

CYBERSPACE PEER SUPPORT / DEVELOPMENT PLATFORM FOR PARENTS WITH DISABLED CHILDREN: A QUALITATIVE STUDY

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ABSTRACT

The aim of the present study was to explain the experiences of parents of peer support in cyberspace. This is a qualitative conventional content analysis study. This study was performed on 17 people (11 females and 6 males) of parents with disabled children. Data analysis leads to the emergence of 13 subthemes and 4 main themes, interactive network (group formation, intimate interaction), comprehensive support (peer education, emotional, service delivery), spirituality propagation (companionship in religious rites, consolation in the God's attention, peers as good listeners (inspiration), growth and progress (familiarity with peer problems, acceptance of disability, endurance promotion, problem-solving). Cyberspace created an opportunity for parents to use the experiences and support of peers with help theme accept their child's disability.

Keywords: Adolescents; Advanced Nursing Practice; Caregiving; Clinical Education; Family care

INTRODUCTION

Disability is one of the aspects of human life that has existed throughout history and in all societies. The World Health Organization estimates that 10 percent of the world's population is physically, mentally, and socially disabled [1]. Studies have shown that the parents of these children face with several problems including mental health disorders [2], disrupted social relationships [3], substance, alcohol and drug abuse, relentless fatigue and physical disorders caused by the child movement problems [4]. According to the results of the study by Nyanatet al. (2019) support for the parents of these children is very important [5]. Also, according to the results of previous studies, peers have been able to play a supportive role for most patients or different educational groups [6,7].

Peers are among the groups involved in promoting health status [8]. They help group members develop approaches that help them cope with stress. A study by Karen L Fortuna (2020) showed that a peer support network has great potential for impact [9].

Today, one of these communication and information technologies is cyberspace. The attractiveness of this space is so much that it has been able to be the focus of a large number of people in the society to receive and share various information, including health information. This space has provided a way to communicate, especially about diseases, and to share experiences and mutual support, especially during Covid-19 pandemic [10-12]. Studies by Natasja Kingod et al. (2017) and Julie Prescott et al. (2017)

showed that peers were able to communicate and support each other through cyberspace[13,14]. Most of these studies, however, focus on communication between patients, while there have been few studies on communication between parents of children with disabilities who have their own specific concerns about the ambiguity of the child's condition as well as confusion about how to treat and rehabilitate them.

Considering the impact of cyberspace on various aspects of human life and the transfer of experiences and direct and indirect education through this technology of the new era and the development of online communication during the Covid-19 period and that there have been fewer studies on the experiences of parents with disabled children in cyberspace, this qualitative study was conducted with the aim of explaining parents' experiences of peer support in cyberspace.

MATERIALS AND METHODS

This a qualitative research of conventional content analysis. Participants of the present included study were selected by purposive sampling method. Inclusion criteria include parents of disabled with confirmed disability for at least one year, willingness to participate in the research and the ability to communicate properly with the researcher. The process of selecting participants continued until reaching data saturation. Considering the principle of maximum variation, attempts were made to use participants belonging to different age, sex, level of education, social classes. Data was saturated with 17 parents including 11 women and 6 men.

In order to collect data, in-depth unstructured interviews and open-ended questions were used based on the objectives of the study. At baseline, questions about demographic information were asked and then the interview was asked using guiding questions such as "Share your experiences of communicating with peers in cyberspace." Guiding questions such as "Please explain more" or "Explain what you mean" were also used to clarify the content being studied. The duration of each interview was 40 to 60 minutes, and depending on the circumstances and necessity, several interview sessions could be conducted with each participant.

Data analysis was performed using Graneheim's&Lundman's method [15]. After each interview, the content of the recorded interviews was transcribed on paper, the text of the interviews was reviewed and re-read several times by the researcher, and a general sense of the participants' speeches was obtained. In fact, data analysis was performed simultaneously and continuously with data collection.

Trustworthiness of research was established through credibility, dependability, conformability and transferability. To fulfill this objective, prolonged engagement with data, constant comparison analysis, member checks, peer checks and maximum variation of sampling were accomplished[16].

It should be noted that at baseline, the study aim and method were fully explained to the participants and written and informed consent was obtained from them. The participants were assured about the confidentiality of their identity and information during the research.

RESULTS

A total of 17 people including 11 women and 6 men participated in the present study. Participants were in the age range of 30 to 52. Participants ranged from middle school to PhD. Data analysis led to the emergence of 13 subthemes and 4 main themes. (Table 1).

Table 1: Categories and subcategories of qualitative content analysis of interviews

Subtheme	Theme
Group formation	Interactive network
Intimate interaction	
Peer training	Comprehensive support
Emotional support	
Providing services	

Accompaniment in religious rites	Spirituality propagation
Consolation in God's attention	
Peers as good listeners	
Inspiration	
Familiarity with peer problems	Growth and progress
Acceptance of disability	
Endurance promotion	
Problem-solving	

1. INTERACTIVE NETWORK:

1.1: Group formation

Most participants felt the need to use their peers' experiences due to their child's ambiguous circumstances. Participants stated that they always wanted to be able to listen to their peers for even a short time, which may not have very been possible. One participant, said, " I wanted a mother or a family member of children with disabilities whom I have to see and talk,considering Covid-19 limitations.I decided to form a group on WhatsApp, and came got their numbers from our occupational therapist and told them to coordinate with them that I want to form such group ... "(P.3).

1.2: Intimate interaction

Participants stated that their peers interact well in cyberspace with each other, respect each other, and have friendly relations. One of the participants, said, "I was treated very warmly when I joined one of these groups by the group admin, who himself had a disabled child, and introduced me to the group. I was greeted and it was more interesting to tell me that consider us as your family members and because I was an strangerin this city, I was very happy with their treatment"(P. 10).

2. COMPREHENSIVE SUPPORT

2.1:Peer training

Participants stated that cyberspace provided them with the opportunity to use peer training. One of the participants, who had a deaf child, said, "I did not know how to work with this device when it was implanted, because their device is also very sensitive. I was afraid that it would break." The implant was carried out for my child, whenever I had a question from him, I would make a video call to him and he would teach me very nice "(P. 7).

2.2: Emotional Support

Most of the participants believed that parents of children with disabilities need support due to the difficult living conditions of their child with mental disabilities, and in the meantime, peer support has more positive effects. A mother said, "We formed anonline group with some of our parents. There are two of us in our group, God bless them. These are full positive energy. They always make funny clips, or send us content that makes us happy and changes our spirits"(P. 5).

2.3: Providing services

Children with disabilities need more services, some of which may not even be available in the cities where they live. A mother with an 8-year-old daughter with a disability said, "I live in anurban village. She was in charge of informing the parents in the WhatsApp group, and we coordinated with him and he told us when to bring the baby and the baby surgery was performed" (P. 17).

3.SPIRITUALITY PROPAGATION:

3.1: Accompanying in religious rituals

Some participants stated that a group of peers attended online spiritual and religious gatherings held by parents. The father of one of the disabled children, who was a cleric, said: "Every once in a while, I recite

the Quran in cyberspace according to the circumstances, and inform them by a group whose parents are members of that group, and each of them do the recitation of the part of the Quran depending on their ability"(P. 8).

3.2: Consolation in the God's attention

Whenever some parents have the opportunities to communicate with the peers, they try to console them by talking about God's grace, mercy, and attention in solving problems. A participant said: " I play the role of an elder in the group, I talk to other parents that God would bestow upon his grace to his humans when a person is at the peak of troubles, and in this way I try to calm them down "(P.2).

3.3: Peers as good listeners

Most participants believed that their peers understood each other well. One participant said: "Sometimes, as much as time allows, I even spend hours talking to a few other mothers about my problems and concerns on WhatsApp, and they pay attention to what I say and even think about the solution" (P. 16).

3.4: Inspiration

Familiarity with peers motivated some parents. A mother of a child with impaired hearing said: "When I saw the pictures sent to me by one of the mothers,that her 8-year-old child could not speak a single word despite being cochlear implanted. From that day on, I was really more motivated to do speech therapy with my child because my child only had hearing aid in only one of his ears, and he had some difficulty speaking" (P. 13).

4. GROWTH AND PROGRESS

4.1: Familiarity with peer problems:

Parents have been able to knowabout the problems of their peers through cyberspace. A participant stated: "When I saw one of the disabled children in the video that his mother share in the group.I sawthat this child has neither the physical ability to walk, nor the mental concentration, and is just deaf, I said, oh God, how patient this mother is. I think that this video helped me a lot so that I do not just magnify my own problems" (P. 9).

4.2: Acceptance of disability

Cyberspace helped parents to accept their child's disability and to cope more easily with the disability-related conditions and limitations. A mother of a disabled child, said: "I cried every day until I met some of my parents, and it was hard for me to accept that my child was disabled, but now I accept it and saw that their situation id much worse than me, and I accepted my conditions "(P. 10).

4.3: Endurance promotion

After getting acquainted with the problems, patience and tolerance of peers in the face of problems, most parents stated that their patience and tolerance for disability and the resulting conditions has increased since the early diagnosis of child disability.One participant said: "When I see and hear about the problems of other parents in groups, I learned from them that I need to be more patient and resilient in the face of problems" (P. 11).

4-4: Problem-solving

The efforts and activities of some of their peers in cyberspace to solve their own and others' problems had taught parents that they could be an independent and efficient person, both for their own family and their disabled child, and in order to solve the problems of others. A participant in this regard stated: "I was a dependent person in the beginning, but since the day I saw Ali's mother, has been trying to solve the problems of other families alone, to go to welfare, charitable organizations and etc., I also learned from her and I try to solve the problems as much as possible and I do not expect much from my relatives"(P. 15).

DISCUSSION

The aim of the present study was to explain the parents' experiences of peer support in cyberspace. According to the results of the present study, parents tried to form or join online groups to communicate with their peers. When parent joined the groups, their peers sincerely accepted them and interacted well with them. In a qualitative study, Kingod et al. (2017) showed that users needed to connect with people who felt like themselves and sought to exchange information and gain their experiences, andempathetic

relationships were formed between them at the same time [13]. One of the themes of Walsh et al.'s (2021), was to set up online communication to ask questions from others, and participants began interacting with others in different ways and asked their questions in this way [17].

Cyberspace provided an opportunity for peers to fully support their parents. Through this space, they provided the necessary training, psychological support, and the provision of required medical services. The results of a study by Walsh et al. (2021) showed that online support communities were able to provide emotional support and training when answering each other's questions online [17]. In a study David Mazzani et al. (2014) found that some patients sought information about hospitals, specialist clinics, and physicians' online [18].

Peers were able to spread spirituality to parents, they accompanied parents in holding virtual religious ceremonies and hoped for God's grace and care, and listened to hear their concerns, and parents were motivated by the efforts of peers and They hoped that their child would recover. The results of a study by Pandya et al. (2017) showed that parents use spirituality as a protective variable to deal with problems [19]. In a study Stephen Gallagher et al. (2015) found that religious spiritual confrontation was the last resort to solve their problems [20]. Also, in a study Mazzoni et al. (2013) found that some patients communicated with the aim of sharing hope and listening to others [18].

Cyberspace provided a platform for parents to get acquainted with the problems of their peers. On the other hand, they saw the patience and tolerance of their peers in the face of these problems, which helped them to deal with the problems more patiently, which in turn made it easier for them to accept the child's disability and gain the ability to solve problems. According to a study by Rudy et al., patients wanted to talk to those who had gone through a crisis and accepted their disease so that they could seek help to accept and cope with their own disease [21].

CONCLUSIONS

Parents faced many difficulties and sufferings in caring for their disabled child, especially in the context of restrictions imposed by Covid 19. In the meantime, cyberspace paved the way for the development and improvement of skills acquired by parents from teaching rehabilitation methods, benefiting from the unique experiences of their peers, and finally increasing their ability to face problems. Therefore, planning to use the potential of companionship and support of peers in cyberspace will help parents with children with disabilities, especially in special situations such as the Covid 19 epidemic.

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