



# Hope Facilitators in Parents with Children Suffering from Cerebral Palsy: A Qualitative Study

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## Abstract

**Background:** There is ample evidence indicating that the parents of children with cerebral palsy report the experience of hope, despite all problems to which they are exposed.

**Objectives:** This study aimed to explain the factors facilitating hope regarding the experiences of parents having children suffering from cerebral palsy.

**Methods:** This qualitative study was carried out using the content analysis method. The experiments of 17 parents (11 females and 6 males) having children with cerebral palsy were collected in in-depth unstructured interviews in 2019, and then content analysis was performed using Strauss and Corbin's approach. The purposive sampling method was used as long as data saturation was reached. After that, the collected data were analyzed using the content analysis method.

**Results:** In this study, several factors were extracted as facilitators of hope in parents of children with cerebral palsy. These effective facilitating factors were classified into four main categories: promising treatment, positive beliefs, motivational drivers, and support networks.

**Conclusions:** Various factors can be effective in promoting hope in parents of children with cerebral palsy, the detection of which would help developing educational and counseling programs and providing support for such parents.

**Keywords:** Cerebral Palsy, Facilitator, Hope, Parents, Qualitative Study

## 1. Background

Cerebral palsy (CP) is the most common neurodevelopmental disorder, impairing children's motor skills (1). This disorder results from a non-progressive lesion in the developing brain and is often associated with a range of cognitive and behavioral disorders limiting children's involvement in social activities (2, 3). This chronic disorder disrupts the child's functioning and is associated with serious negative consequences for his/her family (1). The consequences of this disorder can be to the extent that some parents fail to return to normal life.

The problems and challenges posed by the birth of a disabled child in the family may lead to a series of psychological problems and even cause chronic sorrow in the parents, which would be associated with a feeling of disappointment in the treatment and future of their disabled children (4). Parents with the CP children are exposed to psychological problems, stress, family conflicts, and social problems, all of which affect the family's quality of life and

overall functioning (5).

Although many previous studies have reported severe problems among the parents of children with CP (6-8), some recent studies have revealed positive and promising attitudes in these parents. In other words, some parents have seemingly overcome their problems and returned to normal family life (9, 10). Hope is generally regarded as a critical predictor indicating the parent's acceptance of their child's disability (11). It is a calming force against anxiety and depression and a predictor of individuals' satisfaction and happiness in life (12). According to Snyder's Hope Theory, hope is not a passive emotion arising only in the darkest moments of life; however, it is a cognitive process through which individuals seek to achieve their goals actively (13).

Hope is significantly associated with reduced distress in low-income families (14). According to some previous studies, it plays a crucial role in improving mental health, quality of life, and resilience in the parents and families

of children with developmental disorders (15). In this regard, Shikako-Thomas et al. (16), in a study on the parents of children with CP, indicated the role of parents' hope in improving the quality of life and health of children with CP and their families. Although hope has been a hotbed of research in the literature, few studies have examined the factors promoting hope, especially in families of children with special needs (e.g., CP children) (17).

## 2. Objectives

Evidence suggests a significant and close relationship between the family's normal functioning and children's health status. Considering the high prevalence of CP in Iran, the family life of these children, as well as the effective factors in developing hope and improving their quality of life, need to be addressed. Accordingly, the present study aimed to explain the factors nurturing hope based on the experiences of the parents with children suffering from cerebral palsy. The present study was part of a research project entitled "explaining the process of creating hope in the parents of cerebral palsy children" and was to detect hope facilitators in the parents of children with CP.

## 3. Methods

This qualitative study was carried out using the content analysis method. Since this study aimed to extract hope facilitators using the participants' real-life experiences, a qualitative approach seemed appropriate. Generally, qualitative research provides better insights into human experiences and perceptions and reveals some details in this regard, which have been disregarded in previous studies (18, 19). Content analysis is described as a qualitative method linking data to the main topic, and its end products are concepts and categories describing the phenomenon under study (20). Accordingly, this type of analysis seemed appropriate for extracting categories describing hope facilitators.

The present study encompassed the parents of CP children referred to the rehabilitation clinics in Semnan, Iran. The sampling method was determined based on the qualitative research principles outlined by Corbin and Strauss (20). In this study, the purposive sampling method was adopted to select five parents with CP children, who had positive experiences of hope development, were successful in their lives, and were known as successful members of the society. Then in-depth interviews with the parents were conducted. With the emergence of conceptual categories during the data analysis process, more participants were included in the study using the theoretical sampling

method for open coding. Sampling continued as long as data saturation was reached, and no additional information was obtained.

### 3.1. Data Collection and Analysis

In-depth unstructured interviews were conducted to collect data from the participants directly. The codes and categories were extracted using an inductive process, and the concepts were developed based on mutual characteristics and aspects (18, 20). Prior to the interviews, the research objective was explained to the participants, and written consent forms were obtained. The interviews, which lasted for 45 - 90 minutes, were completely recorded.

In this study, 17 interviews were held. The interviews began with general questions such as "How did your life change after you found out about your child's illness?" or "What helped you accept the problem and succeed in life?" The subsequent questions were raised based on previous questions and data analysis, which revealed in-depth, consistent, and transparent data about the parents' attitudes toward their child's problems, their hopes, and hope facilitators from their point of view.

In this qualitative study, qualitative content analysis was performed based on Corbin-Strauss' (2008) method. For this purpose, all the interviews were studied line by line, reviewed, and coded using open, axial, and selective coding methods. Moreover, categories and subcategories were detected by comparing the codes in terms of similarities and differences in the concepts. To ensure the accuracy of the collected data, we used different methods such as data review and confirmation by the samples (member checking), assessment of researcher validity, credibility assessment of the findings, prolonged engagement, persistent observation, integration of data collection methods, and feedback from colleagues (peer debriefing) (20).

The study was approved by the University of Social Welfare and Rehabilitation Sciences (ref.: IR.USWR.REC.1399.109). The research objective and procedures were explained to the participants, and their informed written consent was obtained. The participants were ensured that their personal information would remain confidential and anonymous. Moreover, the participants were allowed to leave the study whenever they wished.

## 4. Results

The study sample encompassed 17 parents (11 mothers and 6 fathers) having children with CP. The parents' mean age was 33.9 years, and the CP children's mean age was 3-11

years, and they were at the 2 - 4 level on the GMFCF scale. The children had no severe comorbidities such as severe mental retardation, blindness, deafness, or uncontrolled seizures. Of 17 parents, 15 individuals were successful in their lives and successfully cope with their children's disability, as they themselves and those around them stated. Furthermore, two parents had no hope for their children's disorder and were selected as the negative sample. Table 1 presents the demographic characteristics of the samples in detail. Table 2 also represents the analysis of the data regarding hope facilitators in the parents of CP children. The analysis of the data revealed four main concepts, namely "motivational drivers", "positive beliefs", "promising treatments", and "support network", which are described below:

**Table 1.** Distribution of Participants by Gender, Age, Level of Education, Children's Gender, Age, and GMFCS Level

Variables	Values
<b>Gender</b>	
Male	11
Female	6
<b>Age</b>	
Max	42
Min	29
Mean	33.9
<b>Education</b>	
Diploma	4
Bachelor	12
MSc	3
<b>CP child's gender</b>	
Boy	10
Girl	7
<b>CP child's Age</b>	
Max	3
Min	11
Mean	6.7
<b>GMFCS level (CP child)</b>	
2	7
3	4
4	6

Abbreviations: GMFCS, Gross Motor Function Classification system; MSc, master of science.

#### 4.1. Motivational Drivers

Motivational drivers are among factors affecting parents' hope and encouraging them to continue their efforts.

These internal and external drivers help parents achieve their goals and maintain hope. The inner drivers include positive and motivating beliefs, motivation for progress, and positive and negative emotions such as love for one's child and stress or fear of the child's deteriorating health status. In this regard, one of the parents noted,

"I was always motivated. My goal was to help my daughter get better, and I always tried my best to do so. There were a lot of problems I managed to overcome by my faith and motivation. I did not let others disappoint me".

Moreover, some external motivational drivers such as the child's progress and positive characteristics help the parents advance their goals and promote their hopefulness. According to the present findings, many parents considered some positive characteristics of their children (e.g., smartness, love, communication, and cooperation with the therapist and other family members) as factors affecting their efforts and nurturing hope. One of the participants remarked,

"My daughter had no problem speaking. She was even so talkative that she caught everyone's attention. Maybe that is why no one paid attention to her hand problem".

#### 4.2. Positive Beliefs

One of the prerequisites to maintain parental hope is to hold positive beliefs. The parents of children with CP considered these beliefs as a critical factor in overcoming problems and frustration. The parents reported their belief in God's help, child's goodness, and their fruitful efforts as contributing factors. In this regard, one of the participants described faith in God as the most remarkable factor preventing him to be frustrated:

"I was never disappointed because I had faith. I was sure that God would show me the way. God would never leave His servants alone".

Generally, many beliefs are rooted in religious, cultural, and social norms. In other words, some accepted social norms and beliefs seem to be effective in reducing pressure on families. In this study, the participants believed that their problems would not remain and that there was a rationale behind everything.

#### 4.3. Promising Treatments

The effective treatment of CP can nurture hopefulness in the parents of such children. Generally, the CP treatment is a long process, during which parents experience many positive and negative changes as such, their experiences are sometimes unpleasant and sometimes pleasant. According to some participants, appropriate and stable treatment conditions play a critical role in reducing stress and maintaining hope in the parents. In this regard, one of the parents mentioned,

**Table 2.** Outline of Detected Facilitators and Their Subcategories

Extracted Concepts (Categories)	Relevant Concepts (Subcategories)
<b>Motivational drivers</b>	1, Motivation and desire for progress; 2, fear of the future; 3, positive changes; 4, positive characteristics of children
<b>Positive beliefs</b>	1, Spiritual beliefs; 2, self-confidence; 3, belief in one's ability
<b>Promising treatments</b>	1, Effective treatment; 2, skilled and committed therapist
<b>Support network</b>	1, Practical support of families; 2, emotional support of relatives; 3, supportive and empathetic couples; 4, communication with the parents of other CP children

“Of course, if my child’s condition had not changed, I would not have had the motivation for treatment. My child could stand and walk on all fours following the occupational therapy. I could truly enjoy the fruits of my labor”.

To achieve positive therapeutic results, the presence of experienced, skilled, and committed therapists and specialists is of paramount importance. In addition to appropriate treatment and follow-ups, the timely diagnosis of disorders can increase the effectiveness of treatment and accelerate the therapeutic process. Moreover, proper training and counseling can prevent future problems in children with CP and improve their performance. The participants believed that therapists played a key role in raising individuals’ awareness and nurturing their hope by providing proper guidance. One of the parents stated,

“My daughter’s therapist often encouraged us to continue our efforts. Our daughter’s progress showed us that we were not working seriously enough. She warned us about her future, and this had a positive impact on our behaviors and attitudes”.

#### 4.4. Support Network

According to the participants, one of the main factors affecting the promotion of hope in the parents of children with CP is a proper support network. Most of the parents admitted that they would not have continued their efforts in the absence of a supportive network. Three main themes were extracted regarding the support networks in this study: practical and emotional support by relatives and acquaintances, supportive couples, and empathy and communication with other families having children with CP. One of the parents argued,

“The hope that our loved ones, like my parents or my wife’s family, gave us was effective. It was heartwarming to share our pain with them or be calmed down”.

Communication with the families of other CP children, who have a similar experience, may provide a significant source of support for the parents. Communication with these families may be established directly in medical, rehabilitation, or educational centers or may be provided via virtual networks and social groups such as the Cerebral

Palsy Association. This type of communication would positively affect the parents’ coping mechanisms, attitudes toward their problems, and even the recognition of their children’s talents and abilities. In this regard, one of the parents mentioned,

“I felt relaxed when I went to the clinic and talked to other mothers because they understood what I was saying”.

## 5. Discussion

This study aimed to explain hope facilitators in parents having children with cerebral palsy. The results revealed several factors as hope facilitators, including motivational drivers, positive beliefs, promising treatment, and support networks. The concepts extracted in the present study represented the role of internal and external motivational factors, including the desire for progress, fear of the future, positive changes, and positive characteristics of CP children (e.g., child’s smartness), in nurturing hope in the parents.

Motivation and some positive and negative emotions such as love for the child or stress and fear of the child’s deteriorating health status are internal motivational drivers encouraging the parents move forward and maintain hope. In this regard, Kausar et al. (17) considered motivation as an effective internal motivational driver to create hope in the parents of children with developmental disorders. If the parents are motivated enough to overcome their obstacles, they can reach their goals and maintain their hope by planning (13). In other words, the parents’ hopefulness represents their eagerness to provide growth grounds for their children (21, 22).

Moreover, external factors, including a support network, were among the main themes extracted in this study. The participants believed that social support networks encompassing the support of relatives, friends, and family play a critical role in nurturing hope in the parents. They claimed that their support networks promoted their tendency to succeed. In this regard, Pfeiffer et al. (23) considered family members as the main source of support for the caregivers of children with CP. According to Horton

and Waldner, social support effectively reduced confusion and maintained hope in mothers of children with chronic physical disorders (15). Furthermore, Skok et al. (24) note that social support effectively maintains the health and quality of life in mothers with CP children.

According to the present findings, positive attitudes and beliefs are another factor promoting hope in children with CP. Positive beliefs seem to be effective in reducing stress, creating resilience, and improving parents' mental health in the case of chronic disorders (25). This study also indicates that spiritual beliefs such as belief in God's help play an important role in maintaining hope in the parents of the CP children. Numerous studies have also documented a relationship between hope and spirituality (14, 26, 27). In this regard, Kilpatrick and McCullough (28) argued that spirituality plays a key role in the adaptation and hope of parents with disabled children.

According to the participants, one of the positive beliefs was to believe in one's ability to make a difference (29). The birth of a disabled child appears to be associated with decreased parental self-confidence and self-esteem (30). According to Horton's findings, hope in the parents of disabled children is correlated with their self-esteem, as hopeful parents have higher levels of self-esteem than the hopeless (15). Moreover, another hope facilitator was access to appropriate treatment facilities. According to the participants, the availability of appropriate medical services and experienced and committed therapists were some factors nurturing hope. These findings are consistent with those put forth by Raeis-Dana et al. (31), suggesting that access to treatment facilities (e.g., skilled and experienced therapists and the use of counseling and rehabilitation services) would boost the parents' motivation and encourage them to pursue treatment. Such communication seems to make the parents more aware of their child's abilities and problems as they can compare their child with other children and exchange information (32).

Some limitations of this study are as follows: The human participant's ethical principles on voluntary participation in the study did not allow us to collect information about those who did not agree to cooperate. Another limitation was the use of self-report data, as some participants failed to convey their experiences and perceptions of hope well.

Since this study aimed to extract hope facilitators according to the real-life experiences of parents having children with CP, the findings would contribute to designing educational, rehabilitation, or counseling programs.

### 5.1. Conclusions

According to the present findings, factors such as promising treatment, support network, communication

with the parents of other CP children, internal and external motivational drivers, and positive beliefs effectively create and promote hope in the parents of children with CP. Although these factors cannot be generalized to the other populations, they may be effective in similar cultures and contexts. Because the parents of the children with CP are often exposed to major problems, the present findings highlighted the need for providing special support for this group as well as the significance of their beliefs and attitudes. These findings can be used as a guide for treatment and rehabilitation teams to increase functioning in these families and improve the quality of their lives.

The study findings also indicate how a group of individual and social factors such as attitudes, support, communication with peers, and access to facilities can be effective in nurturing hope in parents of children with CP. Accordingly, these factors and training provided to parents can facilitate the nurturing process of hope. Some effective measures to be adopted for parents are strengthening positive attitudes, teaching child care, teaching parents to receive support, facilitating parents' communication with other parents of children with disabilities, and holding group meetings to transfer experiences and receive empathy.

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### Footnotes

**Authors' Contribution:** Hossein Alibakhshi and Manoochehr Azkhosh contributed to the development and design of this research. Hossein Alibakhshi collected the required, and the content analysis was performed by the team of researchers.

**Conflict of Interests:** The authors declare that there is no conflict of interest.

**Ethical Approval:** The present study was approved by the ethics committee at the University of Social Welfare and Rehabilitation Sciences (ref.: IR.USWR.REC.1399.109).

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