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Rehabilitation Needs of People with Cerebral Palsy: a qualitative Study

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Abstract

Background: Cerebral palsy (CP) describes a group of disorders regarding the development of movement and posture, which causes limitations in activity. In fact, it is attributed to non-progressive disturbances that occur during brain development in fetus or infant. CP disorders may accompany by speech, auditory, visual abnormality, seizure, learning disorder, mental retardation and etc. Due to the variation in disorders and ultimately the needs that are made in the wake of the diseases, understanding the needs of these patients is essential.

Methods: This research was a qualitative study, with phenomenology method and sampling was purposeful. The participants were 17 cerebral palsy people (6 female and 11 male, with aged 15 to 43). Data were collected by deep interview with open-end questions and analyzed by collaizi method.

Results: During the interview sessions, notes and ideas were classified and assorted, so that, the rehabilitation needs of people with CP were understood according to the statements of participants. The results of this study were placed in four domains, 3 themes and 22 subthemes. The domains included social, emotional needs, economic, and therapeutic needs.

Conclusion: The requirements studies in this research were particularly introduced by patients with CP. People in the society, who might have contact with these patients, are responsible to help them to overcome their problems and disabilities.

Keywords: Cerebral palsy, Rehabilitation needs, Qualitative study, Phenomenological method.

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Introduction

"Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, attributed to non-progressive disturbances that occur in the developing fetal or infant brain development" (1). The disability in movement are often accompanied by disturbances of speech disorders (2), visual (3), auditory, seizures (4), digestive and nutrition (5), pulmonary (6), teeth (7), muscle contraction and deformity of limbs (8) and variety of cognitive disorders, some degree of mental retardation (9) and epilepsy (10). The prevalence of CP is different in various countries and has been reported between 0.6 to 5.9 cases per 1000 live births, but most statistics show that there are two cases per 1000 live births (11). Due to the high prevalence of this disorder and ultimately the needs that are originated from these problems, it is very important to help these people and solve their problems. In this regards, it is necessary to understand their true needs within the domain of rehabilitation, and when they

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wanted and hence look after their essential needs. Sometimes, rehabilitation service provider seems to misunderstand their needs; and incapable of fulfilling them. Thus, the balance for supply and demand in this domain (rehabilitation) is lost and it would lead to difficulties in planning and usage of resources, time and manpower. Therefore, understanding the true needs of the target group-people with CP, it means, issues that proposed by their perspective mind, are very important and must be considered. For example Kersten et al in a study in 2000 reported that needs for rehabilitation services and resources for people with disability are perceived differently by people with disability and thus it is very important both users and providers views to be analyzed to provide better services (12). Many studies were done in different countries recently in the needs of different groups (12-14) and researchers attempt to explore their true needs. Many different studies should also be conducted in Iran on different groups especially in both patients and service providers.

This study was performed to analyze issues involving people with CP and to find a correct estimation of the true needs, based on their point of view.

Methods

This study was a qualitative study performed by phenomenological method.

Qualitative researches study life experiences of people to understand how to create a phenomenon in their natural states (15).

Qualitative research answers questions such as, ‘what is X, and how does X vary in different circumstances, and why’ (16)?

Phenomenology is essentially the study of lived experience or the living world. This inquiry asks “What is this experience like?” as it attempts to unfold meanings as they are lived in everyday existence (17).

Due to nature of qualitative research and phenomenology method, now it is possible to understand life experiences of people (with CP), and used it in study.

Participants in the study included all people with CP who had received a confirmed tab of the medical commission of Welfare Organization in Tehran. Over 14 years of age and willingness to participate in interviews were used as inclusion criteria and mental retardation as exclusion criteria. This study was performed with purposeful sampling method and 17 people with CP, consisted of 6 female and 11 male from 15 to 43 years old were selected. It was attempted to ask the people who were mostly older for sampling, because they have more experiences than the other participants. In this study, the data were collected through deep interviews. Interviews were conducted by non-governmental organization (NGO) in Tehran. In deep interview, the researcher attempted to penetrate in deep layers of the mind of interviewees to achieve the most correct and accurate information. In this regards, interview guide was used. The interview guide prevented wasting time and talking outside the issue. The interview guide consisted of general questions about how to travel, NGO center and its, the relationship with family, friends and relatives, marriage, job, and required treatments, economical condition.

Totally, 20 interviews were conducted in about 55 to 75 minutes; this duration was depended on the interviewee's willingness to continue the conversation. Except three interviews that were done in the presence of two other cases (the interviewer and interviewees agreed), other interviews were done on the individual base and separately. In the single cases, they felt free and when the interviewee felt that his/her information was kept private, without any problem, they spoke frankly with comfort. In this study, interviews were also recorded on a laptop and performed in provider centers of rehabilitation services. The participants were assured that the interviews will be kept completely confidential and their name would not be used during analyses and description of the cases. To prevent future problem in this issue, a written informed consent was signed, based on law of ethic.

Data analysis was carried out based on

questions and selected topics. After each interview, the researcher converted the recorded remarks to the written texts as sentences, phrases and quotations, so it could be used to evaluate people's experiences and level of understanding various phenomenons. In the next step, the researcher used important phrases to classify the meanings which lead to achieving the subthemes. The subthemes also were used for writing what participants had experienced in the theme cover. Finally, themes were placed in a cover of wider range as domain. In order to interpret and analyze the obtained information, Collaizi method was used; as follow:

1. All of the Descriptions (all of Participants) were studied.
2. The original handwritten and key phrases were extracted
3. The meanings of important sentences were extracted.
4. Formulated meanings organized in clusters of themes.
5. A comprehensive description of the phenomenon was provided.
6. The Comprehensive description of the phenomenon was set in an explicit statement.
7. Results were returned to the participants with questions about the new findings (18).

To validate the gained information, it was referred to participants with their adjusted comments (19). To ensure the accuracy of the results of interviews, experts in provider centers (19) of rehabilitation services, professors and colleagues in the various fields of rehabilitation in Rehabilitation School of Iran University of Medical Sciences gave their opinions and comments as final analysis. Also the interview participants' responses were compared with the findings of other studies.

The main limitation in this study was non-cooperation of affiliated institutions of welfare organization to record the interviews. In order to solve this problem, interviews were recorded in NGO centers. This study was performed eight months, for confirmation of the proposal and data analysis.

Results

According to the aforementioned descriptions, the center for rehabilitation needs of people with CP understood the statements of participants. In this study, the obtained results were placed in four domains, 13 themes and 21 subthemes. The domains were follow:

1. Social needs
2. Emotional needs
3. Economic needs
4. Therapeutic needs

1. *Social needs*

Social needs included 7 themes: support and companionship from others, marriage, social acceptance, access to urban facilities, labor, education and supportive organizations. Needs to support and companionship by the others was one of the issues that was mentioned in the statements of some participants. Depending on the ability level to perform different tasks, they stated the peoples need in terms of their personal and impersonal affairs. For example, participant number 1 said: I can do a series of works by myself but not completely, and like other people I need to ask the others to give me a hand. I get some helps from others. For instance, to wear the pants, because of the problem in my hands, I cannot close my pants button. I should get help from someone." Marriage was one of the themes that the participants spoke about. All participants were single (one person divorcee, and the others never married). According to the expression of the participants there were two sub-themes: the disabled person needs and the needs of other person to be involved in marriage matter. Most participants expressed marriage as their demand and need. For example, Participant number 2 stated: "(Need of the other disable friends) I think another friend's problem is the same. If they have a job and another one is that he can have an opportunity to get married. ... It is known that the parent's

kindness and love is different, brother is different, sister is different but this disability affected us morally, because they have already been limited to choose a partner... Disable persons are supported only by their family and they cannot fulfill everything, their need is an ideal wife." The statements of interviewees expressed the need for social acceptance in different forms. These statements were placed in two subthemes: believing and worth giving, and the proper attitudes. For example, Participant Number 6 stated: "Only healthy people, believe in disabled community. If healthy people in society believe in people with disabilities, life will be so easy for the disabled people. It's easy; however, it will be much easier for them. ... They just need to be a believer." One of the needs that was mentioned by the participants was need access to urban facilities. Participant's statements about this need were placed in two subthemes: transportation systems and places and passages. For example participant number 14 said: "the canals must be fixed in the streets. They should make low-width canals so that disabled people can pass through, in the roads, too." Statements by some participants indicated the need for job from the social perspective and its aspect at the community level. Only three of the participants were employed, and other had jobs temporary. The need for permanent and appropriate labor was considered as an important need for the most participants. For example, Participant Number 6 stated:" I would love to work because it is a source of income and because I can prove to everybody that I earned the money because of doing a job. Money is not important, but I prove that I did the job. I did it successfully." One of the themes that were found in this study, it was education. Statements of participants were placed in two subthemes: education in high school and education in higher level such as universities. The range of participants' education varied from intermediate school to high school diploma and almost half of them had high school degree. Some of them mentioned their desired for continuous their education at the higher levels such as university. For example, participant number 11 stated:" I am anxious to go to university, I really love to go." All participants were registered in welfare organization and also using NGO centers' assistance. As a result, these organizations (NGO and welfare centers) were considered as subthemes. Participants followed receiving different social, economic and health services of the organizations. They also tended to do affairs by the welfare organization. For example, participant number 8 said:"…for example, my hands are ok, but I cannot move a wheelchair. I feel a little pain in my hands during moving the wheelchair. If we had an electric wheelchair it would be much better." Participants also mentioned about the NGO centers. Such statements were expressed by participant number 6: "Well, this Centre (East Raad: Its name of a charity institution in Tehran), that you can see, is a center that has gathered disabled peoples. Obviously, we are handicapped persons and we should be prospective. Then, we have to look for our future. We have to constitute family, live in the society. After all, this Institute is a charity institute that does not charge disables people. The Institute has organized a series of programs to train different skills. Such as computer skills, language, art work with woods, calligraphy, sewing and arts. These courses and programs train people for their future life to use these skills in the near and far future. I also came here to attend in the classes so that I can be trained."

2. *Emotional needs*

Emotional needs were included two themes of family, friends and relatives. Statements of some participants showed lack of love and value and attention to them. They do not feel any love from their family and relatives and demanded more attention and affection and also Friendly communication. For example, participant number 11 stated: "I always think (my mother) has found me as a fosterling ... They behave very aggressive to me. ... I

Table1. Classification of requests (domains, themes, Subthemes)

Domains	Themes	Subthemes
Social needs	support and companionship from others	personal affairs impersonal affairs
	marriage	the disabled person needs to be involved in marriage matter the needs of other person to be involved in marriage matter
	social acceptance	believing and worth giving the proper attitudes
	access to urban facilities	transportation systems places and passages
	labor	
	education	in high school in higher level as universities
	supportive organizations	NGO welfare centers
Emotional needs	family	love value and attention
	friends, and relatives	attention and communicate Friendly
Economic needs	Housing	
	Job	suitable job high income home employment
Therapy needs	Medical	to visit specialist doctors surgeries
	Rehabilitation	occupational therapy, physiotherapy, hydro-therapy and speech therapy assistive devices and equipment

really feel lack of emotional behavior. Sometimes I say that mom coax on my head. I am your child. … I force her to love me." Or participant number 6 said:"You see when I came here I found a lot of friends; while my father's family before coming here disowned me. They reject me it means that now still they do so."

3. *Economic needs*

A number of interviewees pointed to economic needs. According to interviewee's statement, two major groups of these needs are housing and job. For example, about housing theme, participant number 9 said: "(My need is a house with the lower grade than the job." In the field of job, participants reported their need to a suitable job, with high income and home employment. For example, participant number 5 stated: "I need suitable job in the society with high payment. Earn at least 400 thousand Tomans (~ $170) that I could do something with it."

4 .*Therapy needs*

Some of the participants indicated the need for therapeutic facilities. The therapy needs are also two medical and rehabilitation themes. Medically, participants talked about need to visit specialist doctors and surgeries. For example, participant number 5 stated:"I have seen physician many times. But, because I was very young, I do not remember where I went and what I did." In rehabilitation theme**,** the participants also pointed to the need for occupational therapy, physiotherapy, hydrotherapy and speech therapy and assistive devices and equipment. In this item also, for example, participant number 4 stated: "I went to Pich e Shemiran (Welfare Organization of Tehran) for physiotherapy and occupational therapy and speech therapy" (Table 1).

Discussion

Social needs are one of the major needs of CP people. According to the results of this study, seven themes as support and accompanying by others, marriage, social ac-

ceptance, access to urban facilities, labor, education and supportive organization that constitute major and important dimensions of these people lives, were placed in domain of social needs. The support and accompanying by others theme has been reported by some researchers. Participants mentioned the need in the personal and the impersonal affairs. In fact requirement for support and help was not indicating lack of independence for participants. Independent life is controlled and considered to be a decision making in life by person for his daily tasks and without using professionals, family members or other individuals.

In the reported study by Larivière-Bastien et al. 2011, several participants explained that the support of relatives or family members was necessary in these situations for their basic needs to be met (20). In another study in Sweden 27% had never been able to walk, 64% could walk with or without walking aids (21).

Various studies have been done in the past about people with CP, however, in the 1990s, studies began to explore how adults deal with CP (22). Recently, the studies have also focused on participation and social issues." The results are different; however, the general message is that social participation, sexual relationships, employment and leisure activities are restricted among many youths and young adults" (23, 24). These studies were conducted in Western countries, and only had been considered sex issues and treating problems (25). But having sexual relation in Iran is only considered when couple are married. Participants generally believed that understanding the position of both parties in marriage is very important. The need for social acceptance was mentioned by participants. They have stated that believing and worth giving, and the proper attitudes to them are parts of their needs. Belief proper attitudes for disabled persons in community can encourage them to be active in community. Reported study on attitudes by offices for disability issues showed that participants (people with disability) had experienced negative attitudes which led to their expulsion from the community (26). In other study that was conducted qualitatively on people with CP, participants reported about the challenges faced them during the medical consultations. The challenges were reported "e.g., rude attitudes, belittlement, inadequate communication, and lack of consideration" (20).

Another need that was explored in this study was access to urban facilities. **"**Human in a social environment always tries to make a new contact with his surroundings. Building either a new relation through participating in surrounding areas and having access to critical activities. Humans are able to work and have activity in different fields of the life and appropriate socioeconomic payoffs. By making proper urban environment, all people- including disabled people and non-disabled are allowed to have access to a wide vareity of urban environment and activity in different fields of the life which is required for human life" (27), and It is also found in article 9 of convention on the right of persons with disability:" To enable persons with disabilities to live independently and participate fully in all aspects of life, states parties should take appropriate measures to ensure enough access, to the physical environment, transportation, information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas for disables" (28). In the present study the participants reported need to access transportation systems and places and passages. A study, in Shiraz city (in Iran) by Bezi et al. (2010) showed that **i**nappropriate public transportation and lack of access are among the most problem by 23.4% of people with disabilities and veterans. Moreover, 21.3% of disables declared inappropriateness of sidewalks, uneven walking surfaces and pits (29). The need for employment is very important to all people in a society. One of the objectives of "Disability Services Act" is organized of pro-

grams and services that might focus on achieving positive outcomes for people with disabilities, such as increasing independency, employment opportunities and integration within the community (30).

There are limited job opportunities in our society and it is urgently necessary to be increased. Among those who have participated in the present study, only 3 people employed and the rest were searching for a suitable job. In the classification of social needs, job mostly focuses on its social aspect in the community. It is possible for a person with disabilities; to prove his/her ability to others by the job. According to the published reports 33% and 36% of adults with CP in Australia and the Netherlands, respectively, had paid employment. However, it was reported that only 18% in Italy and 7% in the UK had employment (31).

Even though, in developing countries, people with disabilities are deprived of education in schools and universities, but the need for education in these levels is not ignorable. In the present study, education was also one of the needs posed by the participants. In another study by Larivière-Bastien et al. on 14 participants with CP, only 2 people had university education (20).

High tuition fee was an obstacle for higher education level by some participants. This factor had caused problem in acquiring education for themselves. Due to the high cost of living for people with special needs, it is very necessary to create facilities for their education.

The main organization in charge of the services for disabled people in Iran is a Welfare organization. This organization offers various services to its clients including social, economic and health. Though, the large number of people with disabilities and vulnerable with their growing needs does not allow to extent the area of supports. In this study, the interviewees reported economic issues such as the need to provide resources, services and salaries, housing and loans. Some participants also pointed to the need for rehabilitation facilities. They believed that these facilities can be provid various form of rehabilitation therapy, and rehabilitation assistive devices. In the social domain, the participants wanted the creation of jobs, the construction of a recreational and sports site, facilities in transportation, abilities for training of people with disabilities to non-disabled people and suitable response for them. A number of participants declared that NGO centers provide such services as vocational training, counseling and problem solving by appropriate methods and certified training to get a job. In another study in 2008 that was conducted on people with CP in the Netherlands, the need for official health and social services reported as unmet needs by participants (14).

Emotional needs are a part of human needs. The need to love and be loved, and attention are considered as an essential component of each individual. Abraham Maslow introduced the need for love and belonging, and respect and value as the third and fourth humans need (32). Although criticism of how the ranking of the needs has been entered but it is very obvious the need to love and respect as a part of needs of each person and certainly fulfilling these needs would result in the provision of mental health. In the present study, a number of participants believed that their needs were not sufficiently responded by their family, friends, and relatives. They claimed that their family and friends and relatives paid a little attention to them and do not show real kindness. A study by Brehaut et al (2004) on children with CP indicated that they experienced emotional problems e.g. sadness or little interest in life (33).

Economic needs of the communities constituted an important part of people's needs. Obviously, the people with disabilities have physical and social problems, hence they need to participate actively in various fields of social activities and this issue requires a good economic support. In the present study, needs of participants in the economic domain was introduced mainly in housing and job needs. They wanted suitable jobs

with sufficient incomes. Some also pointed to the need for employment at home. A study by Andersson and Mattsson (2001) on adults with CP showed that "most of the participants lived in their own apartments and only 13% lived with their parents. It is pointed that in Sweden, especial apartments were designed for disabled people and they are equipped with extraordinary services for personal assistance, which may explain the high proportion of independent living. They also reported that one-quarter of the participants worked full-time" (21). However, as noted in the present study, only three of the participants were employed and their income did not cover their expenses, completely. Study of Hilberink and et al. (2007) on 54 patients with CP showed that 24% of participants found sheltered work and 26% had a regular paid job (34). The need for housing was an urgent need for a large financial support to build a confident in future.

Therapeutic need of people with CP was one of the major concern: treatment their and associated disorders include drug interventions, surgical and therapeutic rehabilitative interventions and Complementary & Alternative interventions. In the present study, the participants reported the needs to be visited by a physician and surgeon and rehabilitation center including occupational therapy, physiotherapy, speech therapy, and also the need for assistive devices and equipment. A study in 2000 that was "set out to explore whether there were systematic differenced in unmet needs for rehabilitation services and resources as identified by disabled people and nominated key professionals. There was fair agreement between them (disabled participants and professionals) in five areas of unmet need." Need for physiotherapy and equipment were among them (12). Moreover, the Fauquier County Disability Services Board (DSB) in 2009 revealed that the four priority core areas of need were: "(1) assistive technology; (2) medical & therapeutic services (3) transportation; and (4) counseling" (13).

Conclusion

Human being is complexed, with the aspects of broad range of his/her needs. People with CP are disables with identical their requirements for non-disabled persons in society and additionally they have special requestes that might not be needed by others. They are also members of their society that just like the rest of the members their needs must be answered. In this research various needs (social, emotional, economic, and therapy) were introduced by participants. People in society and community that have direct contact with disable people have rresponsibility to provide their needs and support them to overcome their problems and thrive better in life.

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