

PROFESSIONAL HELP FOR VISUALLY IMPAIRED MOTHERS RAISING A CHILD

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Summary

Introduction. The operative laws in Hungary state that each person is entitled to equal treatment, while avoiding strengthening the judgment of one's state as 'illness'. Professional guidelines do not make it necessary to care for the visually impaired mother as endangered, but it is recommended that they be cared for based on their special needs, imparting them higher attention.

Aim. The goal of our research is to get to know the difficulties and experiences of the visually impaired mother, as well as their expectations of professionals working in health care, in order to facilitate successful personal care. Our goal is also to examine their opinion regarding the attitude of professionals based on their personal experience during the use of health care services.

Material and methods. The research was done in Budapest and its surroundings among visually impaired mothers (n = 11) each parenting at least one child/young adult up to the age of 24, all agreeing that the interview be made in their homes. The interviews were taken between 3 August 2012 and 31 October 2012. The questions of the interview are divided into seven sections based on the examined topics: sociodemographical data, the opinion of visually impaired mothers on the attitude of health care professionals based on their experiences during the time of pregnancy, childbirth, and parenting, their relationships with their spouses, their contact with special institutions, and their expectations of any person helping them.

Results. The welcome of the pregnancy is positive on behalf of the family and neutral on behalf of professionals. The primary and most useful help is given to the mother by the family.

Conclusions. In order to give professionals help in offering services of higher efficiency and better quality it is necessary to do further research on the topic, to get to know and publish the medical, social and other needs of visually impaired mothers as well as meeting these needs.

Key words: visually impaired, mothers, parenting, prejudice, equal treatment

INTRODUCTION

Families expecting a child are helped by multiple departments of the social supportive system, in which health care is a prominent one (1).

Professionals in contact with families constantly need to adjust to changing trends in establishing a family (2).

The professional knowledge and the attitude of the professional worker is essential in gaining the active participation of the client in protecting their health. In the case

of a disabled person this feature grows exponentially. Optimal cooperation can be hindered by the prejudice of the professional on one hand, and by an intensified sensitivity of the disabled person on the other hand. The factors mentioned above and equal treatment that is required by the Hungarian law – emphasised specifically in health care – confirm the need of examining and encouraging the correct attitude towards the disabled. While caring for these people we must ensure that their consciousness of illness is not strengthened (3-6).

The number of the visually impaired in Hungary is 82.482, the number of visually impaired women is 49.528, from whom 8.043 are at a fertile age (15-49) (7).

Visual impairment means the loss of function in the eye, which results in the individual's restricted communication and participation as the active member of society. Hungarian law states that the visually impaired are hindered in taking advantage of their rights compared to those living without impairment, therefore it is reasonable to give them advantage in every possible situation (8).

THE DEFINITION AND CLASSIFICATION OF VISUAL IMPAIRMENT

Hungary uses the definition of WHO (World Health Organization), according to which "the person with a maximum of 30% or less vision on their better eye ($V = 0,3$), or with a maximum of a 20 degree field of vision counts as visually impaired". "The field of vision is the part of space that a person sees while keeping the head and eye motionless". The restriction of the field of vision can cause serious problems in orientation (9).

Based on the classification of WHO, (which is also used in special needs education in Hungary) there are three levels of visual impairment (tab. 1). Blindness is when no stimulus is perceived by the eye. People with extremely low vision are those whose vision is less than 10%. This group can be divided into three further groups: those with photosensitivity, those who see shapes and figures, and those who read using their fingers. Photosensitive people have a visus that cannot be measured. They use "blind techniques" in everyday life but they can use the small perception of light in orientation or when using transportation. Those who see shapes and figures, have a visus of maximum 4%. They are able to use the remainder of their perception in everyday life. They are capable of learning to read and write using optical or/and electronic tools. Most of them use Braille-reading. Those who read using their fingers ($V = 0.04-0.1$) are also capable of reading and writing using special tools, but their vision is not sufficient to be exclusively used for the purpose of orientation, they use other parts of the sensory system as well when educated. People with low vision have a visus of 10-30% They can rely on their sight exclusively when being educated. Their education happens visually in every possible case (10, 11).

THE AIM OF THE RESEARCH

There is extremely little literature on the topic of caring for visually impaired mothers raising a child. One of the goals of our research was filling this gap.

Other goals of our research were getting to know the circumstances of a child being born into the family among visually impaired mothers, finding the available sources of help in their environment in order to care for them efficiently, to study their relationships with special institutions for the visually impaired, to study the role of these relationship at this special time of their life, to study the welcome of their pregnancy, and to assess whether they really do receive higher attention when being cared for.

The aim of our present study is to study the welcome of the pregnancies of visually impaired mothers and summarizing the reactions of the family and professionals.

METHODS OF THE RESEARCH

Since there is hardly any literature on the topic, we put a lot of effort into researching the available literature.

After getting to know the literature, we contacted the mothers personally. Our research was in Budapest and surroundings, from 3 August 2012 to 31 October 2012. The interviews were taken in an environment that ensured a calm and unstressed conversation, most of the times in the homes of mothers. The interviews were registered by voice files and in written form as well. The mothers agreed to letting us use what had been said anonymously.

The questions of the interview can be divided into seven sections, based on the researched topics: sociodemographical data, the opinion of visually impaired mothers on the attitude of professionals based upon their experience throughout the time of pregnancy, birthing and parenting, their relationships with their spouses, their relationships with a special institutions for the visually impaired, their suggestions for and expectations of professionals. In our present study we will only present questions relevant to our present aim.

SAMPLE

Our research was done among seven completely blind mothers, two with extremely low vision and two with low vision. The cause of their visual impairment is retinitis pigmentosa in one case, atrophía nervii optici in another case, retinopathia praematurorum in four cases, and unknown in five cases.

Table 1. Classification of visual impairment based on visus and education.

Classification based on the severity of impairment	Blind	Extremely low vision			Low vision
		Photosensitive people	Shapes and figures	Finger-readers	
Visus	not measurable	not measurable	< 0.04	0.04-0.1	0.1-0.3
Education	by touch	by touch	with special tools	with special tools	integrated education possible

The average age of those participating in the research was 36.9. Five of those answering our questions had a college or university degree, two had finished high school, one had studied a profession at a non-graduate school, and two only finished 8 years of elementary school. Three worked as a call operator, two as medical massage therapists, one as a semi-skilled workers, and two as teachers.

The average age of having their first child was 28.4. Eight were married, two had been divorced, one had never married before. Seven mothers with one child and four mothers with two children answered our questions. None of the children being raised had visual impairment. Out of eleven ladies nine had planned their pregnancies, two had not. 6 had a cesarean section, out of which four was preplanned in order to prevent further sight loss.

RESULTS

During the time of the research we gathered the available literature in Hungary, as well as taking a look at international resources. We also explored the special institutions involved in the rehabilitation of the visually impaired.

Visually impaired mothers averagely bear their first child at the age of 28.4. The child is most often planned and born to married parents. All of the children have sight. All of the participants had a job and an income of their own. Most of them had studied a profession, five of them had a college or university degree.

Our research had a pleasant welcome among the participants. They were open to giving detailed answers and they gladly talked about their experiences.

They were very supportive of the research in process. Some quotes of what had been said:

“We need to have literature on this topic, the next generation will sure be wiser by it”.

“It’s great that someone has started to study these questions and not only special needs’ teachers are emphasising this topic”.

To the question regarding the welcome of the pregnancy among family members we received a surprisingly high percentage of positive answers. Only in two cases did the mothers mention that one of their family members did not receive the news with joy. In both cases the family member was a grandparent.

Five ladies mentioned the joy of the father, six mentioned the family, two mentioned grandparents and one mentioned her educator. One of the mothers put it this way: “Our family and those living around us welcomed the pregnancy with joy. Seeing my lifestyle, they did not presume that I wouldn’t be able to care for a child”.

Those answering our questions regarded the reaction of professionals working in health care positive in four cases, neutral in five and negative in three. A connection can be spotted among those who graded the attitude of the professional to be negative and those who were offered an abortion – the only mothers with an explicitly negative opinion on the attitude of professionals were those that were asked about abortion.

The mothers shared their opinion on twelve doctors. After being offered to abort the child, one mother decided to find another obstetrician-gynecologist.

The mothers put their opinion into words in the following way:

“The problem is probably this: they aren’t prepared for the fact that there are blind parents and they can easily find themselves in a situation where their patient is a blind mother”.

“The sighted society does not know them (...). They do not want to look down on us, but if they don’t know us, how could they know what we are capable of?”.

“I went and said that I was pregnant. Then he starts telling me to go to the family something... I don’t know what it’s called. But why? – I asked. “Because of the abortion”. “But I do not want an abortion!”.

Part of the research was exploring what kind of help the mother receives in the time of pregnancy. Most of them mentioned the father of the child, all except for 3 mentioned how much their partner helped them. Five of them mentioned grandparents, five mentioned other people (godmother, sister, sister-in-law, great-grandmother), and many of them mentioned friends. One of the mothers told us about her good relationship with the pediatrician even before the child was born.

Regarding the perinatal period the mothers named family members and several professionals working in the hospital. The father was mentioned most of the times (eight cases), six ladies mentioned the obstetrician, four mentioned the grandparents, three mentioned the midwife, and two mentioned the health visitor working in the hospital. Three ladies graded their partner, imparting the father with the maximum 10 points for their help in this time. Four of the ladies graded their obstetrician, giving them an average 9.5 points. Two mothers shared their opinion about the midwife, grading them with 10 points, and two graded the nurses with an average of 7 points. Regarding the help they received in learning how to care for their child, four mothers mentioned the health visitor, three mentioned grandparents, three mentioned a friend. One person developed the techniques she used on her own, another person was helped by her roommate in the hospital. One mother learned her technique from the pediatrician, one from the nurse at the hospital, and one from her husband.

A couple of suggestions and opinions from the mothers:

“I had much trouble with the doctors. I simply didn’t feel that they would be treating me equally to a seeing mother (...). Then once, I got so tired of it, I said to my mom”, “Come, let’s go to the doctor together”.

“If a non-seeing mother goes to them, they should not view her as someone with less value. They should try to have a behaviour and attitude that do not reflect that they are dealing with a disabled person that should not have a child, and treat them in accordance”.

“The mother needs to be asked about her opinion. What can she do on her own and what does she need help with? If they do this together, it will work. Because all people are unique. Some can do more, some can do less”.

“There is no satisfactory communication between the nurse and the patient”.

“They should have an open-minded attitude towards the parents. If they have any questions, they should be able to openly discuss them with one another”.

CONCLUSION

We do not know about any other research in Hungary on our topic, that would aim to fill the gap in medical literature.

Those participating in the interviews were very open and helpful. Those doing the research met some responsible mothers who deserve the highest respect. Their experience provided a better knowledge of those concerned and made the communication better with them.

The mothers who participated in the research had their first child at an age corresponding to the Hungarian average (12). Their approach focuses on the family (marriage, parenting, harmony in the family). All of them had a job, making a living on their own, separately from parents.

The family and friends of the participants received the news of the pregnancy with joy and helped the mother with a supportive attitude. They had no doubt that their disabled family member is capable of caring for a child. Their attitude was positive. No prejudice could be spotted on their part.

Regarding professionals this question is somewhat more complicated. In certain cases the mothers give an account of a positive experience due to a supportive professional. Many of the ladies did not grade the work of the professionals, but those who did, gave a high grade. Generally – as the quotes show – the professionals found themselves in the described situations unprepared. Most of the time this only caused uncertainty, in other cases the additional prejudice caused the professional to offer abortion, which is professionally incorrect.

SUGGESTIONS

In the light of our research we agree that the key to successful professional work among the disabled is the cooperation of professionals with the individual and the family (13).

Visually impaired mothers need to be imparted high-attention regarding their special needs. They and their families need to be supported as much as possible.

Communication is critical in working with those concerned. Professionals have little opportunity to practice working with families in this special situation, therefore their lack of experience and knowledge in this area is not

surprising. To solve this difficulty, we suggest active communication, with special attention to having the courage to ask questions. On one hand, asking questions does not diminish the prestige of the professional, on the other hand the parent will value the special attention provided.

The most informative, the clearest and the most usable tool for a professional is to have first hand information on the client's expectation – described in the client's own words. It is necessary to adjust the caring plan to these expectations in order to meet the visually impaired mother's special needs. The visually impaired mothers' approach on life can be an example to us all.

There have been attempts to deal with the difficulties mentioned above (14, 15), but in order to attenuate prejudice and meet the special needs of visually impaired mothers raising a child, we still find it necessary to publish a booklet, that is based on the opinion, experience and expectations of those concerned and contains the correct way of treating the disabled, basic information on their life-style, and information for medical experts on helping them in a professional way. To reach this goal we plan to continue this research and make more interviews. □

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