

## Original Article

## The Experienced Problems of Mothers Having Children with Hydrocephalus: A Qualitative Study

**Ayşe Gürol, PhD**

Assistant Professor, Atatürk University, Health Services Vocational School, Turkey

**Yurdağül Erdem, PhD**

Professor, Kırıkkale University, Faculty of Health Sciences, Department of Pediatric Nursing, Turkey

**Feyza Yazar Taşbaşı**

Nurse, RD, Atatürk University, Faculty of Medicine, Neurosurgery Clinic, Turkey

**Corresponding author:** Ayşe GÜROL, Assistant Professor, Atatürk University, Health Services Vocational School, Erzurum, Turkey, 25240 e-mail: ayseparlak42@gmail.com

**Abstract**

**Background:** The children with hydrocephalus are treated acutely with a cerebrospinal fluid shunt. If hydrocephalus is untreated, can lead to diffuse brain injury, mental and growth retardation. The development of hydrocephalus and its management present major challenges later in children and their parents' life, requiring multidisciplinary care from pediatricians, neurosurgeons, nurses, rehabilitative therapists, and others.

**Aims:** This study was designed to evaluate the mothers' problems that are experienced in hydrocephalus treatment process.

**Methods:** It was used the focus group methodology and in-depth interviews for qualitative studies in the study. Interviews were performed with 15 mothers having children with hydrocephalus treated at the Neurosurgery Clinic from 2012 to 2013. Data was collected using a semi-structured questionnaire prepared by the researchers through screening. The questionnaire focused on the selection of the problems during hydrocephalus treatment process.

**Results:** In this study, the only nine of mothers were informed about the process of the disease. Mothers who were not informed about the disease and process stated that this disease can be treated and their children can recover. All mothers mostly experience transportation and financial problems during the treatment period starting with the diagnosis of hydrocephalus, and they have at least one complaint about their own health.

**Conclusions:** Mothers were more interested in problems to be experienced by themselves and their children in the near future and the physiological dimension of the disease. However, they were aware of their children's future, home-care and special education needs.

**Key words:** Children, Hydrocephalus, Mothers, Problems, Turkey.

**Introduction**

Hydrocephalus is defined as an active distension of the ventricular system due to mismatch between cerebrospinal fluid production and its absorption (Erdoğan Bakar et al., 2010; Jouibari et al., 2011). It represents one of the most common pathologic conditions affecting children requiring neurosurgical treatment (Abhaya et al., 2008). The prevalence of congenital and infantile hydrocephalus has been estimated as 0.48 to 0.81 per 1,000 live and stillbirths (Jouibari et al., 2011).

The children with hydrocephalus are treated acutely with a cerebrospinal fluid shunt (Abhaya et al., 2008; Smith et al., 2009; Kardeş et al., 2013; Naftel et al., 2013). If hydrocephalus is untreated, can lead to

diffuse brain injury, mental and growth retardation (Kardeş et al., 2013). The development of hydrocephalus and its management present major challenges later in children and their parents' life, requiring multidisciplinary care from pediatricians, neurosurgeons, nurses, rehabilitative therapists, and others (Abhaya et al., 2008). Children with hydrocephalus face many challenges and their parents play a very important role in helping them to overcome these challenges (Kulkarni, 2007).

Having a child with a serious illness can have a detrimental psychological effect on parents (Kent et al., 2000). Concerns about their child's health and future can create stress that cannot only impact on the parent's own health, but may feedback to impact

the child, as well (Ohleyer et al., 2007). Parents must be empowered through education and social support (Naftel et al., 2013).

Recommendations from research relating to the hydrocephalus in children have stressed the need for healthcare professionals to value and listen to parents' concerns (Watkins et al., 1994; Iskandar et al., 1998; Garton et al., 2001; Barnes et al., 2002; Oliveira et al., 2010). However, no study appears to have explored or evaluated the knowledge, education, and problems of mothers having children with hydrocephalus. For this reason, this study was planned to evaluate the mothers' problems that are experienced in hydrocephalus treatment process.

### Methods

Focus group methodology was employed in this study. Interviews were held with the 15 mothers having children with hydrocephalus, treated at the Neurosurgery Clinic from 2012 to 2013. The mothers of children, who were treated for shunt dysfunction or shunt infection after shunt surgery at clinic during the study, consisted of the universe of the study. Total 15 mothers were included in the study. The mean age of the children treated at the clinic was  $13.13 \pm 16.81$  months. All of the children were made shunt surgery. Data was collected using a questionnaire. The questionnaire is made two parts (mothers' and their children's demographic characteristics and semi-structured questionnaire prepared by the investigators through screening). The semi-structured questionnaire focused on the selection of problems experienced from the mothers during the hydrocephalus treatment process. The interview guide progressed from general to more specific topics (i.e., from "Have you ever been informed about your child's disease by clinical doctor or nurse?" to "What are the areas you have difficulty with your child care?"). The themes of the interviews included mothers' information about the disease and treatment process, their views on the future of children with hydrocephalus, change in their life in the treatment process, and other areas of their difficulties. A voice-recording device was used during the interviews, face-to-face interviews were performed in a suitable physical environment. The

mothers' verbal consent was obtained after they were given information about the study and voice recording. The focus group interviews lasted for approximately 30 minutes and were moderated by a concerned investigator who was working in the Neurosurgery Clinic as a nurse.

The voice recordings were deciphered by first documenting to determine the points that were mentioned most frequently and the differing points and then they were turned into a written report. The collected data was analysed using the content analysis method. The descriptive properties of demographic characteristics were given as percentage and mean. Necessary permission from the academic board and informed consent from mothers' was obtained due to ethical issues before the study commenced.

### Results

In Table 1, the demographic characteristics of the mothers are presented. The average age of 15 mothers were aged 19-40 years who participated in the study was  $27.40 \pm 6.80$  years. It was found that 75.4% of mothers were illiterate and 12 mothers were living with their extended family. The mothers usually came from the lower socioeconomic strata. The economic strata of the mothers was described as income greater than expenditure (high), income equal to expenditure (middle), or income less than expenditure (lower) using a self-report given by the mothers. It was stated that 3 of these mothers had 6 children, 1 had 4 children, 4 had 3 children, 1 had 2 children, and 6 had 1 child. It was found that children with hydrocephalus had an average age of  $13.23 \pm 16.81$  months and while 4 were female, 11 were male. 66.7% of children of mothers participated in the study are diagnosed hydrocephalus during the pregnancy or at birth (Table 2).

#### *The first time at which mothers learned the diagnosis dealing with their children*

Five mothers (7,8,10,11,13) expressed that their children were diagnosed with hydrocephalus during their pregnancy, while five more mothers (3, 5, 9, 14, 15) expressed that upon birth they were informed that their children had hydrocephalus.

**Table 1. Descriptive characteristic of the mothers**

<b>Mother</b>	<b>Age</b>	<b>Education</b>	<b>Type of family</b>	<b>Income</b>	<b>Number of children</b>
<b>Mother 1</b>	24	Secondary School	Nuclear family	Middle	3
<b>Mother 2</b>	38	Secondary School	Extended family	Middle	6
<b>Mother 3</b>	26	Illiterate	Extended family	Middle	3
<b>Mother 4</b>	38	Illiterate	Nuclear family	Lower	6
<b>Mother 5</b>	29	High School	Nuclear family	Middle	3
<b>Mother 6</b>	31	Illiterate	Extended family	Lower	4
<b>Mother 7</b>	19	Primary School	Nuclear family	Middle	1
<b>Mother 8</b>	19	Primary School	Extended family	Lower	1
<b>Mother 9</b>	40	Illiterate	Extended family	Lower	6
<b>Mother 10</b>	22	Secondary School	Extended family	Lower	1
<b>Mother 11</b>	22	Secondary School	Extended family	Middle	1
<b>Mother 12</b>	28	Primary School	Extended family	Middle	3
<b>Mother 13</b>	22	Secondary School	Extended family	Lower	2
<b>Mother 14</b>	25	Illiterate	Extended family	Lower	1
<b>Mother 15</b>	28	Primary School	Extended family	Middle	1

**Table 2. Descriptive characteristics of the children**

<b>Mother</b>	<b>Child's age (months)</b>	<b>Child's gender</b>	<b>Time Since Diagnosis</b>
<b>Mother 1</b>	10	Male	7 month old
<b>Mother 2</b>	3	Male	1 month old
<b>Mother 3</b>	5	Male	At birth
<b>Mother 4</b>	7	Female	2 month old
<b>Mother 5</b>	2.5	Male	At birth
<b>Mother 6</b>	18	Male	1 month old
<b>Mother 7</b>	1.5	Female	in the womb
<b>Mother 8</b>	1.5	Female	in the womb
<b>Mother 9</b>	6	Female	At birth
<b>Mother 10</b>	6	Male	in the womb
<b>Mother 11</b>	6	Male	in the womb
<b>Mother 12</b>	30	Male	40 days old
<b>Mother 13</b>	4	Male	in the womb
<b>Mother 14</b>	20	Male	At birth
<b>Mother 15</b>	18	Male	At birth

### ***Opinions of mothers regarding disease process, recovery and their future of their children with hydrocephalus***

Mothers (5, 6, 8, 9, 10, 11, 12, 13, 15) who were informed about the disease and process by the clinical doctor, stated that their children carry the possibility of being mentally retarded or disabled in the future, the disease shall last for a lifetime but still the treatment process shall be shaped by time.

Mothers (1, 2, 3, 7, 14) who were not informed, stated that they believed that this disease can be treated and their children can recover. However they said that they experience uncertainty although they have positive expectations about their children's future. All children included in the study underwent shunt operation and all mothers stated they knew that shunt is permanent.

### ***Opinions of mothers regarding the changes between present life of their children and the time before they were diagnosed with hydrocephalus and hospitalized***

All mothers defined the change in their daily lives during treatment process as a disruption in the housework and daily routines because they only take care of their children with hydrocephalus.

Mother 12 having 3 children, including a 30-month-old boy with hydrocephalus, defined the change in their daily lives not only as a disruption in their housework but also as distress due to father's job.

Mother 13 having 2 children, including a 4-month-old boy with hydrocephalus, said that the change in their daily lives in a more general and reproachful way: "I only take care of this child, I cannot do anything else."

The majority of the mothers defined the change in their social lives during treatment as lack of social life, and not being able to get out of the hospital or the house continuously.

Mother 6, having 4 children including a 18-month-old son with hydrocephalus and Mother 9, having 6 children including a 6-month-old daughter with hydrocephalus, stated that they thought of their other healthy children and they were all in different places because they could not take care of other children.

Mothers (4, 13 and 14) said that they faced a change in their social lives during treatment and complained

about not being able to communicate with their family members and relatives and they felt that they were unable to have enough time for them.

The majority of the mothers defined the physical and/or emotional changes they went through during treatment as feeling sadness, stress and fear.

The statement of Mother 15, having a 18-month-old son with hydrocephalus, was interesting. When defining the physical and/or emotional change she went through, she expressed that she was on bad terms with her husband and they experienced problems.

Mother 8, having a 1,5-month-old daughter with hydrocephalus, Mother 9 and Mother 10 having a 6-month-old son with hydrocephalus, defined the physical and/or emotional change as nervousness, headaches and sleeping problems.

### ***Opinions of mothers regarding the matters that are difficult for them while taking care of their children with hydrocephalus***

When the question "What are the matters that are difficult for you while taking care of your child with hydrocephalus?" was asked to mothers. Mothers (2, 4 and 6) stated that the education of their other healthy children were disrupted, and Mothers 6, 10, 11, and 15 expressed that they had difficulties in meeting their hygienic needs, bathing them and most mothers specified that they experienced financial problems.

### ***Opinions of mothers regarding the problems they experience in their own health due to the care of their children with hydrocephalus***

Mothers that participated in the study listed the changes they experienced in their own health due to the care of their children respectively as follows: fatigue (40%), sleeping problems (40%), headache (26.7%), psychological problems (26.7%), loss of appetite (13.3%), exhaustion (13.3%), stress (13.3%), pain (13.3%), unhappiness (6.7%), stomach ache (6.7%), leg pain (6.7%), crying (6.7%), nervousness (6.7%), and forgetfulness (6.7%).

### **Discussion**

The number of children with chronic diseases is increasing every day (Nuutila et al., 2006). Hydrocephalus is a disease that is diagnosed in early childhood and creates chronic health problems

(Smith et al., 2009). Having a child diagnosed with a chronic disease causes compulsory and expected changes in the lives and daily routines of the whole family. It is also the reason of a long term relation between the child, child's family and medical personnel. When this relation is used well, it may be a good resource for the family. Medical personnel must be aware of the burdens caused by the chronic diseases for the child and child's family. Main stand point of a pediatric nurse must be the idea that the child with the disease is never alone and family must also be taken into consideration for the daily care of the child (Nuutila et al., 2006). Information given by the health care team decreases the feeling of helplessness in the families, enables families to feel that the situation is under control; whereas lack of knowledge results in feelings of uncertainty, concern and loss of control (Erdim et al., 2006). Education decreases stress of the child and the family, and increases their level of knowledge about the disease (Li et al., 2010). Therefore, informing the family and their cooperation with the health care team are essential for the family to be able to cope with the child's situation effectively (Erdim et al., 2006).

The majority of the mothers participating in the study expressed that they learnt about the child's diagnosis during pregnancy or upon birth. Recently, thanks to the developments in the field of medicine, most of the congenital diseases can be diagnosed in the womb or soon after birth.

Mothers informed about their children's diseases and treatments had more realistic expectations about the future of their children. However, mothers who expressed that they were not informed had a positive but non-realistic expectation that their children would recover and continue with their normal lives. According to the results of the studies conducted; education provided for parents has been reported to be helpful for them to cope with the situation of having a sick child (Atkin, 2000; Pain, 1999; Van den Borne et al., 1999). Smith et al. (2009) obtained similar results in their studies, and reported that mothers having children with hydrocephalus were not informed sufficiently and families were not involved in the care and treatment decisions taken during treatment. In the diagnosis phase, parents need to be informed about their children's disease and treatment. Information should be conducted in a clear way. Additionally, it is also important for families that health care professionals should respect the feelings of parents and communicate with them in an empathetic way (Nuutila et al., 2006).

Providing care brings a full day responsibility for the individual and creates changes in the daily activities of the family. Family members who are responsible for taking care of the sick child experience problems such as limitation of their time and freedom, economical problems caused by the disease, loss of revenue, limitations of their relationships with families and social environments in daily life, and tension in their home atmosphere. These experienced problems create a risk for the physical and mental health of the care-giver (Erdem et al., 2013).

As the child's care need increases, some daily activities are hindered and future plans may be affected (Erdim et al., 2006). In the study, all mothers whose children received treatment in the clinic defined the change in their daily lives as not being able to do the housework. Houseworks such as cleaning the house, laundering, etc. were very important for them. Within the structure of the traditional Turkish family, responsibilities of women are quite high, women are supposed to both mothers and people that look after the house. Therefore results of the study were appropriate in terms of the traditional structure and were not surprising.

Within the study, most mothers expressed that they could not go out, stroll around, communicate with their family members and relatives and they could not spare enough time for them. According to the report of World Health Organization (WHO)'s meeting held in May 1998, the classification of international disability has been revised in order to comprehend human functions and disability in a biopsychosocial aspect (World Health Organization, 1998). This result is an indication of how important mothers having a child in need of a chronic and long term care could not be able to communicate socially. Additionally, in the region where the study was conducted, women generally have many children and live in extended families. Since a fatalist attitude is common in the mothers living in the region, it could be thought that they deal with daily problems more rather than the future of the child.

In addition to the stress experienced by parents of the children with chronic diseases during treatment, they have difficulties in meeting the needs of the daily life, and they become nervous in their interpersonal relationships particularly in marriages and emotional relationships. Reactions not appropriate to this traumatic situation and the feeling of guilt felt by the family make the parents sink into depression and also the extra need of time, money and energy necessary for the care of the child causes stress for the parents

(Akçakın et al., 2001). Majority of mothers in the study talked about the emotional problems they faced in the process of treatment rather than their physical problems. In the study, majority of mothers defined the physical and/or emotional changes they experienced as feeling of sadness and stress; however, generally mothers whose children were diagnosed with hydrocephalus during pregnancy or upon birth mentioned physical ailments and communication problems with their husbands. Diagnosis of congenital malformation or chronic disease is difficult to accept and cope with for parents. Having a child whose state of health is not good and the child's long term need for medical care may cause psychosocial changes in the family. Having a child with disability while expecting a healthy child leads to feelings of loss and grief. Feelings of grief and guilt cause tension in marriages and among other family members (Yıldırım et al., 2004).

Mothers participating in the study stated that they experienced fatigue, sleeping problems, headache and psychological distress due to the care of the children. Erdem et al. reported that almost half of the mothers developed health problems and these problems were rather psychological problems (depression, stress, sleep disorder), head and back pain, fatigue and forgetfulness (Erdem et al., 2013). Parents experienced health problems such as chronic fatigue, sleeping problems, weakness, gaining or losing weight, headache, back pain, muscle strain, indigestion, and muscle cramps during treatment at the hospital (Tuna et al., 2012). Results of the study were in line with literature.

### Conclusion

According to the results of the study, mothers mostly experience social problems during the treatment period starting with the diagnosis of hydrocephalus, and they have at least one complaint about their own health. Mothers were more interested in problems to be experienced by themselves and their children in the near future and the physiological dimension of the disease. However, they were aware of their children's future, home-care and special education needs. It is clear that the responsibility of nurses is very important in helping mothers receive social support. Nurses should be aware of the concern of mothers and solve this problem with their educative, counseling and supportive roles. "Turkish Society of Hydrocephalus" is a recently founded association in Turkey. It is upsetting that in the clinic where study was conducted; nurses, doctors and families having

children with hydrocephalus were not informed about the societies and their activities. Therefore, it should be aimed to communicate with societies and groups, bring people with this diagnosis and families together, and increase activities in an efficient way.

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