

UNIVERSITY OF PÉCS
FACULTY OF HEALTH SCIENCES

NURSING CARE AND PREVENTION AMONG THE FAMILIES
BRINGING UP AUTISTIC CHILDREN

DOCTORAL (PHD) THESIS

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1. INTRODUCTION

There are a lot of **prejudice and stereotypes** against the mentally handicapped and people with autism in our country where ignorance and fear are generally in the background. One important experience of the social sciences is that negative attitudes hinder cooperation. It is important to change primarily the attitude of the professional helper which can cause positive change in the attitudes towards people with disabilities among the immediate and wider environment.

In the past 10-15 years there have been some efforts to solve these problems. Legislation has been protecting the interests of people with disabilities, a number of advocacy organizations work and more and more attention is paid to the integration. The public, however often refuse the families bringing up disabled children and active attitude to help is not typical at the vast majority of the population.

For these reasons, my goal was to explore the number of children and families living with autism in Hungary, the effectiveness of nursing care, prejudice and discrimination coming from the social and health services, and education have experienced by gap analysis. The problems to be solved are revealed in the light of the affected families' demographic data. We get answers to the reasons, the method, the frequency and the location discrimination. The socio-demographic characteristics that may adversely affect the child's severity are formulated.

A social network is taking shape the supporters of the families can be known and what burdens should they bear alone. The investigation can show a picture of how we can help as individuals, as communities and as a society.

After setting out in the introduction and the literature review, the following **research problem** can be defined:

What factors influence the situation of the socially disadvantaged families bringing up children with autism?

2. OBJECTIVES

To answer to the research problem mentioned in the introduction the following research objectives were set:

- Determine the number of children with autism between the age 0-18 years living in Hungary
- To explore the reasons for exclusion from society and their influencing factors.
- Describe the factors that increase the disparities of families with autistic children, and improve the social disadvantages.
- Uncover the socio-demographic situation of the families raising children with autism and the network of relations among the parents.
- To explore the opportunities, strengths and weaknesses of the domestic and external supportive environment.
- Consider how to improve early diagnosis as soon as possible after recognition, and what role a health visitors plays in it.
- Examine the availability of regional distribution of the health, social and educational institutions.
- Collect all problems, expectations, and responsibilities in connection of the health visitor's care.

3. HYPOTHESES

The research objectives will be answered along the following hypotheses.

- 1. At least 50% of the affected families experience exclusion from the society which was influenced by the following factors: settlement, education, age and marital status of the parent, income per capita, the labor market situation, the child's age and child's severity.*
- 2. Families with children with autism are isolated, have fewer immediate social relations, and consequently left alone with a child in need of special care, they can count on only themselves and their spouse, which can affect the cohesion of the parent as well.*
- 3. Developmental anomalies, early signs of autism, are recognized by parents considered excessive by professionals or are not recognized by them, as a result 2-3 years are passed between the detection and diagnosis.*
- 4. The following factors could adversely affect the assessment of severity at families with children with autism: the socio-demographic status of the family, the age of the children, the state of health of the family members, institutional care.*
- 5. I assume that families affected with autism live primarily in the Central-Hungary region and the cities, as they have a better institutional (health, social services and education) supply.*
- 6. The health visitors obtain information on practical experience about people living with autism because during the education and the further trainings do not receive adequate special information to deal with the problem.*

4. TEST METHODS AND EQUIPMENT

In order to answer the research problem, as holistic as possible, I carried out two researches (a quantitative and a qualitative) closely related to each other. The quantitative data collection (research "A") contains the data of the National Autism Research carried out by the Jelenkutató Intézet (a research institute) that was implemented with a simple designed sampling by multi-stage method. During the research as the first step the Autistic Association and its member organizations were selected (with a total membership included in the sample, ie the query was comprehensive). As the second step the families were reached through them. 358 postal examinational questionnaires were sent; the interviewers visited 312 families. During my analysis the data of the samples between year 0-18 were used (**276 people**).

The questionnaire of research "A" was compiled by a group of experts with the leadership of Jelenkutató Intézet.

The postal **questionnaire** contained eight large parts after the filter question. The filter question was needed to find those who have a diagnosis of autism and put only them to the sample.

Topics outlined in the questionnaire were as follows:

- Diagnosis
- Problems experienced symptoms
- Use of institutions, obtaining information
- Health status in the family
- Family relationships, task sharing
- Employment, labor market situation
- Income, financial situation
- Demographics, household

In the case of closed questions the individual response options were numbered in the viewpoint of categorization. Questionnaires filled during research "A" were under general duty control. The data were recorded using the SPSS (Statistical Package for the Social Sciences) for Windows 17.0 statistical software package, using the methods of descriptive statistics. After the frequencies were determined measuring the relationship between the variables Chi-square test and logistic regression were used.

In the case of qualitative data collection, the expert mini-focus (research "B"), the primary goal was to give voice to the representatives of more areas so that they can share their opinion on autism. Compiling the groups the main aspect was to have both homogeneous and heterogeneous groups. In the light of the hypotheses the selection of a homogeneous group

was obvious.

A parent group and a group of health visitors were definitely needed. I was looking for those professionals to the heterogeneous group who encounter children with autism, and their families, are involved in their care, development and therapy. So, a special education teacher, a teacher, a psychiatrist and a health visitor were involved in the professional group. In case of **Research “B” an interview** outline development was taken place. The question catalog covers four major areas. They are as follows: opening, introductions, association, autism topic. The last part includes 7 main groups of questions and topics which lead from the concept of disability to the view of future of the children with autism.

5. RESULTS

Summarizing my research results and taking into consideration my hypothesis, we can conclude the followings.

5.1 At least 50% of the affected families experience exclusion from the society which was influenced by the following factors: settlement, education, age and marital status of the parent, income per capita, the labor market situation, the child's age and child's severity.

According to the research results, those families raising an autistic child are in a disadvantageous position. They have lower qualifications, they live in villages and due to these two factors it is harder for them to find a job. As a result, these parents have lower income but higher expenses as caring for an autistic child is expensive.

Examining the socio-demographic situation of families raising autistic children, we can say that parents filling out my questionnaire live mainly in the Central Hungary region, while the region of South Transdanubia is poorly represented. Families live mainly in towns. According to sex, the rate of boys is nearly four times higher than of the girls. The average age of parents is 38.5 years. Their marital status looks as follows: 73.4% raise their children together with their spouse. Caregivers have higher qualifications than the population average, the rate of parents with a college or university degree is 30%. Comparing the variables, it can be concluded that the number of divorces and separation significantly increase as the child gets older. The age of the parents influences their judgment on their health condition. The younger the parents are, the more energy they have and the more they evaluate their own health satisfactory.

36% of families believe that their child has to suffer discrimination including dismissal from school (35%), inappropriate attitude of the teachers (31%) and the denial of care in health care institutions (29%).

The appearance of social disadvantages is influenced by – besides the factors mentioned above – the job market situation of families. Among the parents who filled out the survey, 45% are working thus strengthening the financial situation of the family and their own self-esteem. However, 38% of parents have already been unemployed. These parents live mainly in villages. Those parents who are unemployed at the moment are very keen on finding a job but unfortunately they are quite often rejected as they would be able to have only a part-time job due to the health status of their child.

The analysis contained the financial situation of families; the average income per person (48.4%) is between 35-55.000 HUF. A significant relationship can be pointed out between the amount of income and the parents' judgment of their financial situation meaning that parents are able to describe their own financial situation as it is in reality. Finances of a family are strongly influenced by the extra costs of travel, medicine, child development sessions and child surveillance.

I have not found a significant connection between the severity of the child's health status and the current employment of parents however parents' unemployment is influenced by the health status of the child.

My first hypothesis is thus is being justified as the above mentioned demographic variables have an effect on segregation. More than 50% of concerned families experience social exclusion in one or more fields of life.

5.2 Families with children with autism are isolated, have fewer immediate social relations, and consequently left alone with a child in need of special care, they can count on only themselves and their spouse, which can affect the cohesion of the parent as well.

Besides social exclusion, the families raising an autistic child have to suffer segregation as well, in which however they play an active role. It is up to a family, if this will happen to them. Segregation can be traced in constrained social interaction too. My statement proved to be justified: social relations of families raising an autistic child are strongly limited. Due to the health status and attitude of the child, the parents lose their previous friends and they can rely on only the close family. Caring for the child means a great burden for family members who would have less time for each other. As a result, the small amount of time spent together becomes really precious and family programs done together have an important role. Parents can hope for help mainly and exclusively from family members, other children in the family or from the grandparents. However, we cannot find any relations between the family cohesion and parents' social life.

After examining the social life of families raising an autistic child, I came to the conclusion that only 4% of them have received and 12% has given help. Results might depend on the distance, lack of knowledge and segregation. However, it must be seen that these families are well-educated, members of organizations and associations and they still cannot keep in touch with each other. Giving help means also organizing discussions among the families, planning excursions or forming parent-groups.

As a health visitor, it is crucially important to prevent the segregation of these families and help them to find other families with the same situation. In case of some concerned families, the health visitor can be the organizer of a helping parent group.

5.3 Developmental anomalies, early signs of autism, are recognized by parents considered excessive by professionals or are not recognized by them, as a result 2-3 years are passed between the detection and diagnosis.

Both of my hypotheses proved to be right. It can be seen from my research results that in 76% of the cases the parents recognize the first symptoms. Besides, my second statement is justified too, that in 70-80% of the cases there is a minimum of two years between the detection of the symptoms and the diagnosis. It results in late development, while the possibility of early intervention cannot be made use of also. It would worsen the children's chances for integration. In most of the cases, the parents were the first who recognized the symptoms, while doctors and health visitors recognized autism in only 4 % of the cases.

It frequently happens that parents detect the symptoms early but according to the professionals' advice they wait which delays the start of development. After the symptoms are recognized, the diagnosis is made in a shorter or longer time. There is a long way from the first visit to the doctor until the diagnosis is made. The results show that the younger the child, the more characteristic the symptoms are, so it takes a shorter time to make the diagnosis. The older the child, the longer it takes to make the diagnosis. The reason for this might be the specificity of the symptoms. It is acceptable that the medical approach of autism varies over a wide range. It is hard to diagnose autism nevertheless it cannot be accepted as an explanation for the long and struggling waiting. In 60% of the cases, the parents did not agree with the first medical opinion and seeks for another doctor or committee.

As health visitors, it is our job to detect early symptoms or observe the child in case of parental request. If the health visitor recognize the signs of abnormal development, she reports it immediately to the GP or the child's own doctor. Health visitors should support further professional examinations too. Health visitors should help parents to find an institution where diagnostic procedures are carried out and help them to get to that place.

With close monitoring, in most of the cases it is possible to shorten the time until the diagnosis is made and the development is started. Besides, providing the parent with information, health visitors should support the family emotionally as well with paying attention and showing understanding.

Provided that the appropriate institution is found after early diagnosis the development

can be started. A health visitor can be that health professional who is continuously part of the everyday life of the family and gives information about the operation of institutions that provide early child development.

With these results in my hands, I thought about equality and equal chances in health care. Is the Hungarian health care accessible for everyone, free for everyone and is available at the same quality for everyone? The answer to this question is obviously – no.

Families included in this study is shown to have a higher level of education, better financial circumstances than the average Hungarian population. Consequently, it is thought-provoking to consider if the children of poorer and less-informed parents can reach the proper care without help. According to the revealed information it can be said that these children do not always receive the adequate care. The symptoms of the children involved in the research are the same as described in the literature, from which language skills, speech, behavior, sleep and eating disorders are highlighted in my analysis.

Agry behavior must be mentioned among behavioral disturbances (69%), the rage of applications (75%), stereotyped movements (83%), compulsive habits. "Embarrassing behavior in front of others" is not typical among the participants of the study and self-harm neither. The behavioral disturbances have to be mentioned in the angry behavior (69%), the rage of applications (75%), stereotyped movements (83%), compulsive habits. The study participants did not feature among the "embarrassing behavior in front of others" and self-harm either.

Examining the self-suportiveness of the children with autism in certain areas (grooming, dressing, eating) we can conclude that they require little assistance. On average, they are 1-2 years behind their healthy counterparts in the fields of necessities mentioned above. However, these functions can be developed well if there is no other associated disease.

At the daily life of the parent it means that she can not leave her child alone at home in the street, or at transport. They should have some level of supervision, which is defined by the severity of their condition. There is a great need of care institutions, living or residential, that are a little relief to families, providing them the opportunity to find jobs.

5.4 At the families involved in the study the severity assessment is adversely affected by the following factors: the socio-demographic status of the family, their age, state of health of family members, institutional care.

Subjective assessment of severity was based on the parents' opinion according to them very serious (13.4%), moderate (51.1%) and mild (35.3%) categories can be distinguished.

Our fourth hypothesis was confirmed, as the perception of the severity of the condition is determined significantly by the following factors increasing the chances of falling into a serious category. The comparison of variables shows that the younger the parent is the more likely to consider her child's problem as minor.

The child's condition adversely affects the parent's perception of their own health, severe physical symptoms cause psychological or mental discomfort to parents, which can have an affect on the parent's subjective well-existence as well. The older child is being tested the more likely to have behavior problems and speech disorders.

Examining the relationship between the variables with logistic regression, we can see that considering the state of autism as sever is significantly increased by parental age, parental education level, and health status. The child's behavior, and their independence in the field of needs have not only an effect on the assessment of the state but they are dominant in it; performance was 13.6%, and autonomy 11.7%.

5.5 I assume that families affected with autism live primarily in the Central Hungarian Region and in the cities, as they have a better institutional (health, social services and education) supply.

Institutional care has a major part in the everyday lives of the families with children with autism. The 90% of children involved in the study attend some kind of institution. Examining the institution types colorful picture can be seen about the supply system. Institutional change occurs often, because the parents are looking for the most appropriate institution for children with special needs. Children spend different length of time in different types of institutions depending on their age and condition.

The quality of life for families is significantly affected by traveling to the institution the burden of travel. Half of the children attend an institution within 30 minutes while 10% of them spend more than an hour with traveling. These distances are usually forced to take by car or on foot because the majority of the children with autism are unable to use public transport. The most common reason for that is that they do not like the crowds, as well as behavioral problems can have been multiplied in a new situation. The 90% of parents surveyed are satisfied with the institution chosen for their children completely or mostly, in case of educational program, equipment and the cooperation of parents, children and teachers. The only shortcoming mentioned by the parents is the special skills of the teacher. The children attend the institutions appropriate for their age starting with a 1-2 years 'delay'.

My hypothesis is partially proven, statements about the regional location of the families,

and town-structure have been obtained from the data. The type of institution has a direct affect on the amount of time spent by parents with their child at home, since the less time the child spends in the institution (also influenced by their condition), the more time is left for home improvement and programs together. However, this can affect the employment of the parents, the less time the child spends in school, the more likely the parent can take only part-time.

Based on this, it can be stated that a well-established nationwide day care home, or weekly residential institutions are needed, their development and the extension of the number of professionals are necessary. With the help of these institutions, the parents will be able to apply for a job that can improve their financial situation and their relationships can expand. Further advantage of the children getting the appropriate development according to their state is to meet their peers. Besides all these positive factors they will remain in the family, the emotional bond between parent and child is strengthen, and it can be beneficial to the harmony of the family.

5.6 The nurses obtain information on practical experience about people living with autism because they do not receive adequate special knowledge during the education and further trainings to deal with the problem.

The answer my last hypothesis was based on the qualitative data collection. Parents regard their relationship with their health visitor good if it is regular. It happens in many cases that the nurse is unable to assist the family in caring for the child and their development. This is due to the fact, according to the health visitors, that college does not supply sufficient knowledge, they hear only tangentially on the issue of autism. The current network plan includes nursing care for people with disabilities only as a non-compulsory course, from which there are only 2 lessons about the doctrine of autism symptoms. During practice they also meet rarely autistic children.

So, most of the health visitors face the issue of autism only during their work for the first time and they are on their own to solve this problem. Presumably, this is the cause of visiting these families less frequently because they can not provide specific help for the parents. On the basis of these, it can be said that there are a lot of unsolved challenges in this area of the health visitor care.

6. CONCLUSION

The application of M-Chat questionnaire mentioned in the professional is set forth in the National Strategy for Autism, as a potential screening test, which appeared in 2008.

The Strategy mentions the following as the main objective of an early screening: "The early diagnosis leads to a targeted early intervention and it has such an impact on children with autism that they are more likely to participate in supported integration; a major improvement can be expected in terms of their skills, their quality of life. The early detection demands pediatricians and health visitors to be aware of both the early signs of autism spectrum disorders and the appropriate tasks about them (e.g. appropriate specialist management). The task is to develop screening tests and launch trainings for primary care workers.

Our goal to achieve tasks as set out in the Strategy is awaiting for us in the future; further assistance can be provided by SROP 6.1.4 published in June 2012, launched from 1 October. Early Childhood (0-7 years) priority project. It is aimed to support the healthy start of the lives of the children between the age of 0-7 and their successful beginning at schools by monitoring children's development, facilitating their inherent skills, exploring the developmental risk factors and filtering the children having different development indicators in the primary health care.

The aim of the project is to design integrated, up-to-date skills and methods that increase the efficiency of the work of primary care professionals and the consciousness of the parents in connection with their children's development. The proposal set out the most important tasks in line with the results described in this thesis and with the proposal of the professional protocol. These are the following: to monitor progress, identify the different development, the recognition of risk factors and make the appointment and renewal of prevention.

Our goal with the obtained results is to develop a care protocol, where early intervention is an important part and on the basis of this constructing a nationwide "first filter" condition-level system, where health visitors are active participants in its implementation.

7. SUMMARY

Today we reached the point, when autism is not just another category of disabilities, but a specific group mentioned with its own ICD code. At the beginning of my research only a few specialists were familiar with autism it is now becoming a known clinical picture. Because of the influence of the CSOs the knowledge of the members of society is increased gradually, April 2 became the World Day of autism so this disease becomes more widely known. The utmost importance of the problem is shown by the fact that from September 2012-n BGGYTF (Hungarian special education college) the specialization in autism can be chosen by special education teacher students, which gives hope that the care of the increasing number of diagnosed autistic children will be improved in the future.

As health visitors we can get acquainted with the daily lives of children, the problems of the families and their "survival" techniques from the results of the research; the causes of prejudices and their incidence rates become visible. In all of these we can stand as a support beside the parents ensuring them an understanding and accepting environment which can not be experienced at many of the health, social care and education. Our main task as prevention experts is still to be the first to recognize the symptoms.

The professional guidelines mentioned above try to contribute to this, which is attached to the questionnaire which has been used in several Western European countries. This questionnaire is currently only available in Hungarian translation, its adaptation to the domestic situation has not happened yet.

My other goals include early intervention, by adapting the questionnaire, and its full implementation of the nursing practice.

PUBLICATIONS

RELATED PUBLICATIONS

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Tobak Orsolya: A fogyatékosok gondozásának egészségügyi és pedagógiai dimenziói a védőnői tevékenység tükrében

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