Volume 5 / Number 6 / 2011

HealthMED

Journal of Society for development in new net environment in B&H

Address of the Editorial Board: Sarajevo, Bolnicka BB
phone/fax 00387 33 956 080
healthmedjournal@gmail.com
http://www.healthmedjournal.com

Published by DRUNPP, Sarajevo
Volume 5 Number 6, 2011
ISSN 1840-2291

HealthMED journal with impact factor indexed in:

- Thomson Reuters ISI web of Science,
- Science Citation Index-Expanded,
- Scopus,
- EBSCO Academic Search Premier,
- Index Copernicus,
- getCITED, and etc.

Sadržaj / Table of Contents

Sadržaj / Table of Contents

Sadržaj / Table of Contents

The analisys of the syndroms appearing among children living with autism in Hungary

Orsolya Tobak[1], *Mónika Balogh*[2], *Kinga Lampek*[3]

[1] University of Szeged, Faculty of Social and Health Science, Health Visitor Labor and Methodology Department, Hungary,

[2] Universitas of Szeged, Pedagogy PhD School, Hungary,

[3] Universitas of Pécs, The Faculty of Health Sciences, Institute of Health Insurance, Department of Health Promotion, Hungary.

Abstract

Present results are part of an overall exploratory research dealing with the quality of life in the families bringing up children with autism, which aims to support the effectiveness of health visitor (Hungarian specialty) nursing care.

Our goal was to map the symptoms, which can be the basis of a professional guideline for health visitors and professional nurses. During our research among families in Hungary raising children living with autism 276 families were asked by a questionnaire. The age of the children were between 3-18. The qualitative data collection occurred in three focus groups (parents, autism specialists and health visitors), some elements of which are described in the study. No similar social-demographic background can be recorded among the examined families, all of them have to face many challenges with only a very little help. The appearance and the frequency of the symptoms are the same as mentioned in the literature. They have different expectations toward the professionals taking care of them, which are presented in this study in details.

Key words: Autism, health visitor, symptoms, health care

"In a perfect world, everyone is healthy and happy, people understand and care about each other.

In a perfect world there are no ill people, no damaged ones.

In a perfect world, everyone has equal opportunity to fulfill their latent talent.

But our world is far from being perfect ..."
a disabled youth

Introduction

The number of people living with deficiencies is increasing year by year in Hungary, due to the development of diagnostics there are more and more opportunities for early detection and to begin intervention as soon as possible. These developmental interventions, can support and improve the quality of life for families, increase the cohesion and the cooperation, of the family, and they can help solve the problems.

One of the major problems in connection with the families is the prejudices and stereotypes against the mentally handicapped, and autistic people which usually comes from ignorance and the fear of them. An important experience of social sciences is that negative attitudes prevent cooperation. It means that primarily the approach of helping professionals needs to be changed, which may affect the positive attitudes of the immediate and wider environment toward people with disabilities. The efforts of solving the problems have intensified over the past 10-15 years. Legislation has been defending the interests of people with disabilities in Hungary, many advocacy organizations are working, mainly in big cities, and more and more attention is being paid to integration. However people often avoid families with disabled children, and an active attitude to help in the vast majority of the population has not been characterized yet.

Objectives

The present study aims to introduce the current situation of the 3-18 year-old autistic children living in Hungary, especially in light of demographic data. This way we are going to have an overview of the residential, age distribution, marital status, educational attainment and financial situation of the families as well as the appearance of the frequent symptoms. The results of focus group interviews can inform us about their daily lives and the problems that hinder them from social integration. We can also get an idea about how they feel about the work of professionals dealing with children.

Introducing Approaches

The quantitative analysis uses the data of the National Autism Research (OAK) prepared by the Jelen (Present) Institute. In the research the aimed and comprehensive sampling procedure covered all the people in the population living with autism, and members of an organization, or association in Hungary.

The written interview method that was applied by OAK, used two types of questionnaires. One detailed questionnaire covering several areas was filled out by interviewers, the other was a self-filled one sent by mail to the parents. In my own survey I used the data from the postal questionnaires, specifically the families who are raising children between the ages of 0-18. Due to the sampling procedure 276 valid questionnaires were returned.

The focus group study (qualitative) occurred in three groups, where I used the same questionnaire catalogue. Beside the parent group I asked health visitors and a group of heterogeneous professionals dealing with children with autism in their work. The SPSS version 15 was used for the data analysis.

Analysis

Among the qualitative results of the survey the present study covers only the presentation of the demographic variables and the present situation.

On the basis of the literature the clinical picture of autism can be summarized as follows.

Social isolation, which can be noticed since infant age. Children with autism do not make physical contact with their parents, they „freeze" if anyone touches them. Do not keep eye contact, show a complete indifference to other people, even to their mothers. Strongly linked to objects which they can do the same movements with for hours. (Ranschburg 1997)

Mental lag behind: Today's researches show that 70% of the autistic are mentally handicapped some degree. Their verbal intelligence is low, whereas during performational tests they significantly outperform their peers. (Ranschburg 1997)

Language and communication inadequacy is characterized by the autistic. Half of the children do not learn to speak, and those who do in most cases it is echolalia when they repeat what they heard exactly, but mechanically. Although they learn to speak, but unable to communicate, they can not follow the constant change of perspectives. Another common peculiarity of speech is to switch pronouns. (Ranschburg 1997)

Their fantasy game is poor and shallow, they can not play spontaneously and creatively, especially with others. The upset of their usual agendas the slightest change in the furniture of the room or the usual people confuse them and drives to despair.

The ritual nature of motor activity and abnormal reactions to external stimuli.

Some autistic people have special skills on those areas where social skills are not required.

During the research, the situation of families raising children with autism was examined. To get to know this the accurate assessment of the seriousness of autism is essential. However, there were no objective means to establish this, since the ICD codes and medical report could not be known. We could only rely on the subjective opinion of the parents, which is not always plausible, but it can serve as clues for further analysis.

The 50% of the parents nurturing their children considered the problem of their children as serious only 13.4% of them as very serious, and a third as mild. This data may have an impact on institutional care, parental employment, recreational programs, discrimination etc. This ratio can be considered as good in the light of foreign researches and other statistical data. This could have several reasons, but in most cases can be traced back to the child's age. The society accept the behavior of the younger children experienced by parent more easily than of adolescents'. During childhood the parents still hope that this state is reversible, can be improved.

In the following, I present the data, based on the results of the studied population, which are typical or atypical symptoms of autism that have a great influence on the family life, and their "well being".

One such area is the speech, which can be judged in itself, but also can be divided into two separate parts, speaking, and comprehension. 30% of the children speak well, but 18% do not speak at all. In the case of children at the age of 3-4 it can happen as a result of development that later they will be able to formulate words or short sentences. 29% of them express themselves simply, in words and short sentences while 22% of them in most cases only repeat information what they already heard.

The problematic function going beyond speech among autistic people is comprehension. It explains the reason for the fact that we got different proportions than in the previous question. In 77% of the cases they understand well, or almost well what is said to them. Around 22% the proportion of those who have little understanding of the information they received, even in one case, according to the parent, that child does not understand what they say to them. In this case another disability is probable that prevents comprehension (eg, deafness, severe mental disability).

Autism may affect the sleep-wake cycle. It was not experienced by the 63% of the parents and 32% experienced mild cases of sleep disturbance, in 14 cases the child's problem was considered as serious by the parents. In parallel, the eating disorder must be examined as well. During focus group interviews it appeared several times as problem worsening with the age. Present study shows that the eating disorder is more common than sleep problem. In 51.4% there was no reported eating problems so far, 37.7% have already detected nutrition-related problems of the child while 11% causes very serious problems for parents and children alike. The most common eating disorder mentioned by the parents is the lack of appetite, and in this context, the rejection of certain foods (because of shape or color).

In addition to the speech behavior disorders are another big problem for parents. The survey also highlights a number of specific behavioral problems such as short-tempered behavior, which "never occurs" in 31% of the children, 59% of the parents "experience it sometimes" and is frequent in 9%. Rage often occurs in 19% of the children, at 54% of the cases rarely and it "never can be seen" at 25%."Strange, stereotyped movements" are often found by 49% of the parents, rarely detected in 33% and 17% did not experience such symptoms at all. This is a typical characteristic of autism symptoms, which can be evident even to a lay observer. Gets a similar proportion of "compulsive behavior" which is often in 57% it is rarely encountered in 31% and 12% are common.

The "embarrassing behavior before others" does not show any outstanding rates, 58% sometimes, 23% frequent and 18%, there is none. Self harm is not typical at the 63% of the examined children, , 30% sometimes, and only 7% of the parents experience it often. The research did not address the ways of self-harm behavior. The study suggests that the most common habits at most children are stereotypical, strange movements, but self-harm behavior, rage and angry, embarrassing behavior is rare.

In order to evaluate the possible incidence of behavioral problems better, I created a new variable. The obtained data shows that in case of two children behavior problems were not experienced by the parent. They are likely to show signs of mild autism in other areas as well. The assumption that they are little children is not confirmed, because one of them is 8 the other is 10 years old.

Aggregating the scores on behavior it can be seen that the more problem they have and the more severe they are the more points the respondent gets. It can be said that a few problems can be experienced at the 15% of the children while in case of 41% of them a slight difference can be experienced all areas or one or two cases we can meet more serious disorders. The third group (36% of) always have a slight problem for sure, but more than one also occurs more frequently. At 7% of the children behavioral problems often occur in all areas.

The questionnaire took down experiences in the field of autonomy of the child based on the needs. Using toilets works at 86.5% of the tested children with autism alone or with a little help. A lot of help is required in this area by 13% who are probably younger, not yet housebroken, as it can be said and also mentioned in the literature, that the usage of toilet appears later among them. In the field of other hygiene needs 66%of them is self-sufficient or requires less assistance while 33% of them is in need of assistance. This ratio can be observed in the healthy groups as well with similar age distribution. Dressing is completely independent at 28% of them, 47% requires smaller assistance while 25% of them needs more. What is meal concerned 93% of them is completely self-sufficient only 7% of them requires more help. The data shows that these ratios are almost the same as at the healthy population of similar age. If we compare the results with the age of the children one or two years of lagging behind can be experienced but we can say that at the examined areas in most cases these children become independent at elementary-school-age or only little help is needed. Each of the four variables (dressing, eating, grooming, toilet use) were taken into account during aggregating the scores, so the higher the value of a child is, the more likely to require more frequent assistance in certain areas. In cases where a lower number is received, we can say that the child can fulfill their own needs alone. Fully independent in all areas or just a little help is needed by the 44.9% of the children while 38.4% of them requires at least some help in all areas. 16.7% of them certainly needs a lot of help or support to meet their needs.

After the distribution of the symptoms we address the review of qualitative test results.

The analysis of focus group interviews

The aim of the interview was to reveal the opinion of parents and professionals to define shared goals and plans and to improve the quality of life for children with autism.

Three groups were studied during our research: concerned parents, health visitors, and professionals (psychiatrists, health visitors, special education teacher, teacher).

The results obtained during the research are the following.

The families of disabled children encounter the prejudices of society. It regularly occurred in the families surveyed that they got negative verbal opinions declaring that the parents could not discipline their children. The prejudices from outside affect the acceptation of the diagnosis as well. According to the opinions of the health visitors the parents who have already accepted the child's problem, they actually use the term autism, while those who have not identified with the status of their children yet use the word disabled in everyday conversations. *"If they hear autism, two things occur to them: Oh my God, how serious it is, the other is what he is a genius in. Two extremes. Perhaps a talented genius, but he can not exist in this world. "(A parent)*

The prejudice and a general lack of knowledge make it more difficult and in some cases prevents, or even destroys the social relations of the children and families. They try to move to a place where the immediate environment is acceptant and tolerant to the contingent fuming and screaming of the child. Several people have said that the previous relations are worn, and the only really good friends remained. "The precious people who accept us, remain." (A parent)

The symptoms of autism, obvious to the experts interviewed, can be stated in general that while the parents mentioned positive and negative symptoms, the experts can only point out the negative characteristics. The experts particularly see the problems and their knowledge can be linked only to the difficulties. These are good foundations of transmitting the prejudices and explain their stability. Besides approaching this primarily emotional way, a wider range of knowledge can also be observed in the case of parents, since being concerned leads them on a constant learning endeavor.

The diagnosis of children often occurs only at the kindergarten age. The reason for this is that it is difficult, geographically limited, and slow to reach the health care system for diagnosis. Another reason may be that health visitors, as primary prevention professionals do not have sufficient knowledge so that they could help in the early diagnosis and effective treatment, however according to parents and professionals early diagnosis has greater developmental efficiency. The opinion of the parents is that they are not satisfied with the nursing care of the health visitors can be supported by the facts mentioned above and that they except more help from their health visitors. The situation could be improved by the expansion of the nurses' knowledge, and development of the professional protocols.

Parents of autistic children are doing their best in order to help their child, assume all the burden, but they do not receive adequate social assistance. Less public assistance and support is given in Hungary to the families involved than in other EU countries. The financial burden of development is gradually increasing, but the subsidies are stagnating. In spite of this, parents are looking for opportunities to develop the children as much as possible. Each of the families surveyed participate in programs organized by the Autism Association, which help the integration of children.

The vision of families bringing up children with autism is uncertain due to the weaknesses in the Hungarian health care system. There is no adequate institutional care for autistic adults. All goes well, until they go to school, but after that there are only day-care institutions, which relive the burden of the parents. There is no solution to the situation where the parents are no longer able to stand beside them. We can read a lot about well-functioning autistic farms abroad, but only a few attempts were made to implement them in our country. "*The parents sacrifice themselves as long as they can but what happens after that ...The parent would like to accustom their children to an institution where they would provide for the child.*" (A health visitor)

Summary

The autistic children mainly live in the Central Region of Hungary, with a Budapest center. It can be said that they are brought up mainly in full families. The financial situation of families is more difficult due to the special needs of the children, and because of the fact that only 45% of parents are able to work besides taking care of the child.

Objective symptoms, the age of the parents, the number of siblings, the current age of injured children and the measure of the help they can expect in caring the child have an effect on judging the severity of the conditions.

The parents are the ones who usually detect the first symptoms, but the professionals ask them to be patient "this kid is developing a bit slower." It is an important lesson for health care professionals to consider the signals coming from the parents in all cases.

The presented results and the parents reactions show the actual problem we are facing with. It is necessary to speak of autism, to help in early detection, to support parents in child development and to lobby the government for the health care of adults with autism and to improve social conditions. Besides training professionals it should be mentioned as an important objective to expand the knowledge of lay people as well in order to prevent the discrimination of disabled people in society.

"We want it to be accepted as a special thing that is completely different than a mental disability. You can live with it, live together with it, and they can be adorable, but you can go insane because of them. "(A parent)

References

1. *Bánfalvy, Cs. (2005). A fogyatékos emberek és a munka világa. Szakképzési Szemle, 2, 180-193.*
2. *Chikán, Cs. (2001). Esélyegyenlőség, fogyatékosság. Budapest, Hungary: Mozgáskorlátozottak Pest Megyei Egyesülete (Publisher)*
3. *Ranschburg J. (1998). Pszichológiai rendellenességek gyermekkorban. Budapest, Hungary: Nemzeti Tankönykiadó.*
4. *Kőpatakiné Mészáros, M., & Salné Lengyel, M. (2001). Fogyatékos tanulók helyzete az ezredfordulón. Új Pedagógiai Szemle, 7-8, 20-29.*
5. *Petri, G., & Vályi R. (2009). Autizmus – Tények – Képek. Budapest, Hungary: AOSZ, Jelenkutató Alapítvány*
6. *Szabó L. (2003). A boldogság relatív – fogyatékosság és szubjektív életminőség. Szociológiai szemle, 3, 86-105.*

Corresponding author
Orsolya Tobak,
University of Szeged,
Faculty of Social and Health Science,
Health Visitor Labor and Methodology Department,
Hungary,
E-mail: tobako@etszk.u-szeged.hu