

Identification of Barriers to Self-Care Behaviors in Patients with Cerebral Palsy

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Abstract

Background: There are many barriers to self-care behaviors in adult patients with cerebral palsy (CP) that can cause various problems in their daily life and social activities. Barriers to self-care behaviors affect various aspects of adult CP patients' lives, causing physical, psychological, and social problems.

Objectives: The present study aimed to identify the barriers to self-care behaviors in CP patients.

Methods: This study was conducted using a qualitative method based on the grounded theory. The participants were selected through purposive sampling among the clients of the Cerebral Palsy Supporters House and Raad Charity Educational Center in Tehran, Iran, in 2020. The participants included six men and nine women with CP, aged 20 to 40 years. The data were collected via semi-structured interviews. After interviewing 15 participants, we reached theoretical data saturation. The interviews were recorded and then transcribed. Data based on Corbin and Strauss's theory (2008) were analyzed using open, axial, and selective coding.

Results: The barriers to self-care behaviors were conceptualized into 39 open codes and seven categories using axial coding. The categories were as follows: "Psychological barriers to perceiving the importance of self-care behaviors", "physical and motor disabilities", "dissatisfaction with body shape and appearance", "excessive family concerns and support", "employment limitations", "negative and judgmental views of the society", and "economic and financial concerns and uncertainties about the future".

Conclusion: The results showed that barriers to self-care behaviors in CP patients affect their well-being and quality of life. The results of the present study can contribute to our understanding of the barriers to self-care behaviors and help us develop interventions and strategies to educate CP patients and their families.

Keywords: *self-care, barriers, cerebral palsy, qualitative study*

Introduction

Cerebral palsy (CP) is a group of permanent movement disorders that develop in early childhood. CP involves non-progressive abnormalities in the developing brain, leading to movement disorders and functional limitations in daily life. Besides movement disorders that affect the CP child's participation in different activities, environmental factors can also increase or decrease the child's participation level [1,2]. Moreover, movement disorders in CP patients are

complex and include primary defects and symptoms, such as muscle spasms, muscle atrophy, and loss of transitional motor control, in addition to secondary defects, such as muscle contraction and bone abnormalities.

The main disorders associated with CP are movement disorders, leading to restrictions in daily activities, such as walking. Generally, the severity and type of disorders vary in the CP population [3]. These motor disabilities are caused by a brain injury or dysfunction and are

often associated with speech and hearing disorders, seizures, gastrointestinal, nutritional, pulmonary, and dental problems, contractions and deformities of the limbs, osteoporosis, cognitive disorders, mental retardation, and epilepsy [4]. It is estimated that there are more than 17 million CP patients globally, ranging from infants to 90-year-old adults [1]. The prevalence of CP has been reported to vary from 0.6 to 5.9 per 1000 live births in different countries. Also, the prevalence of CP and the organs involved have been investigated in different countries [5]. Given the high prevalence of CP and its associated disorders, in addition to the needs of these patients due to the disease, it is important to understand their rehabilitation needs [4,6].

Many risk factors for CP have been identified so far, including neonatal prematurity, low maternal age, multiple pregnancies, and maternal genital infections. Prematurity is currently the most common cause of CP [2]. CP is classified according to physiological characteristics or the affected cognitive domain. Different types of CP are grouped as spastic and semi-spastic physiological indicators (e.g., hypotonic, atonic, athetoid or dyskinetic, and compound) or spatial indicators (e.g., hemiplegia, diplegia, and dual pleural effusions). These classifications can help us identify the severity, location, and time of CP [7].

Self-care behavior, according to Orem's definition, is a key concept in health promotion, which refers to the decisions made and activities done by a person to adapt to a health problem by improving his/her health [8]. Self-care behavior is influenced by various factors. It has been experimentally shown that there are significant differences in the disability reactions, social functioning, and physical activities of two people who are in the same medical and traumatic situation. Psychological components, such as the individual's core thoughts and underlying beliefs, are among factors that can account for these differences [8,9].

Self-care is a consciously and purposefully learned action and behavior that is performed to ensure, maintain, and promote health [9]. It is a continuous activity that is done by the individual, for the individual, from birth until death [10]. Self-care is a learnable behavior that can meet many of the patients' needs when they become ill

or develop health problems [9]. The American Medical Association has emphasized that therapeutic approaches should seek to enhance one's capacity for self-healing, independence, and self-reliance and focus on self-care education rather than treatment or reliance. Engagement in self-care behaviors increases the person's willpower to perform voluntary actions and enables him/her to do things purposefully. In developing countries, self-care is in its infancy, and consequently, the available references about self-care are very limited, and there has been no significant progress in this area [11].

CP patients face physical problems and social life barriers to acquiring self-care skills [12]. It has been shown that lack of self-care threatens the psychological health of CP patients [13]. Independence in activities of daily life gradually develops in early childhood and is shaped around the age of seven. This type of development is influenced by different factors, such as cultural, family, and individual factors. Acquisition of self-care skills is also associated with the development of motor skills. However, in the absence of fine and gross motor skills, it is difficult to significantly achieve independence [11,14]. Cultural and social differences can be effective in understanding the barriers and facilitators of self-care behaviors about diseases in each country [15]. Therefore, identifying the barriers to self-care behaviors in CP patients can help them improve their lives and independence in daily activities. On the other hand, lack of awareness and knowledge about the barriers of self-care behaviors deprives these patients of self-confidence and motivation to live without care [14].

The present study aimed to identify the barriers to self-care behaviors in CP patients to help them have a better and more effective life and enable them to find appropriate strategies for discovering and eliminating the barriers and promoting their self-care behaviors. It seems necessary to explore the barriers to self-care behaviors in the Iranian youth and consider the cultural, social, and psychological contexts for a better understanding of the problems of these patients in Iran. Besides, removing the barriers to self-care behaviors in this group of patients can lead to the individual/social independence of patients and help them improve their quality of life. Generally, qualitative

research is the most effective approach to identify self-care behaviors in young adult men and women with CP, because it is a suitable method for discovering the underlying causes of problems and accounting for human experiences and perceptions. Therefore, we used this design for the present study to identify the barriers to self-care behaviors in CP patients.

Methods

This study was conducted based on the grounded theory. According to this theory, rather than testing the relationships between variables, we need to discover the related categories and the relationships between them and relate them in a new way [16]. In this study, the participants were selected through purposive sampling among clients, presenting to the Cerebral Palsy Supporters House and Raad Charity Educational Center in Tehran, Iran, in 2020. The inclusion criteria were being in the age range of 20-40 years, having the ability to speak, and having normal intelligence. A psychologist, a speech therapist, and an occupational therapist, working in these centers, determined if a patient met the inclusion criteria. After conducting interviews with 15 participants, we reached data saturation (i.e., the point at which no new information or theme was observed in the data collected through the interviews).

In this study, the data were collected through semi-structured interviews. The interviews were conducted face-to-face and via phone calls [17], and the participant's voice was recorded. Data, collected based on Corbin and Strauss's theory (2008), were analyzed, using open, axial, and selective coding. First, the interview questions were prepared. At the beginning of all interviews, the researcher tried to establish a good relationship with the interviewees and ensured them that all their information would be recorded as anonymous codes and deleted at the end of the study.

Questions, such as "what problems and obstacles do you face in your daily life?" and "how do you typically spend your day?", were asked in the interviews. Each interview lasted about 45 to 60 minutes (total time of interviews: 840 minutes). Conceptualization was performed using open coding while considering the research variables, the questions asked in the interviews, and the statements made by the participants. Besides, to refine and separate the categories, statements with similar meanings were categorized, using axial and selective coding [16].

The credibility of the data and the research procedure was evaluated based on the criteria proposed by Guba and Lincoln [18]. To examine the reliability and validity of the data, it was peer-checked by professors and nurses of the Nursing Department of the Nursing Research Center of Golestan University of Medical Sciences. After extracting the data, evaluating the credibility of the findings regularly based on the professors' comments, and matching them with the research problem (i.e., self-care behaviors), the next step was taken for further validation of the data. In the second step, the collected data was assessed by the participants. For this purpose, the researcher contacted five participants and asked them if they confirmed the results of the study.

Written consent was obtained from the participants for conducting and recording the interviews. The participants were assured that their participation was voluntary and that they could leave the study at any time. Besides, they were informed that their names, addresses, and phone numbers would be kept confidential and that their recorded voices would be stored after transcribing the interviews for five years.

Results

The participants included 15 CP patients, aged 20 to 40 years (mean age: 33.02 ± 11.41 years). The participants' education level ranged from primary school to a doctoral degree. Table 1 presents the participants' demographic data.

Table 1: The descriptive statistics of the participants' demographic data

code	Birth order	Gender	Age	Education	Occupation	Number of siblings	Father's job	Mother's job	Type of cerebral palsy	Economic position	Mode of interview
1	Second	Male	22	Bachelor's degree	Manager of Cerebral Palsy Supporters House	1 sister	Retired	Housewife	Hemiplegia	Poor	Phone
2	First	Male	27	Bachelor's degree	Accountant Weightlifting champion	1 brother	Psychologist	Teacher	Hemiplegia	Moderate	Phone
3	First	Female	23	Master's degree	Instagram Admin	1 brother	Self-employed	Housewife	Monoplegia	Good	Phone
4	First	Female	29	Master's degree	Secretary	1 brother	Self-employed	Housewife	Hemiplegia	Poor	Phone
5	Fifth	Male	37	Master's degree	Employee	2 brothers and 2 sisters	Factory owner	Housewife	Hemiplegia	Good	Face to face
6	First	Female	27	Master's degree	Employee	1 brother	Retired	Tailor	Hemiplegia	Moderate	Face to face
7	Sixth	Female	32	Diploma in humanities	Marketer	4 brothers and 1 sister	Self-employed	Housewife	Hemiplegia	Good	Phone
8	First	Female	24	Associate's degree in social work	Unemployed	1 sister	Self-employed	Teacher	Monoplegia	Moderate	Face to face
9	Seventh	Female	35	5th-grade primary school	Unemployed	4 brothers and 2 sisters	Self-employed	Deceased	Diplegia	Moderate	Face to face
10	First	Male	35	Diploma	Other	2 brothers and 3 sister	Self-employed	Housewife	Hemiplegia	Poor	Face to face
11	Second	Female	21	Diploma in humanities	Unemployed	1 brother	Self-employed	Housewife	Diplegia	Moderate	Face to face
12	First	Male	25	Diploma in humanities	Unemployed	1 twin brother	Self-employed	Housewife	Diplegia	Good	Face to face
13	First	Female	37	Ph.D. in Psychology	Counselor	1 sister	Self-employed	Housewife	Diplegia	Poor	Face to face
14	Third	Female	38	Diploma in graphics	Unemployed	2 sister	Deceased	Kindergarten teacher	Athetoid	Moderate	Face to face
15	First	Male	27	Diploma in humanities	Worker	1 twin brother	Self-employed	Housewife	Monoplegia	Moderate	Face to face

Thirty-nine codes were extracted through open coding from the participants' statements. Besides,

seven themes were identified through axial coding from the codes, as shown in Table 2.

Table 2: The open, axial, and selective codes extracted from the participants' statements

Open codes	Axial codes	Selective codes
Self-denial, low self-esteem, not accepting the reality, feeling of lack of control over personal life, not accepting the disability, feeling of isolation	Psychological barriers to perceiving the importance of self-care behaviors	The barriers to self-care behaviors in CP patients
Lack of independence in self-care, limited mobility in performing personal duties, severe disability, physical problems caused by repeated surgeries	Physical and motor disabilities	
Feeling ugly, dissatisfied with appearance, feeling ashamed of body shape, not paying attention to take care of oneself due to dissatisfaction with appearance, lack of physical attractiveness	Dissatisfaction with body shape and appearance	
Parents' worries about the patient's inability for self-care, the performance of the patient's tasks by the mother, strong dependence on the mother to do all personal affairs, lack of encouragement for independence and personal care, high dependence on the family, especially the mother, constant parental control and supervision, disbelief in the independence of the child, inducing feelings of fear and helplessness	Excessive family worries and support	
The employer's unawareness of the patient's abilities, unwillingness to employ people with disabilities, limited and part-time employment such as peddler or marketer	Employment constraints	
Instilling a sense of inadequacy, a pitiful look, inducing a sense of difference, a contemptuous look, a sense of rejection, verbal harassment, disbelief in marriage and having a marital life	The judgmental and negative view of society	
The desire for financial independence, freedom from being a tenant, the inability to pay for basic living expenses, financial inability and lack of money, having difficulty in providing medical and rehabilitation expenses, having one's own house	Economic and financial concerns and an uncertain future	

As shown in the table above, the barriers to self-care behaviors were classified into seven

categories: "Psychological barriers to perceiving the importance of self-care behaviors", "physical

and motor disabilities”, “dissatisfaction with body shape and appearance”, “excessive family concerns and support”, “employment limitations”, “negative and judgmental views of the society”, and “economic and financial concerns and uncertainties about the future”.

The psychological barriers were classified as the first theme by analyzing six open codes, including self-denial, low self-esteem, non-acceptance of reality, feeling of lack of control over personal life, non-acceptance of disability, and feeling of isolation. These factors accounted for all the negative emotions and feelings that a person might have toward oneself concerning CP, with significant effects on one’s understanding and acceptance of the disability and engagement in self-care behaviors. In this regard, one of the participants said:

“I still cannot cope with cerebral palsy. I mean I have difficulty accepting the disease, and I have to see a counselor so that I can manage it. I am a very sensitive person, I was not sensitive before, but after a while, I became very sensitive about the disease.” (Participant #3)

Regarding the lack of control over personal life, one of the participants stated:

“I honestly find everything difficult. I cannot do anything on my own or be independent. I need to have a nurse beside me to do things for me.” (Participant #9)

The second main theme, that is, physical and motor disabilities, was extracted by classifying five open codes, including lack of independence in self-care, limited mobility in performing personal tasks, severe disability, and physical problems, caused by repeated surgeries. This theme included all physical conditions caused by CP that restrict the individual’s ability to perform different activities. Concerning the physical and motor disabilities, one of the participants said:

“For example, when I want to take off my blouse, I suddenly become spastic. I cannot raise my hand, and when I get out of the bathroom, and my body gets a little wet, I cannot wear my clothes. I cannot live independently at all.” (Participant #9)

Regarding exposure to repeated surgeries, one of the participants said:

“From the age of four to seven, I used to crawl on my hands and feet just like a cat. At the age of eight, I underwent a difficult surgery, which was

promising, but I lost weight in my legs after the operation.” (Participant #7)

Dissatisfaction with body shape and appearance was the third main theme, which was classified into five open codes: Feeling ugly, dissatisfaction with physical appearance, feelings of body shame, lack of attention to self-care due to dissatisfaction with physical appearance, and lack of physical attractiveness. These codes covered all the feelings that the patients had about their appearance; in other words, they were displeased with their physical appearance. Overall, these factors demotivated the patients to engage in self-care behaviors, which was even more common among female patients. In this regard, one of the participants stated:

“Because I thought I was the only person with this problem at school, I felt scared and the students were unkind to me. Some students said that I had a prosthetic hand and harassed me both mentally and verbally.” (Participant #6)

Excessive family concerns and support was determined as the fourth main theme and categorized into eight open codes, including the parents’ concerns about their child’s inability for self-care, mother’s engagement in the child’s personal affairs, child’s strong dependence on the mother for all personal affairs, lack of encouragement for independence and self-care, high dependence on the family (especially the mother), constant parental control and supervision, disbelief in the child’s capacity for independence, and promoting feelings of fear and helplessness in the child. These factors accounted for all feelings and worries of the families about the performance of self-care behaviors by their children, who considered their family’s concerns as a major barrier to their self-care behaviors. In this regard, one of the participants stated:

“Because of my physical condition, my mother thought that she should have more control over me; this did not allow me to have functional independence to do my personal affairs at home. My mother even did not allow me to take a bath or go to the toilet alone, but I could do these things on my own.” (Participant #5)

Another participant said:

“My mother always worries about me. My main problem is that my mother always assumes that I am not mature enough to do things on my own.” (Participant #6)

Employment limitations, as the fifth main theme, were categorized into three primary open codes, including the employer's unawareness of the patient's abilities, organizations' unwillingness to employ people with disabilities, and limited or part-time employment, such as salespersons or marketers. It is obvious that lack of independence and self-reliance can seriously damage the self-care of patients with disabilities. This theme represents the feedback and reactions of the community to CP patients who try to engage in social activities. These people are commonly excluded from the workforce due to their physical disabilities (albeit mild). In this regard, one of the participants stated:

"I have never had the chance to do anything other than sales." (Participant #10)

The sixth main theme of this study was the negative and judgmental view of the society. This theme was conceptualized into seven open codes, that is, instilling a sense of inadequacy, people's pitiful look, feeling of being an outcast, people's contemptuous look, feeling of rejection, verbal harassment, and disbelief in marriage or marital life. It is known that self-stigma is a negative factor in self-care behaviors. Self-stigma and social stigma minimize the patients' abilities to care for themselves. This theme reflected the community's inconsiderate attitude and uninformed judgments about CP patients, leading to resentment. As a result, these patients try to hide themselves and their disabilities from others. One of the participants stated:

"Unfortunately, we have many problems in our relations with the community and people around us. They have negative feelings about us and look at us pitifully." (Participant #13)

Another participant added:

"I got very annoyed in public places, and the way people looked at me made me upset; I felt humiliated." (Participant #3)

Economic and financial concerns and uncertainties about the future constituted another theme of this study. This theme was extracted from six open codes, including the person's desire for financial independence, desire to live independently, inability to pay for basic living expenses, financial inability and lack of financial income, having difficulty meeting medical and rehabilitation expenses, and having one's own home. Generally, one of the most important barriers to self-care behaviors in CP patients is economic problems. When a CP patient decides to do something independently, he/she needs financial resources. Besides, the costs of treatment, rehabilitation, occupational therapy, speech therapy, physiotherapy, travels, and housing are important concerns of CP patients. The high cost of treatment prevents these patients from pursuing treatment and ultimately leads to poor self-care. In this regard, one of the participants remarked:

"I took a lot of financial risks, such as selling drugs to make money because I was worried about my financial situation. I want to marry and have a family someday. My family members are living as tenants now. They paid for me to recover from my illness, and now they are living in a rental house; I always think about having a house for myself. My surgery costs were so high that they had to sell the house. Now I feel responsible for my family." (Participant #1)

Another participant added:

"I felt embarrassed that my family had to pay for me. I stopped going to Saba Clinic in 2007 when my mom told me that my treatment in the clinic required a lot of money and that she could not afford it." (Participant #10).

Figure 1 shows the barriers to self-care behaviors in CP patients:

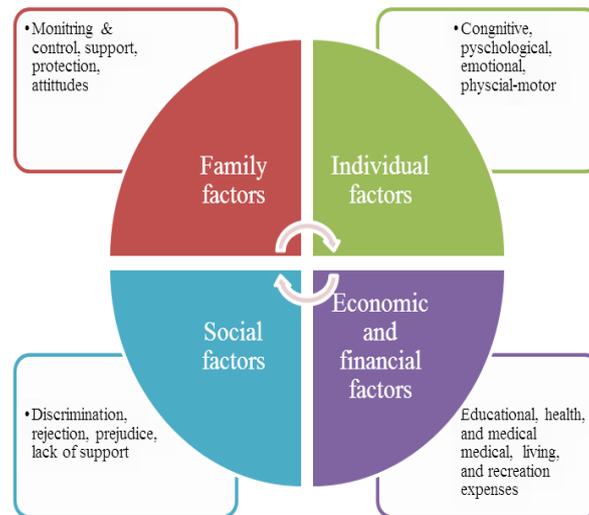


Figure 1: The barriers to self-care behaviors in CP patients

As can be seen in the figure above, the barriers to self-care behaviors were as follows: 1) Individual factors (psychological, cognitive, emotional, and physical-motor); 2) family factors (monitoring and control, support, protection, and attitudes); 3) social factors (discrimination, exclusion, prejudice, and lack of support); and 4) economic and financial factors (education, health and medical, living, and entertainment expenses). All of these factors were related to one another

Discussion

The present study identified the barriers to self-care behaviors in CP patients. The results showed that the barriers could be classified into seven categories based on axial coding, including “psychological barriers to perceiving the importance of self-care behaviors”, “physical and motor disabilities”, “dissatisfaction with body shape and appearance”, “excessive family concerns and support”, “employment limitations”, “negative and judgmental view of the society”, and “economic and financial concerns and uncertainties about the future”.

The present results were in line with the findings reported by Kautz et al. (2020) on self-care barriers. They found that self-confidence is a key factor in self-care behaviors of CP patients. Also, the frequency of self-care behaviors had a positive relationship with self-confidence in self-care, but was not associated with any other criteria of family functioning. The caregivers used different

strategies and faced significant obstacles in self-care; therefore, self-confidence in self-care may be associated with lower levels of stress and greater satisfaction [10]. Another study by Reedman et al. (2017) suggested that interventions, including physical education, activity participation training, mixed physical therapy, and behavioral change, could increase the participation of young CP patients. Although these patients need to discard a disorder-oriented approach, disruption or inadequate reporting of complex interventions is a major obstacle to their progress [19].

Moreover, Öhrvall et al. (2010) showed that physical problems can affect the participation of children with CP in daily and social activities [11]. Besides, Gannotti et al. (2019) studied the views of adult patients with CP and physiotherapists with similar education about social success, personal goals, employment, and family support. It was shown that adults with CP show greater resistance and stability needed for success. Both groups described happiness as spending time with the loved ones, doing recreational activities, and having a purpose in life. Adults with CP recognized the importance of accepting happiness. For both groups, health meant self-care for a healthy mind and body, cardiovascular and musculoskeletal health, and physical fitness [20].

Additionally, Dalvand et al. (2013) suggested that the lack of practical training is the main challenge

in managing children with CP at home. They also emphasized the importance of therapeutic exercises and considered the lack of child's active participation in therapeutic exercises as the main problem of clinics. Also, lack of care-based handling and abuse was the main challenge of child management at school and in the community [15]. Besides, lack of suitable employment or uninsured employment, social problems (e.g., social exclusion), and the negative views of the society about physical disabilities were other problems faced by people with disabilities in gaining independence and self-care skills [21,22]. Generally, adult CP patients have different experiences of environmental problems (e.g., access to services and support, transportation, accommodation, and safety), family and peer involvement, and social participation (e.g., recreational, school, and social activities). These patients also described their experience of change in their body structure and function, including physical functioning, mental health, fatigue, and an unpredictable physical status. Also, daily activities and health were among the main concerns of these patients [23].

Bagatell et al. (2017) identified many challenges of CP during adulthood, including the adults' knowledge, surveying systems and services, understanding of body management, and dealing with stereotypes and social prejudices that require a comprehensive approach to care. To engage in self-care behaviors and combat chronic diseases and disabilities, daily exercise and physical activities are recommended by rehabilitation specialists and psychologists [7]. In this regard, Gjesdal et al. (2020) interviewed eight adults with CP (four women and four men; age: 26-60 years). Almost all subjects reported that their walking routine was restricted over time and affected by physical problems, such as pain, fatigue, loss of balance, and fear of falling. Besides, environmental problems, public space limitations, and adaptation to the environment affect their level of activity [24].

In another study, Downs et al. (2020) showed that adult people with physical disabilities need to know that physical activity is necessary for their health. Besides, motivation is a key factor in being active, as it provides social opportunities for the individual in appropriate and safe environments [25]. In this regard, Kato et al.

reported that patients with self-stigma and social stigma minimize their ability to care for themselves. Self-stigma had a significant relationship with low self-care behaviors in patients [26]. Therefore, to improve the quality of life of CP patients, special attention must be paid to the underlying factors in two main ways. First, measures must be taken by focusing on the underlying individual and family factors that highlight the role of psychological issues, highlighting the importance of the individual's personal and physical motivations and support, and considering the positive or negative attitudes of the family toward self-care in these patients. Second, considering the role of social, economic, and financial factors, governmental agencies need to provide specialized assistance by rehabilitation consultants and health professionals for these patients. Overall, without creating an inclusive culture and solving the existing social problems and barriers to the adaptation of these patients, it is not possible to change their self-care behaviors. The present study had some limitations. First, the study sample was limited to male and female patients, presenting to the Cerebral Palsy Supporters House and Raad Charity Educational Center in Tehran in 2020. Second, in this study, we used a qualitative design to identify the views and experiences of Iranian patients with CP. Therefore, our findings cannot be generalized to other CP patients with different cultural, geographical, and social backgrounds.

Conclusion

The present results showed that the barriers to self-care behaviors in CP patients could be conceptualized into the following categories: Psychological barriers to perceiving the importance of self-care behaviors; physical and motor disabilities; dissatisfaction with body shape and appearance; excessive family concerns and support; employment limitations; negative and judgmental views of the society; and economic and financial concerns and uncertainties about the future. The most important factors that hindered self-care behaviors in CP patients could be the absence of psychological training, motivating skills, lack of an optimistic view by the families and patients, mismatch between the community and the household environment, and lack of

access to adequate and inexpensive social and rehabilitation services due to economic problems.

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Conflict of interest

We declare that there is no conflict of interest.

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