzed base on the Corbin and Straus method (2008).

Results

The results were grouped into seven main categories: motherly care, coping with unusual co-occupation, confusion with the roles being played, trying to meet special care needs, managing dynamic co-occupations, continuing care and an inefficient environment. "Coping with unusual co-occupation" was extracted as the core concept.

Conclusion

Understanding the challenges of caring for a child with CP and the experiences of mothers when engaging in caring with their child can also help them to be empowered for achieving the proper management and effective care. The results of this research could provide a broader perspective to therapists; rehabilitation managers and policy makers for understanding the needs, meeting challenges and concerns of caregivers and children with CP, for a comprehensive plan for caring of children with CP.

Key Words: Caregivers, Cerebral Palsy, Child, Co-occupation, Grounded theory.

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1- INTRODUCTION

Cerebral palsy (CP) is one of the most common causes of disability in children (1). The motor disorders of CP are often accompanied by activity limitation in eating, dressing, bathing, functional mobility and toileting (2). In Iran more than 95% of caregivers of children with CP are mothers that are taking care of their children at home (3). Normally, mothers are engaged in co-occupations while caring for their children. Co-occupation is the engagement of two people in an occupation, such that each person influences the other. It involves aspects of shared physicality, shared emotionality, and shared intentionality (4). Mothers of children with CP need to embrace co-occupations in almost all of their children's activities (5). This experience of mothers of children with CP is difficult and challenging (6), consuming a lot of their time and energy (7) and has negative effects on the well-being, freedom and independence, physical and mental health and financial status (8).

Dalvand et al. (2014) reported that co-occupations are one of the most complex concepts in caring; also, they are major challenges for the caring mothers of children with CP undertake and restrict them in their own occupations of everyday life (9). To the best of our knowledge; it seems that there are few studies that explore the mothering co-occupations process in caring for children with CP at home. Previous studies have focused mainly on the parent's satisfaction with special care training (10), effect of special care training on gross and fine motor skills of children with CP (11, 12), quality of life (QOL) (13-15) and parent's knowledge (3). From the perspective of an interaction between mother, child and the environment in which that child lives, mothering co-occupations in the caring of children with CP are complex, multifaceted, and integrated socio-cultural

phenomena (16). When considering available literature on mothering co-occupations in caring, there is no model of mothering co-occupations in caring for children with CP and their families in an Iranian context and a dearth of studies in general is evidenced. Applying grounded theory allows researchers to explore a phenomenon from a new perspective and therefore derive conceptual and theoretical bases for behavioral processes from the collected data (17). In this study, we developed a grounded theory approach to exploring the mothering co-occupations process in caring for children with CP at home in an Iranian context.

2- MATERIALS AND METHODS

The current study was conducted using a grounded theory approach aimed at explaining the mothering co-occupations process in caring for children with CP in an Iranian context. This study included three groups: caregivers, who take care of the children [mothers and father of children with CP (n = 12, n=1) and a mother of a normally developing child (n=1)]; occupational therapists (n = 5), a physiotherapist (n=1) and manager of rehabilitation centers (n = 3) (**Tables 1, 2**).

The inclusion criteria for selecting participants were: 1) mothers who had experience taking care of children with CP in the levels of I to V Gross Motor Function Classification System Expanded & Revised (GMFCS – E&R). GMFCS E&R was used to assign functional mobility. Children at level I of GMFCS E&R could walk and perform all the activities of age-matched peers, without limitation. Children at level V had to be transported, had extreme difficulties with trunk posture, and little voluntary control of limb movements (18, 19). This Persian translated classification system indicated good reliability (20). 2) Occupational therapists with experience working in therapy with this group of children; and, 3)

managers who supervised the treatment environments for children with CP. All participants who were recruited for the purpose of this study met two general inclusion criteria: (a) intimate personal experience with mothering co-occupations in caring for children with CP, (b) willingness to participate in this study and describe their experiences. Participants were identified by contacting clinics under the supervision of the University of Social Welfare and Rehabilitation Sciences (USWR) and private rehabilitation centers in Tehran. Our sampling continued in two steps. First, we employed purposeful sampling to provide maximum diversity in participant selection. Second, we used theoretical sampling, a strategy based on the emergence and then saturation of concepts, sub categories and categories.

2-3. Data collection

We used semi-structured, in- depth and face-to-face interviewing as the main tool for data collection. This strategy allows participants to share sensitive personal experiences in a comfortable environment and permits interviewers flexibility to pursue interesting lines of questioning before moving on to other areas (21). Interview information was collected via both digital recording and field notes. Interviews started with general open-ended questions about the mothering co-occupations in caring for children with CP at home. Example opening questions for mothers include "Please describe a day of living with your child" and "what activities do you do to care for your child?" An example opening question for an occupational therapist was "which strategies do you think should be adopted to ensure better care for these children". An example opening question for rehabilitation managers was "what are your views of the process of caring for children with CP?" We continue, concordant with theoretical sampling, with more specific and detailed questions.

All interviews were carried out in Persian, which was the mother tongue of both the interviewer and interviewees; other coauthors checked the English version of the translation, coding and the coherence of the categories. A native English speaker checked the final English version for clarity of the language used; the interviews lasted from 45 to 60 minutes.

2-4. Data analysis

The content of interviews was tape-recorded and transcribed verbatim. Information obtained was read many times to gain a general understanding, following the recommended grounded theory approach of Corbin and Strauss 2008 (17). The data were analyzed using the constant comparative analysis methods. Using this method, words or short phrases from interviewees that symbolically represent and capture a datum's primary content and essence were recorded as codes. Research team members used a shared coding plan and in vivo coding was completed line by line from the transcribed interviews. Codes were integrated and refined to develop concepts, sub-categories and categories. Data were considered saturated when no more codes could be identified and properties and dimensions of the category were coherent or made sense. Active involvement in data analysis by the full research team (two qualitative researchers, two occupational therapists) led to agreement about interview guidelines and the emergence of main concepts and categories.

2-5. Trustworthiness

Rigor was established in four criteria recommended by Chwandt et al. (22). Credibility was evaluated via triangulation. In addition to semi-structured interviews, field notes together with prolonged engagement with the subject matter provided credibility (17). Furthermore, triangulation of researchers in the research team helped to take into account different

views when conducting coding checks (23). Peer checks were assured via weekly research team meetings for discussion and review of emerging data and data analysis among the research group as well as with experts. Member checking was enabled by a summary of the analyzed interviews and extracted codes being provided to participants to incorporate feedback. To ensure conformity of codes, categories and concepts, an experienced researcher checked through the reviews to compile ideas and concepts identified by other researchers (24). Transferability of data was provided by offering a comprehensive description of the subject, participants, data gathering, and data analysis (22). Dependency is assured through the current manuscript that offers detailed information enabling replication by others.

2-6. Ethical considerations

Approval was given by the Ethical Committee of (USWR), Tehran, Iran for this study. All participants provided informed verbal consent to participate. Participants were aware that the conversations would be recorded, recognized that they could request to withdraw from the study at any time, and understood that they could request the taped interviews to be deleted or destroyed. The research team members have extensive backgrounds in pediatric occupational therapy especially working with children with CP and mothering co-occupations in caring; no adverse consequences of participating in the research was recognized.

Table-1: Demographics characteristics of the participants (n=17).

Participant	Age	Family, relative	Paid work status	Child's age (year)	Child's condition	GMFCS – E&R
1	34	Mother of a CP child	Householder	5	CP, Spastic quadriplegia	V
2	30	Mother of a CP child	Householder	4	CP, Spastic diplegia	III
3	36	Mother of a CP child	Full-time	11	CP, Spastic diplegia	II
4	35	Mother of a CP child	Full-time	7	CP, Dyskinetic	IV
5	36	Mother of a CP child	Householder	11	CP, Spastic quadriplegia	IV
6	29	Mother of a CP child	Householder	9	CP, Spastic quadriplegia	V
7	40	Mother of a CP child	Householder	6	CP, Spastic quadriplegia	IV
8	32	Mother of a CP child	Householder	8	CP, Spastic diplegia	III
9	42	Mother of a CP child	Householder	13.5	CP, ataxic	II
10	28	Mother of a CP child	Full-time	6.5	CP, Spastic diplegia	III
11	40	Mother of a CP child	Householder	14	CP, Spastic diplegia	III
12	29	Mother of a CP child	Householder	12	CP, Spastic quadriplegia	V
13	43	Father of a child with CP	Full time	9	CP, Spastic quadriplegia	IV
14	26	Mother of normally developing child	Householder	10.5	Normal child	---
15	16	Child with CP	Student	15.5	CP, Spastic diplegia	III

16	12	Child with CP	Student	17	CP, Spastic hemiplegia	II
17	15	Child with CP	Student	16	CP, Spastic diplegia	III

CP: Cerebral palsy; GMFSCS E & R: Gross Motor Function Classification System Expanded & Revised.

Table-2: Demographics characteristics of the practitioners (n=9).

Practitioners	Age	Gender	Profession	Professional specialty	Years of experience
18	38	Male	Occupational therapist	Children with CP and their Families	13
19	34	Female	Occupational therapist	Children with CP and their Families	9
20	36	Male	Occupational therapist	Children with CP and their Families	11
21	32	Female	Occupational therapist	Children with CP and their Families	10
22	40	Female	Occupational therapist	Children with CP and their Families	8
23	37	Male	Physiotherapist	Children with physical disabilities	17
24	47	Male	Manager (Occupational therapist)	Children with CP and their Families	19
25	44	Female	Manager (Occupational therapist)	Children with CP and their Families	19
26	49	Male	Manager (Occupational therapist)	Children with CP and their Families	19

CP: Cerebral palsy.

3- RESULTS

Seven main categories and 17 subcategories were extracted from data via the grounded theory approach, including: motherly care, coping with unusual co-occupation, confusion with the roles being played, trying to meet special care needs, managing dynamic co-occupations, continuing care and inefficient environments. The main concern of parents in the process of mothering co-occupations in caring of children with CP was the "confused with the roles being played". Facing unusual co-occupations can result in caregiver confusion during role engagement and trying to obtain special care. Gradually over time, caregivers appear to learn ways to take better care of their children at home and managing their co-occupations. With the increasing age of the child, caregivers can be faced with unusual co-occupations that

may cause caregivers further confusion with the roles. In this study "coping with unusual co-occupation" was extracted as the core concept (**Figure.1**).

3-1. Motherly care

Motherly care is routine care that all mothers do for their children naturally, and is the central point of mothering co-occupation at home for mothers of children with CP. At this point a mother of a normally developing child said: "He wakes up in the morning around 7.5 -8 AM. I have tried first changing his nappy and then washing his hands and face and; giving him breakfast; if he needs I've changed his clothes. Usually 2-3 times a week I bath him" (P23).

3-2. Coping with unusual co-occupation

During the interviews, all caregivers of children with CP stated that they were faced with unfamiliar and unusual co-

occupations while taking care of their children. One of the mothers who were caring for two children with CP said: "The first and most important problem was that we did not know what problem he had. We also wondering about the problems Children with CP have. For instance why are they agitated and crying all during the night? Why do they have difficulties with eating and drinking? Why are they constipated? Why is sleeping hard for them? (Participant 1[P1]).

Another mother with a daughter diagnosed with spastic diplegia said: "I did not know what my daughter's problem was? Why was she crying? Was it because of that she is hungry? She could not sleep well?; and I really did not realize what her problem was? So I was just crying, and I was nervous, I did not know what to do, I felt disappointed, I felt guilty, I asked myself, why should I feel this much helpless and not to be able to solve my problem"(P2).

3-3. Confused with the roles being played

When a mother is faced with unusual co-occupation that she has not previously experienced and about which she has no information, she tends to feel confused and troubled about caring for her child. She realizes that her child's characteristics are different from those of a child developing according to regular milestones. One of the fathers stated: "He was our first child, we were totally confused and not only we but also our parents did not have enough experience to take care of this child, however, for us it was very difficult especially for me and his mother, because we had no information on what we are facing in the future and how we should look after him, we were very overwhelmed" (P17).

One of the mothers said: "When he was born I knew that my child had a problem and he would need special care. I was looking out for his care and treatment, but

I didn't know what I should do to sort out this problem" (P4).

3-4. Trying to meet special care needs

Mothers of children with CP realize gradually that they cannot take care of their children with ordinary caring and they need to seek knowledge and skills related to special care. Special care refers to the particular and unique care of children with CP applied in the areas of occupational performance by caregivers (mostly mothers). One of the mothers said: "When she begins to cry, I do not know, what's the problem? I think that I have already fed her, but she still cries. She might be thirsty, I give her some water, it might calm her down or not, perhaps she has is in pain, stomach pain or something else. Firstly, I try traditional medication. For example, I give her mint extract or rock candy, it might calm her down or not, if the problem continues, I give her Acetaminophen and then Diazepam (available pain killers), Because when she cries continuously, it might turn to seizure, so I give her Diazepam to prevent the seizures" (P6).

One of the occupational therapists stated his experiences as follow: "Unfortunately, many of the clients are referred to occupational therapy services too late and the caregivers through trial and error and experiments learnt how to take care for their children. However, remember that this way of caring, could be right or wrong" (P23).

3-5. Managing dynamic co-occupations

Over time and gradually, caregivers will learn the best ways to take better care of themselves and their children. They will gain new experiences to provide a balance between their occupation and children's occupations known as co-occupational management of caring. In this respect, one of the mothers stated: "During these years I learned how to meet his needs and take care of him. I put him into bed safely, now

I know how to engage him in the activities that he likes. Now I understand when he is hungry and needs food. His bathing and toileting is comfortable for me. I have just learned how to lift and carry and position him and that's easy for me" (P7).

3-6. Continuing care

Children with CP, based on their types of disability, require continuous caring throughout life; their needs will change according to age, motor development and over time. One of the mothers stated her experiences in the following way: "These children as they grow up, need more care. Right now, I'm worried about my daughter's school and as she gets older it seems community healthcare needs to be more prominence" (P8).

One of the managers, about continuing care in the children with CP said: "When children with CP grow up, they also expand the possibility of engagement in activities of daily living and need more care. In addition to caring at home, they need caring at school and in the community" (P14).

3-7. Inefficient environment

The participants in the study expressed the opinion that caring for a child with CP in an inefficient environment had an impact on the mothering co-occupations process in caring for children with CP. The study showed that the mothering co-occupations process in caring could be influenced by inadequate knowledge and skills, low social and financial support, inappropriate home modification and negative public opinion. Most participants, especially caregivers, occupational therapists and rehabilitation managers, expressed that one of the major problems was the lack of experience and skills on caring for children with CP.

One of the mothers stated: "Since my son was our first child, we didn't have the experience and skills to take care of him. It

was very difficult for me and his father, because we didn't have information and didn't know how to take care of him" (P9). In this respect, one of the occupational therapist said that: "The therapist's experience about caring for children with CP is low. For example, I really don't know how to feed or bath a child with severe spastic CP" (P24).

Parents of children with CP perceived that they were under distress due to economic issues. Their pensions were not enough to cover their life needs due to rehabilitation and treatment expenses. They believed that the social insurance system should support them. Regarding social and financial support one mother said: "We cannot afford private rehabilitation clinics. Our salaries are not enough to cover that private rehabilitation clinic or hiring a nurse for our child. We don't have social insurance to help and support us" (P10).

More mothers of children with CP stated that they are required to obtain and use assistive devices as well as complete home modifications in order to create a more accessible environment to be able to provide better and easier care for their children. One mother said: "First, we have little information about the use of assistive devices; second, these devices are not easily obtained or they are so expensive that we can't afford them and the government doesn't assistance does not cover these services" (P11).

Participants stated that unfortunately there is negative public opinion about children with CP and their caregivers. One mother said: "When my son was younger and had no head control, I did not know the right way of holding him; therefore his head was hanging out of his control. Once while I was in a taxi the driver got angry at me because of this and considered me as a careless mother and forced me to get off of the car. He thought that I don't deserve to have a baby and I cried because of this cruel judgment for hours" (P12).

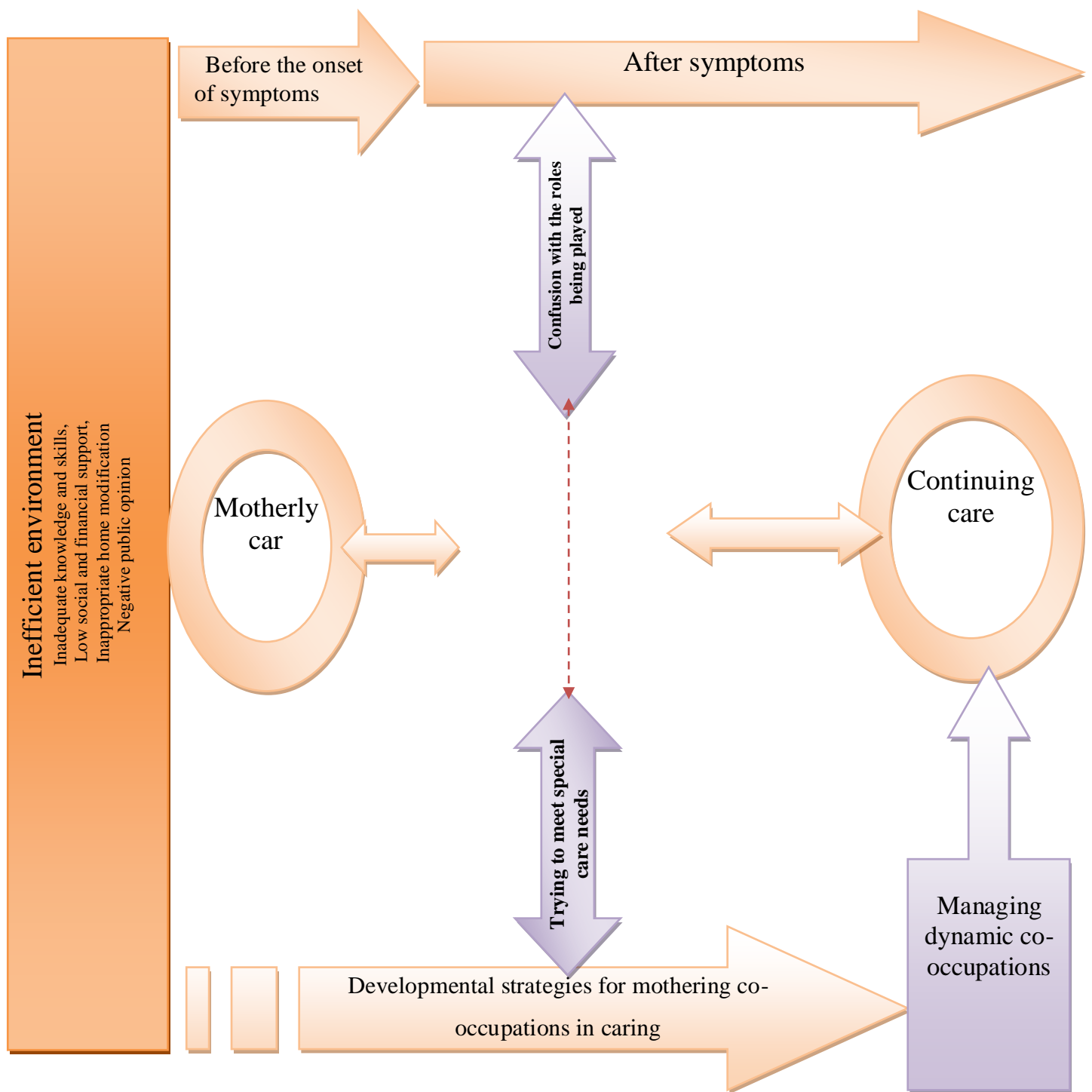


Fig.1: Mothering co-occupations process in caring for children with cerebral palsy.

4- DISCUSSION

This study has focused on exploring the mothering co-occupations process in caring for children with CP at home in Iran. Results identified that the main problem in mothering co-occupations in caring for children with CP was being need to deal with unusual co-occupations. Child care is a natural feature of parenting (25). The majority of everyday occupations of children with CP requires mothers' co-occupation to facilitate participation and assist to improve their ability to perform the required occupations (26). In the process of caring for children with CP, caregivers face with unusual co-occupations that they have not experienced before. They really do not know how to feed their children who have dysphasia. Novak (2011), in a qualitative research study stated that parents of children with CP while taking care of their children at home were faced with problems that they had not experienced before; their knowledge and information about these circumstances therefore is insufficient (27). One of the main categories generated from the data was the confusion experienced between roles.

A majority of caregivers stated that limited experience and knowledge about how to care for their children was one of the main problems that made them feel inadequate about taking care of their children, leading to confusion and bewilderment. One of the main categories generated from the data was that of trying to obtain special care. Because the co-occupations were unusual and specialized, the mothers had little information, knowledge, and experience to guide them. Therefore the simplest strategy for an untrained caregiver with inadequate knowledge and experience is trial and error (28). Alaei et al. (2014) argued that parents face with difficulties in caring for this group of children, thus moving ahead through trial and error. This approach was even more "hit and miss" in

managing conditions appropriately through daily activities if they did not have time for participating in training about appropriate ways to care for their children. This argument is consistent with the findings of the present study (29). Powell et al. (2006) demonstrated that parents' enhanced knowledge of caring for children with CP could lead to some variations, including changes in attitudes and beliefs, which in turn caused enhancement of adaptation and ultimately decline in stress and the promotion of QOL (30).

Caregivers use the guidance and supportive involvement of and with occupational therapy intervention models and programs to build confidence about how to help their child (27). One of the other main themes in the present study was managing dynamic co-occupation. Caregivers reported that after several years of caring, they developed effective ways to manage their child's care in different situations. Finding of Khanjani et al. (2008) study showed that parents need training on different approaches of handling their children by enhancing their sense of empowerment in their caring role, and to continue the caring within their home (25).

Furthermore, some researchers, argued that employed parents, the presence of several children in the family, little support of friends, family members and service charges are considered as the barriers of co-occupational management of caring at home (26). One of the main categories of data extraction was continuing care. Participants' experiences showed that caregivers after co-occupational management are trying to continue caring. Some caregivers continue more willingly to care because they know their child as part of themselves and caring for them is a part of their life priorities. Others continue to provide caring duties inevitably because they see this as their responsibility and, except for continuity of caring, there is no

other choice for them. Participation of caregivers in taking care of the child increased child satisfaction, giving the child more confidence and less anxiety (10). This creates a greater understanding of the individualized needs of the child and has a positive effect on child health and QOL (31).

4-1. Limitations of the study

The findings of the present study should be considered with its limitations. Sometimes home interview sessions were interrupted by a child's immediate need for help (such as toileting); this limitation was resolved through managing and controlling the interviews and also providing mothers with assistance when needed even during interview time. Some families did not allow home observation. Because of religious matters, they do not like the presence of unrelated men in their home, thus limiting the total number of observations. In addition, observation of some co-occupations was impossible such as the mother bathing her child. In these situations, the mother was asked to explain the method she used to bathe her child. Another limitation arose from the data being interpreted by the investigator; this may have resulted in bias being reflected in the findings.

5- CONCLUSION

The results of this study showed that mothers of children with CP in the process of caring for their children were confronted with unusual co-occupations about which they had no previous information or experience. Role confusion tended to result in some mothers having to face problems when caring for their children. Since the children need special and long time care, the mothers had to change their role to being a key caregiver for their child and the motherhood and wife roles are diminished over time. The mothers need to develop confidence and skills in areas of special care that take a lot

of time, energy and effort. The consequences of the pressures of providing special care for mothers may include: tension; increase in the perceived burden of care; and, reduction in individual tolerance of physical and psychological pressures that limit mothers' caring capacity. Key inputs that increase parental self-esteem and senses of empowerment and help in the co-occupational management of caring include are: the acquisition of direct experience; improved knowledge; comprehensive support; comfort with the use of assistive devices; installation of home modifications; and training in special care models, approaches and specific skills. Further studies are recommended to explore the processes of mothering co-occupations in caring for children with CP in different cultures and in urban and rural areas. One major element of this research would be to focus on the identification and recognition of various factors influencing participation and co-occupations, and the interaction effects between these factors in caring for children with CP.

6- CONFLICT OF INTEREST: None.

7- ACKNOWLEDGMENTS

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