

Family – Health – Disease

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Grażyna Dębska, Jerzy Jaśkiewicz

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Wprowadzenie *Introduction*

We hereby submit the monograph entitled Family - Health - Disease. This publication includes opinion and research papers written by authors with academic backgrounds from the Czech Republic, Slovakia and Poland. The monograph consists of 14 chapters and the order of them refers to the relationship between the family and the health of its members. The first seven texts concern children's health problems. The next two concern widely defined issues of nutrition and adult nursing. The next four discuss health issues of the elderly, while the last describes the dilemma of bereaved family members who have to decide about organ donation.

The individual chapters show different aspects of family participation in the treatment and care of children, the elderly, the chronically ill, and the disabled. The discussed topics are a part of the wider issue of social medicine. A very important issue is the interdisciplinary problem of interaction between health and illness and their influence on the family, which is on one hand embedded in medical science, while on the other hand it refers to the social sciences, especially family sociology, psychology, pedagogy, and also social policy to some extent.

The authors of the monograph also discuss the issue of life quality of the elderly living in domestic environments and the health and social problems they face. The authors also analyse the role of nurses in promoting health, such as immunisation, rational nutrition, and ethical aspects such as the screening of newborns.

This monograph is addressed to all who work or want to work with families and support them in the difficult challenges posed by disease. The authors hope the monograph will increase understanding and familiarity with the health problems of relatives.

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Postawy rodziców wobec obowiązkowych szczepień dzieci *Parental attitudes towards children's vaccination*

Streszczenie

Cel: Mimo jednoznacznego wpływu szczepień na zmniejszenie występowania chorób, które jeszcze do niedawna były przyczyną wielu zgonów, coraz częściej spotykamy się z odmową szczepienia dzieci przez rodziców. Przyczyną są obawy poważnych komplikacji, jak na przykład: autyzm, cukrzyca. Celem pracy było zbadanie poziomu wiedzy i postaw rodziców w odniesieniu do obowiązkowych szczepień dzieci oraz czy występują różnice w odniesieniu do płci rodzica.

Metody: W badaniach wykorzystano kwestionariusz ankiety własnej konstrukcji. Badania przeprowadzono wśród 170 rodziców dzieci pierwszych klas szkoły podstawowej. Współzależności zmiennych zostały zweryfikowane przez metody statystyczne.

Wyniki: W toku przeprowadzonych badań stwierdzono, że szczepienie jako obowiązek uznaje 50,7% rodziców, z tego 47,2% stwierdziło, że ich wiedza o zaletach szczepienia dla społeczności jest niedostateczna, 61,3% rodziców odpowiedziało, że źródłem informacji był lekarz pediatra. Tylko 34,5% powiedziało, że się spotkało z negatywnymi opiniami na temat szczepień, 40,8% rodziców wyrażało wątpliwości przy podejmowaniu decyzji o konieczności poddania dziecka szczepieniu.

Zakończenie: Wyniki badań jednoznacznie pokazały, że istnieje potrzeba aby lekarze oraz pielęgniarki podstawowej opieki zdrowotnej znaleźli czas na przekazywanie rodzicom naukowo potwierdzonych informacji na temat najnowszych trendów w szczepieniach.

Słowa kluczowe: kalendarz szczepień, szczepienia, przeciwnicy szczepień

Summary

Introduction and objective: Despite the obvious merits of immunisation on the incidence of fatal diseases, it is increasingly common that parents refuse to vaccinate their children. This reluctance is due to the risk of severe complications such as autism or diabetes mellitus. Physicians warn against

the collective immunity decrease that may be the result of such parental attitudes. The objective of this survey was to find out the opinions, knowledge and attitudes of parents towards compulsory vaccination of children and their dependence on the gender of the parent.

Methods: The research was performed in the form of a non-standard personal questionnaire. Within the survey, the authors distributed 170 questionnaires to the parents of primary school children. Correlation of variables was verified by statistic methods.

Results: The results showed that 50.7% of the parents consider vaccination necessary, even though 47.2% stated that their knowledge about the advantages of vaccination and its societal value was insufficient. 61.3% of the parents specified paediatricians as their primary source of information. Anti-vaccination opinions induced doubts in 40.8% of parents when making decisions regarding the necessity to have their child vaccinated, whereas only 34.5% stated that they had encountered these opinions.

Conclusion: It is necessary for doctors and primary contact nurses to take sufficient time to properly educate parents and provide them with scientifically substantiated information on the latest trends in immunisation.

Key words: vaccination calendar of the Slovak Republic, vaccination, vaccination opponents

Introduction

Humankind has been endangered by infectious diseases and epidemics since ancient times. It is known from preserved historical sources that ancient civilisations in China, India, Greece and Rome tried to prevent infectious illnesses by procedures that are similar to current vaccination. The content of smallpox pustules was taken from the ill and put on the skin of healthy individuals, or tampons with ground variolar crusts were put into children's noses and they were dressed in infected shirts. These measures, defined as *variolisation*, led to artificially induced infection and the further spread of disease. Death risk was high and these methods did not lead to any reduction in disease. *The first variolisation in Europe* was performed by Doctor Maitland at the British royal court in 1721. In the same year in Prešov, a county doctor called Ján Adam Reyman used variolisation for the first time in continental Europe. Variolisation was replaced by *vaccination* (Kapšová, Hrabovská, 2010) after the invention of Englishman E. Jenner in 1796.

For the past two centuries since the invention of Edward Jenner, immunisation has progressed considerably and active protection against infective illnesses has become a common part of life (Kovács, 2012). The principle of vaccination is the administration of an antigen of infectious agents to elicit an immune response similar to infection, but free of disease. Vaccinations stimulate the immune system to respond. This is known as active immunisation. The direct administration of preparations containing specific immunoglobulin antibodies of human or animal origin is known as passive immunisation (Dluholucký, 2009). According to Malovecká et al. (2014), vaccination presents one of the most efficient and effective methods of preventing infectious diseases and has a better

impact on the occurrence of infectious diseases than the development and usage of antibiotics. For this reason, most countries are controlled by an immunisation program guided by the recommendations of the World Health Organisation. A well-designed immunisation program is a reflection of the quality and functioning of the health system of a given country.

In parallel with the effort to eradicate infectious diseases by vaccination, the 'anti-vaccination movement' is growing strong. Its activists use pseudo-scientific argumentation or real facts, but displaced from the overall context.

Some parents refuse to have their children vaccinated due to concerns about vaccine safety and severe illnesses that they attribute to vaccination. Kuková and Košťálová (2007) call attention to the fact that inoculations are administered to infants and children in the period when certain illnesses are clinically demonstrated. Proof of causal relation requires symptoms to occur more frequently in vaccinated children than non-vaccinated children of similar age and place of habitation. Questioning the need for vaccination may lead to outbreaks of epidemics of almost forgotten diseases. Vaccination in some countries forms part of the collective immunity of the country's population and parents who reject vaccines are summoned before a committee made up of doctors, psychologists, lawyers, sociologists and representatives of insurance companies. Such an approach is a sign of concern about the protection of citizens (Nováková, 2007). According to Kovács (2012), doctors' awareness of the benefits of vaccination and their ability to respond adequately to parents' concerns and doubts are a key method of reducing refusal of vaccinations.

The main *survey objective* was to find the opinions, knowledge and attitudes of parents towards compulsory vaccination of children.

In order to achieve the main objective, we set the following partial objectives:

- Find parents' opinions on compulsory vaccination of their children.
- Find parents' satisfaction with the current vaccination calendar in the SR.
- Find parents' interest in non-compulsory vaccination.
- Check parents' knowledge related to the adverse effects of vaccination.
- Ascertain the most common sources of vaccination information for parents.
- Find out up to what extent anti-vaccination proponents influence the decision making of parents.

Methodology

In order to find the necessary data, we used an *empirical questionnaire method* that focused on analysing parent's attitudes, opinions and awareness related to vaccination of their children. Using a combination of methods of choice, we asked directors of elementary schools in Zvolen for permission to distribute the questionnaire to children's parents. Questionnaires were distributed by class teachers in the months of December 2011–January 2012 to the parents of first

year children in basic schools. 170 parents were addressed in six randomly selected basic schools in Zvolen. We questioned parents of even numbered children in an alphabetical list using a systematic sampling method. Questionnaires were distributed in such a manner that we would gain homogeneous representation of men and women. The high return rate of the questionnaire, 88% ($n = 150$) may be attributed to the fact that the questionnaires were distributed and collected from parents by form teachers. 8 questionnaires were rejected due to incomplete data. Statistically, 84% ($n = 142$) of the questionnaires were evaluated. The core of the questionnaire consisted of 20 items (12 closed, 7 half-open, and 1 open) and four categorising items that served as a demographic profile of the survey sample. The demographic was 50.7% ($n = 72$) female and 49.3% ($n = 70$) male, with most having completed secondary education (59.7% of women and 48.6% of men). Medical education was specified by 9.7% ($n = 7$) of women and 5.7% ($n = 4$) of men. The most represented age category of parents was 31–40 years (73.6% of women and 57.1% of men). More than 50% of parents stated that they had two children. The questionnaire items mapped the parents' knowledge of the valid vaccination calendar and vaccination justification in the present period or their interest in vaccination against certain diseases above the extent of compulsory vaccination. Parents' sources of information and their experiences with adverse vaccination effects were also investigated. The final items on the questionnaire focused on the impact of anti-vaccination attitudes on parents' vaccination decision making.

Results

For the empirical data processing, we used MS Office Excel 2007 and MS Office Word 2007 software. The aim of our study was to describe parents' attitudes to the vaccination of children. We used descriptive statistics as a statistic method. We did not examine relationships between variables. We present our results in absolute numbers and relative count.

Within the survey group, we found a high vaccination rate of children (Table 1).

Table 1. Children's immunisation according to the vaccination calendar of the SR

Vaccinated child	Women		Men		Total	
	N	Relative count	N	Relative count	N	Relative count
Yes	70	97,2%	64	91,4%	134	94,4%
No	1	1,4%	2	2,9%	3	2,1%
I do not know	1	1,4%	4	5,7%	5	3,5%
Total	72	100,0%	70	100,0%	142	100,0%

70 women (97.2%) stated that their child is vaccinated according to the vaccination calendar. Similarly, 64 (91.4%) of men also responded positively. Of the three respondents who responded negatively, two had refused vaccination against pneumococcus and one against measles, mumps and rubella.

Table 2 shows parents' *views on vaccinations classified within the vaccination calendar of children in the SR*. 10 (13.9%) women and 3 men (4.3%) have a complete overview of vaccinations. 28 women (38.9%) and 13 men (18.6%) responded that they know approximately when and against what their child is supposed to be vaccinated, but they do not have the vaccination calendar available. 32 women (22.53%) and 48 men (33.80%) stated that they do not have any overview of their child's vaccinations and gain information about vaccinations from paediatricians after vaccination. Only 2.8% (n = 4) of the parents stated that they are not interested in this matter.

Table 2. Respondents' vaccination calendar overview

Overview on vaccinations in the vaccination calendar	Women	% expression	Men	% expression	Total	% expression
	Count		Count		Count	
I know it exactly. I have the vaccination calendar available	10	13,9%	3	4,3%	13	9,2%
I know it roughly. I do not have the vaccination calendar available	28	38,9%	13	18,6%	41	28,9%
I have no overview. I gain information from paediatrician in advance (e.g. during consultation)	19	26,4%	31	44,3%	50	35,2%
I have no overview. I gain continuous information from paediatrician (e.g. in the form of invitation for vaccination)	13	18,1%	16	22,9%	29	20,4%
I have no overview. I gain information from the paediatrician after the vaccination	0	0,0%	1	1,4%	1	0,7%
I have no overview and I am not interested	2	2,8%	2	2,9%	4	2,8%
Different answer.	0	0,0%	4	5,7%	0	0,0%
Total	72	100,0%	70	100,0%	142	100,0%

As many as 77.8% (n = 56) of women and 64.3% (n = 45) of men believe that only some vaccinations are obligatory. 4.9% (n = 7) of the parents do not consider any vaccination to be compulsory (Table 3).

Table 3. Parents' overview on vaccination liability

Vaccination liability	Women	%	Men	%	Total	%
	Count	expression	Count	expression	Count	expression
All vaccinations are compulsory	10	13,9%	14	20,0%	24	16,9%
Only some vaccinations are compulsory	56	77,8%	45	64,3%	101	71,1%
No vaccination is obligatory	2	2,8%	5	7,1%	7	4,9%
I do not know	4	5,6%	6	8,6%	10	7,0%
Total	72	100,0%	70	100,0%	142	100,0%

40 women (55.6%) agree with absolute necessity of vaccination according to the current vaccination calendar. 36 men (51.4%) think that it is only necessary to be vaccinated against certain diseases (Table 4). 28 respondents (19.7%) would extend the vaccination calendar to include cervical cancer, hepatitis A and rotaviruses.

Table 4. Respondents' overview on vaccination necessity

Vaccination necessity	Women	%	Men	%	Total	%
	Count	expression	Count	expression	Count	expression
Yes	40	55,6%	32	45,7%	72	50,7%
Not against certain illnesses	31	43,1%	36	51,4%	67	47,2%
Not at all	1	1,4%	2	2,9%	3	2,1%
Total	72	100,0%	70	100,0%	142	100,0%

43.1% (n = 31) of women are satisfied with their knowledge regarding the adverse effects of vaccination, whereas partial knowledge is specified by 47.2% (n = 34) of women. Only 20% (n = 14) of men stated their awareness of the adverse effects of vaccination (Table 5). In real life, 24.6% (n = 35) of respondents had seen an undesirable reaction, 21.1% (n = 30) of respondents did not know how to respond to this item. The most frequent responses were increased

temperature TT, 62.9% (n = 22) and a swollen, reddish reaction to the needle, 48.6% (n = 17). Despite undesirable reactions, 77.1% (n = 27) of respondents did not change their opinion on vaccination.

Table 5. Knowledge of adverse effects of vaccination

Knowledge of vaccination adverse effects	Women	% expression	Men	% expression	Total	% expression
	Count		Count		Count	
Yes	31	43,1%	14	20,0%	45	31,7%
No	7	9,7%	22	31,4%	29	20,4%
Partially	34	47,2%	34	48,6%	68	47,9%
Total	72	100,0%	70	100,0%	142	100,0%

51.4% (n = 37) of women consider their knowledge regarding vaccination to be insufficient and 45.7% (n = 32) of men do not even consider the quality of their knowledge. 61.3% (n = 87) of respondents indicated their paediatrician was their primary source of information. 27.5% (n = 39) mentioned radio and television and 20.4% (29) indicated that friends were their primary source.

According to the subjective expression of the respondents, 42.3% (n = 60) of them have good knowledge on the advantages of vaccination for the recipient and society, 47.2% (n = 67) of them are not quite sure about their knowledge.

Recently, more and more information about the risks of vaccination and the refusal of parents has emerged. In our survey group, 34.5% (n = 49) of respondents had encountered the opinions of anti-vaccination activists. In Table 6, we list how this influenced their opinions on vaccination.

Table 6. Parents' opinions on vaccination after meeting anti-vaccination activists

Opinion on vaccination after activists' influence	Women	% expression	Men	% expression	Total	% expression
	Count		Count		Count	
No, I do not doubt the advantages of vaccination.	17	63,0%	12	54,5%	29	59,2%
Yes, it brought doubts into my decision making	10	37,0%	10	45,5%	20	40,8%

Discussion

The results of our survey helped us form an overview of some opinions and attitudes of parents related to immunisation of their children. We find it positive that despite the increasing activity of various opponents of vaccination; only 3 (2.1%) parents refused some compulsory vaccinations due to concerns about severe adverse complications. In a similarly focused survey, the authors Malovecká et al. (2014) list 100% vaccination rate in a group of 240 children.

Compulsory vaccination is the most frequent reason for visiting a paediatrician in the first year of a child's life. Leaflets and posters about vaccinations are available in most outpatient departments, and some maternity wards provide promotional materials to mothers related to everything they need to know about childcare in the first year of life. It is therefore highly surprising that only 10 (13.9%) women and 3 men (4.3%) have a complete overview of vaccination and the current vaccination schedule. 32 women (22.53%) and 48 men (33.80%) specified that they do not have any overview of their child's vaccinations and obtain information from their paediatrician. Only 36 (25.4%) of those questioned consider their knowledge of the given issue to be sufficient and 44 (31%) did not think about it at all. The survey conclusions of the authors Malovecká et al. (2014) confirmed the correlation between the variables of age, sex, education, and parents' opinions on their knowledge and awareness related to immunisation.

Vaccination, similarly to any other medication, may be associated with adverse effects. Most of these are of a moderate and temporary nature and their occurrence varies depending on the vaccine type. Concerning local reactions, the most frequent are swelling, erythema and pain in the location after needle application. Other symptoms included increased temperature, vomiting, diarrhoea, and lymph-node swelling. In our survey, 92 (64.8%) respondents knew about the possibility of complications, but only 45 (31.7%) could name the most frequent. The most common reaction the respondents had experienced in their child was increased temperature (62.9%), swelling and erythema (48.6%) and pain (42.9%). In 27 (77.1%) parents, the occurrence of complications did not negatively influence their opinion on vaccinations.

From the doctors' perspective, we consider it obvious to inform parents about possible reactions and their severity, as well as management methods. Šupínová, Virgulová (2012) consider that parents' awareness could be enhanced by establishing practical post of community nurses and improving communication between patients and outpatient department nurses.

In our survey group, 80 (56.3%) respondents were informed by a doctor, while 33 (23.2%) respondents reported sporadic education. Insufficient knowledge provision from doctors may lead to searching for necessary information in various parental forums where parents who have had negative experiences are most likely to contribute. Many of these contributors directly associate illness

in their children with vaccination. Therefore, it is understandable that parents start doubting the safety of vaccinations. According to the chairwoman of the Slovak Epidemiologic and Vaccinology Association, Zuzana Krištúfková, there are a growing number of parents in Slovakia who have decided not to have their child vaccinated for fear of adverse effects. "Despite the proof that this relation was repeatedly and reliably rebutted by relevant studies, it remains a frequent argument of parents." The fact remains that vaccination is associated with reactions that are unpleasant and may require medication or a short stay in hospital.

The most commonly stated source of information was paediatricians. In both sexes, radio and television were in second place: 34.7% of women ($n = 25$) and 20% of men ($n = 14$). Only 14.8% of respondents ($n = 21$) of both sexes stated nurses as a source of information. Regarding the increasing number of nurses completing higher education, we incline to the opinion of Šupínová and Virgulová that their knowledge potential and erudite approach may also be used in outpatient departments to provide quality education or educational materials for parents.

Obligatory vaccination has increased collective immunity, which has immense society-wide significance, from the health protection of society to economic advantages. The decrease in infectious diseases in our country may lead to the belief that vaccination is not necessary. Diseases against which vaccination is applied do not generally occur; therefore, the fear of vaccination naturally exceeds the fear of disease. People do not realize that we should thank elaborated models of vaccination for the absence or only minimum occurrence of infectious illnesses (Malovecká et al., 2014). However, the risk of their spread is becoming real due to the worldwide migration of people. In addition, if the vaccination rate falls lower than 95%, this creates an opportunity for repeated infections to spread, thereby endangering young children, elderly people and adults with decreased immunity. Refusal of vaccination is becoming not only an issue affecting the individual, but also the whole of society. Following our survey, 60 (42.3%) respondents know of the societal significance of vaccination according to their subjective opinion. This relatively low percentage signals the need for better edification. This is also important due to ever-growing pressure from various opponents of vaccination. Even though a relatively low number of respondents, 49 (34.5%), had encountered their opinions, we think that consistent and comprehensive argumentation is needed from professionals in order to eliminate doubts related to the importance, efficiency and safety of vaccination.

Conclusion

Immunisation is one of the greatest achievements of medicine. Just as with any other medical intervention, vaccination is also related to the occurrence of severe complications. Increased concerns on the side of parents regarding vac-

cination may be attributed to the fact that when small children are involved, any disease causes high emotional stress. Parents' fears and concerns cannot be underestimated. A reasonable solution is a perceptive and empathic approach from paediatricians, and in individual cases there should be the possibility of consultations with vaccinology physicians. The results of our survey also show the need for edification focused on increasing the societal importance of vaccination related to the globalisation and increased migration of people.

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Radzenie sobie z sytuacjami trudnymi w rodzinie dziecka przewlekle chorego *Coping with stress in families with a chronically ill child*

Streszczenie

Wstęp: Punktem wyjścia dla napisania niniejszej pracy był wzrost liczby występowania chorób przewlekłych u dzieci; choroby te z kolei przyczyniają się do wzrostu obciążenia w rodzinie. W niniejszej pracy poddano analizie radzenie sobie z tego rodzaju obciążeniem w rodzinie.

Cele: Celem pracy było określenie, w jakim stopniu przewlekła choroba dziecka obciąża rodzinę oraz w jaki sposób i za pomocą jakich środków rodzina radzi sobie z tego rodzaju obciążeniem.

Metody i materiał: Przeprowadzono badania ilościowe, przy czym zastosowano kwestionariusz, który dostarczono do przychodni gastroenterologicznej i dziecięcej oraz do agencji opieki domowej. Próbkę badawczą stanowiło 100 respondentów - rodziców dzieci chronicznie chorych.

Wnioski: Okazało się, że istnieje znacząca zależność między statusem społeczno-ekonomicznym rodziny a miarą obciążenia w rodzinie. Co więcej, okazało się, że w uzyskiwaniu informacji na temat przewlekłej choroby dziecka, rodzina bardziej preferuje informacje pochodzące od pracowników służby zdrowia niż informacje zasięgnięte z innych źródeł. Rodziny, które szukają pomocy ze strony stowarzyszeń obywatelskich, radzą sobie z obciążeniem bardziej skutecznie niż rodziny, które izolują się od społeczeństwa. W badaniach jednak nie udało nam się potwierdzić hipotezy, że istnieje zależność między współpracą z personelem medycznym i radzeniem sobie z obciążaniem w rodzinach z dzieckiem przewlekle chorym.

Zakończenie: W pracy przedstawiono teoretyczne aspekty zdrowia i choroby, jak również aspekty radzenia sobie z obciążeniem w rodzinie z dzieckiem przewlekle chorym. W ramach badań próbowano określić, jak w praktyce rodziny radzą sobie z obciążeniem związanym z przewlekłą chorobą dziecka. Zaproponowaliśmy zalecenia, które należałoby wprowadzić w życie. Niniejsze badania nie były obszerne, ale pozwoliły sformułować kilka wniosków, które wskazują obszary, wymagające szerszych badań w przyszłości.

Słowa kluczowe: dziecko przewlekle chore, radzenie sobie z obciążeniem, rodzina, pracownicy służby zdrowia, stowarzyszenia obywatelskie

Abstract:

Background: The increasing number of chronic diseases created the foundation for this thesis because of the stress these diseases cause in families. This thesis analyses how families cope with this stress.

Aims: The aim of the thesis was to determine to what extent chronic disease of a child changes families and how they cope with this change.

Methods and material: We conducted quantitative research using a questionnaire which we distributed to gastroenterologic and paediatric outpatient departments and to home nursing care agencies. The 100 respondents which comprised our research sample consisted of parents of chronically ill children.

Results: We found that there is a considerable relation between socio-economic status and the measure of stress in a family. Furthermore, we discovered that when a family collects information about a child's chronic disease, parents give priority to information from medical staff over information from other sources. When families turn to civil associations, they cope with stress more easily than families without support. We could not confirm whether there is a relation between cooperation with healthcare professionals and more effective coping with stress in the family.

Conclusion: In our thesis we described theoretical aspects of health and disease and how families cope with stress. In the experimental part, we tried to find out how families cope with stress caused by chronic disease of a child in practice. We proposed recommendations for practice. Our research was not extensive; however, we were able to formulate some important conclusions which should be developed in the future.

Key words: chronically ill child, coping with stress, family, healthcare professionals, civil organisation

Introduction

Chronic diseases affect approximately 7-10% of the child population [1]. The causes are global trends and the source of this problem largely lies in lifestyle changes.

Chronic disease in a child can often be a serious issue for the whole family and a heavy burden which changes the behaviour of the whole family. Family stress can be caused not only by discovering that a child is chronically ill, but also by other factors such as financial load, the overall attitude in the surrounding environment, or inclusion of the child in everyday activities. A family is often not able to cope with this problem by itself and seeks resources to help manage the stress.

Subjective and objective life factors of a chronically ill child

The factors influencing the life of a chronically ill child can be divided into subjective and objective. Some can be changed and some cannot; therefore, we can only compensate for them or eliminate negative impacts. At the same time, we need to note that the majority of the following factors or aspects overlap or have combined character or consequences.

Subjective factors influencing the life of a chronically ill child include:

- health condition and the resulting limitations, i.e. chronic diseases or permanent disabilities which cannot be completely treated with therapy and which essentially influence the perception, mobility, communication, understanding, emotionality, and behaviour of a person;
- characteristic features of a person, determined by a complex of native predispositions and affected by learning (influence of family, school, community and society);
- self-evaluation in relation to health disadvantages and real opportunities to achieve life goals;
- ability to manage unfavourable life situations; influenced by character features, will and motivational aspects of personality;
- external influences on which an individual is dependent, i.e. family or activity background, immediate social environment, and community [2].

The aforementioned aspects have a great influence on the life of a chronically ill child and determine the success of the socialisation process; however, this can be influenced only to a certain extent.

Objective factors which depend less on the personality of a chronically ill child include:

- social conscience, attitudes to the disabled;
- state of the environment;
- social policy, the attitude of the state towards disadvantaged people;
- education policy; the level of education provision and professional education of chronically ill people;
- employment policy, i.e. the will and possibility to create jobs and secure the utilisation of skills of disadvantaged people;
- social services which adequately, ethically and worthily satisfy the needs of chronically ill people and compensate for limitations which are a result of particular types of disability.

For those socially disadvantaged due to chronic disease, continuous care should have a balanced, qualified, and sensitive influence on the aforementioned determinants in order to remedy social relations and attitudes and limit the overall negative impact on the social target, a minority group [2].

Reaction and adaptation of a family to a child's chronic disease

A disabled child is very stressful for parents. The way in which parents cope with the situation and how they react to it codetermines to what extent the disability is a burden for the child.

A child's health is of significant value to parents and disability is perceived as an unfair threat. The substantial difference between the reality (the disability)

and the standard expectation of healthy development of the child leads to great stress that stimulates various defence reactions [3]. In such situations, parents react with a combination of differing emotions.

A child's disease is a significant stress situation for parents. It is also perceived as an unfair threat to an important value: the child's health. Heavy stress stimulates various defence reactions, especially anxiety, dismay (threat to the child), anger (realisation of the loss, which is perceived as unjust), sadness or depression (resulting from being aware of limited opportunities to protect the child). In most parents, the disease stimulates active defence reactions. Parents refuse to accept the situation and fight to heal the child, or at least an improvement in the child's health condition. These activities often have an insignificant influence on the child's state, but help the parents to cope with the charge.

The period when the parents of a chronically ill child are confronted with reality can be described as a crisis of parental identity [4]. This is a phase of adverse reaction to the dissimilarity of their child and his prospects.

The adaptation process can be theoretically perceived as a resilience process. The resilience of an individual and the family system is not static, but evolves dynamically. The notion "resilience" is translated as "indomitability, tenacity". Hartl and Hartlová [5] describe resilience as a complex of agents which help the individual to survive in adverse conditions such as stress, loneliness, a dysfunctional family, severe illness etc.

Within a family we can define resilience as the ability of a family to constructively solve problems and respond together to life challenges within the dynamics of family relationships with the use of internal and external resources [6].

Strategies for managing stress in the family

Each individual manages stress differently. This always depends on various factors such as situation, environment, social support, and the physical and psychological condition of the individual. Family members should help each other since the stress of one member affects others. Healthy family behaviour can be defined as the ability to effectively manage demanding stressful life situations and adapt to changes [7]. This is the capability of a family to adapt to stress and find a new balance. The stress level depends on the seriousness and intensity of the stressor. It is important how the stressor (situation) is perceived by the family, the resources of the family and the psychological and physical condition of family members during the stressful situation [8]. This state can be negative (distress) when a family perceives disharmony and imbalance as unpleasant, chaotic and threatening; or positive (eustress) when the accrued imbalance is perceived as a challenge that the family needs to accept and solve [7].

The crisis experienced by a family can be divided in transitory (foreseeable) and intransitory (unforeseeable or catastrophic). During an intransitory crisis,

a family needs to cope with and adjust to events such as loss of employment, divorce, serious disease, or death of a family member. Events and situations which negatively intervene in family life are called paranormative. On the contrary, events with positive character are called normative, such as weddings, childbirth, start of school, birth of a grandchild, retirement etc. [9].

We need to be aware of the fact that a family as a group of individuals and relationships is at any time affected by each of its members. A change in one member necessarily causes change in others and as a result changes the family as a unit [10].

We assume that all families have strengths and skills that can be developed (social support network, appropriate communication in family, how a family feels about its situation). The so-called strength-based approach focuses on the strengths of a family. When a family learns new stress management strategies, it supports the well-being of individual members and the overall family atmosphere [7].

Stress management strategies are used by families to acquire and utilise family resistance resources. These strategies are dynamic processes focused achieving balance in a family. McCubbin, Thompson, McCubbin [11] classify the strategies in the following way:

- strategies focused on decreasing the family demands;
- strategies focused on gathering further resources;
- strategies focused on continuous tension management;
- strategies focused on evaluation of the situation and understanding its significance.

The comprehensive management style of the family according to Sobotkova [11] is influenced by the following factors:

- character of the situation or event;
- perceived threat to family relationships or goals;
- resources available to the family;
- previous experience with challenging life situations.

Based on the type of situation, Křivohlavý [2] introduces the following strategies of managing difficult life situations:

- conditional and unconditional strategies;
- static and dynamic (changing over time) strategies;
- simple and complex strategies.

Two types of management strategies of life situations were identified 25 years ago:

- strategies aimed at solving problems which arise due to illness;
- strategies aimed at coping with emotional states caused by illness.

A strategy aimed at solving a problem means proactive task execution and an effort to resolve the actual situation, i.e. treating the disease or eliminating the cause of fear and habits that worsen the overall state of a child.

A strategy aimed at coping with the emotional state caused by illness means influencing the emotional state of a person who has been dramatically changed as a result of the disease [12].

How a family copes with worries and anxieties depends on many factors, especially the current family situation. As long as a family has been used to resolving problems by sticking closely together and involving all family members, in any similar future situation they will be able to resolve issues with more success.

Research Problem

Does a chronic child's disease mean a burden for a family? How does a family cope with this burden? Which kind of help and support helps a family to cope with this burden?

Research Goals

1. To identify how a family reacts to finding out about a child's disease.
2. To identify the level of the burden in the family of a chronically ill child.
3. To identify their coping strategies.
4. To identify what kind of help a family expects from the health system.
5. To identify if the help of civil organisations impacts the effectiveness of a family's coping with the burden.

Methodology

For data collection, we used a non-standard questionnaire containing 27 items covering the research problem and three demographic questions (gender, age, and education of respondents). The questions were either closed or semi-closed and the answers were designed according to the Likert scale.

A pilot study was performed before the initial research. Afterwards we gave out 150 questionnaires between September 2014 and February 2015. 129 were returned (86%), out of which 29 were only partially completed and could not be used for our research. In total, we evaluated 100 questionnaires.

Research Participants

The group contained 100 respondents. The selection of respondents was intentionally based on specific criteria: the parents of chronically ill children.

The majority of respondents were female (94%). Respondents were mostly in the 31-40 and 41-50 age groups. Sixty-two percent of the respondents had college education and 38% had university degrees.

Results

The relationship between the socio-economical state of the family and the level of burden

Caring for chronically ill children does not present a psychological burden for 12 respondents (12%), presents a slight burden for 33 respondents (33%), a moderate burden for 31 respondents (31%), a heavy burden for 20 respondents (20%), and an extreme burden for 4 respondents (4%).

Ten percent of the respondents do not feel any financial burden regarding the illness of the child; for 20 respondents (20%) there is a slight financial burden, for 42 respondents (42%) a moderate financial burden, for 16 respondents (16%) a heavy financial burden, and for 12 respondents (12%) an extreme financial burden.

We discovered the relationship between the socio-economical state of the family and the level of burden by statistical evaluation of the data using Spearman's rank correlation coefficient. The value 0.8 demonstrates that the relationship between the socio-economical state of the family and the level of the burden is statistically significant.

Table 1. The relationship between socio-economic status of a family and level of burden

Q 14. Caring for the chronically ill child is financial burden	X _i	Q 3. Caring for the chronically ill child is psychological burden	Y _i	x _i	y _i	d _i	d _i ²
	10		12	1	2	-1	1
	20		33	2	1	1	1
	42		31	3	3	0	0
	16		20	4	5	-1	1
	12		4	5	4	1	1
						Σ d _i ²	4
						p = 0.8	

X_i = respondents' answers to question 14

Y_i = respondents' answers to question 3

x_i = sorting of X_i data

y_i = sorting of Y_i data

$d_i = x_i - y_i$

$d_i^2 = (x_i - y_i)^2$

Significance of information from healthcare professionals

Furthermore, we studied the sources from which families of chronically ill children get information. Fifty-six respondents (56%) mentioned that they most often seek the opinion of healthcare professionals. Thirty-two percent use the internet to search for information about the disease of their child. Seven percent of respondents take information from books and specialised magazines, and 5 respondents (5%) ask their friends.

We found that the parents of a chronically ill child primarily trust healthcare professionals and the information they provide. Černay [13] states that chronically ill children receive the most care from paediatric healthcare professionals [14].

Further, we studied whether the families of chronically ill children prioritise information from healthcare professionals over information from other sources.

Seventeen respondents (17%) stated that they never consider information from healthcare professionals over information from other sources. Twenty-four respondents (24%) rarely prioritise information from healthcare professionals, 15 respondents (15%) sometimes, 30 respondents (30%) often, and 14 respondents (14%) always.

By statistical evaluation of the data, we obtained a coefficient value of 0.3 on the Spearman's rank correlation that confirms that families with a chronically ill child prioritise information from healthcare professionals over information from other sources.

Table 2. Significance of information from healthcare professionals over other sources

Q 17. Source of information	X _i	Q 18. Preference information from healthcare professionals	Y _i	x _i	y _i	d _i	d _i ²
	56		17	1	1	0	0
	32		24	2	5	-3	9
	7		15	3	2	1	1
	5		30	4	4	0	0
	0		14	5	3	2	4
							Σ d _i ²
						p = 0.3	

X_i = respondents' answers to question 17

Y_i = respondents' answers to question 18

x_i = sorting of X_i data

y_i = sorting of Y_i data

$d_i = x_i - y_i$

$d_i = (x_i - y_i)^2$

The influence of the healthcare professionals on the coping effectiveness of the family

The goal of our research was also to discover if the support of healthcare professionals contributes to a family's coping with the burden. Thirty-eight respondents (38%) stated that the support of healthcare professionals helped them considerably and 12 respondents (12%) maximally. According to the evaluation scale of the questionnaire, 14 respondents (14%) are moderately helped by healthcare professionals, 28 respondents (28%) slightly, and 8 respondents (8%) not at all.

From these results we can conclude that more than 90% of the respondents use the support of healthcare professionals.

In the next question, the respondents evaluated the cooperation they received from healthcare professionals. Thirty respondents (30%) ranked the cooperation as excellent, 42 respondents (42%) as very good, 16 respondents (16%) as good, and 12 respondents (12%) as fair.

By statistical evaluation of this data we obtained a coefficient value of 0.0 on the Spearman's rank correlation, meaning there is no obvious relationship between the healthcare professionals' cooperation and the coping effectiveness of families. Despite of the fact that 72% of respondents value the cooperation they receive, only 50% state that the cooperation actually helped them effectively cope with the burden.

Table 3. The influence of healthcare professionals' cooperation on the coping effectiveness of the family

Q 23. The influence of health professionals' cooperation	X _i	Q 22. Cooperation with health professionals	Y _i	x _i	y _i	d _i	d _i ²
	8		30	1	4	-3	9
	28		42	2	1	1	1
	14		16	3	3	0	0
	38		12	4	5	-1	1
	12		0	5	2	3	9
						Σ d _i ²	20
						p = 0.0	

X_i = respondents' answers to question 23

Y_i = respondents' answers to question 22

x_i = sorting of X_i data

y_i = sorting of Y_i data

$d_i = x_i - y_i$

$d_i^2 = (x_i - y_i)^2$

The support of civil organisations and their influence on family's coping

The fact that families search for social support within civil organisations as a coping strategy has already been stated by Lazarus and Folkman in 1984 [15]. We discovered the following: 6 respondents (6%) very often turn to a civil organisation when coping, 22 (22%) often, 37 (37%) sometimes, and 35 (35%) never.

In the next question we asked if civil organisations help the respondents cope with the burden. Thirty-four respondents (34%) stated that these organisations do not help, 30 respondents (30%) slightly, 20 respondents (20%) moderately, 14 respondents (14%) considerably, and 2 respondents (2%) maximally.

By statistical evaluation of this data we obtained a coefficient value of 0.9 on the Spearman's rank correlation which implies that non-profit organisations significantly help families cope with the burden.

Table 4. The support of civil organisations and their influence on family's coping

Q 24. Search support of civil organisations	X _i	Q 26. The importance of civil organisations	Y _i	x _i	y _i	d _i	d _i ²
	35		34	1	1	0	0
	37		30	2	2	0	0
	22		20	3	3	0	0
	6		14	4	5	-1	1
	0		2	5	4	1	1
							Σ d _i ²
p = 0.90							

X_i = respondents' answers to question 24

Y_i = respondents' answers to question 26

x_i = sorting of X_i data

y_i = sorting of Y_i data

$d_i = x_i - y_i$

$d_i^2 = (x_i - y_i)^2$

Recommendations for practice

Based on the analysed reference and the research results, we suggest that healthcare professionals and civil organisations should implement the following ideas:

- healthcare professionals should advise families on cooperation with civil organisations;
- civil organisations should get more involved in projects and activities which improve the effectiveness of burden coping;
- healthcare professionals should collaborate with community centres to support the families of chronically ill children;
- healthcare professionals should develop their knowledge in socio-paediatrics by participating in further education.

Conclusion

Our research is based on small survey and is not extensive; therefore, we were unable to compare it with other research. However, we were able to formulate important conclusions which should be developed in the future.

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Wpływ odżywiania na organizm człowieka *The impact of nutrition on the human body*

Streszczenie

Odżywianie stanowi jedną z istotnych funkcji życiowych organizmów. Skład i właściwe proporcje składników odżywczych w diecie warunkują dobrostan organizmu.

Odżywianie człowieka jest jednym z podstawowych warunków jego życia, zdrowia i sprawności fizycznej, a także źródłem satysfakcji z zaspokojenia potrzeb socjalnych i hedonistycznych. Wiele zaburzeń rozwojowych i schorzeń wieku dojrzałego jest rezultatem wadliwego, jednostronnego i niepełnowartościowego żywienia.

Ciągły nadmiar energii z pożywienia skutkuje nadwagą i otyłością, które stały się chorobami cywilizacyjnymi. Racjonalna dieta jest kluczem do zachowania zdrowia i dobrego samopoczucia.

Słowa kluczowe: dieta, prawidłowe odżywianie, zaburzenia odżywiania

Abstract

Nutrition is one of crucial factors affecting living organisms. The composition and proper proportions of nutrients in the diet determine the well-being of the body.

Human nutrition is one of the basic conditions of life, health and physical fitness, as well as a source of satisfaction that fulfils social and hedonistic needs. Many developmental disorders and adult health conditions are the result of poor, imbalanced and incomplete nutrition.

A continuous excess of energy from food results in adiposity and obesity, both of which have become lifestyle diseases. Balanced diet is the key to our health and well-being.

Key words: diet, proper nutrition, eating disorders

Nutrients

Nutrients define compounds found in food products of animal and vegetable origin that are digested and absorbed from the gastrointestinal lumen into the blood after ingestion. The nutrients that make up food play structural and regulating roles in the body and provide energy [1].

The main nutrients are proteins, fats, carbohydrates, vitamins and minerals. An average person of moderate physical activity consumes daily approximately 2,500 g of water, 400 g of carbohydrates, 80 g of fat, 70 g of protein, and 20 g of minerals, thus providing 2,600 kcal [2].

Energy requirements of the body

Life is a process of burning calories, thereby providing the body with the necessary energy. The energy used by humans derives from the chemical energy contained in food, the source of which is solar energy and the nutrients contained in animal and vegetable products [3]. When a person eats correctly, the source of energy is carbohydrates and fats [4].

The primary purpose of nutrition is to meet the energy needs associated with:

- basal metabolic rate;
- thermogenesis;
- physical activity.

If the food consumed supplies more energy than a person requires for the aforementioned purposes, the excess is stored, mainly in the form of adipose tissue [5]. If insufficient energy is provided by food, the body utilises stored energy reserves in the form of glycogen and spare fat. Continuous excess of energy from food results in adiposity and even obesity [6].

Basal metabolic rate

Basal Metabolic Rate (BMR) defines the lowest level of metabolic changes that ensures the preservation of the essential vital functions of the body, such as the cardiovascular and respiratory functions, body heat retention, or the cell regeneration process [7]. The BMR value is determined by numerous factors, such as:

- height and body weight – these are the main determinants of daily energy expenditure in humans;
- age – humans have the highest BMR values in the first two years of life due to rapid growth and building of tissue. High basal metabolism is also observed during adolescence and in youth; however, BMR decreases in old age. It is estimated that in an adult human over the age of 21, the BMR value falls by approximately 2% for each subsequent 10 years of life;
- sex – the differences in BMR values between the sexes are a result of the differences in the composition of male and female bodies. As women typically have a higher proportion of body fat, their energy needs are lower;
- physiological condition in women - higher BMR values in women are observed during menstruation, in the second half of pregnancy (20-25%), as well as during breast-feeding;

- nutritional condition - BMR values are typically lower in malnourished people;
- health status - in the event of fever, it is estimated that for every 1°C above 37°C the energy needs increase by 12%;
- thyroid gland disorders - in the case of hypothyroidism, a decrease in the BMR value is observed, and in the case of hyperthyroidism, BMR increases by as much as 80% [8].

Thermogenesis

In addition to the basal metabolism, the overall metabolism is also affected by the process of thermogenesis, i.e. heat production. Since humans are endothermic organisms, they need to maintain a constant body temperature. This is best achieved at an ambient temperature between 22-23°C for an adult [1]. Staying within this temperature range does not entail changes in the production of heat and the metabolic rate. When exposed to lower temperatures, the body is forced to start the process of additional heat production, called thermogenesis [7].

In physiology, the terms of shivering thermogenesis and non-shivering thermogenesis are distinguished. Shivering thermogenesis is a reaction of the system to reduced air temperature and increased heat loss that is expressed by spontaneous muscle tremors that intensify their catabolic processes and increase the production of heat by the system. Non-shivering thermogenesis is induced not only by changes in temperature, but also by the very act of food consumption.

Postprandial thermogenesis means a periodic increase in the rate of the metabolism and energy expenditure of the system that is mainly associated with digestion and the absorption and transport of nutrients. Postprandial thermogenesis is dependent on the composition and amount of food.

Physical activity

Physical activity has a big impact on the amount of energy expended over 24-hours in humans. The diversity of physical activities undertaken throughout the day causes significant fluctuations in the level of energy expenditure, amounting to several dozen percent compared to basal metabolism. In professionally employed people, energy expenditure depends on the type of work and the environment in which it is undertaken; however, the most important factor is the amount of muscular exertion [9].

In the current nutritional standards developed by Ziemiański et al. [1995], three levels of physical activity were defined: low (1.4 or 1.5 BMR), moderate (1.7 BMR), and high (2.4 BMR) [8].

Obesity as a result of eating disorders

According to the World Health Organization (WHO), there are approximately 1.6 billion overweight people in the world, of which more than 522 million are obese [10].

Obesity is a major social problem. Every year the number of obese and overweight people increases, despite educational campaigns promoting rational nutrition and intensive physical activity. In Poland, approximately 40% of men and 28% of women are overweight, and obesity occurs in 16-20% of adults of both sexes. Over 15% of children and youth are currently overweight [11].

Obesity poses a threat to human health and life due to the increased risk of developing chronic non-communicable diseases such as cardiovascular diseases (hypertension, heart failure, strokes and other vascular diseases), many types of cancer, type 2 diabetes, respiratory diseases, degeneration of the osteoarticular system, and gallstones [10].

Balanced nutrition

The development and life of humans is inextricably linked to satisfying physiological needs. The basic physiological needs are classified as consumption and absorption of food; according to Gawędzki, we consume up to approximately 73 tons throughout our entire lifetime. Consumption of food and liquids, physical activities, and how free time is spent fall under the term “lifestyle”, which determines the condition of health by up to 50% [12].

Balanced diet is the key to our health and well-being.

Important principles of healthy nutrition:

1. Meals should be varied. The more diverse the diet, the more nutrients, vitamins and minerals are delivered to the body. No dietary supplements can replace a well-balanced diet. Much greater benefits are derived from the consumption of fruit and vegetables rich in antioxidant vitamins than from the supplementation of these vitamins. In practice, one should attempt to ensure that the main source of vitamins is food products. The possibility of supplementation should only be considered in the event of a suspected deficiency or low-calorie diets.
2. One should consume a lot of fruit and vegetables. These should always constitute at least half of the components of a meal because they are a very good source of vitamins and minerals. They also contain a large amount of dietary water-soluble fibre, as well as water itself, but contain little fat.
3. Whole grain cereal products, particularly groats, should be the main source of energy and consumed according to needs.
4. One should limit consumption of salt, the daily standard of which should be no more than one teaspoon (including salt in processed foods).

Use large amounts of seasoning herbs, as these give dishes flavours and aromas that are more varied; for example basil, thyme, mint, rosemary, oregano, and many others.

5. The best snacks are nuts, seeds and vegetables. These may be enjoyed between meals.
6. One should avoid sugar and sweets as well as soft drinks and sweeteners. Sweets may be replaced with fruit.
7. Choose seasonal and local products.
8. Buy the least processed foods possible.
9. No more than 500 grams of meat should be consumed per week. This may be substituted with eggs, fish and leguminous plants.
10. Limit the intake of saturated fats (butter, lard, margarine). These may be replaced with cold-pressed virgin vegetable oils, consumed raw.
11. At least 1.5 litres of liquids, preferably mineral water, spring water, infusions, and fresh juices should be drunk daily. Avoid sugary drinks and alcohol.
12. Never leave home without breakfast.
13. Care should be taken to maintain the recommended body weight [2].

The food pyramid

The food pyramid is a graphical representation of dietary guidelines. The commonly known Food Guide Pyramid developed by the US Department of Agriculture (USDA) dates back to 1992. Since then, the pyramid has constantly evolved and undergone changes, taking into account scientific reports on the impact of food on the body and human health [13].

Physical activity has been introduced to the currently valid food pyramid for Poland, proposed by the Food and Nutrition Institute (IŻŻ) in 2009. Physical exercise has now been recognised as an integral part of lifestyle [8].

The food pyramid shows the importance of fibre in the human diet, and thereby the recommended consumption of whole grain, low-processed products, legumes, vegetables and fruit [14]. On account of the essential fatty acids of the omega 3 family, nuts, cold-pressed vegetable oils and marine fish have all gained recognition, while fibre, vegetables and fruit have been included as a source of vitamins and minerals. Legumes, (a valuable source of protein), fibre, and phytoestrogens have been included alongside meat and fish. Milk, dairy products and eggs represent a source of complete proteins, while dairy products are a rich source of calcium. Consumption should be significantly reduced of processed forms of red meat and carbohydrates such as white bread, pasta, white rice, meal and potatoes [8].

The food pyramid shows correct portion sizes. It suggests food groups and the amounts and frequency of their consumption [4]. The base of the pyramid is

constituted by cereal products, which should be consumed five times a day (in each meal) and one 50 g serving of bread (1 slice) or 30 grams of porridge or rice (counted as the dry weight of the product). Carbohydrates contained in products in the form of starch provide energy to the muscles, whereas fibre regulates intestinal function. Vegetables, which should be consumed in a quantity of at least four servings a day, are placed above cereal products. Vegetables, which are low-calorie and supply vitamins, minerals and fibre, may be consumed in virtually unlimited quantities and accompany each of the consumed daily meals. The importance of fruit was ranked above vegetables. Fruit is subject to slightly higher quantitative restrictions; it is recommended to eat approximately three servings per day, but not more than 300 g. Fruit contains more calories and may cause an increase in the level of postprandial glycaemia and triglyceride in the blood. The next level of the pyramid contains milk and dairy products such as cheese, curd, yogurts, and kefir. Products of this type should be consumed in two portions per day, whereas approximately 200-300 ml of milk or yogurt type products (a large cup) or 40 g of cheese are considered a single portion. The penultimate level of the pyramid is occupied by meat, fish, eggs, and protein substitutes (legumes). These should be consumed in moderation, meaning they may be eaten once a day or once or twice per week in the case of red meat and eggs. The very top of the pyramid is occupied by vegetable oils and margarine. Products to be avoided that are not included in the pyramid are confectionery, biscuits, cakes, pies, chocolate, ice cream and alcohol. Alongside the pyramid there is water, which is very important in everyday life due to its significance for human metabolism [8; 15].

The importance of food quantity

Dietary patterns and the consumption of specific food products may act as both a cure and a poison for humans [16]. It is harmful to eat too much, too little, the wrong proportions, or at inappropriate frequency [8]. A deficiency of nutrients may contribute to a range of health and physiological effects, such as decreased immunity, muscle protein loss, emaciation, and wound healing problems. An excess of calories or eating processed products may contribute to such conditions as obesity, diabetes, atherosclerosis, hypertension and even cancer [4; 8].

Products that are safe, wholesome, and uncontaminated may be called healthy food. The foundation of proper nutrition is to maintain energy balance [17]. The amount of supplied energy should equal the amount of energy expended. The energy requirements of the body depend on a number of factors, including age, sex, physiological condition, health, or physical activity, which is particularly important [18]. Excessive energy mainly in the form of carbohydrates or fat, but also proteins, is transformed into spare fatty tissue, which in the short or long term leads to obesity [6].

A methodology may be used in order to determine the energy requirements of a particular person. Using a formula to calculate the basal metabolic rate and multiplying it by the activity rate (1.4-1.5 for low activity, 1.7 - for moderate, 2.0 - for high activity) produces the total energy needs for a particular person [9]. Pre-defined tables can also be used as these provide standard energy demands for the Polish population, dependent on sex, age, body weight and physical activity. One may also use predefined tables in the form of the standard energy needs of the Polish population, dependent on sex, age, body weight and physical activity [19]. The simplest method is to use the healthy eating pyramid and model food portions developed according to the average standards for women (1,800 kcal) and men (2,270 kcal). Food portions have been averaged for both sexes to 2,000 kcal [19].

Meal intake frequency

Due to the better utilisation of nutrients and proper sugar management in the body, it is recommended to consume smaller meals more frequently [20]. In practice, the optimum number is 4-5 meals spaced at equal intervals throughout the day. Meals should be varied in terms of product selection, maintain acid-base balance, and be characterised by a variety of colours and cooking methods [15].

The daily menu should include breakfast, lunch, dinner, afternoon snack and supper. Meals of smaller volumes are better digested and absorbed by the system, which can then automatically draw nutrients for metabolic processes. Eating irregularly, too rarely, or with long intervals between meals also results in a greater decrease of blood glucose level, which increases the subsequent sense of hunger [1]. Studies show that people who eat meals irregularly and erratically have lower thermogenesis, which results in lower energy requirements, which in turn leads to an increased risk of weight gain. Further studies show that people who do not eat breakfast consume many more calories per day than those who do. The first meal should be eaten shortly after getting out of bed, with the last one three hours before bedtime [18].

Conclusion

Human life is closely linked to the consumption and absorption of food. Therefore, the development of humanity is related to satisfying these basic physiological needs [21]. Humans are omnivorous; therefore, their food consists of both animal and vegetable products [7]. The primary role of eating is to supply essential nutrients to the body so that it can function properly [22]. However, in human society, food has become such an indispensable part of life that it has become much more than simply a means to satisfy basic needs. Eating has become one of the pleasures pursued by humans [11]; however, this has led to diseases associated with nutrition. The fact that a meal tastes good does not mean that

it provides all the necessary ingredients. Nowadays, this has become one of the major problems in the field of nutrition. The growing popularity of highly processed and fast food type products has led to an epidemic of obesity.

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Opieka pielęgniarska w sytuacji obciążenia rodziny chorobą dziecka *Nursing care in families with sick children*

Streszczenie

Obciążenie związane przeżywaniem choroby oddziałują na zdrowie, nie tylko jego członka, ale i całej rodziny. Celem badań była identyfikacja poziomu obciążenia oraz zasobów radzenia sobie z nimi, podczas opieki nad zdrowym i przewlekle chorym dzieckiem.

Do badań wykorzystano kwestionariusz *Family Hardiness Index*. Próbkę badawczą stanowiły dwie grupy rodziców: zdrowych dzieci oraz przewlekle chorych. Rodzice chorych dzieci wykazali się wyższym poziomem spójności i więzi podczas przewidywania obciążeń. Są w stanie lepiej i bardziej efektywnie wykorzystać zasoby osobowe, częściej polegają na własnych siłach, zdolnościach i umiejętnościach. Rodzice zdrowych dzieci z drugiej strony potrafią bardziej elastycznie i aktywniej reagować na niespodziewane zmiany w rodzinie niż rodzice chorych dzieci. Dlatego opieka nad rodziną powinna mieć zawsze charakter interdyscyplinarny. Poziom i sposób opieki zależy od tradycji kulturowych, modelu pracy z rodziną i rozwiązań organizacyjnych

Słowa kluczowe: rodzina, obciążenie, pielęgniarstwo, odpowiedzialność, wyzwanie

Abstract

In families and society as a whole, stressful situations are everyday occurrences that affect the health of both individuals and their families. The aim of the paper is to determine the degree of resistance and sources of hardiness in families taking care of either healthy or chronically sick children. A Family Hardiness Index Questionnaire was used to collect empirical data. Respondents were in one of two groups: parents of healthy children and parents of chronically sick children. When coping with stress, parents of sick children relied more on their own strength, capabilities and skills, displayed more cohesiveness and interconnection, and applied to a greater extent their character qualities in order to influence and control life situations. Parents of healthy children responded more flexibly and actively to unexpected changes in the family than parents of sick children. Degrees and methods of providing care depend on cultural and traditional models of providing care for the family and on the social milieu.

Key words: family, burden, nursing, commitment, challenge

Introduction

Health care professionals are currently focused on the influence of stressful life events on the health of individuals, families, or groups. In the past, many articles were based on classical research. For example, Raha [1] found that people who had overcome many significant life events, e.g. marriage, setting up home, birth of a child, job change, or death of a partner were more susceptible to illness. More recently, research has focused on seemingly unimportant life events, so-called daily hassles, that may significantly influence health by their accumulation or when they are combined with significant life events [2]. According to [3], specific life conditions or situations may lead to separate outcomes. On one hand, stimulation of psychological development may occur, meaning deliberate regulation of activity and integration of the personality, providing the conditions represent optimum mental strain. On the other hand, a stressful situation may lead to psychological and biological disintegration when a person is not able to control his/her behaviour deliberately or use „effective brain capacity“, causing the person to experience situational pressure, which for him/her means extreme mental strain. The impact of a situation on the mental state of a person thus reflects the actual discrepancy between presumptions, motivation, capabilities, and temperament dispositions on one hand and psychological demands to cope with the situational mental strain on the other.

Lazarus and Launier found that an evaluation of a situation by a person is a remarkable response to stress. The person may perceive the situation as follows:

1. **loss or harm** – i.e. harm that has already occurred, e.g. death of a close person
2. **threat** – an anticipated threat that has not occurred yet
3. **challenge** – a rather positive perception meaning the person might think that the situation is under control [1].

According to Lazarus and Launier, challenge or threat situations are usually chronic, whereas loss is mostly acute. Meleski found that experiences of loss were associated with coping strategies of faith, fatalism and expressing emotions. When a situation is evaluated as a challenge, the coping strategies of rational action, positive thinking, self-adaptation and humour prevailed. When a situation was perceived as a threat, the coping strategies of faith, fatalism and dreamlike escape occurred [4].

Nursing as a field of science uses a methodologically complete (holistic) approach to its subject. The person is the focus of nursing and is the recipient of nursing care. This person is healthy or ill (a person, family, community), perceived not only in the biological context but also in the mental, social and spiritual. In such a context, a person and his health, environment, nursing care, and the relations between them build a paradigm of nursing and at the same time represent a base for individual models and theories. The theories then create a basis for

a complete, specific picture of analysed reality. Such a picture of reality then can be used for systematisation of scientific findings and for explanation and prediction as scientifically based instructions for practical work [5].

Anglo-Saxon literature offers examples of the use of McGill's conceptual nursing model and contextual model of stressful situations in the family (the stressful situation requires adaptation of both partners or even other members of the family). Health is the central concept in McGill's model and is perceived as a dynamic process that includes concepts of coping and development. Coping means an approach to problem solving and to managing the situation. Development includes activities for identifying, mobilisation, and optimisation of potentialities and available sources. A contextual model of strain in the family points to the need to evaluate stressful situations by the family as a whole as well as by its individual members. This contextual model emphasises the importance of evaluating individual, family, and community sources, and their value in the health of individual members and the family as a system. Several authors gradually modified the model, resulting in the model of family adjustment and adaptation. Implementation of the Model of Family Adjustment and Adaptation brings trouble-free or troublesome adaptation leading to family resilience or the capability to return to the previous health condition [6].

An effort to put the nursing theory into practice is reflected in Roy's model, in which the role of the nurse is to help with the adaptive behaviour of the person, family or community by exerting influence over stimuli. Roy's system model deals with stress and adaptation theory and explains the mechanism of coping. Formation of the model was mainly influenced by two theories that also include the two main starting points: Bertalanffy's theory of systems and Helson's adaptation theory. The theory of systems made Roy think that humans can be preferably perceived through integrity (holism), interdependence, systems of behavioural control, information feedback, and the complexity of the human system. She adopted this idea from the adaptation theory that a man behaves adaptively and the degree of adaptation depends on external and internal conditions [7].

Nursing care is required when excessive stress or inability to handle a situation weakens a person to such an extent that he/she is unable to manage effectively. The aim of nursing care is to promote adaptation in all its four adaptive modes (physiological-physical, self-concept-group identify, role function, and interdependence), thus contributing to health, quality of life and dying with dignity [7, 8]. The most important task of nursing care is to enhance individual adaptation in order to change behaviour from inefficient to efficient.

The task of a nurse is defined by interconnection of concepts such as person, environment, health, and caregiving. The task of a nurse is to promote adaptation in health or illness and enhance the possibilities of a person and environ-

ment, thereby contributing to health promotion. Another goal of nursing care is to modify the stimuli that are having an impact on the person. When coping with different stimuli, nursing care proceeds through the following three stages: elimination and weakening of the impact of stimuli, removal of the person from an environment of excessive and harmful stimuli, and enhancement of the individual adaptation capacity [7, 8].

Roy sees adaptation as a process. This system of activities aims to promote positive adaptation by strengthening a person's integrity to improving his/her health. Implementation of dynamisms when coping with stimuli is part of the adaptation process. Coping mechanisms and strategies are involved.

The coping process includes innate and acquired ways of interaction with a changing environment. The innate coping process is automatic, however the person does not realise this. Acquired coping processes are learned or developed through customary responses. Roy views coping mechanisms as biological, psychological and social [8].

Roy explains adaptation mechanisms through coping, but she does not make an explicit difference between coping and adaptation.

Roy distinguishes four levels of coping mechanisms, categorises them as subsystems, and applies them to individuals and groups.

Subsystems applied to individuals:

1. **The regulator subsystem** automatically responds to stimuli through neural, chemical, and endocrinal channels. Stimuli from the external and internal environment act as inputs through the senses to the nervous system (e.g. when a person burns their hand they automatically withdraw it from the source of heat).
2. **The cognator subsystem** responds through a person's cognitive-emotional channels, perceptual and information processing (selective attention, coding, and memory), learning (imitation, reinforcement), emotions (anxiety), and judgement (activities, problem solving, decision making). It enables one to solve problems and make decisions. For example, driving a car requires not only certain skills, but also knowledge, attention and solving the present situation [8, 7].
3. **The Stabiliser subsystem** exerts influence upon the structures, values, and daily activities of a person in the group, for example in the family. If the person fulfils his/her primary function and thus contributes to the standard functioning of the society (e.g. if one member of the family earns money, the other one does housekeeping and raises children).
4. **The innovator subsystem** exerts influence upon changes of a person's integration in a group, changes of his or her behaviour, and promotes growth and development in social environments [8, 7].

A person responds to each new situation with a certain degree of adaptation that results in gradually improving balance of a person. Higher levels of adaptation allow for control and influence of stimuli and thus promote efficient adaptation. This means that the better adaptation leads to improved well-being and health.

According to Roy's definition, adaptation is a mutual response to incoming stimuli and the level of individual adaptation capabilities. Adaptation is thus a sinusoid depicting the focal stimuli and the level of adaptation. Adaptation response may be dual. If the gradient of the sinusoid is in the adaptation zone (adaptation capacity) of a person, the response is adequate and efficient. If the gradient of the sinusoid is very steep and the stimulus is outside the adaptation zone (capacity), the response is inefficient. The effort is not adequate to respond to the stimulus and coping mechanisms are activated, possibly resulting in inappropriate, inefficient behavioural response [8].

According to Roy's model, intervention is defined as a selection of nursing approaches aimed at fostering adaptation through either change of external and internal stimuli (eliminating, extension, reducing, maintaining) or through fostering the individual level of adaptation [7]. Intervention is a way to reach the goal. If the aim is to change behaviour, the intervention is focused either on influencing stimuli that have caused inefficient behaviour, or on promoting coping skills to deal with these stimuli. When coping with stimuli we make use of stimulus change, extension or reduction, elimination or reinforcement. Change of stimuli may lead to a positive response. Thus, intervention results in an efficient response. Considering the reason for inefficient behaviour, we presume that a person copes with a situation predominantly according to a regulator-stabiliser subsystem. When our aim is to make inefficient behaviour efficient, we make use of the cognator-innovator subsystem of the coping mechanism.

Stressful situations in the family

A stressful situation occurs when a person is exposed to strong pressure of adverse circumstances. However, the nature of the situation itself is not enough to define a situation as stressful. Most authors are inclined to think that the deciding factor in assessing the situation as stressful is how a person perceives how stressful a situation is. Only when a person perceives the situation as one that is too stressful for him/her to cope with may we define the situation as stressful. This explains the fact that the same situation may present difficulty for some people, while for others it could be handled easily.

Many physiological and psychological changes are caused by stressful situations that cannot be efficiently coped with. Physiological changes include increased blood pressure, increased breathing rate, headache, aching neck, backache, nausea

and stomach cramps, indigestion, diarrhoea, sweating, weight changes, etc. Psychological symptoms can include uneasiness, anxiety, depression, despair, inability to concentrate, absent-mindedness, feeling of isolation, helplessness, indecision, anger, annoyance, etc. Stressful situations also influence the social functioning of a person, which may lead to dysfunctional relationships. In addition, annoyance, aggressiveness, uncontrolled displays of emotion and withdrawal may be seen. Faith may deepen or be shaken [9]. For example, the death of a child is the most stressful situation ever for parents and has an impact on the whole family [10].

Výrost and Slaměník divide stressful situations into four groups:

1. **universal-moral problems** – situations that include existential and moral problems associated with the immediate environment of the person;
2. **health and life significance** – situations associated with health hazards (illness, injury, death);
3. **marriage, parenthood and friendship** – stressful situations connected with partnership, family and friendship; belonging to intermediate interpersonal relations in the social environment.
4. **work and financial problems** – work, education, financial problems as manifestation of interaction of a person with his/her extended environment [11].

It is also stated that men and women perceive stressful situations differently. Women perceive a situation as stressful not only when they themselves are concerned, but also when the situation affects a close person. Men perceive a situation as stressful only when the situation affects them.

Stressful situations are also part of daily life and affect the health of individuals and their families. There has not been as much research on stress and coping with stress in the family as there has on stress and individual coping with stress. Tasks are handled and problems solved differently by each family, influenced by the system of convictions and opinions held both jointly and individually by the family and its members [12].

The proportion of cohesive forces and forces leading to the autonomy of an individual are different in each phase of the family life cycle. For example, centripetal forces dominate in families with preschool children, while centrifugal forces dominate in families with adolescents.

When coping with the consequences of such situations, families possess certain capabilities of adaptation and active internal forces of the family apply. However, not every family is capable of mustering all its adaptation sources. When this occurs, professional help is necessary.

The needs of a person, family or community, and evaluation of health needs or nurse's intervention is a specific subject of nursing research. Assessment, diagnostics, and solving of nursing problems are distinctive attributes of autonomous nursing practice. Attention is paid to concepts such as adaptation, coping

with stress, hardiness, sources of strength, possibilities, strong points of the family, and family resilience.

Resilience of the family

We can usually talk about family resilience in relation to coping with the demands of extraordinary situations within the family. Family resilience is not an invariable feature that can be measured at a certain moment; it is a continuous and dynamic process. Sobotková states that resilience is as follows:

1. a feature of the family that enables it to maintain sound patterns of functioning even when the family experiences risk factors: it is elastic.
2. the ability of a family to recover promptly from a crisis or temporary event that affected its functioning [12].

Resilience of the family is influenced by stress level, vulnerability, pattern of family functioning, sources of hardiness in the family, the way of assessing and interpreting the situation, problem-solving strategies, coping with stress, and personalities of the parents.

Seriousness of stress – is determined by the extent to which stress influences family stability and how high the demands are compared to the real circumstances of the family.

Vulnerability of the family – is determined by interpersonal relations, family structure, current demands on the family, and normative requirements resulting from the stage of the family life cycle.

Pattern of family functioning – the most favourable pattern is the combination of flexible behaviour patterns and emotional attachments in the family.

Source of hardiness in the family – internal sources (of family system and individual) and external sources (social network, social and economic stability, cultural standard).

Pattern of assessing and interpreting the situation is a variable factor. When stress is understood as a challenge or a task, it is easier to cope with.

Problem solving strategies – the ability of the family to manage the situation, suggest solutions for solving the problem, and implement constructive patterns of communication.

Coping with the strain – using social and spiritual support.

Personality of parents – determines all previous factors and is considered superior to other factors. In terms of family hardiness, the following qualities of personality are considered beneficial: sense of action control, sense of situation manageability, sense of deep-rooted values and devotion to them, accepting life challenges as rewarding and beneficial for personal growth, and active life orientation [12].

Taking care of the family requires an interdisciplinary character. Scope and method of providing care depend on cultural tradition, patterns of family care,

and structure of a specific society. Planning of nursing care may utilise strategies included in Nursing Interventions Classification (NIC). These strategies include family promotion, promotion of family involvement, family mobilisation, family therapy, reducing anxiety, improving the ability to cope, crisis intervention, promotion of integrity in the family, support of a person providing nursing care, and support of siblings [13]. The system of evaluation introduced by Dluholucký in 1988 was proved by practice. This system accurately assesses whether a family is functional or dysfunctional and whether the environment in which the children live presents a danger to them. Overall judgement about the family offers an outline about family life and helps nurses determine areas that require deeper analysis [14].

When selecting the mode of coping and problem solving, the decisive factors are the family's response to the problem/s and the effectiveness of that response, not the number and seriousness of family problems.

Aim

The aim of the paper is to determine the scope of resistance and sources of family hardiness when caring for a healthy child compared to caring for a sick child.

Sample of respondents

Sample of respondents consisted of two groups of parents (parents of healthy children and parents of chronically sick children). From the 360 parents, there were 181 (50%) mothers and 179 (50%) fathers.

1st group: 119 mothers and 119 fathers of healthy children (altogether 238)

2nd group: 62 mothers and 60 fathers of chronically sick children.

The sample of respondents consisted of parents who met the following criteria: consent to be included in the survey, participation in raising children and care of a healthy child in the family (from one to five years of age), and care of a child suffering from psychomotor impairment in the family (from one to five years of age).

Methodology

A standardised questionnaire Family Hardiness Index (FHI) put together by the authors McCubbin, Thompson, McCubbin (1996) was used to record empirical data. Sobotková validated the questionnaire in our local circumstances and published it in her work *Pěstounské rodiny: jejich fungování a odolnost* in 2003 [23]. It measures resistance to stress and is focused on sources of family hardiness. It consists of twenty items arranged in three sub-scales:

1st sub-scale – Commitment (FHI_1) consists of 8 items. It measures cohesiveness, collaboration of parents when coping with stress (load), internal

strength of the parent, interconnection and capability to handle the stressful situation in the family.

2nd sub-scale – Challenge (FHI_2) consists of 6 items. It measures ability of the parent to accept challenges, be active, try new things, and learn from experience.

3rd sub-scale – Control (FHI_3) consists of 6 items. It measures the ability of the parent to influence family life [15].

Respondents answered each item using the scale from 0 to 3. 0 = yes, 1=rather yes, 2= rather no, 3=no. The ANOVA method was used to evaluate answers statistically.

Findings

Data obtained from individual sub-scales compared the parents of sick children with the parents of healthy children. We used basic descriptive methods in order to obtain statistical evaluation: arithmetic average, standard deviation, minimum and maximum values. We used an ANOVA test to evaluate the impact of category variables on the sub-scales questionnaire.

Table 1. Descriptive characteristics FHI_1 (Commitment) – according to health condition of the child

	Child's condition	Arithmetic average	Standard deviation	Minimum	Maximum
FHI_1	sick	2.122	0.5173	0.8	3.0
	healthy	2.037	0.5146	0.5	3.0
	total	2.066	0.5164	0.5	3.0

In the Commitment sub-scale is the scale value of arithmetic average 2.122 for the parents of sick children, which is statistically significantly higher than the scale value of arithmetic average 2.037 for the parents of healthy children. When coping with stress, parents of sick children showed more cohesiveness and interconnection than parents of healthy children.

Table 2. Descriptive characteristics FHI_2 (Challenge) – according to health condition of the child

	Child's condition	Arithmetic average	Standard deviation	Minimum	Maximum
FHI_2	sick	2.061	0.6115	0.2	3.0
	healthy	2.008	0.5914	0.3	3.0
	total	2.026	0.5980	0.2	3.0

Table 2 shows statistically significant differences in the Challenge sub-scale. The average scale value 2.061 for the parents of sick children is statistically significantly higher than the scale value 2.008 for the parents of healthy children. The parents of healthy children respond more flexibly and actively to unexpected changes in the family than parents of sick children.

Table 3. Descriptive characteristic FHI_3 (Control) – according to health condition of the child

	Child	Arithmetic average	Standard deviation	Minimum	Maximum
FHI_3	sick	1.655	0.5234	0.3	2.7
	healthy	1.628	0.5275	0.2	2.8
	total	1.637	0.5255	0.2	2.8

In the Control sub-scale (Tab.3) the average scale value of 1.655 of the parents of sick children is statistically significantly higher than the scale value of 1.628 of parents of healthy children. Parents of sick children utilise more character qualities than those of healthy children to influence and control life situations.

Table 4. Descriptive characteristics of FHI according to child's health condition

	Child	Arithmetic average	Standard deviation	Minimum	Maximum
FHI	sick	1.965	0.3805	1.0	2.8
	healthy	1.907	0.3886	0.8	2.9
	total	1.926	0.3863	0.8	2.9

Table 4 shows an overview of statistically significant differences of the three given sub-scales where the average scale value of 1.965 of the parents of sick chil-

dren is statistically significantly higher than the scale value of 1.907 of parents of health children. The sample group reveals that the parents of sick children rely more on their own strength, capabilities and skills when coping with load than those of healthy children.

Table 5. Findings of analysis of variance with the parents of children as independent variables and the sub-scales of the questionnaire (FHI, FHI_1, FHI_2, FHI_3) as dependent variables

			F	P
FHI * Child	Between Groups	(Combined)	1.837	0.176
	Within Groups			
FHI_1 * Child	Between Groups	(Combined)	2.198	0.139
	Within Groups			
FHI_2 * Child	Between Groups	(Combined)	0.628	0.429
	Within Groups			
FHI_3 * Child	Between Groups	(Combined)	0.220	0.639
	Within Groups			

Analysis of variance of parents of children as an independent variable with variable of FHI revealed significance 0.176. With sub-scale FHI_1 the significance was 0.139. With the sub-scale FHI_2, the significance was 0.429. The significance sub-scale FHI_3 was 0.639.

Explanatory notes to table 5: *F* –ratio of variance among groups and within groups, *p* – significance –statistical significance (*sig.* < 0. 05 means a statistically significant difference)

Discussion

The primary aim of the survey was to identify patterns of family life in order to identify the degree of resistance and sources of hardness in families when caring for a healthy child compared to caring for a chronically sick child.

It is natural that all parents want a healthy, “normal” and even “perfect” child. Even before a child is born, many parents have a vision of how it should look and what kind of profession it should have. Unfortunately, sick children often do not meet these criteria; therefore, they are stigmatised and isolated, which affects the whole family. The more a child differs from standards held by family

members and society, the more the family struggles to make the child conform to the standards. [16].

Social environment also plays an important role as specific expectations about a “proper” child can cause many crisis situations for the family. The impairment of the child affects the whole family, bringing physical, economic, social and emotional stress to the family [17].

Chronic illness of a child may represent a situation for parents that philosophers refer to as existential (e.g. individuals asking questions about their importance to society). This existential situation becomes a new, alternative way of existence, characterised mainly by absence of natural and certain things accompanied by uneasiness and increased anxiety. Parents dealing with a chronically ill child often feel guilty, distressed, empty, dismayed, and isolated. As stated by Matoušek, there is a chance to display one’s dignity in new dimensions of human potentialities. The parents of sick children in our survey manifested stronger cohesiveness and interconnections when coping with stress than the parents of healthy children [18].

Illness of a child affects the parents’ relationship; however, it cannot categorically be classified as negative. Some studies draw attention to increased strength, cohesiveness and interconnection of these families. However, most authors consider a chronically ill child an enormous risk to marital stability. In former Czechoslovakia, Veselá conducted the first research on family structure. The sample group consisted of 924 families with children suffering from various illnesses of varying degrees. This author found that 24% of sick children live in an incomplete family. Our sample group consisted of parents who shared a household and participated in their child’s upbringing and care [17]. As stated by Ruiselová and Strnáďová, in families where both parents provided daily care for the child, the sample group of 40 families revealed that even 95% of these families were mostly stable and functioning. Additionally, other demographic indicators (e.g. number of children and education of parents) were roughly equal to families with healthy children [16,17].

It is difficult to generalise about relationships and interactions between parents and children on a common level as they are influenced by many factors that may permanently lead to a stressful situation. An important role is also played by the highly variable personality structure of individual members of the family.

Emotional support, mutual assurance, feeling of inclusion, and social environment enable parents and children to overcome obstacles. Conflicts become the basic precondition of good self-actualisation of the parent and the family as a whole [19].

Parents prepare their child for life and the child needs parents most of all people. A family with a sick child faces a situation that requires them to change their existing way of life, accept new roles, and deal with new specific tasks. In

order for the family structure to be preserved, it has to adapt to changing external and internal conditions. The ability of the family to adapt is very individual. Matejiček states that the ability of a family to adapt is usually as strong as the weakest member [20].

If the strain surpasses the threshold of what the family can tolerate, the family starts to show signs of dysfunction or even total disintegration. However, this statement is hypothetical. As stated by Bratská, the ability to adapt to strenuous situations is greatly influenced by volitional qualities of individual members of the family (parents, siblings). In addition, a tenacious capacity to overcome obstacles and the readiness to experience pleasant moments in difficult life situations are extremely important [21]. The survey revealed that parents of healthy children responded to unexpected changes in the family more flexibly and actively than those of sick children.

Strenuous situations are in fact emergency situations that activate deeply stored, innate responses with the result being either fight or flight. The parents of sick children in our survey utilised their personal qualities to influence and control the life situation in the family more than the parents of healthy children. Stráňadová points out that in an emergency situation, one automatically relies on innate abilities, without rational thinking, common sense, acquired knowledge and principles [17]. The deeper the emotional involvement of a person in a strenuous situation, the more important for him/her is the result. A bigger risk is that his/her behaviour will not be rational, but highly emotional, which may be manifested either by some kind of aggressive behaviour, or escape behaviour such as submission, crying, or surrender. Neither of these modes leads to adequate coping with strenuous situations.

Suggestions and measures for nursing praxis

The mission of nursing in society is to help individual people, families and groups to determine and carry out roles and tasks promoting and maintaining health and preventing illnesses [22]. The tasks are divided into two main spheres:

1. Tasks of identifying the risk factors when coping with a strain

Nurses working in homes or ambulatory care fulfil the important role of identifying risk factors. Identifying risk factors that disturb healthy functioning of the family is the first step to preventing strategies. Screening methods for identifying risk factors enable immediate identification of needs and application of the appropriate intervention programme. When suggesting prevention measures, we have to mention that there are no family nurses in Slovakia. There is also an absence of professionals specialised in the family environment who would more precisely monitor the structure, roles, relations and expectations of individual family members, actively listen to individual family members, create a loving atmosphere among them, discuss strengths and potentialities of the

family, monitor the family situation in regard to coping with the strain, ensure collaboration of family with appropriate experts with the possibility of cooperation with associations and institutions, recommend other sources of support, and arrange medical consultations.

2. Preventive strategies and preventive programs

a) On individual level

Preparation for purposeful adopting of a healthy life style for every age should be the focus of professionals. The target should be to create and promote such programmes, strategies, and modes of coping that reduce occurrence of risk factors and enhance protective factors concerning an individual, family and community.

Long-term targets of such programmes should be built on lifelong preparation of an individual, family and community for life, ideally with good health, creative comfort, a decent environment, and adequate social security.

Short-term targets should be focused on adopting a healthy life style in individual phases of life.

b) At society level

Nowadays it is necessary to include preventive family care programmes in family policy on local, regional, national and international levels, applying proper therapeutic and professional knowledge. Such preventive programmes include *Health for everybody in the 21st century*, and the *National program of health promotion*.

When implementing preventive programmes, methods that enhance the recognising and solving of strenuous situations are used. It is important that participants in programmes understand the connections between various factors and coping strategy preferences. Such factors include personality, situational factors (life events, various types of strenuous situations), social relation networks, sociodemographic factors, working environment, family environment, health, pathology, gender differences, etc.

These educational processes should be applied in primary, secondary and tertiary levels for prevention of stressful situations.

Conclusion

To most important factors of family harmony, functionality, and stability are transparently determined roles and the attributes of individual members such as, clear communication, way of defining conflicts, and efficiency of interaction when solving conflicts. A healthy family enables independence, personal responsibility, and offers a feeling of emotional closeness among the family members. Family adaptability is important. A functioning family is one that is creatively able to solve situations that life brings and to cope with them adequately in order to positively change family structure.

Precautions aimed at health and its promotion in the family play a significant role in the area of prevention and nursing care. Nurses, doctors, educationalists, sociologists, and psychologists represent important support to families in terms of taking care of the health of its individual members and the family as a whole.

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Asystent rodziny jako wsparcie dla rodzin z problemami opiekuńczo-wychowawczymi *Family assistance as support for families with social and behavioural problems*

Streszczenie

Rodzina ze względu na wymagania stawiane przez społeczeństwo ma do spełnienia wiele funkcji. Funkcje rodziny to: materialno-ekonomiczna, opiekuńczo-zabezpieczająca, prokreacyjna, seksualna, legalizacyjno-kontrolna, socjalizacyjna, kulturalna, rekreacyjno - towarzyska oraz ekspresyjno-ekspresyjna. Rodzina dobrze funkcjonująca w społeczeństwie wypełnia te funkcje przynajmniej w podstawowym stopniu.

Rodzina, która nie potrafi zaspokoić swoich podstawowych potrzeb jest rodziną dysfunkcyjną. W rodzinie niewydolnej wychowawczo problemy rodzinne wynikają z niepowodzeń życiowych, a nie zawsze z powodu zaburzeń w życiu rodzinnym. Funkcjonowanie takiej rodziny jest nieprawidłowe, burzy aspiracje życiowe jej członków, szczególnie tych najmłodszych czy dorastających.

Rodzina jest pierwszym, najbardziej trwałym światem społecznym dziecka. W niej tworzą się pierwsze i najbardziej trwale więzi społeczne. We współczesnym świecie coraz więcej rodzin wymaga wsparcia w różnych obszarach funkcjonowania. Państwo mając na względzie elementarne wymagania polityki rodzinnej stara się podejmować wysiłki w kierunku udzielania wsparcia rodzinom, które tego potrzebują. Asysta rodzinna skierowana jest do środowisk przeżywających trudności w wypełnianiu funkcji opiekuńczo-wychowawczych, a w szczególności do: rodzin z wieloma problemami, zagrożonych marginalizacją lub już wykluczonych społecznie. Zadaniem asystenta rodziny jest więc całościowe wspieranie rodzin dysfunkcyjnych wychowujących małoletnie dzieci.

Słowa kluczowe: rodzina, asystent rodziny, wsparcie dla rodzin

Abstract

A family that cannot satisfy its basic needs is dysfunctional. Problems in educationally deficient families often, but not exclusively, stem from failures in life. The functioning of such a family is incorrect; it shatters the life aspirations of its members, particularly the youngest or adolescents.

Family is the primary and most durable social world for a child and is where the first and most persistent social bonds are formed. In the modern world, an increasing number of families require support in many different areas of their functioning. The state, taking into account the essential requirements of family policy, seeks to make efforts to provide support to families that need it.

Family assistance is addressed to social groups in difficulty with carrying out their care and educational functions, and in particular to families with numerous problems, at risk of marginalisation, or already socially excluded. The task of a family assistant is to provide comprehensive support to dysfunctional families raising young children.

Key words: family, family assistant, family support

“The best way to find yourself is to lose yourself in the service of others”
Ghandi

Family may be defined in at least four areas: as a social institution, a social group, a community, and an association [1]. L. Dyczewski defines family as something natural and so common that it would be hard to imagine life without it [2]. According to Adamski, “family is a spiritual union of a small group of people, gathered in a common household by acts of mutual assistance and care, based on faith in a real and alleged biological bond, social and family tradition” [3]. However, the Social Assistance Act defines family as “persons related or unrelated, remaining in an actual relationship, living together in a household and jointly keeping the house” [4]. Family as an institution is a formal group and is therefore subject to the custody and control of society. It has an inherent structure and fully defined functions in relation to individuals and small communities. The basic characteristics of the family as an institution include the fact that the structure and functions in the family are determined by society. If the family is functioning improperly, it is subject to sanctions of other institutions, e.g. in the case of wrong parental attitudes, a guardian or social worker becomes active. In terms of the number of requirements that are put before it by society and the local community, a family needs to fulfil numerous functions.

In the modern family, functions very frequently translate into roles in the family [5]. A family that cannot satisfy its basic needs is dysfunctional. In an educationally deficient family, problems often, but not exclusively stem from failures in life. The functioning of such a family is incorrect; it shatters the life aspirations of its members, particularly the youngest or adolescents. Several types of family can be distinguished: strict, possibly involving physical punishment or a cool emotional attitude to the child; liberal, characterised by a lack of interest from parents and improper emotional attitude to the child; overprotective, featuring excessive and harmful protection of the child against any effort, excessive tolerance to misbehaviour [6].

A family is a natural social support system that meets the psychological and social needs of humans. As pointed out by J. Nikitorowicz: “a family protects children against the feeling of emptiness and loneliness (...), is the source of life

goals, a chance for long-lasting emotional relationships, and provides satisfaction in life. It is a natural support system that is particularly important in crisis situations and is the most important factor in the education and socialisation of children” [7].

The development of a child’s social skills becomes of crucial significance. Family is the first and most persistent social world for a child and is where the first and most persistent social bonds are formed. This is where children acquire the ability to communicate and become familiar with key aspects of culture. Family provides a social identity in terms of race, religion, and social class. Family is the “source of development potential and real life opportunities of the children who grow up in it, but on the other hand, a source of all social and developmental dysfunctions and the so-called social pathology, and consequently, deviant phenomena leading to social exclusion and stigmatisation of its members” [8]. In such cases, external support from institutions and services dedicated to assisting the family becomes necessary.

In the modern world, an increasing number of families require support in many different areas of their functioning. The state, taking into account the essential requirements of family policy, seeks to make efforts towards providing support to families that need it. This may be achieved through the use of various instruments and the participation of various entities available to the society. Such institutions include schools, social assistance centres, non-governmental organisations, doctors, nurses, and many other institutions [9].

The institutions that provide care and support families in crisis situations also include social rehabilitation facilities (youth educational centres, care centres for minors, correctional facilities, legal guardians, rehabilitation centres) and provide aid to elderly people (day support centres, nursing homes, hospices).

An unquestionable achievement of the last decade is the establishment of the Family Support and Alternative Care System Act, a legislative solution in the field of support of families with educational and care difficulties. The act is key to the implementation of several new family policy instruments that may contribute to a more efficient socio-educational work with families at risk.

The preamble to the aforementioned Act states that “for the sake of children who need special protection and assistance from adults, a family environment, an atmosphere of happiness, love and understanding, for the sake of their harmonious development and future life independence, in order to ensure the protection of their rights and freedoms, for the sake of the family, which is the basic unit of society and the natural environment for development and welfare of all its members, and particularly children, with the belief that effective help for families in difficulty in caring for and raising children and the effective protection and support of children may be achieved through the cooperation of all persons, institutions and organisations working with children and parents - it is hereby resolved: the prin-

ciples and forms of support for families experiencing difficulties in carrying out their care and educational functions; the principles and forms of foster care and facilitating independence of its adult charges and the tasks of public administration in the field of supporting family and foster care system” [10].

The Act therefore refers to important and fundamental values related to the protection of the child and the family and the need to support families, in particular those experiencing difficulties in caring for and educating children, through the cooperation of all persons, institutions and organisations working with children and parents.

Family assistance is addressed to social groups having difficulty carrying out their care duties and educational functions, and in particular to families at risk of marginalisation, already socially excluded, or with numerous problems [11]. The task of a family assistant is comprehensive support of dysfunctional families raising minor children.

In the case of obtaining information on a family having difficulty in carrying out its care duties and educational functions, the manager of a social assistance centre commissions a community interview. If the conclusions from analysis of the family situation indicate the need for comprehensive, systematic, dedicated support, a social worker applies to the social assistance centre manager for the assignment of a family assistant [10].

The decision to grant a family assistant may also be taken by the court. Family assistance is provided in the living environment or in a location designated by the family and agreed between the family and the family assistant.

The Family Support and Alternative Care System Act provides that assistants plan and conduct work with families solely with their consent and active participation, motivating them to cooperate in the implementation of the agreed plan. However, situations may arise in which a family that has previously committed to working with the family assistant does not agree to cooperate.

Family assistants conduct in-depth diagnosis of a family's ability to care and their socio-economic, caring, educational, and social functioning, taking into consideration the family's deficiencies and resources that affect its ability to provide specific types of support introduce specialised activities. They set a flexible plan of changes that is adapted to actual needs and circumstances. Together with the family, they define the scope, purpose, and the expected effects of activities and the roles of all the persons involved in the plan of overcoming the crisis in the family.

A requirement for cooperation is to establish clear rules and gain the trust of clients. When implementing the objectives of the agreement, a crucial task of the assistant is to accompany, support and counsel, continuously motivate and stimulate clients to take responsibility for their own lives. The subject literature indicates that depending on the needs of a given family, the assistant performs

different roles including helper, counsellor, therapist, service coordinator, and teacher-educator. If education is understood as a process accomplished in various environments throughout life, then a family assistant may also be regarded as an educator. Among the three tasks assigned to the family assistant, “methodical” tasks were also prominently marked, referring to the individual stages of working with the family. One may list as follows:

- diagnosing the situation in the family;
- designing a plan to work with the family, both in the long term, and as an “everyday schedule” (e.g., “developing a plan to overcome a difficult situation in life”);
- monitoring the functioning of the family and “regular visits to the home environment” [12].

Another duty of a family assistant is to look at clients and families in terms of their strengths and opportunities, rather than focus on their deficiencies and inability to cope with various situations [13]. The potential of each person should be unlocked in order to overcome their problems (empowerment) [13].

A family assistant complementarily supports the family and its individual members in the process of overcoming difficulties restricting their life functions and meeting their basic and higher needs. They provide help in solving the basic social and health problems of the family and ensure motivation to improve the life situation, acquire the skills of proper household management, seek and maintain gainful employment, and improve professional qualifications or continue education, among other things. They draw attention to health problems and the need for proper nutrition, especially in children. Moreover, they provide psychological and educational support, inter alia, through individual consultations for parents and motivate them to participate in group activities aimed at shaping the right parenting patterns and psychosocial skills. They shape competences in building proper relationships between family members. They educate regarding the most common behavioural problems at the individual stages of child development and the methods of dealing with them. They motivate to actively organise leisure time and participate in the school life of the child. They raise awareness that the closest caregivers are responsible for the care and upbringing of children [14].

The Family Support and Alternative Care System Act demands the cooperation between all levels of local government and interdisciplinary collaboration between different institutions of the same level of local government that is a prerequisite for the success of the measures taken to help families and children in the local community. This corresponds to the principles of the positive parenting policy, which, in accordance with the guidelines of the Council of Europe, is understood to mean taking care of and educating children and creating conditions in the family and immediate environment whose primary purpose is the care for

the child's best interests, their full development and respect for their rights. The essential elements of the positive parenting policy are support for parents by various institutional and non-institutional entities, promotion of education concerning children's rights and positive parenting, reconciling work and family life, and the proper policy at the local level.

Child safety is of crucial importance. Parents' destructive behaviour may at times endanger the health and lives of children. At such times, the parent attempts to change while the child is in short-term foster care. Not every family desires and is able to take advantage of this form of support. However, this role should be understood as a form of support rather than a means of coercion. There are other forms of assistantship, for example guardianship.

On the basis of analysis of the documentation of a family assistant and assessments of family situations, Krasiejko pointed out the characteristic features of families covered by social support, which correspond to the previously mentioned characteristics of risk families, which include:

1. features indicative of poor care and educational skills of parents: poor knowledge regarding the needs and possibilities of the child; typical behaviour at a given stage of development; unrealistic perception of the child's skills and abilities; requirements incompatible with age; lack of knowledge of various educational methods and use of corporal punishment; wrong perception of the child as deliberately annoying including being rude, malicious, and blaming them for various negative states; making a scapegoat of the child; a sense of power and superiority over the child; sense of ownership ("this is my child and I can do with it what I want"); neglecting the child including lack of care, providing food with low nutritional value, rare washing, low stimulation of the child's development;

2. features indicative of low household management skills: rare preparation of hot meals; untidy household and poor hygiene; inability to manage household budget;

3. characteristics indicating a low level of resourcefulness: poor ability to take care of administrative and other matters for the home and family and use services; avoiding contact with representatives of social services and other professions; passivity in the labour market;

4. features indicative of low self-esteem and control over one's life: passivity, apathy, submissiveness, alcohol abuse;

5. features indicative of dysfunctional spousal relationships: the presence of poor, superficial relationships between partners; numerous conflicts; imbalance of power in the family, e.g. a strong man in charge, helpless woman or vice versa; frequent change of partners or returning to previous partners;

6. personality traits or psychological problems of parents; low tolerance level of everyday stress; increased levels of agitation in stressful situations; rigid, strict and punitive attitudes towards children such as the establishment and enforce-

ment of strict rules in everyday life; frequent use of shouting and threats regardless of the nature of disobedience of children; failure to take care of children; submission of the parent in relation to the child; lack of principles in the functioning of the family; dogmatic and authoritarian personality traits; a high level of aggression and poor control of emotions and impulses; emotional lability; depressive states, schizophrenia or other mental disorders; mental retardation; severe physical limitations which may prevent adequate functioning in the parent-child relationship;

7. features indicative of low socio-emotional maturity of parents at any age: individual needs prioritised over the needs of the entire family, for instance by spending money on whims or spending time with friends instead of children; failure to undertake work or further education; lack of desire to change the situation; dependence on social assistance;

8. features indicative of a difficult social situation: lack of partner or spousal support; lack of support from other relatives; inability to use the institutional support system; inability to take rest from children;

9. features indicative of educational difficulties of children: neglecting school duties; failure to carry out orders from adults; truancy; risky behaviour; running away from home and other symptoms of social maladjustment of the child;

10. features indicative of an emergency situation related to the stages of development of the family or situational events birth of another child, partner betrayal, divorce, eviction, death of a family member;

11. features indicative of economic failure of the family: a lack of, low or irregular income; poverty; debt in banks; outstanding payments;

12. features indicative of difficult housing conditions: overcrowding, lack of sanitary facilities, lack of or failure of basic equipment, poor hygiene and disorder, threat of homelessness due to outstanding rent payments;

13. features indicative of low social status of parents: living in enclaves of poverty, low level of education;

14. features indicative of social pathology in the family: alcoholism, drug addiction, domestic violence, prostitution, crime (e.g. drug trafficking, theft) [15].

The definition of these characteristic features is an attempt to gain an understanding of the problem and assess the strengths and weaknesses to cope in difficult situations (constraints, opportunities, and motivations). The definition determines planning and actual work needed in a family.

Social stigmatisation might be revealed in certain cases when carrying out a diagnosis. This is a type of synthetic indicator that defines the stage of social and individual anomalies of the family as a social microsystem [16]. The next stage is to develop a management plan to correct the environment and educational activities, thereby forming behaviour that is more favourable. Another step

is to manage the case according to the developed plan, which allows for adjusting the diagnosis and the plan in order to achieve a better result. Working with a dysfunctional family consists primarily of entering into the family's environment and daily existence, diagnosing the situation, and helping to build a sense of attachment [14].

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Radzenie sobie rodzin opiekujących się małym
dzieckiem z nawracającą ostrą chorobą układu
oddechowego w opinii matek

*Resilience of families caring for a small child
with recurring acute respiratory disease
from the viewpoint of the mother*

Streszczenie

Ostre choroby układu oddechowego są jednym z najczęstszych problemów występujących u małych dzieci. Jeśli powtarzają się okresowo, mogą nadmiernie obciążać rodzinę, zaburzać funkcje i sprawiają, że coraz trudniej jest poradzić sobie z tą sytuacją. Celem badań była ocena odporności i wytrzymałości rodzin z małym dzieckiem cierpiącym na ostre choroby układu oddechowego z punktu widzenia matki. Ogółem 102 matki wypełniły dwa standaryzowane kwestionariusze, *Family APGAR* i *Family Hardiness Index (FHI)* oraz udzieliły odpowiedzi na pytania odnoszące się do uwarunkowań wpływających na funkcjonowanie rodziny. Ankieta *Family APGAR* ujawniła 11 (tj 11%) dysfunkcyjnych rodzin i 20 (odpowiednio 20%) rodzin z nieznacznie upośledzoną funkcjonalnością w zakresie efektywnego radzenia sobie w opiece nad małym dzieckiem z nawracającą ostrą chorobą układu oddechowego. Rodziny, które doświadczały występowania trudności w opiece nad dzieckiem cechowały się znacznie niższymi umiejętnościami i zasobami w porównaniu do rodzin prawidłowo funkcjonujących w tym zakresie. Mimo, że wyniki badań nie wykazały niepokojącego upośledzenia odporności lub funkcjonalności naszej próby badawczej, kwestii tej nie należy bagatelizować. Choroby, szczególnie w przypadku najmłodszego członka rodziny, mogą mieć poważny wpływ na rodzinę jako całość. Dokładne wyjaśnienie i edukacja w zakresie mechanizmów zapobiegania i radzenia sobie okazują się niezbędne.

Słowa kluczowe: Radzenie sobie rodziny - małe dziecko - ostre choroby układu oddechowego

Summary

Acute respiratory disease is one of the most common medical problems in small children. If it recurs frequently, it can overburden and impair the functionality of the family and make it harder for the family to cope with situations. The aim of our research was to assess the resilience of families with a small child suffering from acute respiratory disease in terms of hardiness and from the viewpoint of the mother. A total of 102 mothers completed two standardised questionnaires - *Family APGAR* and *Family Hardiness Index (FHI)* - and answered questions relating to determinants that effect the functionality of the family. The Family APGAR questionnaire revealed 11 (i.e. 11%) dysfunctional families and 20 (i.e. 20%) families with slightly impaired functionality. Dysfunctional families and families with slightly impaired functionality showed a far lower resilience than functional families. Although the results of the survey did not show any alarming impairment of resilience or functionality in our research sample, this issue should not be underestimated. An illness, particularly in the youngest member of a family, may have a serious impact on the family as a whole. Thorough education relating to prevention and coping mechanisms has proven to be essential.

Key words: Family - small child – acute respiratory diseases – resilience of family – hardiness

Introduction

During the course of their work, paediatricians and paediatric nurses commonly witness the influence that families have on their children's physical health, mental development and overall well-being [1]. Acute respiratory system illnesses are some of the most common illnesses, particularly amongst infants and toddlers. If they recur on a frequent basis, the caretaker can end up exhausted. Dyspnoea (a subjective feeling of being short of breath, generally requiring a greater effort to breathe) in children is a very serious symptom, as in small children even slight changes in the clearance of the respiratory tract may seriously restrict the flow of air. This occurs due to narrowing of the respiratory tract due to external pressure, thickening of the wall, or the presence of an obstruction in the respiratory passages. Depending on where the obstruction is, these cases are divided up into inspiratory (upper respiratory passages), mixed, and expiratory (lower respiratory passages) [2].

A functional family plays an important role in every person's life, and is of undeniable significance for children in the first years of their life. If there are problems in a family that accumulate over time and result in the family ceasing to fulfil its basic functions, assistance must be provided to those families [3]. Family functionality, as well as the processes that occur within the family, is closely linked to family resilience and the ability to cope with stress. This topic has been explored by authors such as Matějček, Dytrich and Sobotková [4, 5]. According to Sobotková (2004), healthy family functionality is based on three basic principles: cohesion, adaptability and communication [5]. These three principles are also reflected in the family's ability to cope with stress. A family's level of resilience is affected by several factors, including the severity of the stressor,

the vulnerability of the family, the type of family functionality, the source of the family's resilience (social support network, the cultural and economic status of the family, communication within the family and the individual characteristics of its members), the manner in which the family appraises situations that arise, the strategy adopted to deal with problems in the family, the strategy used to cope with stress, and the personalities of the parents.

Objective

The main objective of this work is to assess, from the mother's viewpoint, the resilience of a family caring for a small child with recurring acute respiratory disease.

The secondary objective was to determine the difference in resilience in relation to

- family functionality (Family APGAR),
- type of illness of the respiratory tract (illness of the respiratory system with or without dyspnoea),
- accumulation of illnesses of the respiratory tract (occurrence of a respiratory system illness in the youngest child or 2 or more illnesses of the respiratory system),
- composition of the family (mother with or without a partner),
- age of the youngest child (up to 24 months or over 24 months),
- number of children in the family (1 child in the family or 2 or more children in the family),
- partner's level of education.

Methodology and characteristics of the set

This was a simple intentional (purposeful) selection. The research set consisted of 102 families or mothers caring for at least one child aged between 6 months and 3 years (36 months).

The families were selected according to the following criteria: normally functional families, or those facing recurring (at least 3 times during the last 6 months) respiratory disease in a small child (confirmed at least by a paediatrician). The parents were orally informed about the survey being carried out and read our appeal for help with the survey in the waiting rooms of three paediatricians' offices. Only mothers took part in the survey, and they did so voluntarily. When they had any questions (regarding respiratory diseases), they could turn to children's nurses or physicians themselves. There was a box with a small opening in the waiting rooms, into which the completed forms were dropped in sealed envelopes. For the purposes of the research, we also divided the illnesses up into those that were and were not accompanied by dyspnoea and then compared these.

Method

A quantitative method of questioning was used to obtain the empirical data. The questionnaire as a whole comprised three parts: a) completion of the standardised Family APGAR questionnaire, b) additional questions relating to determinants that influence the functionality of the family, c) z completion of the standardised Family Hardiness Index (FHI) questionnaire.

Research tools

Standardised Family APGAR questionnaire

Designed by Gabriel Smilkstein in 1978, the name APGAR is made up of the first letters of the words: Adaptability, Partnership, Growth, Affection and Resolve. For each question, the respondent chooses one of three possible options, which are assigned points as follows: Almost always (2 points); Sometimes (1 point); Very rarely (0 points). The points from all five questions are added together. A total of 7-10 points indicates a normally functioning family, a score of 4-6 points signals slight impairment of family functionality, and a score of 0-3 indicates a dysfunctional family [6]. It is recommended that the questionnaire is filled out by all members of the family; if this is not possible, it is important that it is completed by the mother [7, 8].

Standardised Family Hardiness Index (FHI) questionnaire

This questionnaire measures sources of resilience in the family, specifically family hardiness [9]; it contains 20 items/propositions describing the family that are broken down into three subscales:

1. “**commitment**”, contains 8 items designed to measure cohesion, the family’s cooperation in coping with stress, the inner strength of the family, its coherence and ability to work together to deal with stress in the family,
2. “**challenge**”, contains 6 items designed to measure the family’s ability to accept challenges, be active, try new things and learn from experience; and
3. “**control**”, contains 6 items designed to measure the family’s ability to influence life in the family.

In the FHI the respondents assess each statement separately on a scale of 0-3 according to how true that statement is for their family, with the following points assigned: 3 (the statement is true), 2 (somewhat true), 1 (somewhat untrue) or 0 (untrue).

In the additional questions we focused on the determination and subsequent assessment of the following family functionality determinants: composition of the family (family with 1 child, family with 2 or more children, mother living with a partner/mother with no partner), socio-economic situation (mother’s age when

child was born, parents' education, family income, mothers' employment), status (respiratory illness) of the youngest child (Tab. 1).

The data was collected from February to June 2013 and processed using Microsoft Office Excel 2007 and the statistical software SPSS version 15 (SPSS Inc., USA). The hypotheses were verified using Fisher's exact test to create pivot tables; an adjusted residue analysis was used to gain a more detailed analysis of the pivot tables. Due to the abnormal distribution of FHI score values, the validity of the hypotheses was verified using a Mann-Whitney U test. The hypotheses were tested at a significance level of 0.05.

A t-test was used to determine the relationships between family characteristics and the items assessed from the questionnaire. A multivariable comparison was performed using a variance analysis (ANOVA).

Results

Demographic characteristics of the research set

The women who took part in the survey were aged between 24 and 45; the average age was 33. A total of 36 (35.3%) of the mothers we contacted stated that they have 1 child; 66 (64.7%) mothers look after 2 or more children. Of the 102 (100%) women surveyed, 92 (90.2%) stated that they share a home with their partner, and 71 (69.7%) of these were married. Only 10 (9.8%) lived without a partner. Most of those surveyed (90.2%) stated that they had completed a university education or secondary school education with a final leaving examination), while 67.7% of their partners have the same education (university education or secondary school education with a final leaving examination). All the mothers received a parental allowance and all the families lived well above the subsistence level. We found the age of the mothers to be high (i.e. over 35) when their child was born in 27 cases (26.5%).

With the 102 (100%) mothers the APGAR Family screening test revealed 11 (i.e. 10.8%) cases of dysfunctional families and 20 (i.e. 19.6%) cases of slightly impaired family functionality.

Tab. 1 Resilience determinants for families caring for a child suffering frequent acute respiratory illness

Determinants	Subscale			Overall FHI score
	Commitment	Challenge	Control	
Functional families	19.0 18.5 ± 3.6	15.0 14.2 ± 2.9	11.0 10.6 ± 3.1	45.0 43.2 ± 8.0
Families with slightly impaired functionality	14.5 16.1 ± 3.9	12.0 11.7 ± 3.2	10.0 9.8 ± 3.2	37.0 37.6 ± 7.4
Dysfunctional families	12.0 13.3 ± 4.2	8.0 8.9 ± 3.5	10.0 10.3 ± 2.1	31.0 32.4 ± 3.6
P	0.0001	< 0.0001	0.433	< 0.0001
Mothers with no partner	12.0 10.9 ± 4.3	9.0 9.2 ± 4.5	10.0 9.2 ± 3.9	31.0 29.3 ± 11.9
Mothers with a partner	18.5 18.2 ± 3.4	14.0 13.5 ± 3.1	11.0 10.5 ± 2.9	43.5 42.2 ± 6.8
P	< 0.0001	0.003	0.430	0.0002
Youngest child aged up to 24 months	18.0 17.0 ± 4.3	13.0 12.3 ± 3.6	10.0 10.0 ± 3.3	40.0 39.4 ± 8.8
Youngest child aged over 24 months	19.0 18.3 ± 3.6	15.0 14.7 ± 2.6	11.0 11.0 ± 2.3	45.0 44.0 ± 6.3
P	0.124	0.001	0.191	0.011
2 or more children in the family	18.0 17.6 ± 3.8	14.0 13.3 ± 3.4	11.0 10.7 ± 2.9	42.0 41.6 ± 7.1
One child in the family	17.5 17.1 ± 4.6	13.5 12.8 ± 3.7	10.0 9.8 ± 3.3	42.0 39.8 ± 10.2
P	0.723	0.485	0.166	0.441
Illness of the respiratory system with dyspnea	14.0 15.2 ± 4.4	10.5 11.0 ± 4.1	11.0 9.8 ± 3.2	34.5 35.9 ± 6.4
Illness of the respiratory system without dyspnea	18.0 17.8 ± 3.9	14.0 13.4 ± 3.3	11.0 10.5 ± 3.0	43.0 41.6 ± 8.4
P	0.038	0.048	0.600	0.009
Occurrence of 1 illness of the respiratory system in the youngest child	18.5 17.9 ± 3.9	14.0 13.4 ± 3.3	11.0 10.5 ± 3.2	44.0 41.8 ± 8.7
Occurrence of 2 or more illnesses of the respiratory system in the youngest child	16.0 16.3 ± 4.4	12.0 12.2 ± 3.8	11.0 9.9 ± 2.6	36.5 38.4 ± 6.7
P	0.081	0.153	0.385	0.019
Families with lower-educated parents	18.0 18.2 ± 2.6	14.0 13.6 ± 2.6	10.0 10.2 ± 3.9	42.0 41.9 ± 5.9
Families with higher-educated parents	19.5 18.1 ± 3.9	14.0 13.5 ± 3.5	11.0 10.9 ± 2.4	45.0 42.5 ± 7.6
P	0.687	0.625	0.168	0.408

The data in the table is presented as the mean and the average ± SD (standard deviation). The value p shows the level of significance of the Mann-Whitney U test.

Dysfunctional families and families with slightly impaired functionality (according to the APGAR questionnaire) showed significantly lower results on the subscales of commitment and challenge and significantly lower overall FHI scores than functional families. Functional families showed a greater degree of cohesion and parental cooperation in coping with stress and a greater ability on the part of parents to accept challenges and be active. Parents' greater ability to accept challenges and be active as well as higher overall FHI scores were also observed in families with slightly impaired functionality compared to dysfunctional families. See Tab 2.

No significant difference was found on the control subscale.

Tab. 2 Significance of the Mann-Whitney U test with a Bonferroni correction for multiple comparison

	Commitment	Challenge	Total FHI score
Dysfunctional families vs. families with impaired functionality	0.122	0.041	0.037
Dysfunctional vs. functional families	0.0006	0.0002	< 0.0001
Functional families vs. families with impaired functionality	0.021	0.004	0.001

Discussion

This research has provided us with new findings concerning life in families with acute respiratory illness. There is very limited potential for comparison in the Czech and foreign contexts. Most studies focus on the resilience of families with chronic, oncological diseases or disabilities [10, 11]. At the same time, recurring acute illnesses, particularly in the case of a small child, can cause stress for parents, impair functionality, and make it harder to cope with difficult situations in the family.

In our survey only 10 (9.8%) of those questioned lived without a partner, which is higher than the current trend for four-member families [12] and is due to the fact that our survey focused on families with small children. This is a time when problems occur in families and the family starts to face up to them. Families with a mother who lives with her partner showed significantly higher values on the subscales of commitment and challenge and a significantly higher overall FHI score. These families showed a greater degree of cohesion and parental cooperation in coping with stress and a greater ability on the part of parents to accept challenges and be active. No significant difference was found on the control subscale.

Sobotková et al. (2011) stated that women with higher education and more children are pro-family oriented, but are likely to be burdened by far greater de-

mands than mothers with just one child. Our study did not find any significant link between parents' education and family functionality assessed on the basis of the individual FHI subscales or overall FHI score [1].

If problems do arise in the family, such as when dealing with a child who is frequently ill, and those problems accumulate and the family ceases to fulfil its basic purpose, it is essential to provide those families with assistance and focus on eliminating the risks that threaten the child and his or her successful development [3]. Family functionality, as well as the processes that occur within the family, is closely linked to the ability to cope with stress and with family resilience, an issue on which a great deal of attention has been focused in recent years [5]. We see family resilience as a dynamic process that enables the family to remain functional even at times of stress and also to restore harmony and optimise family functionality when this suffers due to stress and family crisis [9].

In our study, mothers with children less than 24 months old showed greater changes in FHI than mothers with children over 24 months of age. In families with children aged up to 24 months, we observed significantly lower results on the challenge subscale and significantly lower overall FHI scores. These families showed a lesser degree of parental ability to accept challenges and be active. No significant difference was found on the subscales of commitment and control.

Research on "Preferred numbers of children in the family" (Svobodová, 2008) showed that at whatever stage in their lives, regardless of whether or not they have children, people clearly prefer two children in the family and this is actually the current trend (84.8%) [12]. Families with 2 or more children did not differ significantly in statistical terms from families with one child as regards their overall FHI score. No significant difference was found, even in the individual subscales of commitment, challenge and control.

As regards assessing the functionality of families with children with respiratory illness, at least 3 times our study identified signs of dysfunction or moderately impaired function in families with small children with recurring acute respiratory system illnesses with dyspnoea. A cross-sectional study which surveyed 25 families with an asthmatic child and 25 asthma-free families showed that families with asthmatic children were more often dysfunctional [13].

No studies have been found on the subject of resilience in connection with respiratory illness. In our survey, carried out in families where small children suffered recurring illnesses of the respiratory system without dyspnoea at least 3 times, significantly higher results were observed on the subscales of commitment and challenge, as well as a significantly higher overall FHI score. These families showed a greater degree of cohesion and parental cooperation in coping with stress and a greater ability on the part of parents to accept challenges and be active. No significant difference was observed on the control subscale. The total FHI score was found to be significantly higher in families where the small-

est child had fallen ill at least 3 times with 2 or more respiratory illnesses. No significant differences were found on the subscales of commitment, challenge and control.

An important inner source of family resilience is family hardiness, indicating the family's inner strength, perseverance and firmness. This term is transferred from the individual level [14]. Families with good resilience see the difficult times they experience as challenges, have a feeling of control over what happens, and are aware that they can actively influence them.

Conclusion

Although the results of the survey did not show any alarming impairment of the resilience or functionality of families caring for a small child between the age of 6 months and 3 years who suffers from frequent respiratory illnesses, it is essential not to underestimate this issue. Thorough education relating to prevention and coping mechanisms has proven to be essential. Illnesses, particularly in the youngest member of the family, may have a serious impact on the whole family.

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Społeczne, psychiczne i ekonomiczne skutki
nietrzymania moczu u osób po 65 roku życia
*Social, psychological and economic effects of
urinary incontinence affecting people over the
age of 65*

Streszczenie

Wielkie zespoły geriatryczne (zwane też wielkimi problemami geriatrycznymi (ang. geriatric giants, dosłownie - geriatryczne olbrzymy) to przewlekłe, wieloprzyczynowe zaburzenia, które stopniowo prowadzą do niesprawności funkcjonalnej, negatywnie wpływając na jakość życia osób starszych. Ryzyko ich wystąpienia wzrasta z wiekiem. Stanowią znaczny problem medyczny, gdyż pacjenci i/lub ich opiekunowie uważają, że zaburzenia te wynikają z procesu starzenia, dlatego nie zgłaszają ich personelowi medycznemu. Nietrzymanie moczu jest schorzeniem, któremu poświęca się stosunkowo mało uwagi, a którego nie powinno się bagatelizować, gdyż wpływa deprymująco na osoby nim dotknięte. Osoby z inkontynencją rzadko zgłaszają się do lekarza, nie szukają pomocy i godzą się tym samym na znacznie gorszą jakość życia, co może skutkować pojawieniem się problemów natury psychologicznej i społecznej. Artykuł porusza społeczne, psychiczne i ekonomiczne aspekty nietrzymania moczu u osób po 65 roku życia. W pierwszej części przedstawiam istotę choroby oraz czynniki predysponujące do jej wystąpienia. Druga część opisuje psychiczne, społeczne i ekonomiczne skutki inkontynencji. Całość kończę podsumowaniem i wnioskami.

Słowa kluczowe: starość, nietrzymanie moczu, wykluczenie społeczne, problemy psychiczne

Abstract

The geriatric giants are chronic, multiple and intersectional disorders that gradually lead to functional disability, while negatively affecting the quality of life of the elderly. The risk of their occurrence increases with age. The geriatric giants represent a significant medical problem. Patients and/or their caregivers believe that these disorders result from the ageing process, which is why they are not often reported to medical personnel. Urinary incontinence is a condition that receives relatively little attention, but should not be ignored due to its depressive effect on those concerned.

People with incontinence rarely seek medical care, do not look for help, and subconsciously accept a significantly poorer quality of life that can lead to both psychological and social problems. The following article presents the social, psychological, and economic effects of urinary incontinence in people over the age of 65. The first part shows the nature of the disease and the factors predisposing to its occurrence. The other part of this paper describes the social, psychological, and economic effects of incontinence. The article ends with a summary and conclusions.

Key words: senility, urinary incontinence, social exclusion, mental disorders

Introduction

Senility is a period of human life associated with a decrease in body efficiency, deteriorating health, change of social role, the risk of dependence, and the emergence of many chronic diseases. What is more, the aging of the human body is a multi-step and multi-faceted process that lasts for many years. The aging process of every human being is individual. Moreover, it has a certain specificity and dynamics and its origins lie in earlier stages of human development. Nowadays, aging is considered jointly in several aspects: biological, concerning the body and sense organs; mental, including mind and feelings; and social, expressed in social activity [1,2].

Urinary incontinence of the elderly population is a common but usually concealed ailment. It is estimated that only one in ten people report this problem to a doctor. Women suffer from this ailment about twice as much as men. The problem of urinary incontinence occurs in the population of active women, although the intensity of discomfort increases sharply with age, especially after menopause. The scale of the problem may be much larger since many people suffer in silence, delaying a visit to the doctor [3]. Lack of awareness of the causes of urinary incontinence, unjustified shyness, ignorance, or the belief that urinary incontinence is the normal part of the aging process, often result in complete alienation from the environment, isolation, mental health problems, depression (high dependency ratio) and avoidance of social or family ties. The effects of incontinence may also include changes in decubitus, skin irritation, recurrent urinary tract infections, sleep disorders, and even falls and fractures. The emergence of this problem is one of the causes of social exclusion and placement of those afflicted in nursing homes and other institutions [4].

Definition of urinary incontinence

According to the World Health Organization (WHO) and the International Continence Society (ICS), urinary incontinence (UI) is defined as an objective lack of control over urination [5, 6, 7]. This condition occurs in the course of many diseases; therefore, there are several types of urinary incontinence with temporary or permanent characteristics.

Urinary incontinence affects a large part of modern society. At the same time, this is an affliction is often concealed from family members and doctors. It is estimated that about two-thirds of all cases of urinary incontinence are withheld because of shame, embarrassment, and insufficient information about treatment possibilities. On average, nine years pass between the appearance of symptoms and revealing it to a doctor. According to the International Continence Society Standardisation, the most common types of urinary incontinence include:

1. stress incontinence,
2. urge incontinence
3. overflow incontinence,
4. reflex incontinence,
5. extra-urethral incontinence.

Stress urinary incontinence (SUI) is the involuntary leakage of urine without pressure due to failure of the bladder locking mechanism. Urine leakage occurs during sneezing, coughing, laughing, or lifting weights, as well as when there is a sudden pressure increase in the abdomen. The cause of this symptom is mainly changes in the muscle system of the pelvic floor. Furthermore, such changes may result from pregnancy and childbirth, lower genital tract and genital birth defects of the urinary organs, injuries, and surgery.

There are three clinically distinguished degrees of stress urinary incontinence (by Stamey):

- I. - leakage of urine at any sudden increase in pressure within the abdominal cavity;
- II. - leakage when standing up, walking, any movement;
- III. - leakage in the lying position [8].

Risk factors include obesity, heavy physical labor, professional sports, perimenopausal estrogen deficiency, and weakening of connective tissue [9, 10, 11]. Urinary incontinence may occur in the course of many diseases, for example heart attack, Parkinson's disease, Alzheimer's disease, diabetic neuropathy, alcoholism, prostate hypertrophy, spinal cord injury, CNS injury, serious intervertebral discs, the state after prostatectomy, diseases of the urethra, and cancer of the urinary system.

The diagnosis and management of urinary incontinence

An interview plays a key role in accurate diagnosis and appropriate therapeutic management. A directed interview is the basic element that allows the type and severity of symptoms to be assessed or the factors that predispose the appearance of dysfunction to be determined. Furthermore, specially prepared questionnaires and standardised questionnaires such as the Incontinence Impact Questionnaire (IIQ) and the Urological Distress Inventory (UDI) are very use-

ful, but less commonly used tools to facilitate diagnosis of urinary incontinence. In addition to the interview, many specialised laboratory tests are carried out. In most cases, urinary incontinence is curable regardless of the age of patients. However, it is a progressive disease; therefore, untreated symptoms lead in time to further degradation. The longer the elapsed time from the first symptoms to medication, the worse are the effects. Studies show that therapy is most effective when implemented in the first four years of the first symptoms. Basic diagnostics are sufficient for treatment of 80-85% of cases [7, 11, 12].

After conducting a thorough diagnosis and recognition of the causes and type of incontinence, the doctor can proceed to the appropriate conservative treatment or surgery. However, it should be noted that the treatment of people with urinary incontinence is generally a lengthy process that must be conducted systematically, often requiring the cooperation of several specialists. During pharmacological treatment, the patient should carefully follow recommendations, should not modify doses, and should not take medicines that have helped another person [11, 13]. If conservative treatment does not have the desired impact or is not possible, surgical procedures might be applied such as perineoplasty, episio-perineoplasty, plastic surgery of the urethra or (for men) partial or total resection of the prostate in cases of hypertrophy [11, 14, 15]. Conservative incontinence treatment results in increased attention being paid to physiotherapy. The most important physiotherapy treatments include pelvic floor muscle training, electrical stimulation, biofeedback, ETS technique, and magnetotherapy [2]. Another type of treatment is behavioural therapy, which involves lifestyle changes including the acquisition of new hygiene habits and eliminating risk factors such as obesity, constipation, and smoking. It covers a range of activities aimed at producing conscious patient behaviours and reactions that control and to some extent modify the mechanisms related to the control of urine. The patient should learn to urinate regularly, completely empty the bladder, lose weight, reduce the intake of fluids, treat constipation and urinary tract infections, avoid extreme effort, and cease smoking. Bladder exercises, which lead to the restoration of cortical control over bladder function, have been used primarily in the treatment of detrusor instability, but are also useful in the treatment of stress urinary incontinence. Preventing the disorder involves paying attention to hygiene and health throughout life. It is also important to treat any defects and abnormalities of the urogenital system [10, 12, 13].

Contrary to common belief, behavioural therapy is not only used in training the bladder. Symptomatic treatment of urinary incontinence can ease the psychological impact of performing many daily activities. Women with micturition disorders often have emotional disorders because of the troublesome symptoms. The stress involved in stress urinary incontinence (SUI) may vary in intensity depending on the severity of the disease, sometimes even leading to depression.

Women often give up social life, work, or significantly limit or modify their activities in various areas of life. The following are applied:

1. Short-term solutions. A fundamental principle of preliminary interactions is acquainting the patient with the essence of his complaints and explaining the causes, possibilities and directions of treatment. Usually at this stage, it is necessary to show diagrams and drawings to facilitate the assimilation of information, depending on education, imaginative capacity, age, etc. Cultural factors make urination in many environments a socially difficult subject that is both avoided and overlooked. Calming the patient and convincing him that a cure is possible are prerequisites to the good cooperation necessary in the process of rehabilitation.
2. Long-term strategy. Modification of behaviour in specific situations is an effective form of treatment for different types of urinary incontinence. There are several techniques to regulate micturition reflex, all of which involve gaining control of the bladder and sphincter. In most programs, it is essential to manage fluid balance. Not all women are aware that the amount of urine is dependent on fluid intake. In the first week, a patient records the quantity of fluids drunk and urine output, as well as voiding frequency and circumstances of urination. The next step involves a bladder-emptying regime. Micturition takes place at set times of the day with the frequency based on the balance of the previous week. Active people (economically, socially etc.) have to modify these measures according to their schedule. It is recommended to avoid situations that trigger the habitual urge to urinate (ie. actively searching for a toilet in every public place, stepping into an elevator with a full bladder, etc.). These recommendations should be implemented simultaneously with learning to tighten and relax the perineal muscles, and thus, through active contraction, coping in emergency situations [6, 16, 17, 18].

Bladder training

Urinary incontinence is common among adult women and the prevalence of the problem is an indicator of the lack of prevention among respondents. Women are ashamed of UI and do not realise that this is an ailment that can and should be treated. In the presented studies, only 16.8% of respondents were able to identify all the factors predisposing to the emergence of symptoms of urinary incontinence; old age was usually indicated (43.6%) and less than half had heard about Kegel muscle exercises. Just 34.6% of respondents considered Kegel muscle exercises in the prevention of UI and 40.2% confirmed the desirability of taking care of their physical condition. According to the data report prepared on behalf of “Core Wellness - inner strength”, only 14% of women suffering from incontinence believed that they have sufficient knowledge of the subject while 52% of women

who suffer from light incontinence did not know that exercising the pelvic floor muscles might partially or completely cure this ailment. A significant number of respondents were convinced that the only treatment is surgery or drug therapy. What is more, 45% of women suffering from incontinence did not mention this ailment to their doctor [8, 9]. After completing a daylong assessment of urination that includes listing times of urination, urine output, and episodes of incontinence, patients should gradually elaborate the frequency of emptying the bladder to prevent excessive filling and prevent constipation pressing on the bladder. This applies especially to people with incontinence caused by functional disorders of the lower urinary tract. Additionally, patients with stress urinary incontinence should urinate in small amounts as this prevents intravesical pressure increase, which also may result in reduced urethra resistance. Exercises to strengthen the pelvic floor muscles produce a twofold effect. On one hand, the patient learns more consciously to use the voluntary muscles surrounding the urethra. This is especially useful in “emergency” situations such as coughing, sneezing, and laughing. On the other hand, regularly conducting exercises braces the position of pelvic floor and increases urethral resistance, which is essential for patients with stress urinary incontinence. Simple exercises that teach how to control the bladder and urethral sphincter muscles are well suited to certain types of urinary incontinence, urinary bladder incontinence, or pelvic floor muscles. Recommendations relating to fluid intake might also be given [11, 19, 20, 22].

Bladder training consisting of urination at predetermined times gradually increases the time between micturitions. Patient education is very important in this case. The effectiveness of bladder training (reduction or disappearance of symptoms) may reach 90% when properly executed. Within 3 years of stopping regular training, 40% of patients experience a recurrence of symptoms, at which time they may repeat the treatment [6]. Notwithstanding the application of the aforementioned method, additional protection against urine leakage is required with the use of various products, in particular, anatomical diapers and nappy pants, depending on the degree of incontinence. There is a whole range of auxiliaries for people with incontinence on the Polish market. These items are adapted to the needs of different groups of patients. Their implementation takes into account the varying types and degrees of severity of incontinence, as well as differences in the anatomy of patients (sizes from XS to XXL are available and products can be selected according to sex, age, level of independence and type of incontinence). They provide hygiene and comfort to patients undergoing treatment or UI transition, both before and after surgery, and in cases where treatment is not effective. By means of their special properties and high absorbency, these products help to maintain proper hygiene and reduce odor. By virtue of these products, patients can function in the labour market, travel, and even play sports without fear that they will be exposed to unpleasant situations. 44%

of respondents indicated that they use absorption products. This very high percentage can probably be explained by the fact that members of the association have above-average knowledge about auxiliaries for people with UI and the consequences of neglecting hygiene. At the same time, the survey reveals that 80% of absorbent product users pay with their own funds, which is probably a result of the very restrictive rules that exclude most people with urinary incontinence from those eligible for refunds. This state of affairs will continue until urinary incontinence is considered a disease that should receive funding [7, 23].

Psychological, social, and economic impacts of urinary incontinence

According to the World Health Organization, urinary incontinence (UI) is one of the ten most important social and health problems of the contemporary world [24]. The International Continence Society (ICS) defines UI as involuntary urination that represents a hygiene problem and hampers social contact. Due to its complex etiology, this state is treated as a symptom, not a homogeneous disease entity. It is assumed that incontinence affects more women (27.6%) than men (10%) and is a serious medical problem affecting from 17 to 60% of the female population, according to various sources. Age plays an important role in the severity of the symptoms. The greatest severity of symptoms was observed among women over the age of 65 (70-80%). Over the age of 55, the problem affects about 39% of women, 37% between the age of 35 and 54, and 18% below the age of 29 [19]. In Poland, urinary incontinence affects over 3 million people, giving a total treatment cost per year of approximately 1.5 billion EUR. For comparison, the cost of surgical treatment of people with UI and the purchase of absorbent products reimbursed by the National Health Fund in Poland in 2004 amounted to 115 million PLN (data presented at the meeting of the Parliamentary Health Committee in March 2005). However, thorough research has never been carried out on the cost of care and treatment of patients with UI in Poland. It is safe to assume that the sum reaches millions of PLN; these costs are borne not only by the patient, but also by the whole of society. The biggest expense is primarily patient care (permanent costs incurred to the end of the life of the patient) and treatment of complications (infections and irritation of the skin), as well as the use of absorbent products. The costs of drugs and surgical procedures are equivalent to the costs of 10 years of absorbent product use. It is estimated that 2.5 to 3 million women have urinary incontinence. The most common type of this disease is stress urinary incontinence, which mostly concerns patients with concomitant reduction of pelvic organs (63%) and urge incontinence (approx. 25% of cases) [16]. In most environments, UI ailments are an intimate problem considered taboo that negatively affects the level of applied prevention and treatment. Due to the commonly perceived shyness problem and

the lack of readily accessible information about treatment options and supporting products, the average time that elapses between the onset of symptoms and seeking medical help is over five years. Only one in twelve patients report the problem to a specialist and many women even hide this condition from their families. Even women themselves rarely admit to the fact that there is a range of people likely to suffer from this symptom [6].

Urinary incontinence is a serious problem that affects many spheres of life of patients. Although it is not a fatal disease, patients suffering from UI suffer both physically and mentally and often experience stressful situations. Stress intensifies through the fear of soaked clothing or not finding a toilet in time. Patients feel discomfort associated with a lack of control over their own body, odor, and chafing. Many women suffering from urinary incontinence no longer feel attractive [7]. Obviously, this disease causes mental as well as physical suffering, worsening the quality of life of the patient and his family. This hinders the smooth functioning of society as sufferers are forced to change their lifestyle, thus limiting their social contacts [24]. In practice, it restricts movement in public places and even leads to a change of career. UI may lead to loss of dignity and self-esteem, anxiety, changes in sexual activity, deterioration of mood, and a fall in social status. The sense of shame makes patients hide their ailments. Some people mistakenly assume that it is a natural and incurable symptom of aging. A comprehensive approach to the quality of life of people with incontinence is vital and is important due to both diagnostics and practical implications [10]. Quality of life improves with the use of auxiliary materials, such as absorbent products and various types of catheter [25].

Urinary incontinence for most women means becoming introverted and not expecting help from the outside for fear of ridicule or disregard of the disease by other community members, leading to problems in the psychiatric and social spheres. This most often results in limited social contact and reduced quality of life of surveyed women [12]. This is confirmed by, among others, prof. Mariola Bidzan from the Division of Clinical Psychology and Neuropsychology of the Institute of Psychology at the University of Gdansk, according to whom incontinence due to the intimate nature of the symptoms and their debilitating affect on everyday functioning has a huge impact on the psyche of the patient and his family. She claims that urinary incontinence significantly affects the functioning of the patient in the three basic areas of his life:

- family sphere – changes in family life, changes in sexual activity (usually a reduction), a burden on the household expenditure related to the treatment of UI and ensuring the personal hygiene of the patient (purchase of absorption products);
- professional sphere – change of career plans, reduction of professional life, modified work schedule, resignation;

- social sphere - limiting social interaction and socialising, alienation.
- In assessing the quality of life of people with incontinence, we can divide it into several spheres of human life affected by urinary incontinence:
- partnerships - spousal bond and relationship quality. Research by prof. M. Bidzan has shown that the quality of a relationship can affect the course of disease. With the support of a partner, a person with a UI ailment can avoid the psychological effects of UI, such as a feelings of stigmatisation, isolation, and anxiety;
- family relationships - acceptance of ailments by family members and immediate surroundings. Social support in the form of family relationships is an important factor in the adaptation of the patient to conditions. It also contributes to a more positive outlook on life and better physical and mental functioning;
- sexual relationships - sexual activity. Incontinence often decreases the frequency of sexual intercourse between partners, leading in turn to lower quality of life. Lack of sexual health can lead to a variety of disorders, complexes, and reduced self-esteem. This can result in psychosomatic, depressive, and neurotic mental health issues, conflicts and tensions in relations, and even irritability in interpersonal relations;
- economic factors - costs of absorption products, drugs, hygiene products, and laundry. It is estimated that economic factors have a greater impact on the quality of life of older people (pensioners) whose household budgets are not able to cover the costs associated with personal hygiene (purchase of absorption products) and treatment of UI (purchase of drugs). This can lead to isolation from society, avoidance of companionship, and increased fear of leaving the house associated with shame about the odor of urine [6].

Actually, in Poland there is so far no data about the full costs associated with the treatment of urinary incontinence. In the United States, it was calculated that the annual cost of treatment is similar to spending on such diseases as osteoporosis and arthritis. Overcoming urinary incontinence may require lifestyle changes, elimination of risk factors, physiotherapy, drug therapy, or surgery if these methods fail [19]. The data contained in the report on the socio-economic costs of urinary incontinence clearly indicates that the amount patients pay for absorption products is very high, amounting to 55% of the costs incurred for refunds on absorption products of the National Health Fund. It is worth noting that according to current regulations, the National Health Fund reimburses 70% of the cost of such products, while the remainder is paid for by the patient. Unfortunately, as shown by the results of the report, less than 70% of such costs are refunded by the National Health Fund, meaning the patient has much higher costs [22]. 100 women with incontinence took part in a study conducted by

B. Ogórek-Tęcza and A. Pulit. The youngest was 36 years old, the oldest 77. Most respondents (39%) were between the ages of 46-55, 32% were women between 56 and 65 years old, 19% up to 45 years. Every tenth respondent was over 65 years old. The largest group consisted of women who had suffered from incontinence for 5-6 years (27%) and subsequently, 3-4 years (23%), and 1-2 years (21%). Patients who had suffered from UI for less than a year or more than 10 years constituted the lowest percentage of the study population (6%). The survey revealed that the emotions that are most often associated with the disease were a sense of shame (25.6%), anger and sadness (17.4%), and anxiety (16.3%). In addition, respondents reported a lower sense of attractiveness (40%), lack of enjoyment of life (27%), feelings of inferiority (15%), and lack of confidence (9%). Only 5% did not confirm that incontinence limits their social life. The vast majority testified to the negative impact of incontinence on relations with others. More than half of women (56%) participated in social activities only a few times a year, and 34% several times a month. A further 6% of the study group said that UI is unlikely to limit their physical activity. A significant majority of replies (38%) concerned confirming the limitation of physical activity by UI symptoms. The impact of urinary incontinence on sexual activity was declared by 43% of women, while 57% of respondents disagreed. More than half of the group said they avoided sexual intercourse, 21% felt discomfort during sexual intercourse, 12% felt shame, 11% discomfort, and 5% nervousness. UI symptoms worsened spousal relations with 56% of respondents. UI impact on working life was confirmed by 46% of the women. The respondents emphasised that incontinence hinders and disrupts work because of the need for frequent use of the toilet. Family was a support for 49% of respondents. 15% of respondents hid the problem. It is worth noting that none of the surveyed women was offered counselling. The respondents expressed the belief that women with UI should receive psychological care (100% of respondents). Women also expected informational (40.1%) and instrumental support from medical staff (26.0%), followed by emotional (20.0%) and evaluative support (13.0%) [21].

Research conducted by Adamczuk et al. confirmed the significant impact of UI on social life, spousal relationships, and professional and sexual activity. More than half of respondents reported meeting friends less (68%). The negative impact of incontinence on social activities (especially young women) is also confirmed by research conducted by Zielinska, Smolarek and Pisarska-Krawczyk. Urinary incontinence in most cases creates considerable difficulties in daily life. Incontinence affects many aspects of life including psychological, family, sexual, professional, and economic. These factors represent a significant burden on the body – especially the psyche – and are a source of stressful situations that may lead to depressive disorders. It is therefore necessary to take up psychological

therapy, inducing women with UI to use primarily adaptive ways of coping with these problems and, in cases of emotional disorders, implement of effective methods of psychological help [26].

The authors of the article „The demand for education on the prevention of urinary incontinence of women” conducted a study of 179 women with an average age of 47.1, residing in Leżajsk, Lubaczów and surrounding areas in Poland. 61.5% of the respondents had symptoms of urinary incontinence, most often felt when lifting and doing physical activity, but also during sneezing, coughing, and laughing. Female patients showed a very low level of knowledge in the field of predisposing factors for urinary incontinence. In relation to people with vocational (54.55%) and basic education (41.18%), respondents with higher education (80.95%) significantly more often believed that incontinence is a disease and indicated the possibility of treatment. A significant proportion of respondents (75%) wanted to deepen their knowledge in the field of urinary incontinence. The conclusion presented was that the prevalence of urinary incontinence indicates a lack of knowledge about prevention. There is a great need for education on the problem of urinary incontinence and prevention. Dissemination of knowledge on the causes, symptoms, and treatment options would allow for earlier disclosure of the problem, faster and more effective diagnosis and therapy, and ought to help to improve the quality of life of sufferers [20].

A report containing a study was created under the auspices of the World Federation of Incontinent Patients (WFIP) in collaboration with “UroConti” (the Association of People with UI), using materials from the years 2002 to 2015. This programme was carried out on 200 sample UroConti members aged 29-89. 96% of respondents suffered from urinary incontinence, while 4% provided care for a single person affected by this disease. 94% of respondents were female, 4% were men. The majority (87%) of the respondents were retired, 9% were economically active, and 4% were pensioners. 75% of respondents did not have any degree of disability. This study confirms the information presented in the previous section of the report and indicates a lack of a coherent and comprehensive strategy to deal with urinary incontinence issues in Poland such as difficulties in accessing diagnosis, treatment, basic hygiene measures, and consequently the devastating impact of the disease on both private and professional life. It should be also emphasised that the study was conducted among members of the association; people aware of the importance of the problem with knowledge about treatment, reimbursement, and access to professionally conducted pelvic floor exercises or medical consultations organised by this body. Despite these advantages, they still felt a barrier to accessing to appropriate treatment. Therefore, we should assume that knowledge about urinary incontinence is poor among patients, doctors, and especially primary care doctors from small towns, villages, and regions where there are no branches of UroConti [22].

Summary

All over the world, due to the continual development of civilisation, as well as progressive industrialisation and urbanisation, the number of factors affecting our health and life has increased dramatically. Urinary incontinence is one of the leading social diseases. The incidence of urinary incontinence (regardless of type) has been growing steadily and now stands at a high proportion of approx. 10% of Europeans. This disease coexists with a range of lifestyle diseases such as diabetes, hypertension, obesity, and chronic obstructive pulmonary disease. When analysing the economic aspects, it can be seen that the medical expenses of urinary incontinence (both conservative and surgical), rehabilitation, and absorbent products are very high and still rising [5]. UI is perceived by representatives of the World Health Organisation (WHO) as one of the most important global health problems of the twenty-first century. This condition probably affects more than 200 million people in developed and developing countries [16].

Many complications that go far beyond the inability to keep urine in the bladder can develop among patients with urinary incontinence. Immobilised people may suffer from bedsores due to painful perineal skin irritation. Improper handling of people with UI is sometimes the cause of frequent urinary tract infections, which can even lead to sepsis. The psychosocial consequences of this disorder are also significant. People with UI often withdraw from social life, fearing an episode of incontinence in public. This leads to social isolation, which may lead in turn to the onset of depression [13].

The frequency of stress urinary incontinence (SUI) among women in Poland is difficult to assess accurately. Conducting epidemiological studies in different age groups and different social groups requires time and commitment of many resources. It is also difficult for cultural reasons. This issue, which concerns intimate and embarrassing spheres of life, has until recently been overlooked by women themselves, even from environments with a fairly high level of health education. This disease primarily affects women in middle and old age, but it can also affect young women. It is believed that urinary incontinence affects over 30% of people over 65 years old in Poland. This disease is a serious social problem as sufferers have a clearly impaired quality of life and often withdraw from professional and social life, having a dramatic impact on their psyche and family life. In general, it can be concluded that the reasons for which this issue is increasingly being spoken about are associated with the following factors:

1. The growing number of older women. The phenomenon of “aging society” also concerns the Polish population, as more and more women live longer, thereby imposing increased demands on the state.
2. There is a growing level of health education and increased availability of specialists. This allows women to pay more attention to their health and quality of life.

3. Increasing knowledge of urinary incontinence in the medical community focuses the attention of specialists (urologists, gynecologists) and other doctors on this problem.
4. Costs incurred due to stress urinary incontinence are certainly higher than early diagnosis, treatment, and prevention [18, 27].

The geriatric giants are relatively common and neglected phenomena among the elderly. Unfortunately, they are attributable to the consequences of aging and left without diagnosis or intervention. Furthermore, patients often do not remember that natural aging leads to age-related pathologies. The geriatric giants are the result of chronic diseases; however, their course can and should be changed. Diseases often subside with treatment, proper conduct, and rehabilitation supplies, while patients recover functional abilities and independence. Ignoring the geriatric giants leads only to more dependence on caregivers, thereby increasing workloads and social costs [28].

Conclusions

1. An analysis of the issues presented in the article shows that urinary incontinence is a serious problem not only for people suffering from this condition, but also for their surroundings.
2. Symptoms of urinary incontinence induce shame, therefore very few people seek help from doctors.
3. Due to the scale of the problem, there is a need for broad public education and prevention.

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Etyczne aspekty prowadzenia masowych badań przesiewowych noworodków *Ethical Aspects of Neonatal Mass Screening*

Streszczenie

Etyka jest integralną częścią medycyny, a jej ogólne zasady obejmują, w stosunku do pacjenta, jego autonomię, czynienie dobra, brak czynności szkodliwych oraz przestrzeganie jego praw. Prowadzenie masowych badań przesiewowych noworodków wymaga wyjątkowo ostrożnego postępowania, bowiem wpływ informacji przekazywanych rodzicom (rodzinie) ma, również etycznie, charakter znaczący.

Każdy program przesiewowy musi spełniać określone kryteria. Szczególnie ważna jest wiedza o chorobie, możliwości leczenia, wiarygodność testu oraz koszty badania.

Badania przesiewowe noworodków posiadają cechy szczególnie ważne z punktu widzenia etyki takie jak wystąpienie choroby przewlekłej, informacja genetyczna, identyfikacja bezobjawowego nosiciela oraz zrozumienie informacji przez rodziców.

Z punktu widzenia etyki istotna jest znajomość wagi badania przesiewowego w sferze psychologicznej, socjalnej i ekonomicznej oraz faktu, że zarówno dziecko jak i jego rodzice nie biorą udziału w całym procesie.

Ważna jest pełna informacja dla rodziców i pewność, że działa się w najlepiej pojętym interesie pacjenta, jego rodziców i całej rodziny.

Aby zachować autonomię pacjenta należy przedstawić możliwości leczenia i uzyskać akceptację oraz zrozumienie jego stosowania.

Słowa kluczowe: etyka, masowe badania przesiewowe noworodków

Abstract

Ethics is an integral part of medicine; its general principles include autonomy, doing good, absence of detrimental actions, and observing the law while interacting with patients. Special caution is required while conducting neonatal mass screening due to the significance of information conveyed to parents or families.

Neonatal screening is significant from an ethical perspective due to such factors as chronic affliction, genetic information, asymptomatic carrier identification, and possible parental and societal

failure to distinguish between a healthy carrier and an ill individual.

Understanding the significance of a screening test in the psychological, social, and economic sphere is important, as is the fact that the child and its parents do not participate in the screening process. Importantly, parents need complete information and assurance that all activities are in the best interests of the patient, his parents, and the entire family.

To preserve the autonomy of the patient, treatment options should be presented and acceptance and understanding of their employment ensured.

Key words: ethics, neonatal mass screening

Introduction

In human activities, the objective of ethics is to protect the personal interests of particular individuals. According to the Wielka Encyklopedia PWN (Great Encyclopedia, Polish Scientific Publishers), ethics is a term used first by Aristotle in the 4th century BC in relation to *ethos*, which is understood as human character, customs, or in other words, the established mode of behaviour in the environment in which one lives. However, in every-day language ethics is a complete set of moral norms recognised as a point of reference for evaluation and regulation of behaviour [24]. Thus, one should pay particular attention to the issue of moral behaviour in such a significant field as medicine. “*Primum non nocere*” (firstly, do no harm) is one of the principles that was conveyed by Hippocrates in the Oath included in the canon of medical ethics (42-400 BC), and is still valid until this very day. This is associated with searching for ethical rather than legal principles while managing a patient. Ethical principles applicable in medicine may be presented as the following list: autonomy (an ability to choose), doing good, causing no harm (proper management), and adherence to principles (just conduct). The program of neonatal mass screening, being a component of medical management, should also be considered from an ethical viewpoint.

In 1968, the WHO approved the Wilson-Jungner criteria and accordingly introduced screening tests [11]. The criteria are as follows:

1. The disease is an important health-related problem.
2. There is an acceptable therapeutic method for each diagnosed disease.
3. There are available centres where the disease is diagnosed and treated.
4. There are no early clinical symptoms of the disease.
5. A simple and sensitive analytic method for detecting the disease is available.
6. The employed analytical method has been accepted for a given population.
7. The course of the disease from its overt to fully symptomatic form is known.
8. There are expert recommendations qualifying a patient for treatment and the therapeutic method.

9. The cost of disease detection (including diagnosis and treatment) has to be economically balanced with possible expenditures of the health care system understood as a unity.
10. Screening should be a continuous mass process rather than a one-time project.

The above criteria are inseparably associated with knowledge of issues such as the incidence of the disease, its clinical presentation and course, the employed analytical method (its sensitivity, specificity and predictive value), the possibility of a prompt initiation of treatment to protect the patient against the consequences of the disease, and appropriate assessment of the costs of the test (economic balance: the cost of screening is lower than the cost incurred by a case detected too late that requires much higher expenditure).

In 1994, the Council of Europe presented their recommendations addressing the introduction of neonatal mass screening, emphasising that such programs were justified only when the intervention was directed towards an immediate, health-associated benefit for the child. Otherwise, screening should be postponed until the child could be independently capable of reaching a decision concerning diagnostic management [3].

Neonatal mass screening in Poland

In Poland, neonatal mass screening programs were successively introduced in 1964, initially for phenylketonuria and subsequently for congenital hypothyroidism, cystic fibrosis, and rare metabolic diseases [2, 18].

The oldest generally accepted screening programs aimed to detect phenylketonuria and congenital hypothyroidism. It seems that thanks to these programs, considerable progress has been made in the field of public health. They are most likely among the most efficient and effective programs, since they have saved and continue to save thousands of people from severe damage to the central nervous system, or even death. In addition, they are profitable, being a source of savings for society due to the complete, normal development of individuals affected by the detected and appropriately treated diseases. Additionally, these two screening programs have set standards that should be met by each subsequently introduced program. From the viewpoint of ethical problems, it is important that such tests meet the criterion of universality; in other words, each live-born child should be subjected to the test and cannot be excluded from the screening. Thus, procedures have to be introduced that are capable of preventing the above situation. One of the solutions employed in Poland is represented by bar codes with a defined number that are affixed to filter paper strips for blood collection. Each child is allocated a number that is also entered into its medical record book. Laboratory tests should be performed promptly enough to allow for a confirmatory test to be carried out on each child detected by screening and for treatment

to be introduced before the child is two weeks old, or as soon as possible [5, 15, 16, 17].

When valuating the psychological and social aspects of screening, one should pay particular attention to conveying appropriate information to parents. At the time of testing, the child does not participate in the process of reaching the decision to be subjected to such a test. The mother or the parents may refuse to allow their child to be screened after having received complete and full information on the consequences of such a decision. This is associated with the possibility of the disease manifesting at a later date and with treatment failing to bring a complete, positive result due to lesions that may develop in the central nervous system during the overt phase of the disease.

Of high importance is also the information conveyed to parents at the time of diagnosis confirmation. If phenylketonuria is detected, genetic factors are discussed along with possible disease inheritance.

Neonatal mass screening has been extended to include diseases whose treatment is not associated with such spectacular results as with phenylketonuria or congenital hypothyroidism. The development of diagnostic methods has contributed to extending the spectrum of detectable rare congenital defects, but unfortunately, for numerous diseases there is no prophylactic and/or therapeutic management available. The introduction of mass screening for detection of cystic fibrosis has allowed for earlier detection of the condition, while the employed therapy undoubtedly contributes to improving the quality of life and life expectancy. The procedure for the above test is two-stage, since apart from a biochemical test, the same sample serves as a source of material for a molecular study, for which the consent of the parents or legal guardians should be obtained. The consent should be informed, hence providing reliable information on screening tests, their purposefulness, importance and need is necessary [18]. Therefore, ethical issues should concentrate on availability of information and, from a diagnostic viewpoint, properly selected normal values. At the end of each test a decision has to be made by the patient (by the parents in case of the discussed tests), a physician, or an appropriate body that establishes health-associated policy. This is why attention should be focused on proper development of the program, from planning, through organisation and adoption of procedures, to securing adequate financing for its implementation. Of utmost importance is formulating the objective of the screening program, whose meaning may vary between countries, and focusing on the inclusion of various diseases regarded to be serious or life-threatening [1, 4].

The most important ethical principles that form the foundations of planning and implementation of screening programs are related to the principle of doing no harm presented by Hippocrates; thus, we need to remember that not only the actual patient – in this case a new-born – is important here, but also its

parents and extended family. Thus, we should make sure that all activities associated with performing a screening test are done in the best interest of the patient. If consent is granted to perform molecular studies as a supplementation of the biochemical test, one should be governed by the autonomy of the patient, or its parents in the case of neonatal screening [9, 14].

It seems that neonatal mass screening for congenital hypothyroidism (hypothyreosis) and phenylketonuria is beneficial and its possible side effects are minimal. Furthermore, in keeping with WHO recommendations, the benefits allow for the waiving of the requirement for parental consent for subjecting a child to a test and should be obligatory and administered free of charge in all countries where such programs exist [3, 13, 22, 23]. In Poland, the aforementioned tests are carried out based on regulations issued by the Ministry of Health which also covers incurred expenses [6, 7]. As a result of such a solution having been adopted, a very important ethical aspect is fulfilled; namely, access to preliminary and subsequently to confirmatory diagnostic management when disease is detected in the screening procedure. It should be borne in mind that screening tests are preliminary and require verification, unlike diagnostic tests. By virtue of the appropriate analytical assessment, i.e. a determined cut-off value for the test, it is possible to pinpoint the group affected by a given disease and offer such individuals proper confirmatory diagnostic management and treatment. While evaluating mass screening procedures, the possibility of false positives and negatives should not be overlooked, meaning both analytical chemistry specialists and physicians should be available to provide an explanation in such situations.

Due to its two-step character which combines a biochemical and a molecular test, the introduction of neonatal screening for cystic fibrosis has revealed an additional ethical aspect: not only ill individuals are detected, but mutation carriers should also be subject to specialist medical care. Identification of an asymptomatic disease carrier makes the future parents capable of making informed decisions related to having children. It may turn out, however, that the idea of carriership is not understood by the parents, leading to anxiety and abnormal relations between the parents or family members, and at times between the parents and the child.

The availability of new technologies such as tandem mass spectrometry (MS/MS) has increased the number of congenital diseases that may be detected postnatally. These rare conditions must be treated in specialised centres, which leads to additional logistic problems for parents. Mass screening is carried out with this method in Poland and rare metabolic diseases are detected. In classic tests, it is possible to determine only a single parameter, whereas mass spectrometry allows for determining approximately 100 distinct parameters in a single sample. In Poland, neonatal mass screening detects rare metabolic diseases (a panel of 21 conditions) [12, 26]. In 2005, the American College of Medical Genetics and

Genomics (ACMG) performed a critical analysis of the possibilities of identifying genetic diseases by means of MS/MS and concluded that employing the technique was economically sound for two conditions: phenylketonuria (PKU) and medium-chain acyl-CoA dehydrogenase deficit (MCAD) [21]. Nevertheless, continuous development of therapeutic methods has also allowed the employment of extended screening programs to be justified. Although there are arguments suggesting that lack of evidence of health-associated benefits should not delay the introduction of screening tests, it is necessary to collect data as this can be used in the development of further tests and screening programs [12, 25, 26]. Evidence pointing to both benefits and negative effects is necessary. In view of the ethical conduct towards interested parties, information about such tests should be conveyed to the parents, as is done in Poland by means of informative leaflets to be found in obstetric wards, or available as a description of the procedure of neonatal mass screening on the website of the institution responsible for carrying out such screening in Poland – the Department of Neonatal Mass Screening, Institute of Mother and Child, Warsaw.

Storage of test materials should be assessed (filter papers with unused samples) in order to ascertain how long the materials should be stored, who they may be made available to, and their possible use in other research programs. Regarding other research studies being performed, a question should be raised whether consent should be sought from owners of test materials, whether such consent could be withdrawn, and who should actually grant consent: the interested party (the parents or legal guardians), the Ethical Committee, or a body such as the Ministry of Health [10, 19, 20].

Summary

Ethical problems associated with neonatal mass screening programs are identical to ethical problems observed in medicine generally and, for this reason, they should be subjected to in-depth analysis. It is of utmost importance that screening tests are transparent and that reliable information is conveyed to parents. However, such information should be combined with education so parents can properly understand the objectives and benefits derived from the screening test, i.e. the possibility of prompt disease detection and introduction of early treatment. It seems that an appropriate place for such education could be found in institutions offering Lamaze classes.

From an ethical perspective, mass screening programs have special importance. In addition to the unquestionable benefits, they entail certain psychological, social, and sometimes economic risks as preventive endeavours may have limited value due to lack of possible therapeutic measures against some diseases. Finally, we have to face the fact that neither the child, nor in some situations

parents can participate in the decision-making process. Questions are numerous and this is why – in view of the development of analytical technologies allowing for the detection of many congenital diseases – it seems worthwhile to evaluate mass screening programs from an ethical viewpoint. Thus, we have to deal with dilemmas such as acting in the best individual interest of the patient or detecting a disease that is beneficial to the patient but becomes an issue that is difficult to accept by the family, and the autonomy of the parents, who may refuse their consent to therapy or fail to comply with treatment, which is a tragedy for the child. Nevertheless, there is always the option of initiating pilot studies to evaluate benefits and negative effects, thus leading to a responsible introduction of subsequent programs of a mass character.

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Jakość życia seniorów w środowisku domowym i zakładach opieki społecznej *Quality of life of seniors in the home care environment and social care institutions*

Streszczenie

Wstęp

Niniejsza praca poświęcona jest problematyce jakości życia seniorów w okresie starzenia się i starości. Starość to ostatni etap życiowy, w którym seniorzy mają prawo do prowadzenia pełnowartościowego życia. W środowisku, w którym senior żyje, musi istnieć przestrzeń do życia, jak również trzeba w nim stworzyć możliwość utrzymania poczucia własnej wartości i funkcjonowania nawet w przypadku problemów/ograniczeń fizycznych. Seniorzy stają się zależni od pomocy innych, przede wszystkim od dzieci, krewnych, znajomych a w skrajnych przypadkach nawet od pracowników pomocy społecznej czy pracowników służby zdrowia.

Cele: Głównym celem pracy jest określenie jakości życia seniorów jako całości, jakości życia seniorów żyjących w zakładach opieki społecznej oraz w środowisku domowym. Następnym celem pracy jest określenie różnic w jakości życia seniorów w zależności od wieku (60-74 lat, 75 lat i powyżej). Kolejnym celem jest określenie zależności między typem zamieszkania (środowisko domowe i zakłady opieki społecznej), fizycznym a psychicznym stanem zdrowia, poziomem samowystarczalności, częstotliwością występowania chorób przewlekłych i wykształceniem seniorów. Ostatnim celem niniejszej pracy jest analiza ekonomiki zdrowia seniorów.

Próba badawcza: Próbę badawczą tworzyło 120 respondentów – seniorów w wieku 60 lat i powyżej, z czego 59 seniorów mieszka w środowisku domowym a 61 seniorów przebywa w zakładach opieki społecznej.

Metody: Główną metodą empiryczną był zmodyfikowany kwestionariusz dotyczący jakości życia.

Wnioski: Badania wykazały, że jakość życia seniorów jest średnia i mniej więcej taka sama w obu porównywanych grupach. Autorzy stwierdzili statystycznie nieistotną różnicę pomiędzy jakością życia seniorów i typem ich zamieszkania czy wiekiem. Badania dalej wykazały statystycznie istotną zależność pomiędzy typem zamieszkania seniorów a ich wykształceniem oraz częstotliwością występowania chorób przewlekłych, zwłaszcza chorób psychicznych i jaskry. W zakładach opieki społecznej żyją przeważnie seniorzy z wykształceniem podstawowym i chorobami przewlekłymi.

Zakończenie: Wbrew temu, że trudno oczekiwać osiągnięcia 100% jakości życia seniorów, można

stwierdzić, że istnieje stosunkowo duża przestrzeń do jej poprawiania.

Słowa kluczowe: starzenie się, starość, wiek, jakość życia, jakość życia seniorów, zakłady opieki społecznej

Abstract

Background: The authors analysed the issue of the quality of life of seniors during aging and old age. Old age is the last period of life in which seniors are able to lead a fulfilled life. Seniors become dependent on the assistance of their family, friends, and social or medical services. *Aims:* The main research goal was to determine quality of life of seniors, with the focus on social care institutions and the home care environment. The second goal was to determine the difference in the quality of life of seniors aged from 60 to 74 years, and from 75 years and older. The third goal was to determine the relationship between the type of housing (home care and social care institutions) and a senior's health (mental and physical), a senior's independence, the incidence of chronic diseases, and senior education. The last goal was to assess their economic health. *Research sample:* The research sample consisted of 120 respondents aged 60 and over: 59 seniors from home care environments and 61 from social care institutions. *Methods:* The main empirical method was the modified quality of life questionnaire developed by the Faculty of Healthcare, Trenčín. *Results:* The research results confirmed that the quality of life in seniors in home care environments and social care institutions was average (medium) and about the same in both groups of participants. A statistically significant difference was not found between the quality of life in seniors, their age, and type of accommodation. Our research indicated a statistical significance between accommodation type, education level, and chronic diseases, particularly mental illnesses and glaucoma. *Conclusion:* We did not expect that the quality of life in seniors would be perfect, but believed there would still offer considerable room for improvement.

Key words: Aging, Health, Home Care, Quality of Life, Seniors, Social Care Institutions

INTRODUCTION

Aging and old age are basic factors that affect the quality life of every human being. They represent the final stage of life in which human beings are able to lead a full life. Currently, seniors in this period of decline are considered useless, as the prevailing value is the cult of youth, beauty, wealth, and power (Laca, 2012).

Health Condition of Seniors

Aging adults can be objectively considered healthy if they have the ability to adapt and the signs of aging are compensated for. In terms of its impact on quality of life, objective health condition is considered less important than subjective health perception. Aging adults feel subjectively healthy when they do not complain about their health condition, feel good, are socially adaptable, and tolerate their environment well (Hegyi, 1996, p. 34).

Quality of Life in Seniors

The problem of quality of life is one of the most discussed topics in society. According to Draganova (2006), the subjective factors of quality of life include

moral agents, self-esteem, personal relationships, the ability to control life and satisfaction with it, spiritual life, and religious faith. The objective factors include physical condition, cognitive function, emotional status, functional capacity, and social and sexual function. Other important factors according to Draganova are housing, environment, social network and support, satisfaction with government, public institutions, and criminality.

Mental adaptability to changes associated with aging is also quite important for quality of life in seniors (Haškovcová, 2010). Šimová (2004, p. 128-129) states that quality of life of seniors depends on their physical health, extent of independence, cognitive functioning, adaptation and coping, prevailing emotional experience, adoption and provision of psychological support, and spirituality. The authors add that the quality of life of seniors depends also on the adaptation of their own aging.

Caring for Seniors in a Home Care Environment

The main goal of social and health care is to keep seniors in their original family environment (Tobišová, Jarošová, 2009). It was proven in the past that if seniors live where they wish to live, they are happier, healthier, and more self-sufficient compared to those in social care institutions (Litomerický, 1998). There is no doubt that the most optimal environment is the family of a senior that can increase the efficiency of his or her treatment and rehabilitation. Pacovský (1990, p. 54) and Haškovcová (2010, p. 286) share the opinion that the family should meet three basic requirements in order to ensure optimal care for an older member of a family who is not self-sufficient in his or her natural home environment. It is important that family members want to, are able to, and manage to take care of a senior.

Nursing Care of Seniors in Social Care Institutions

The authors Tobišová, Jarošová (2009) and Ibosová (2011) share the view that social service should provide comprehensive care focused mainly on the quality of life of seniors.

Apart from essential care, there is also nursing, rehabilitation and medical care, all of which have an important place in the hierarchy of values in seniors (Hegyí, Krajčík, 2010, p. 63). Care for seniors is demanding both physically and mentally. It is important to provide highly specialised professional carers who have enough empathy to contribute to enhancing the quality of life of seniors. The role of nursing staff is to provide care to seniors that enables them to maintain the maximum possible level of independence (Nemčeková et al., 2000). The criterion of quality of nursing care is a happy senior and family.

RESEARCH PROBLEM

We formulated the research problem as following:

In what ways is the quality of life in seniors who live in social care institutions different from the quality of life in seniors who live in home care environments?

Research Goals

We specified the following research goals:

1. Identify and compare the quality of life of seniors who live in home care environments with the quality of life of seniors who live in social care institutions.
2. Determine the relationship between the type of housing (natural home environment or social care institution) and the physical health of seniors;
3. Determine the relationship between type of housing and the level of independence of seniors;
4. Determine the relationship between type of housing and the mental health of seniors.

METHOD

Participants

The participants included 120 seniors, of whom 59 lived in home care environments and 61 in social care institutions (homes). 64 seniors were aged from 60 to 74, and 56 were aged 75 and more. To collect the data we used a modified questionnaire which included 27 items, of which 13 were closed, 6 open, 1 semi-closed, and 7 on a numerical scale from 0 to 10 (worst was 0, best was 10). The questionnaire was divided into 6 parts: A. Demographic survey; B. Clinical survey; C. Awareness of diseases; D. Quality of life; E. Economics; F. Quality of Life questionnaire EQ-5D.

Process

Research preparation consisted of a pilot study attended by twenty seniors in August 2014.

RESULTS

Quality of life in seniors in social care institutions

Table 1. Evaluation of Quality of Life in Social Care Institutions

Social care institution						
Item	n	%	median	SD	min	max
Current QoL	61	100.00	7	2.23	1	10
Impact of disease on QoL	61	100.00	5	2.55	0	10
QoL in the health	61	100.00	10	1.78	5	10
Current work ability	61	100.00	5	3.19	0	10
Work ability in periods of good health	61	100.00	10	1.58	4	10
Impact of treatment on QoL	61	100.00	6	9.12	0	10
Impact of diseases on QoL of close relatives	61	100.00	9	2.93	0	10

Legend QoL – quality of life, SD – standard deviation, min – minimum value, max – maximum value

First, we evaluated the current quality of life of seniors in social care institutions and found that the median was 7 and the standard deviation was 2.23. The minimum value was 1 and the maximum was 10. When assessing the impact of disease on life quality of seniors, the median was 5 and the standard deviation was 2.55. The minimum value was 0 and the maximum value was 10. When evaluating the quality of life in the period of health of seniors, the median was 10 and the standard deviation was 1.78. The minimum value was 5 and the maximum value was 10. When evaluating the current work ability of seniors, the median was 5 and the standard deviation was 3.19. The minimum value was 0 and the maximum value was 10. When evaluating current work ability in the period of health by seniors, the median was 10 and the standard deviation was 1.58. The minimum value was 4 and the maximum value was 10. When assessing the impact of treatment on work ability of seniors, the median was 6 and the standard deviation was 9.12. The minimum value was 0 and the maximum value was 10. When evaluating the impact of disease on quality of life of close relatives of seniors, the median was 9 and the standard deviation was 2.93. The minimum value was 0 and the maximum value was 10.

Table 2. Evaluation of Quality of Life in Home Care Environment

Item	Home care environment					
	n	%	median	SD	min	max
Current QoL	59	100.00	6	2.05	0	10
Impact of disease on QoL	59	100.00	6	2.38	0	10
QoL in the period of health	59	100.00	9	1.90	0	10
Current work ability	59	100.00	6	2.43	0	10
Work ability in periods of good health	59	100.00	10	1.66	5	10
Impact of treatment on QoL	59	100.00	6	1.93	2	10
Impact of diseases on QoL of close relatives	59	100.00	7	2.26	0	10

Legend QoL – quality of life, SD – standard deviation, min – minimum value, max – maximum value

When evaluating the current quality of life of seniors in home care environments, the median was 6 and the standard deviation was 2.05. The minimum value was 0 and the maximum value was 10. When assessing the impact of the disease on quality of life of seniors, the median was 6 and the standard deviation was 2.38. The minimum value was 0 and the maximum value was 10. When evaluating the quality of life in the period of health of seniors, the median was 9 and the standard deviation was 1.90. The minimum value was 0 and the maximum value was 10. When evaluating the current work ability of seniors, the median was 6 and the standard deviation was 2.30. The minimum value was 0 and the maximum value was 10. When evaluating current work ability in the periods of good health, the median was 10 and the standard deviation was 1.66. The minimum value was 5 and the maximum value was 10. When assessing the impact of treatment on work ability of seniors, the median was 6 and the standard deviation was 1.93. The minimum value was 2 and the maximum value was 10. When evaluating the impact of disease on quality of life of close relatives of seniors, the median was 7 and the standard deviation was 2.26. The minimum value was 0 and the maximum value was 10.

The analysis of selected quality of life aspects showed no statistically significant difference in the impact of housing type on the quality of life of seniors. In all of the items, the p value was $p > 0.05$.

The primary aim was to identify and compare the quality of life of seniors who lived in home care environments with the quality of life of seniors who lived in social care institutions. Based on the results of our research, we can conclude that current quality of life was evaluated similarly by seniors in both compared groups of participants. The impact of disease and treatment on current quality of life was evaluated as average by seniors in both compared groups. The quality of life in periods of good health was

mostly evaluated by groups as best. Dimunová et al. (2013) concluded that the quality of life of seniors who lived in social care institutions was the same or better than the quality of life of those who lived in home care environments. On the other hand, Uher's (2014) research indicated that seniors who lived in home care environments had a better quality of life than those who lived in health and social care institutions.

Our research results indicated that medical conditions of seniors in home care environments affected close relatives more significantly than the close relatives of seniors in social care institutions. This was probably related to the fact that seniors in social care institutions were not in such close contact with their close relatives, thus the care for seniors was provided more by health and social care professionals.

Relationship between the Type of Housing and Physical Health of Seniors

Table 3. Pain – Discomfort

Pain – Discomfort	Social care institution		Home care environment		Total	
	n	%	n	%	n	%
No pain – discomfort	8	13.12	15	25.42	23	19.17
Mild pain – discomfort	20	32.79	20	33.90	40	33.33
Moderate pain – discomfort	25	40.98	16	27.12	41	34.17
Quite bad pain – discomfort	6	9.84	6	10.17	12	10.00
Severe pain – discomfort	2	3.28	2	3.39	4	3.33
N	61	100.00	59	100.00	120	100.00

The secondary aim was to determine the relationship between the type of housing (natural home environment or social care institution) and the physical health of seniors. In social care institutions 8 seniors (13.12 %) said that they felt neither pain nor discomfort. 20 seniors (32.79 %) said they felt mild pain or discomfort. 25 seniors (40.98 %) claimed they felt moderate pain or discomfort. 6 seniors (9.84 %) stated they felt quite bad pain or discomfort. 2 seniors (3.28 %) claimed they felt severe pain or discomfort.

In home care environments 15 seniors (25.42 %) said they felt neither pain nor discomfort. 20 seniors (32.79 %) claimed they felt mild pain or discomfort. 16 seniors (27.12 %) stated that they felt moderate pain or discomfort. 6 seniors (10.17 %) claimed they felt quite bad pain or discomfort. 2 participants (3.39 %) said they felt severe pain or discomfort.

The analysis of results showed no statistically significant difference of the type of housing on the physical health of seniors. The p value was $p > 0.05$.

Relationship between the Type of Housing and the Level of Independence of Seniors

Table 4. Senior Mobility

Mobility	Social care institution		Home care environment		Total	
	n	%	n	%	n	%
No problems	13	21.31	26	44.07	39	32.50
Mild problems	18	29.51	15	25.42	33	27.50
Moderate problems	18	29.51	9	15.25	27	22.50
Serious problems	10	16.39	8	13.56	18	15.00
Incapable	2	3.28	1	1.70	3	2.50
N	61	100.00	59	100.00	120	100.00

13 seniors (21.31 %) who lived in social care institutions stated that they had no walking problems. 18 (29.51 %) claimed they had mild walking problems and the same number (29.51 %) claimed they had moderate walking problems. 10 seniors (16.39 %) said they had serious walking problems. 2 respondents (3.28 %) stated they were incapable of walking.

26 seniors (44.07 %) who lived in home care environments stated they had no walking problems. 15 (25.42 %) said they had mild walking problems. 9 (15.25 %) had moderate walking problems. 8 (13.56 %) had serious walking problems and 1 (1.70 %) was incapable of walking.

Table 5. Ability of Seniors to Take Care of Themselves

Ability of seniors to take care of themselves	Social care institution		Home care environment		Total	
	n	%	n	%	n	%
No problems	31	50.82	46	77.97	77	64.17
Mild problems	11	18.03	9	15.25	20	16.67
Moderate problems	10	16.39	2	3.39	12	10.00
Serious problems	5	8.20	2	3.39	7	5.83
Incapable	4	6.56	0	0.00	4	3.33
N	61	100.00	59	100.00	120	100.00

31 seniors (50.82 %) in social care institutions claimed they had no problems washing, bathing, and dressing. 11 (18.03 %) said they had mild problems with washing, bathing, and getting dressed. 10 (16.39 %) stated they had moderate problems washing, bathing, and getting dressed. 5 (8.20 %) said they had serious problems washing, bathing, and getting dressed. 4 participants (6.56 %) claimed that they were incapable of washing, bathing, and getting dressed.

46 seniors (77.97 %) who lived in home care environments stated that they had no problems with washing or getting dressed. 9 seniors (15.25 %) had mild problems with washing or getting dressed. 2 participants (3.39 %) said they had moderate problems with washing or getting dressed and the same number of seniors (3.39 %) had serious problems washing or getting dressed. None claimed they were unable to wash or get dressed.

Table 6 Activities of Daily Living

Activities of daily living	Social care institution		Home care environment		Total	
	n	%	n	%	n	%
No problems	20	32.79	28	47.46	48	40.00
Mild problems	15	24.59	17	28.81	32	26.67
Moderate problems	15	24.59	7	11.86	22	18.33
Serious problems	4	6.56	6	10.17	10	8.33
Incapable	7	11.47	1	1.69	8	6.67
N	61	100.00	59	100.00	120	100.00

20 seniors (32.79 %) who lived in social care institutions stated that they had no problem performing activities of daily living (ADL). 15 seniors (24.59%) claimed they had mild problems with ADL performance. 15 seniors (24.59%) said they had moderate problems with ADL performance. 4 participants (6.56%) claimed they had serious problems with ADL performance. 7 seniors (11.47%) said they were not able to perform ADL.

28 seniors (47.46%) who lived in home care environments claimed they did not have any problems performing ADL. 17 seniors (28.81 %) claimed moderate problems with ADL performance. 6 seniors (10.17 %) said they had serious problems with ADL. 1 participant (1.69 %) stated inability to perform ADL.

According to Trachtová (2006), the term ‘self-sufficiency’ means the level of autonomy and participation of an individual in the performance of daily activities such as hygiene and getting dressed. The third aim was to determine the relationship between the type of housing and mental health of seniors.

The research results showed that both groups of participants contained seniors who had reduced mobility or walking problems. The majority reported mild to moderate mobility or walking problems. Seniors living in social care institutions had slightly more mobility problems than those in home care environments. The results showed no statistically significant difference between the two groups of participants. In terms of ADL, especially washing and getting dressed, the results indicated that in social care institutions approximately half of seniors claimed that they had no problem caring for themselves, whereas in home care environments more than a half of seniors had problem taking care of themselves. The results show that seniors living in social care institutions were less capable of being self-sufficient than seniors in home care environments.

The results showed no statistically significant difference of the type of housing on the self-sufficiency of seniors. From the aspect of performing activities of daily living (washing and getting dressed) similar results were obtained in both groups of participants. Seniors in most cases claimed they had no problems or mild to moderate problems with self-sufficiency during washing and getting dressed. Similar research results were obtained by

Virgulová and Schedová (2013), whose results showed no statistically significant difference between seniors in home care environments and in social care institutions, depending on their physical condition.

The analysis of selected items of self-sufficiency (the level of independence) showed marginal statistical significance in the item “activities of daily living” ($p = 0.05$).

Relationship between the Housing and Mental Health of Seniors

Table 7. Anxiety – Depression

Anxiety – Depression	Health and social care institution		Home care environment		Total	
	n	%	n	%	n	%
No anxiety – depression	27	44.26	24	40.68	51	42.50
Mild anxiety – depression	20	32.79	23	38.98	43	35.83
Moderate anxiety – depression	12	19.67	7	11.86	19	15.83
Strong anxiety – depression	2	3.28	3	5.08	5	4.17
Severe anxiety – depression	0	0.00	2	3.39	2	1.67
N	61	100.00	59	100.00	120	100.00

In social care institutions, 27 seniors (44.26%) stated that they felt neither anxiety nor depression. 20 (32.79%) stated they felt mild anxiety or depression. 12 (19.67%) claimed they felt moderate anxiety or depression. 2 (3.28%) stated that they felt strong anxiety or depression.

In home care environments, 24 seniors (40.68%) stated they felt neither anxiety nor depression. 23 (38.98%) claimed mild anxiety or depression. 7 stated (11.86%) they felt moderate anxiety or depression. 3 (5.08%) claimed they felt strong anxiety or depression, and finally 2 participants (3.39%) claimed they felt severe anxiety or depression. The fourth aim was to determine the relationship between type of housing and the mental health of seniors. The results showed no statistically significant difference of the type of housing on mental health of seniors. The p value was $p > 0.05$.

According to Čevela et al. (2012), absence of depression is a factor that affects the quality of life of seniors. The research results of Oswald et al. (2007) and Halvorsrud et al. (2012) indicated that seniors living in home care environments (when they are not self-sufficient) had less symptoms of depressive syndrome and indicated better overall well-being. In our research, approximately half of seniors in both compared groups felt mild anxiety or depression.

Discussion and Conclusions

The purpose of this study was to test the quality of life in seniors living in social care institutions and the quality of life in seniors living in home care environments. The research method was a questionnaire. The data was subsequently analysed, statistically evaluated, and compared between the two groups of participants. Most of the definitions were summarised to identify the most important factors involved in the quality of life of an individual. Due to different perceptions of these factors, it is very difficult to define them. The health, economic, environmental, and social domains especially have direct or indirect impact on human and social development of an individual. The other group of factors that affects quality of life is particular and specific, for example age, sex, educational attainment, family situation, values, economic situation, and culture (Dvořáčková, 2012).

Hartl and Hartlová (2000) believe there are several problem domains in old age that affect the quality of life of an individual, such as physical activity in the sense of mobility, self-efficiency in self-care, and independence. The loss of these abilities can cause degraded quality of life. Dvořáčková (2012) considers age to be one of the factors affecting quality of life.

By comparing the two groups of senior participants, we found that in social care institutions, more than half of seniors were aged 75 or more, and seniors who lived in home care environments were aged from 60 to 74 years. This means that seniors over the age of 70 decided to stay in social care institutions. Tobišová

and Jarošová (2009) claim that the main goal of social and health care is to keep seniors in their natural home environment as long as possible. The family is considered to be the most reliable and stable support for seniors and can affect their adaptation in the new environment of social care institutions. In this context, another interesting question is why families cannot take care of their elderly. The most frequent reason is that seniors are very old, frail and ill and their family members have to stay at work all day, or live too far from them (Bartošovič, 2006). The health condition of seniors is related to increasing age, as well as the ability to take care of themselves in common daily situations. In old age, chronic diseases are so prevalent that there is only a very small percentage without chronic disease. Only 20% of adults over 60 years state that they have no disease, but the rest of older adults claim they have one or more illnesses (Balogová, 2009).

The research problem of the study was defined as following: In what ways is the quality of life in seniors who live in social care institutions different from the quality of life in seniors who live in home care environments?

Our research results indicate that the quality of life in seniors is average and about the same for seniors who live in social care institutions as those who live in home care environments. Even if we did not expect that quality of life in seniors would be one hundred percent, this premise would still offer considerable room for improvement.

- Home care environment: For seniors living in a home environment it is important to adapt the household and modify practical tools that enable them to perform common activities and help them be self-sufficient as long as possible in their own houses (habitat). When close relatives of seniors want to keep them as long as possible in their homes, it is important to engage the help of medical doctors and nurses, home nursing agencies, and nursing services. Relatives of seniors should also receive information about health and compensating aids and access to social services. Within this context, psychological support of relatives who take care of seniors is also very important in order to avoid burnout syndrome caused by long-term care for a senior.
- Social care institutions: For seniors staying in social care institutions, contacts with their relatives, children and grandchildren, and friends are very important in terms of maintaining their mental balance and adaptability. Their visits and relationships can affect contentment and good mood in seniors. In this sense, this support is very important for seniors. Family members should not forget that by placing seniors in social care institutions, their care of seniors does not end, but begins in a new way. For institutionalised seniors it is important for them to feel that they are important to their close relatives and that they have not been abandoned. Seniors should be informed that they were placed in a social care institu-

tion because their close relatives did not have enough professional abilities and time to take adequate care of them.

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Kontekst rodziny w podejmowaniu decyzji o oddaniu narządów od zmarłego bliskiego The context of the family in consenting to deceased organ donation

Streszczenie

W artykule przedstawiono uwarunkowania procesu decyzyjnego rodziny potencjalnego dawcy dotyczące zgody na oddanie narządów po śmierci.

Transplantacja jest leczeniem z wyboru dla pacjentów z niewydolnością narządową. Prawie wszystkie publikacje dotyczące dawstwa narządów cytują poszerzającą się lukę między podażą dawców a popytem (listą oczekujących). Członkowie rodzin potencjalnych dawców odgrywają istotną rolę w decyzjach dotyczących dawstwa narządów w chwili śmierci ich bliskich, a niski odsetek zgody rodzin potencjalnych dawców narządów jest głównym czynnikiem ograniczającym sukces transplantacji narządów. Istnieje kilka powodów odmowy przez rodziny potencjalnych dawców: brak zrozumienia rozpoznania śmierci mózgu; brak wiedzy, co do woli zmarłego; niewystarczający wywiad rodzinny; wiara w utrzymanie integralności cielesnej i zagadnienia religijne. W pracy przedstawiono przegląd czynników zarówno kulturowych jak również uznanych czynników determinujących decyzje dotyczące dawstwa narządów. Zrozumienie czynników wpływających na proces podejmowania decyzji przez rodziny potencjalnych dawców narządów jest niezbędne w celu maksymalizacji dostępności narządów, jak również opracowania strategii wsparcia dla rodziny a także edukacji.

Słowa kluczowe: dawca organów, transplantacja, decyzja, rodzina

Abstract

This study aims to understand the role of families in the process of making decisions about donation of organs of brain-dead relatives.

Transplantation has become the treatment of choice for patients with organ failure. Almost all the literature on soliciting organs for donation cites the ever-expanding gap between supply and demand (waiting lists). Family members of potential donors continue to play a prominent role in donation decisions at time of death. However, the low rate of consent by families of donor-eligible patients is a major limiting factor in the success of organ transplantation. There are several reasons given by families for refusing organ donation: lack of understanding of brain death diagnosis; lack of knowledge about the wishes of the deceased person; insufficient family interview; maintenance

of bodily integrity and religious concerns.

The paper presents a critical review of the cultural and familial determinants of organ donation decisions. Understanding the factors affecting the decision-making process of organ donor families is essential in order to maximise organ availability and develop a strategy for providing families with support and raising their awareness.

Key words: organ donor, transplantation, decision, family

Introduction

Organ and tissue transplantation has become an effective method of treatment that saves or at least improves people's lives. In spite of its increasing availability from a technological perspective, the gap between the number of people waiting for transplantation and the number of deceased donors widens each year globally.

Due to legislative initiatives, policy changes, and educational campaigns, organ donation rates are rising [1, 2]. However, researchers have continued their efforts to understand better the decision-making processes involved in deciding to donate organs upon death. A growing body of research on organ donation has focused on individual attitudes and willingness to become organ donors [3-5]. Public opinion polls have shown that the public is aware of the overall issues of organ donation. In 2012, CBOS (the Public Opinion Research Centre) determined that 74% of Polish people surveyed had agreed to donate organs after death, but since then this percentage has fallen [6].

The legislation and guidance on brain death determination binding in Europe specify the criteria that are both necessary and sufficient for diagnosing brain death. Brain death was first defined in or before the late 1960s [7]. Despite the definition being repeatedly modified and amended over subsequent decades, each country providing organ donation services has clinical criteria for determining brain death in potential organ donors. All European countries except the UK are obliged to meet the criterion of whole-brain death diagnosis. This definition requires that all clinical brain functions (including the function of cerebral hemispheres, diencephalon, and brainstem) must have ceased. Brain death diagnosis requires the irreversible end of all brainstem activity including loss of the capacity to breathe and loss of the capacity for consciousness [8].

The timing of the request for donation

The relatives of potential organ donors play a critical role in determining whether organs will be procured for donation. The need for consent or family authorisation is particularly important when the wishes of the deceased are unknown.

The issue of proper timing of the organ donation request to the family first appeared in the literature in the late 1980s. Authors proposed that family mem-

bers needed time to accept the occurrence of death before being presented with the option of organ donation [9, 10, 11]. The timing of the approach was considered a critical factor in the consent process and influential in family grieving [12, 13].

A systematic review carried out by Simpkins et al. in 2009 indicated that the timing of the request for organ and tissue donation was one of the main modifiable factors associated with consent or refusal to organ donation given by relatives [14]. These factors underlined the significance of the timing of the approach to discussing organ donation. The formal request to the family for their consent to posthumous donation is usually preceded by confirmation of death by the country-specific testing of brain function.

Legislative system of consent for donation

The impact of the family decision on cadaveric organ donation depends on the legislative system of consent. Two types of legislation underlie cadaveric organ donation: presumed consent legislation and informed consent legislation. In informed consent system countries, people can only become donors posthumously if they registered as a donor while alive. In presumed consent countries, anybody is a potential donor when deceased. Presumed consent is supposed to be more ethical as it involves the family in the decision-making process.

In Poland, about 10% of families object to organ harvesting from deceased relatives [15]. The general legal framework for the authorisation of organ procurement in Poland is described along with the solutions implemented by countries in which both implicit and explicit consent models exist. The law does not permit organs and tissues to be acquired from the bodies of people who are known to have objected to organ donation, even if their families wish to donate.

The legislative system is based on three forms of potential donor objection: the Central Registry of Refusals, oral objection and signed objection [16]. Physicians ask the family about the attitude and existing objection to organ donation of the deceased relative. Although presumed consent regulations are binding in Poland, the family of the deceased is always asked to find out what the wishes of the deceased were during his/her lifetime and organs are not procured without their consent. Medical practice gives families the power of veto over the use of their deceased relative's organs in transplantation [17, 18].

Distress

Perhaps the most frequently cited reason for giving decision-making authority to the family concerns the distress suffered by family members at this tremendously difficult time. Many suitable organ and tissue donors die suddenly and prematurely. The decision about whether to donate has to be made very quickly and families might find themselves unable to give their consent. If their

objections to donation are overruled, even if in accordance with the wish of the deceased to donate, this might well increase the distress already experienced by families.

Many people are appalled to discover that their wishes to donate organs are not binding. They often believe that people who signed a donor card or selected the donor box on their driving licence consented to donate and that this consent should be binding [19]. Close relatives consider themselves to be protecting the interests of the deceased. The decision of the family is therefore regarded as a protection of individual autonomy and as an alternative to the decision of the deceased. If they are not familiar with the deceased person's will, the family can adopt a different perspective, making a decision at their own discretion without any consideration of the deceased person's will. The family then decides on the basis of their cultural, religious and social background, and often they do not respect the decision of their relative.

Cultural sensitivity

In certain countries, reasons for refusal may stem from strong local cultural and religious beliefs, whereas many common themes can be found worldwide. The most common causes are the following [20]:

- Relatives not wishing surgery on the body or concerns regarding disfigurement.
- Feelings that the patient had suffered enough.
- Uncertainty regarding the wishes of the deceased.
- Disagreements within the family unit.
- Religious or cultural reasons.
- Dissatisfaction with healthcare staff and the process.
- Concerns over delay to funeral and burial arrangements.
- Inability to accept death or lack of understanding of brain death.
- Concerns regarding the integrity of the process (unfair organ allocation, illegal organ trafficking).
- Decision of relatives that organs would not be suitable.
- Longstanding negative views on organ donation.
- Emotionally exhausted relatives.

The Polish community is Catholic. Catholicism tends to be associated with a favourable attitude towards organ donation [21], which can be considered by Christians as a genuine act of love. The transplantation process is acceptable in terms of Christian moral law.

The Catechism of the Catholic Church provides the following explanation:

(...) organ transplants are in conformity with the moral law if the physical and psychological dangers and risks to the donor are proportionate to the good sought for the recipient. Organ donation after death is a noble and meritorious act and is to be encour-

aged as an expression of generous solidarity. “It is not morally acceptable if the donor or his proxy has not given explicit consent. Moreover, it is not morally admissible to bring about the disabling mutilation or death of a human being, even in order to delay the death of other persons.” [22]

Culturally sensitive strategies to communicating a donation request must consider ethnic origin and language preference. As women are more likely to consent to donation than men are, this may prove highly helpful in facilitating contact and negotiations between healthcare providers and families concerning organ donation [23, 24].

Factors related to family consent to organ donation

The literature reviews concerning factors associated with family consent to organ donation classify them into two categories: modifiable factors and non-modifiable factors.

The modifiable factors identified by Simkin et al. in their review involve the following [14]:

- The provision of adequate information on the process of organ donation and its benefits.
- The perceived provision of high quality care to potential organ donors
- Ensuring relatives had a clear understanding of brain death.
- Separating the request for organ donation from notification of the patient’s death.
- Request made in a private setting.
- Trained and experienced healthcare professionals (physicians, psychologists, transplant coordinators) involved in the request process.

The modifiable factors are associated with communication between healthcare professionals and families. People do not understand the state of brain death. The study by Wilczek-Ruzyczka et al. showed death to be caused by cardiac arrest (8.9%), brain death (85.3%), respiratory arrest (3.7%), and all three (1.57%) [25]. Trusting health professionals in the process is also important. In the same study, the participants claimed that health professionals follow the law during the brain death declaration process (68%), while 14.1% did not agree with this statement [26]. Health professionals who deal with potential organ donor procurement are trained in special communications skills. Consistent communication is critical once death has been clearly determined. In this situation, nurses take great care to use specific language when communicating with the family [27]. Other publications stress that family consent rate is highest when the next of kin are aware of the deceased person’s wish to become an organ donor, meaning that the individual had signed a donor card or expressed his/her wish verbally or in writing to family members prior to death. It is therefore important to raise aware-

ness about organ donation and encourage people to make their wishes known to their next of kin [25, 28].

Non-modifiable factors

Non-modifiable factors are mostly related to demographic characteristics of the family and/or the donor. The following non-modifiable factors were found in the research:

- Demographics: family consent rates have been found to be higher when the donor is male, young, or Caucasian [29, 30]
- Certain religions are associated with low consent rates, i.e., Jehovah's Witnesses, Shinto [31, 32]
- Consent rates were higher when death was caused by trauma as opposed to non-trauma [31].

Reasons for family refusal to donate

Refusal to organ donation often stems from misunderstanding or misinformation. The reasons compiled from the literature are as follows:

- Feelings that the relative suffered enough.
- Uncertainty regarding wishes of the deceased.
- Refusing surgery on the deceased person's body.
- Disagreement between family members.
- Religious or cultural reasons.
- Concerns about delays to the funeral or burial process.
- Inability to accept death, lack of understanding of brain death.
- Negative view on organ donation.
- Unfair organ donation procedures and illegal organ trafficking.

Communicating organ donation wishes to relatives

The knowledge of family members about their deceased relative's wish concerning organ donation is arguably the most important factor determining their decision. This should make medical staff realise that the information regarding organ donation provided to society ought to encourage people to discuss donation and join a donor register. [33]. Discussing posthumous organ donation with family members involves the uncomfortable acknowledgment that at some point, their relatives or they themselves may die in a way that is conducive to organ donation. Death is a taboo subject even in the absence of the question of organ donation; therefore, discussing it may cause distress or be considered as a fateful, traumatic experience [34]. Knowledge about organ donation may offer families the comfort of knowing that they followed the wish of the deceased person, as well as minimise stress and family conflict during the period of extreme sensitivity and emotional burden.

Experiences of the family of a potential organ donor

Family members generally have little time to adjust to the loss before they are informed about organ donation and may struggle with the enormity of the events that are unfolding around them. Sque & Payne propose in their study a theory of dissonant loss in order to explain the donation process as experienced by relatives of the donor. The authors define dissonant loss as a mourning of loss characterised by a sense of uncertainty and psychological discordance [35]. In the course of the donation process, relatives experience conflict in two particular forms, namely, as a series of events over which they have no control, such as, the ambiguity of brainstem death, and the decision about the required donation. These decisions take place in highly charged emotional environment. Another study sought to explore the bereavement of donor families by establishing the role and importance of grieving and the reaction to a relative's organ being donated to a recipient. The findings of the research that aimed to explore the hospital experiences and end-of-life decision-making processes of relatives who chose to refuse organ donation proved death of an organ donor to be difficult to accept to both families and healthcare providers, which is confirmed by neurological criteria in contrast to society's expectation regarding the process of dying.

Understanding brain death

The critical injury and subsequent death of individuals who are eligible to become organ donors are usually sudden and unexpected. The difficulty of understanding and accepting brain death when a relative is on a ventilator is a common theme arising in the literature on family experiences of the organ donation process. Long et al. report that a 'visually alive' relative being diagnosed as braindead seems to trigger an emotional and cognitive conflict, which may only be resolved when the body is consistent with the conventional schema of a dead body, i.e., cardiac death [36]. For that very reason, health care professionals play the key role in ensuring relatives have a full and clear understanding of brain death. It has been recommended that the delivery of information about injury and brain death should involve a variety of communication strategies such as visual aids, verbal information and written information.

Interacting with health professionals

The research provides accounts of respondents' experience regarding communicating with health professionals, both positive and negative. Accounts of more positive interaction with health professionals were provided by respondents who felt that the staff had communicated well and recognised them as 'important' to the deceased person [37]. Family perceptions of the care provided to their deceased relatives had a significant effect on their experience, as they had

some intimate last moments to say goodbye before the donation procedure was initiated. In order to enhance information processing and maximise the positive impact of initial care on subsequent grief, the relatives need [38]:

- time to accept the nature of brain injury and to discuss this matter with other family members, and seek reassurances for any concerns;
- recognition of their special role as next of kin, their inner turmoil, and the understanding that this could impact their information processing abilities;
- care in how and where information is presented and the understanding that the situation they find themselves in will remain in their minds for years to come.

Deciding whether to donate

In accordance with quantitative research, qualitative studies emphasise the knowledge about the deceased person's wish regarding organ donation is often the most important factor in the family consent decision [38]. The opportunity to help others and to turn such a negative experience into something positive also motivates family members to agree to donation. A qualitative study conducted by Martínez et al. on families in Spain found the respect for the wish of the deceased to be the predominant reason given by the next of kin for their consent to donate. Other reasons involved [39]:

usefulness: in that the organs are no longer of use to the deceased and could save multiple lives;

- generosity: willingness to help others;
- reciprocity: thinking about other relatives who may one day need a transplant;
- transcendence: the idea that the donor may 'live on' in another person after organ donation

Following the donation, many relatives asked to be informed on the fate of the organs of their relatives.

Summary

This paper highlights the complexity and multifactorial nature of organ donation decision-making, which involves not only the family members of the deceased person, but also the approach of healthcare professionals. At this very highly stressful and sensitive time, it is important that relatives are enabled and supported in making the decision that is right for them, whether that be to donate or not to donate, thereby minimising the risk of regretting their decision.

The relatives' awareness of the donation wishes of the deceased individuals is one of the most important factors that determine their decisions; in the majority of cases, the family follows the wish of the deceased person.

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Stanowisko pielęgniarki szkolnej w promowaniu zdrowia dzieci z perspektywy rodziców *Parents' Perspectives on The Role of School Nurses in Promoting Children's Health*

Streszczenie

Artykuł skupia się na znaczeniu utworzenia stanowiska pielęgniarki szkolnej w Słowacji z punktu widzenia rodziców, ze względu na jego pozytywny wpływ na rozwój, promocję i ochronę zdrowia dzieci. Zbieranie danych przeprowadzono w styczniu 2015 przy użyciu niestandardowego kwestionariusza, który został dostarczony rodzicom dzieci w szkołach podstawowych w miastach Kežmarok i Spišská Stará Ves. Przebadanych w sumie zostało 262 rodziców dzieci z 1 i 2 stopnia szkoły podstawowej. Do oceny danych zastosowano metody statystyki opisowej. Wyniki badań wykazały, że jedną z głównych ról, jaką powinna odgrywać pielęgniarka szkolna według opinii rodziców, jest edukacja zdrowotna w szkołach. Podstawową działalnością pielęgniarki szkolnej na rzecz dzieci według rodziców jest udzielenie pierwszej pomocy. Do trzech najczęściej poruszanych tematów w opinii rodziców zaliczano tematykę dotyczącą wzrostu i rozwoju dziecka, szczepienia oraz zdrowe żywienie. Rodzice dzieci ze szkoły podstawowej 1 stopnia potwierdzili większą korzyść ze współpracy z pielęgniarką szkolną a wykształcenie wyższe rodziców odegrało bardziej pozytywny wpływ na potrzebę utworzenia stanowiska pielęgniarki szkolnej.

Słowa kluczowe: pielęgniarka szkolna, dziecko, zdrowie, rodzice, instytucja edukacyjna

Abstract

The paper focuses on the importance of establishing the role of the school nurse in Slovakia from a parent's perspective, proving that it has positive effect on the development, promotion and protection of children's health. Research data was collected in January 2015 by using a non-standardised questionnaire that was distributed among parents of children at primary schools in Kežmarok and Spišská Stará Ves, producing a sample consisting of 262 parents. Data was evaluated by means of descriptive statistical methods, as well as by a nonparametric method represented

by a Chi-square test. The findings showed that from a parent's perspective, teaching health education in schools is one of the major roles of school nurses. According to parents, the primary duty of a school nurse is first aid for children. Both groups of parents stated that growth, child development, immunisation and nutrition were the three topics most discussed. Parents of children in the first grade of primary school indicated greater benefits from cooperation with the school nurse. Similarly, parents with higher education responded positively to the creation of the role of the school nurse.

Key word: school nurse, child, health, parents, educational institution

Introduction

Community health nursing is one of the clinical fields of nursing that is based on the concept of nursing. It can be divided into two categories: community health nursing oriented to the health of a community, and community health nursing oriented to the community itself [1].

Community care is generally provided outside of health centres to individuals, families or groups of persons. It focuses on health protection, prevention of diseases and health education since it is important that individuals learn how to protect their health and take responsibility for their health [2]. Community care is a system of support, assistance and therapy that is constructed in such a way as to help individuals suffering from serious diseases to live in normal conditions in the most satisfying way possible. This means not only that care should be provided by specialists, primarily in a community, but also that a community should have a supportive function. In 1974, the World Health Organization (WHO) introduced three integral parts of community health nursing in order to emphasise the specificity of this discipline, i.e. sense of responsibility, care for vulnerable groups, and care for the patient [3].

In community nursing, **the patient** is not an individual, but the entire community. Hanzlíková et al. [4] define the community in conformity with the WHO's definition, i.e. as a social group determined by geographical boundaries or common values and interests. Its members know each another and interact. The aim is to create a distinctive social structure, anticipate and create certain norms, values and social institutions. According to Bauman [5], a community is a social unit characterised by certain social relations among its members and their specific position outside this unit in the social environment. Community boundaries cannot always be clearly determined.

An important part of community care is mobilising assistance and self-assistance in cooperation with state or local programs. Community care is provided to patients in their domestic environment and concentrates on the prevention, enhancement, and promotion of health, and education on how individuals can be responsible for and take care of their health, whilst detecting the need for assistance and providing it to patients. These activities are performed mainly

by nurses, who can easily earn the trust of individuals and work independently. They are called community health nurses. The name 'community health nurse' originates from an English translation and comprises numerous functions: public health nurse, family nurse, school nurse, institutional nurse, paediatric nurse, etc. [2,3,6]. Pursuant to current regulations in Slovakia, when nurses obtain specialist qualifications to perform specialist professional activities (within the scope of issues related to nursing care in a community), they use the occupational title of 'specialist community health nurse'.

A child and adolescent community health nurse should have knowledge of all stages of child development. She concentrates on prevention, psychomotor development, growth, psychosocial development, child's needs, etc. Prevention and care are important at every stage of a child's life and care is provided within primary, secondary and tertiary prevention. A community health nurse selects a model to evaluate a child's needs, which allows her to assess the child's condition as well as define current and potential needs. Care is provided through nursing processes in the same way as in the case of bedridden patients. A nurse not only cooperates with the child and the child's parents, but also applies medical, nursing, educational, interpersonal, communication and pedagogical skills. Her character, ethics, professionalism, emotional and social stability are also of great importance. A nurse is perceived as a role model [7]. Good communication with patients requires: building a nurse-patient and nurse-family relationship to improve cooperation, using effective communication to provide well-coordinated, high-quality care [8], communicating with respect, creating an adequate environment which gives a feeling of safety, examining physical health, mental health and physical condition, and assuring patients that they can turn to the nurse for help if necessary [9].

In these times of rapid social-economic, political, cultural, epidemiological and health care changes, the health of children and adolescents poses several challenges for healthcare professionals. Promoting healthy schools, health-related state programs, as well as regional and global initiatives provides a mechanism for integrating health promotion and care in schools and communities that consequently prevents the prevalence of diseases and morbidity caused by chronic diseases. Nurses, together with teachers, other healthcare professionals, students, parents and community members, are the primary intermediaries whose task is to introduce and support changes in schools aimed at creating a health-promoting environment [10].

Boledovičová [11] states that as far as community health nursing is concerned, school nursing represents an independent sector. From the public health perspective, it should have a positive influence on the health and balance of school-aged children in the future.

A school nurse plays a key role in the promotion of children's health. We will explain the concept of community health nursing by looking at the position of a school nurse in the United States and in Poland. School nurses in the United States represent an integral part of the school environment. The first school nurse in the United States was appointed in 1902 to reduce student absence by cooperating with students themselves and their families [12]. In order to implement changes beneficial to the health of all students, the focus is not only on families with problems reflected in children's performance at school, but also on teachers and headmasters. School nurses promote healthy eating habits and fitness programs. To prevent the spread of disease they promote hand washing and hygiene. Another role of a school nurse in the United States is to provide first aid in event of sudden health problems, bodily injuries or poisoning. The U.S. health policy has increasingly focused on prevention and community care, searching for problems before they even arise. Despite all the benefits offered by the presence of a school nurse, not all U.S. schools employ them. There are several reasons for this, the most important one being financing [13].

A school nurse in Poland cares for children and adolescents subject to compulsory education. The scope of her activities is determined by the Ministry of Health decree on guaranteed health care services within the scope of primary health care (2009) as well as by Decree no. 72/2009 of 2009 on primary health care services [14].

A school nurse's duties include:

- provision of first aid in event of sudden illness, bodily injury or poisoning,
- participation in ensuring the safety of students in the school environment, establishment of food and sanitary conditions at school,
- organisation of oral health training, prophylaxis, oral hygiene (fluoride formulas),
- implementation and evaluation of screening whose purpose is to identify various diseases such as hearing impairment, vision defects, motor organ disorders, problems with blood pressure and physical development defects,
- provision of advice to children with positive screening test results,
- provision of active advice to disabled children and students suffering from chronic diseases,
- participation in planning, implementation and evaluation of health education,
- promotion of a safe environment for students, food, establishment of food and sanitary conditions at school,
- organisation of health surveillance,
- active management of nursing care,

- keeping medical documentation pursuant to the relevant regulation,
- other duties within the scope of student care [15].

The salary of a school nurse depends on the number of students attending the schools the nurse is employed in. A monthly capitation fee is paid for every student. Although the capitation fee has increased, it does not compensate the financial situation of school nurses. The great deal of responsibility resting on the shoulders of school nurses also poses a problem. A school nurse works alone and often has to make important decisions. In some cases, health evaluation requires immediate and decisive action and deciding whether medical assistance should be requested [14].

As in other countries, a school nurse could provide comprehensive nursing care in Slovakia to both healthy children and children suffering from chronic diseases with special needs in the school environment. The above reason became the focus of our considerations and subsequently an encouragement to conduct further research in this area.

Research Objectives

The main objective of the research was to **examine the interest of parents in introducing the position of school nurse** as part of the improvement and development of health care of children in schools. In addition to this, we investigated whether **parents' level of education and primary school grade of their children (základná škola – abbrev. ZŠ)** positively or /negatively affects their attitude towards the idea of appointing school nurses.

Methods

The research was conducted in January 2015, with the consent and cooperation of the principals of Grundschule in Kežmarok and the primary school in Spišská Stará Ves.

In order to acquire empirical data, we chose a quantitative study method, i.e. a non-standardised questionnaire. The questionnaire was anonymous and was developed for the purposes of our research. The questionnaire consisted of 28 questions whose purpose was to examine parents' interest in the presence of a school nurse in the school environment, their knowledge of the term 'school nurse', her competencies, and her potential to become their trusted partner. Our intention was also to get an overview of the source of parents' information on health and childcare as well as on the person they were most likely to talk to and cooperate with on the above issues. The last part of the research consisted of five demographic elements comprising parents' age and level of education, children's year of birth, parents' and grandparents' relations with children, and place of residence (village, city).

The choice of respondents was **intentional**. The study group comprised 262 parents whose children attended the first and second grade of the aforementioned primary schools. The parents were personally asked to complete the non-standardised questionnaire. As far as the social-demographic profile is concerned, 124 respondents were parents of children attending the first grade of primary school and 138 were parents of children attending the second grade of primary school. Parents residing in cities slightly outnumbered the remaining participants in both groups. While parents aged 28-35 were the most numerous group with regard to the first graders, parents aged 41-50 were the largest group with regard to the second grade of primary school. Persons with secondary education were dominant in both groups.

Statistical analysis

The obtained empirical data was analysed by means of descriptive statistics in MS Excel and interpreted in the form of **tables**. A nonparametric statistical method - **Chi-square test (χ^2)** was also used.

Results

Our primary objective was to determine whether parents would welcome the presence of a school nurse in the school their children attend. The frequency of individual answers is presented in Table 1. While **96 parents (77.42%) of children attending the first grade of primary school gave a positive answer**, six (4.84%) were against that idea and 22 (17.74%) did not have an opinion. Parents of children attending the second grade of **primary school** gave the following answers: 97 parents (70.29%) agreed with the idea, 18 were against (13.5%) and 23 (16.67%) did not have any opinion.

Table 1. Parents' interest in the presence of school nurse in schools

	1 st level of ZŠ		2 nd level of ZŠ	
	n=124	[%]	n=138	[%]
yes	54	43.55	48	34.78
rather yes	42	33.87	49	35.51
no	4	3.23	10	7.25
rather no	2	1.61	8	5.80
I do not know	22	17.74	23	16.67

We were also interested in respondents' opinions on introducing health education into the curriculum as a separate subject in primary schools. The obtained results are presented in Table 2. The parents of students attending the first grade of primary school were rather supportive of this idea: 109 parents (88.62%) were for, 11 (8.95%) were against and 3 did not have an opinion. As far as the parents of students attending the second grade of primary school are concerned,

100 parents (72.46%) supported the idea, 23 (16.67%) were against it and 15 (10.87%) did not express any opinion.

Table 2. Introduction of health education as a separate subject

	1 st level of ZŠ		2 nd level of ZŠ	
	n=124	[%]	n=138	[%]
yes	44	35.77	43	31.16
rather yes	65	52.85	57	41.30
no	6	4.88	15	10.87
rather no	5	4.07	8	5.80
I do not know	3	2.44	15	10.87

Another important matter was the respondents' opinions on who should teach health education. There were four options to choose from, the results being presented in Table 3. The answers given by parents of children attending the first grade of primary school are as follows: 71 parents (54.62%) declared that the subject should be taught by a nurse, 22 parents (16.92%) believed that health education should be taught by a physician, 18 parents (13.85%) chose a teacher and 19 parents (14.62%) opted for the answer 'other', but did not specify a particular person. Parents of children attending the second grade of primary school responded as follows: 81 parents (58.70%) opted for a nurse, 37 (26.81%) chose a physician and 20 parents (14.49%) wanted health education to be taught by a teacher. Based on the answers provided by both groups, the most suitable person to teach health education is a nurse.

Table 3. Health education teacher as viewed by children's parents

	1 st level of ZŠ		2 nd level of ZŠ	
	n=124	[%]	n=138	[%]
teacher	18	13.85	20	14.49
physician	22	16.92	37	26.81
nurse	71	54.62	81	58.70
other... (specify)	19	14.62	0	0.00

In one of our questions, we asked parents whether the cooperation between the nurse, physician and teacher would improve the overall care of their children (Table 4). The majority of parents in both groups gave a positive answer (192 parents), 21 parents gave a negative answer and 49 did not know whether the cooperation would be beneficial. This neutral attitude is likely to be related to the answer of those parents who did not have an opinion on the role of a school nurse.

Table 4. Improvement of care resulting from cooperation between the nurse, teacher and physician

	1 st level of ZŠ		2 nd level of ZŠ	
	n=124	[%]	n=138	[%]
yes	46	37.10	44	31.88
rather yes	52	41.94	50	36.23
no	2	1.61	7	5.07
rather no	4	3.23	8	5.80
I do not know	20	16.13	29	21.01

Table 5 presents a list of issues most frequently discussed by parents with a specialist (physician/nurse). Parents were allowed to choose several answers.

The most popular topics discussed with specialists by parents of children attending the first grade of primary school are vaccinations (81 parents, 21.89%), child growth and development (80 parents, 21.62%) and healthy diet (67 parents, 18.11%). Parents of children attending the second grade of primary school are also most likely to discuss vaccinations (89 parents, 21.19%), child growth and development (84 parents, 20%), dental care (82 parents, 19.51%) and healthy diet (72 parents, 17.14%). Some parents of pupils attending the first grade (8 parents, 2.16%) chose the answer 'other' and stated that they discussed diseases and prophylaxis with specialists. However, a few of them indicated that specialists did not always have time to discuss these matters. Parents of pupils attending the second grade of primary school who chose the answer 'other' (8 parents, 1.90%) wrote that they consulted specialists to discuss current diseases and physiotherapy of their children.

Over the course of the research, we asked parents about the scope of duties of a school nurse. Parents had the opportunity to give multiple answers to this question. The obtained results are presented in Table 6. According to the research, most parents consider that a school nurse should provide first aid, accompany children and teachers during school trips, cooperate with regard to health education of children, ensure that hygiene rules are obeyed in the school environment and provide care to children suffering from chronic diseases. The above options were the most popular answers. The answers given by parents of children attending the first and second grade of primary school were very similar.

Table 5. Issues discussed by parents with specialists

	1 st level of ZŠ		2 nd level of ZŠ	
	n=124	[%]	n=138	[%]
healthy diet	67	18.11	72	17.14
hygiene	20	5.41	17	4.05
dental care	51	13.78	82	19.52
child growth	80	21.62	84	20.00
development vaccinations	81	21.89	89	21.19
upbringing	19	5.14	12	2.86
rest and sleep	13	3.51	7	1.67
suitable activities and sport	20	5.41	31	7.38
prevention of addictions in children	11	2.97	18	4.29
other... (specify)	8	2.16	8	1.90

We also wanted to identify the influence of parents' level of education on their attitude towards the idea of appointing school nurses, based on the assumption that higher education gives parents a broader view as well as knowledge of the importance of school nurses and their benefits for parents. We compared the answers given by parents with higher education with the answers provided by parents with a lower level of education. As far as the question 'Do you support the idea of introducing the position of a school nurse?' is concerned, 'rather yes' and 'yes' were considered to be positive answers. 'Rather no' and 'no', on the other hand, were designated as negative answers. Out of 262 parents who participated in the research, 62 had higher education. Full or partial disapproval of introducing the position of a school nurse was expressed by 24 parents, 2 of whom had higher education.

By using the **Chi-square test** (χ^2), a nonparametric statistical method, it was confirmed on the significance level ($p \leq 0.1$) that there is a relationship between parents' level of education and their attitude towards the position of a school nurse (Table 7).

Table 6. Duties of a school nurse as perceived by parents

	1 st level of ZŠ		2 nd level of ZŠ	
	n=124	[%]	n=138	[%]
asserting the needs of chronically ill children and supervising medicine administration	55	8.81	66	9.17
	28	4.49	32	4.44
recommending further examination of a child (specialist examinations, psychological examinations, contacting a social worker if necessary)	29	4.65	43	5.97
providing medical check-ups, maintaining vaccination records, vision and hearing examinations	40	6.41	32	4.44
educating children and their parents on self-sufficiency in healthcare	33	5.29	27	3.75
medication administration and consultancy of its effects, medical aids and correct lifestyle	49	7.85	60	8.33
providing and administering first aid	103	16.51	113	15.69
participating in the health education of children (developing plans and participating in practical classes)	58	9.29	57	7.92
accompanying children and teachers during school trips	60	9.62	76	10.56
ensuring that hygiene rules are obeyed in the school environment	56	8.97	64	8.89

It was assumed that parents of younger children (grade 1-4) would be more interested in the presence of a school nurse in the school environment than the parents of older children (grade 5-9). As for the first grade of primary school, 96 parents out of 124 gave a positive answer, 22 a negative answer and 6 a neutral answer. The answers provided by parents of children attending the second grade of primary school were as follows: 97 for, 23 against, 18 neutral. Neutral answers were not taken into consideration.

By using the Chi-square test (χ^2), a nonparametric statistical method, it was confirmed on the significance level ($p \leq 0.1$) that there is a relationship between the chosen variables. Parents of first graders have a more positive attitude to-

wards the presence of a school nurse in the school environment than parents of second-grade students (Table 8).

Table 7. Parents' attitude towards the idea of introducing the position of a school nurse depending on their level of education

	No higher education	Higher education	Total
positive attitude towards the introduction of the position of a school nurse	178	60	238
negative attitude towards the introduction of the position of a school nurse	22	2	24
Total	n=200	n=62	n=262
Test criterion	G = 3.438		
Critical value	p ≤ 0.1		
	$\chi^2_{(1-a); df} = 2.076$		

Table 8. Attitude towards introducing the position of a school nurse in terms of primary school grade

	Parents of 1st level students of ZŠ	Parents of 2nd level students of ZŠ	Total
positive attitude towards introduction of the position of a school nurse	96	97	193
negative attitude towards introduction of the position of a school nurse	6	18	24
Total	n=102	n=115	n=217
Test criterion	G = 5.243		
Critical value	p ≤ 0.1		
	$\chi^2_{(1-a); df} = 2.076$		

Discussion

The objective of the strategy of health protection development is to maintain the health of individuals and communities through health enhancement, preventing diseases and injuries and provision of healthcare [16]. In this context, one should consider extending the duties of nurses to the school environment where the aforementioned strategies could be implemented. In our article, we use the expression 'school nurse' although the position does not currently exist in our healthcare or education system and if it does exist, it is financed from addi-

tional funding of various organisations. Due to the important function of school nurses in health promotion and protection in other countries, we conducted scientific research that demonstrated the prevailing opinion on her role in a school setting. Parents of primary school pupils were invited to participate in the study. We chose parents who, when looking at the work of a school nurse, could see the impact of her health- and education-related actions.

Based on our findings, the vast majority of parents would be interested in the presence of a school nurse in primary schools. Linda Davis-Alldritt, President of the National Association of School Nurses, recommended that parents support the presence of school nurses in the school environment. Parents are the ones who send their children to school and expect that from the moment children leave home to the moment they return from school, they will be cared for and be safe and protected [17].

Parents involved in the research stated that it would be useful to introduce health education into the curriculum as a separate subject. Based on respondents' answers, the subject should be taught by a nurse. The authors [18] of the Canadian publication stated that as far as public health is concerned, nurses have many years of practical experience in promoting physical, mental/emotional and social health and preventing diseases and health impairments arising during their life. We share the belief that the presence of nurses in the school system is justified by their professional training in the context of international actions, including Slovakia. According to the National Association of School Nurses, the minimum professional qualifications of nurses include being licensed as a registered nurse and being granted a Bachelor degree by an accredited higher education facility [17].

The respondents stated that their conversations with specialists mainly concerned child growth and development, vaccinations and healthy diet. Australian researchers [19] report that in many countries, school nurses' duties include health promotion and implementation of preventive actions in schools. Secondary school students are usually more aware of the adverse effects of smoking or alcohol consumption, reproductive health, eating habits and their influence on health, as well as the advantages of physical activity.

The majority of parents in our research identified that a school nurse should conduct activities associated with health and first aid provision. Adequate and timely provision of first aid brings relief, reduces pain and suffering of the injured person, and improves and shortens the subsequent healing and recovery. In a critical situation, it can save life or increase the chances of survival during further intensive treatment [20]. Approximately three-quarters of parents expressed the belief that cooperation between nurse, teacher and physician would contribute to better healthcare provided to children. Society perceives schools as a transition from the family to society [21]. Therefore, it is ideal if the coopera-

tion can be observed in various areas of children's lives. School nurses should thus be treated as fully-fledged partners in the healthcare system. A school nurse manages diverse activities, works independently and assesses pupils' needs. She is the connecting link between the school, family and specialists [11]. Parental engagement is an interesting proposal to improve cooperation between parents and schools in support of children's health. In 2012, the Centre for Disease Control and Prevention issued a document promoting various strategies to make parents more engaged in the matters of school health [22].

Parents with higher education had a positive attitude towards the introduction of the position of school nurse, compared to parents without higher education. We can assume that parents with higher education have more information about the risk of injuries, acute and chronic diseases and post-traumatic conditions. The parents of first grade students of primary school were more positive about the introduction of the position of school nurse than were the parents of second grade students. The parents of younger children presume an increased risk of accidents and infectious diseases and hope that the intervention of nurses will be more common in the future.

Health 2020 [23], the European policy for health and well-being, primarily provides information that financially effective political solutions can have a direct influence on the improvement of human health. One such solution could be a credible and at the same time courageous step towards the integration of the position of school nurse as part of the improvement and development of healthcare in schools.

The objective of our research was fulfilled. Based on our results, the majority of parents agree that the school their child attends should employ a school nurse. A school nurse could participate in all the activities associated with protection of children's health. We believe that the work of school nurses offers possibilities for the positive influence and promotion of children's health.

We would like to present several recommendations that are based on our findings, knowledge about the duties of school nurses in some countries where this position exists, and the positive attitude of parents towards school nurses:

For educational institutions:

- support national and international health promotion programs targeted at children and adolescents,
- publish results related to the role of school nurses and its practical implementation in professional journals,
- promote the issue of community health nursing in media, with the emphasis being placed on raising awareness of school nursing,
- promote the idea to introduce the position of school nurse in cooperation with the professional nursing organisation,

- engage in the educational process of parents of school children, aimed at broadening their knowledge of preventive actions and healthcare,
- document the educational process with individuals, groups or communities; evaluate the education process; record the feedback,
- propose the introduction of the health education (as a separate subject) into the curriculum of primary schools.

For nurses:

- pursue independently the systematic medical examinations of children and adolescents,
- organise medical examinations in kindergartens,
- participate in outpatient clinics,
- map sanitary-epidemiological care, primarily focusing on marginalised communities and vulnerable groups,
- educate about the benefits of vaccination, maintain the accurate and comprehensive documentation of the vaccination schedule,
- cooperate with physicians with regard to necessary preventive measures in the context of infectious diseases,
- participate in regular inspections of school canteens,
- map the safety of school environments; eliminate the risk of potential injuries and health hazards,
- teach health education – classes, teachers' boards,
- participate in the identification of socially disadvantaged children and their potential discrimination or bullying in the school environment,
- handle, in cooperation with the teachers' board, inappropriate student behaviour, including intimidation; identify possible solutions,
- visit families or children at risk; cooperate with parents.

Conclusion

In order to achieve better mental and physical quality of life of school-aged children, it is necessary to concentrate on education itself and a responsible approach to one's own health. The above goal can be achieved with the help of national health promotion programs, programs to improve healthcare of the entire population, as well as various projects approved by the governments of WHO member states. Their main purpose is to promote and prevent diseases and to ensure high quality healthcare provided not only to individuals, but also to society as a whole.

There is a trend in healthcare to move closer to where people live and work. This is the essence of community care, where healthcare is provided by nurses in patients' home environments. Nurses focus not only on individuals, but also on the entire community. They identify the needs of the community, provide assistance, undertake preventive actions and educate.

The issue of introducing the position of the school nurse applies in several areas and concerns not only the health service and the education system, but also the social sphere. Our goal was to draw attention to a gap in the paediatric healthcare system that has to be remedied. Dimunová [24] states that the nursing profession is undergoing a difficult process of development and change. The solution is to integrate the position of school nurse in the healthcare and educational system. In this regard, it is necessary to address numerous issues such as financing and defining competencies and responsibilities.

Parents, teachers and healthcare professionals are all currently trying independently to achieve the same objective: the healthy development of children. A comprehensive solution would be to introduce the position of a school nurse who would combine all these professions. Such cooperation would create new possibilities that could lead to the more effective achievement of health-related objectives. Recommendations aimed at health protection and improvement are effective only if they are stable, coherent, repeatable and if they have an influence on children, families and community on all levels. We consider it important to raise future generations so that they are aware of the importance of their own health as well as the health of individuals living in the same community. The impulse should not only come from families, but also from the school and kindergarten environment in which children spend a considerable amount of time.

Ethical aspects and conflict of interest

The research implementation was approved by obtaining consent to conduct the study in various primary schools. The fundamental ethical rules were followed during the performance of the research. Questionnaires were anonymous and the obtained data was used exclusively for research objectives. All references were quoted. The authors declare that the research does not involve any conflict of interests.

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Szumy uszne – zadanie dla pielęgniarki
Tinnitus as nursing issue

Streszczenie

Cel badań: Celem niniejszej pracy było badanie zależności *tinnitus* (szumów usznych) od innych zaburzeń słuchu, wynikających z oddziaływania hałasu w miejscu pracy oraz identyfikacja czynników, wpływających na percepcję szumów usznych.

Metoda: Do analizy uzyskanych wyników zastosowano dwie metody badawcze. Jako pierwszą zastosowano audiometrię z wyznaczeniem stopnia całkowitego ubytku słuchu (CSS), według Fowlera. Badanie przeprowadzono w okresie od marca do sierpnia 2014 roku. Jako metodę drugą, zastosowano badanie z wykorzystaniem autorskiego kwestionariusza ankiety, przeprowadzonej w celu skompletowania audiogramu dla każdego badanego. Z populacji 1678 ankietowanych, w badaniu wzięło udział 140 respondentów, którzy zauważyli występowanie u siebie zjawiska szumów usznych. Badanie potwierdziło występowanie utraty słuchu w różnym stopniu u 125 badanych. Z kolei u 15-tu badanych zdiagnozowano występowanie szumów usznych bez objawów uszkodzenia słuchu. Badaniem objęto łącznie 123 mężczyzn i 17 kobiet. Średnia wieku badanych wyniosła 49,97 lat. W celu określenia istotnych zależności pomiędzy zmiennymi ilościowymi, wyznaczono współczynnik korelacji Pearsona (r). *Wyniki:* Analiza wykazała większą częstotliwość występowania szumów usznych u mężczyzn - w 123 przypadkach (87,85%), niż u kobiet – w 17 przypadkach (12,15%). Stwierdzono, że 45 badanych (32,14%), co

stanowi najliczniejszą grupę w populacji, odbiera szумы uszne przez ponad rok. U większości badanych (90 %) szумы uszne występowały sporadycznie, a anki-etowani szумы te określili jako dźwięk gwizdka (51,43 %). *Tinnitus* występowało najczęściej u osób, wykonujących zawodowo pracę fizyczną - 91 badanych (65 %). Większość, aż 79 badanych (56,43%), doświadczyło zaburzeń słuchu w pracy przez okres od 11 do 19 lat. Szумы uszne występowały najczęściej u respondentów z umiarkowanymi zaburzeniami słuchu – u 66 badanych (47,15%). Współzależność między stopniem ubytku słuchu i występowaniem szumów usznych (*tinnitus*) w badanej grupie nie została potwierdzona ($r = -0,014$). Najczęściej wymienianym czynnikiem, powodującym ubytki słuchu w związku z *tinnitusem*, okazało się narażenie na oddziaływanie hałasu w pracy zawodowej, co wskazało 103 badanych (73,57%). Z kolei czynnikiem ograniczającym negatywny wpływ *tinnitusa* okazało się, zdaniem 107 respondentów (76,43%), słuchanie radia i oglądanie telewizji. Natomiast 136 badanych (97,10%) wskazało, że szумы uszne zakłócają ich sen i odpoczynek. *Wnioski:* Zależność statystyczna pomiędzy stopniem ubytku słuchu, a występowaniem szumów usznych (*tinnitus*) nie została udowodniona. W badanej grupie nie zaobserwowano zaburzeń utraty słuchu, wynikających z długotrwałego narażenia na działanie hałasu w miejscu pracy. Uzyskane wyniki dowodzą skuteczności stosowania w tym zakresie środków zapobiegawczych.

Słowa kluczowe: szумы uszne, ubytek słuchu, środowisko pracy, hałas

Abstract

Aim: The aim of this study was to verify the presence of tinnitus, analyse the link between tinnitus and other hearing disorders caused by noise exposure at work, and identify factors influencing the perception of tinnitus. *Methods:* Two research methods were used to acquire data. The first method was audiometry, with total deafness assessment calculated according to Fowler. The study was conducted from March to August 2014. The second method used was a non-standardised questionnaire designed by the authors in order to complete the audiogram of each subject. 140 out of the 1,687 questionnaire respondents were enrolled in the study because they stated they had tinnitus. After examination, 125 subjects were diagnosed with hearing loss of varying degrees. 15 subjects had tinnitus; however, impaired hearing was not proven. The study group consisted of 123 men and 17 women. The average age of the subjects was 49.97 years. A significant interaction of quantitative variables was assessed using Pearson correlation coefficients (r).

Results: The analysis revealed a higher incidence of tinnitus in men 123 (87.85%) than in women 17 (12.15%). The largest group of respondents 45 (32.14%) had experienced tinnitus for more than 1 year. In the majority of subjects (90%), tinnitus occurs intermittently and is described as a whistling sound (51.43%). Tinnitus was most common in subjects who do physical work for a living 91

(65%). Most subjects 79 (56.43%) had experienced occupational noise for 11 to 19 years. Tinnitus most often occurred in subjects with moderate hearing impairment, 66 (47.15%). Interdependence between the degree of hearing loss and tinnitus was not confirmed in the study group ($r = -0.014$). The most frequently reported factor causing worsening of tinnitus symptoms was noise exposure at work, 103 (73.57%). 107 (76.43%) subjects reported improvement of tinnitus by listening to the radio and watching television. In 136 (97.10%) subjects, tinnitus disturbs their sleep and rest.

Conclusion: The statistical correlation between the degree of hearing loss and the presence of tinnitus has not been proven. Deterioration of hearing disorders caused by long-term exposure to noise at work was not found in the observed group. These findings prove the effectiveness of the set of preventive measures.

Key words: Tinnitus, impaired hearing, working environment, noise

Introduction

Noise, according to Seidman and Standring [1], is defined as unwanted sound or combination of sounds that has unfavourable effects on health. These effects may occur in the form of physiological or psychic damage through various mechanisms. Chronic exposure to noise may cause permanent threshold shifts and hearing losses in certain frequency ranges. According to Seidman and Standring, the general psychological effects of noise are not well described and are often ignored. Their effect, however, may be devastating. They may include hypertension, tachycardia, cortisol increase, or increased physiological stress. These effects may have severe negative results on everyday life. With long-term exposure to noise, e.g. in a working environment, hearing impairment may result, which is often associated with tinnitus.

Tinnitus, according to Kabátová and Profant [2], is a sound phenomenon manifested as a foreign or even disturbing hearing perception or sensation. Rečičárová [3] defines tinnitus as sound perception most often in the ears or head while the actual source of the noise is absent in the external environment. This clinical symptom cannot be improved by treatment. As an unpleasant symptom of an existing hearing disorder, it is mostly subjective. Approximately 80% of individuals have experienced tympanophony (tinnitus) at the onset of hearing impairment. However, it does not always have to be a manifestation of an illness as it also occurs in healthy individuals in whom no illness has been proven.

Kabátová and Profant [2] do not consider tinnitus to be an illness. Instead, they consider it a symptom that does not endanger human life, but markedly worsens the life quality of the affected. The negative phenomena of concentration on tinnitus and the associated negative emotions lead to attention and sleeping disorders, loss of joy in life, depression, and even suicidal thinking in exceptional

cases. Habituation or adaptation to such non-serious sound stimuli as tinnitus may be learnt [2]. The combined handicap of hearing impairment and tinnitus may be very frustrating. Therefore, timely diagnostics and subsequent treatment of this symptom are very important. Prevention is always less costly than treatment. In the USA, according to Sprinzl and Riechelmann [4], 17% of the adult population suffer from tinnitus, more so in higher age categories. In Slovakia, 30% of subjects at the age of over 65 report tinnitus. Bytešníková [5] reports tinnitus occurrence in 15-17% of the whole population in the Czech Republic. This symptom affects white people more, and more men suffer from it than women. Among adults with hearing handicaps, tinnitus incidence rises to 70-85%. No connection has been found between hearing disorder severity and tinnitus [3].

Hahn [6] divides tinnitus into categories:

- Objective tinnitus that can be objectified, recorded on sound medium, and it is audible by the examiner; 1% of patients suffer from it.
- Subjective tinnitus that cannot be objectified and it is heard only by the particular patient; 99% of patients suffer from it.
- Pathological tinnitus that lasts for more than five minutes and is experienced more than once a week.
- Decompensated tinnitus that causes a reduction in health quality [6].

Depending on whether tinnitus ceases after a certain time or not, it is referred to as temporary or permanent.

Tinnitus may be related to a hearing disorder, but this is not always the case. It may occur before or after a hearing disorder and is sometimes related to hyperacusis.

Classification according to the degree (Scottet Lindberg):

1st degree tinnitus is sensed only in silence,

2nd degree tinnitus is disguised by normal noise of the surrounding environment,

3rd degree tinnitus cannot be disguised at anytime, anywhere, by anything [3].

Tinnitus aetiology and pathogenesis are not clearly defined and some unclear issues remain. We can distinguish theories related to the central nervous system and peripheral hearing mechanisms [7]. The latest studies prove that even though tinnitus occurs in the ear, brain centres have a decisive role as they are a centre of attention, feelings, and memory [8]. The brain makes decisions whether we do or do not sense tinnitus through the auditory nerve and various sections up to the auditory centre. The mechanisms that cause tinnitus are not completely clear. It may occur as a symptom in almost all hearing illnesses at any level of the auditory pathway, from the cochlear core to the auditory cortex [9]. 300-400 various aetiological factors that cause tinnitus are specified in the literature. In order of incidence, the most frequent include presbycusis, acute hearing loss, long-term exposure to noise, otogenous trauma, degenerative ear disease, otosclerosis, Me-

niere's disease, cervical spine disorders, cardiovascular diseases, metabolic and hormonal disorders, chronic otitis and sinusitis, head trauma, heredity. Less frequent causes include damages of the temporomandibular joint, inner ear infections, and Lyme's disease [3]. According to Thor & Goebel [8] and Crummer, Hasssan [9], the causes of subjective tympanophony can be specified as auditory, neurological, metabolic, psychological, ototoxic drugs and substances, and other causes. Subjective tympanophony causes can be divided into six groups: auditory, neurological, metabolic, psychological, ototoxic drugs and substances, and other causes.

Auditory causes:

- ear canal blockage by ear wax or foreign matter,
- inflammatory diseases in the middle ear and auditory tube,
- ageing hearing loss (presbycusis),
- otosclerosis,
- professional hypoacusis (hearing damage caused by excessive noise and vibrations),
- Meniere's disease,
- benign tumours [8].

Neurological causes:

- head trauma,
- multiple sclerosis.

Metabolic abnormalities:

- hyperthyroidism,
- hypothyroidism,
- hyperlipidemia,
- anaemia,
- vitamin B12 or zinc deficiency.

Psychological causes:

- depression,
- anxiety,
- panic disorders.

Ototoxic drugs and substances:

- analgesics,
- antibiotics (erythromycin, tetracycline, vancomycin)
- chemotherapeutics,
- diuretics,
- quinine and heavy metals (mercury and lead).

Other causes are dental disorders and maxillary jaw impairment [9].

Even though, according to the previously cited authors [3], no correlation was found between hearing disorder degree and tinnitus aggravation, tinnitus incidence has risen to 70-85% among adults with hearing impairment. The survey

results of Agrawal, Platz and Nipark [10] state that hearing loss is more frequent in Europoid individuals who are exposed to noise, smoke, or exhibit cardiovascular risk.

Noise, according to Šulcová, Čížnár, and Fabianová [11], is the most frequently health damaging factor in working environments. It is the greatest risk factor in the SR, where regional public health authorities make decisions regarding classifying specific workplaces in risk categories based on noise measurement results. Pursuant to Ordinance No. 448/2007, the following are classified within risk degree II:

Jobs in which the upper noise exposure limits are not exceeded, however the standardised level of exposure to noise (LAEX, 8hrs) is higher than 75 dB, or C peak level of acoustic pressure (LCPk) is higher than 130 dB.

- a. Jobs in which working time is flexible or exposure to noise varies over the course of the week. At the same time, weekly average standardised levels of daily noise exposure per 40-hour week exceed 75 dB, but do not exceed upper exposure limits.

Within risk degree III, the following are classified:

- a. Jobs in which noise exposure limits are exceeded. However, the excess level of standardised noise exposure (LAEX, 8hrs) is lower than 10 dB, or the excess amount of C peak level of acoustic pressure (LCPk) is lower than 3 dB.
- b. Jobs in which working time is flexible or noise exposure varies over the course of the week. At the same time, standardised weekly average noise exposure daily levels per 40-hour week exceed the upper exposure level.

Within risk degree IV, the following are classified:

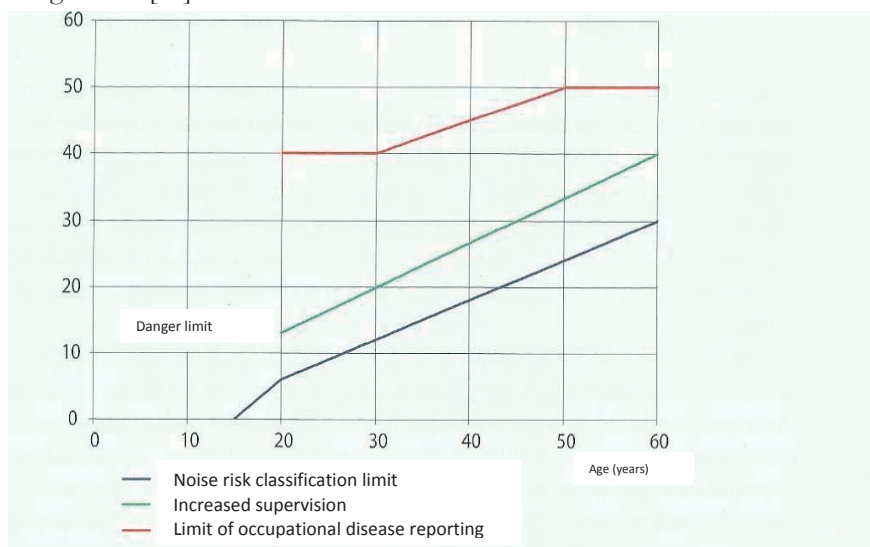
- a. Jobs in which upper exposure action levels of noise are exceeded and the excess amount of noise exposure standardised level (LAEX, 8hrs) is 10 dB and more or the excess amount of C peak level of acoustic pressure (LCPk) is 3 dB and more.
- b. Jobs in which standardised level of noise exposure or C peak level of acoustic pressure complies with the criteria of category III and at the same time employees are examined for auditory changes in relation to noise impact [12].

In order to protect the health of employees, it is important to foresee pertinent dangers and health hazards. The main challenge for preventive occupational medicine is to adjust work methods for each individual so that the working environment and methods are not a source of health risks. The aim is to reduce risk and damage to health related to work and occupational diseases [13]. Noise is one of the most serious and most frequent factors that negatively affect the working environment. According to Flimel [14], noise has been a by-product of production since the beginning of the industrial revolution and has varied impact on human life.

In order to assess noise and evaluate load pressure on employees, certain methods of measuring, evaluation and determination of the highest allowable values are used. Regular hearing examinations of employees exposed to excessive noise only started in the 19th century. The invention of the audiometer in around 1930 enabled the measuring of hearing loss at various frequencies at different noise intensities. Mass production of these devices made mass examinations possible for employees working in hazardous noisy workplaces. This led to important discoveries about how to prevent hearing disorders. Labour ambulance services (PZS) are currently specified for performance of preventive functions and preventive care. These ambulance services are assigned by the Act No. 355/2007 of Coll. (subsequently amended), and by ordinances of the MZ SR. PZS that specify that safe working conditions and consultations must be provided for employers and employees. These support optimum physical and mental health of employees in the workplace and adaptation to employees' physiological virtues and abilities with regard to the condition of their physical and mental health [11].

Initial, periodical, final and unscheduled preventive medical examinations (LPP) are another way to reveal hearing disorders in a timely manner.

Pursuant to the Act of the NR SR No. 126/2006 of Coll., medical examinations in relation to work are performed once per three years for work activities in category II, once a year for work activities in categories III and IV, and for work activities for which exceptional health care is required, intervals are specified by special regulation [15].



Graph 1. Employees' classification according to % of hearing loss depending on their age [2].

LPP frequency is dependent on the work category and is recorded in the health documentation of the employee, who must be informed about these frequencies.

Graph 1 shows the limit of hearing damage risk due to noise exposure and the limit at which the respondent must be removed from a hazardous workplace. The development of disorders is classified as favourable, bearable and unfavourable based on results of hearing disorder development evaluation;

Favourable development of hearing disorder is defined as long-term dynamics of hearing loss that do not exceed 0.5% per year and short-term dynamics that do not exceed 2% per year.

Bearable development of hearing disorder is defined as long-term dynamics of hearing loss that do not exceed 0.5-1% per year and short-term dynamics that do not exceed 2% per year.

Unfavourable development of hearing disorder is defined as long-term dynamics of hearing loss that exceed 1% per year, overall hearing loss that exceeds limit values, or short-term dynamics that exceed 2% per year [2].

If hearing damage or deafness occurs due to unfavourable impact of physical working environment factors, then this illness is defined as occupational disease. According to Batora [16], occupational disease occurs due to pathological adaptation of an employee to the working environment. Physicians who find health condition changes related to work should suspect that it might be occupational disease or otherwise related to the work being performed and send the patient to a specialised occupational medicine clinic. The task of an occupational medicine clinic is to prevent both immediate and permanent health damage by early diagnostics and effective treatment. The patient is examined to confirm or exclude suspicion of health damage due to the work and to take measures to prevent more serious health damage. Work conditions, risk factors, and work performance method are determined by a meticulous hygiene inspection of all aspects. The preventive measures of the organisation are also evaluated, such as organisational, technical, personal protective work aids, work regime, and relaxation [16].

The occurrence of occupational illnesses in the Slovak Republic is monitored, evaluated and published nationally. Yet, despite the gradual decrease of risk factors in the working environment, it is still necessary to put preventive measures in place and reduce risk factors. Working environment quality should be a priority of every enterprise. Motivated, qualified and especially healthy employees have become a decisive factor in productivity and competitiveness. Protection of employees' health in the workplace is understood as investment in employees and the future of the enterprise [17].

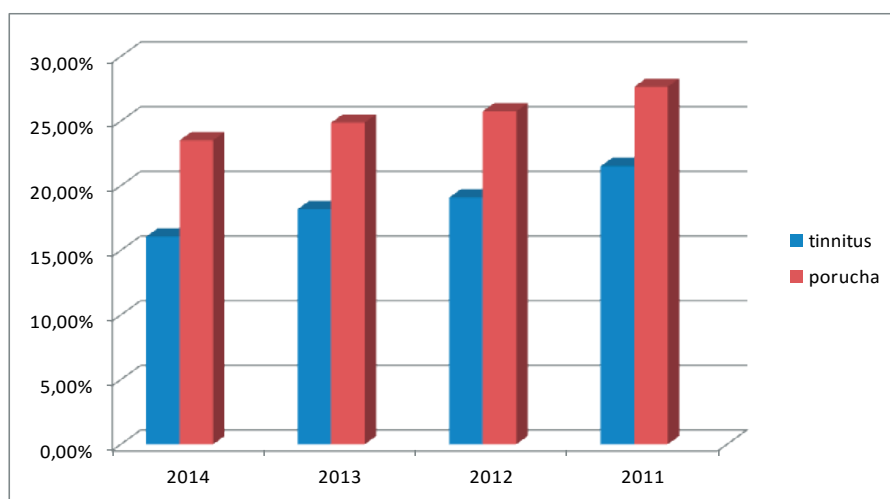
Appropriate work conditions and complex care of employees is not only a sign of advanced company culture, but it also decreases the number of employees who perform hazardous tasks. Taking care of employees and the working

environment is not only beneficial for the company, but also positively motivates employees [18]. Table 1 shows audio examinations performed from 2011 to 2014 at the ORL outpatient department in Žiar nad Hronom. The listed statistical comparisons and graphic illustration (Graph 1) confirm the statements of some physicians, according to whom tinnitus does not always have to be a symptom of hearing illness. Neither has any relation between hearing disorder degree and worsening of tinnitus been found [3].

Table 1. Audio examinations and tinnitus occurrence in the years 2011-2014 at ORL outpatient department

Year	Examined at ORL + AUDIO outpatient department	Hearing disorders + in (%)	Men	Women	Hearing disorder/ tinnitus + in (%)	Men	Women
2014	3489	821 (25.53%)	473	331	561 (16.07%)	331	218
2013	3373	840 (24.90%)	453	358	614 (18.20%)	294	300
2012	3602	928 (25.76%)	515	392	688 (19.10%)	326	341
2011	3223	892 (27.67%)	485	382	694 (21.53%)	375	308
Total	13687	3481 (25.43%)	1926	1463	2557 (18.68%)	1326	1167

(Source: author)



Graph 2. Relation between hearing disorder and tinnitus (Source: author).

The decreasing incidence of hearing disorders is largely the result of regular preventive examinations of respondents working in noisy environments and subsequent treatment.

Role of nurses in preventive examinations of employees working in noisy environments:

- provide quality health services,
- specify nursing care plan,
- provide care in compliance with nursing needs of the employee,
- define affiliated diagnoses for employees in workplaces where they are exposed to noise,
- use nursing process procedures,
- plan activities in active cooperation with employees,
- perform physical examinations,
- plan adequate laboratory testing,
- keep records of audiometric examinations (for possible comparison),
- keep health documentation with recording of hearing disorders (statistics),
- specify usage of adequate personal protective work aids,
- cooperate with occupational medicine nurses.

The work of an audiometric nurse is related to the work of an occupational medicine nurse. When nursing care is provided to employees with hearing disorders, it is firstly provided to employees who are employed in workplaces classified in the risk groups II, III and IV. The work scope of the occupational medicine nurse is to:

- assess the employee's needs in their working environment,
- focus on prevention, support and maintaining health,
- activate the employees' potential for their own health maintenance by effective education at regular intervals,
- admonish organisations for increased health risks,
- specify interventions for adjustments in the working environment, habits in the workplace, and the usage of personal protective work aids,
- keep documentation of illness rates and absences in workplaces,
- provide quality health services ,
- perform professional audits regarding compliance with usage of personal protective work aids,
- define examination intervals,
- analyse effects of hazardous exposures on health,
- specify time off for employees due to noise risk or reassignment away from the risk,
- develop and implement health rehabilitation programs [19].

Tinnitus manifests in each person differently; therefore, the treatment procedure varies. The duration of tinnitus treatment can vary. At the start of treatment, a medicament-related approach is most common. In chronic stages, psychological intervention is predominant. According to Kabátová and Profant [2], it is possible to learn how to adjust to non-serious sound stimuli such as tinnitus. Thanks to brain plasticity, it is possible to adapt to tinnitus by reducing unwanted connections between the autonomous system, the limbic system, and auditory centres. Patients with normal hearing without hyperacusis who have tinnitus but do not suffer from it do not need treatment. For them, education on tinnitus is preferable, such as explanations regarding the detection of tympanophony in the hearing pathway and the importance of correct diet and healthy life style in order to prevent tinnitus worsening. A phoniatriest or audiologist should treat individuals with hearing disorders that are connected with frustrating tinnitus. Conservative, non-surgical treatment aims to eliminate causes that are known to cause auditory tympanophony. The main point is not to expose persons to loud and polluted environments, followed by cessation of smoking and drug taking, healthy diet, physical activity, sufficient sleep, intensive treatment of vascular and cardiac diseases, cervical spine rehabilitation, medication, psychotherapy, hearing aids, noise masking aids, and hearing aids. Surgical treatment of tumours or inflammations of the middle ear does not always eliminate tympanophony [8].

Rehabilitation treatment includes classic rehabilitation in the area of cervical spine, laser treatment, magneto-therapy, acupuncture, hyperbaric oxygenation and electro-stimulation.

Doctors and nurses are expected to explain the cause of tympanophony and the importance of correct diet and healthy life style as the best way to prevent tinnitus worsening. A phoniatriest or audiologist should treat individuals with hearing disorders that are connected with frustrating tinnitus. Audiological tinnitus management is a precisely designed treatment procedure. Audiometric examination of tinnitus together with a psycho-acoustic questionnaire examination (detailed history) and subsequent determination of the most appropriate therapy are important for each individual [3].

Individuals affected by these symptoms seek a quiet and sound-stable environment. People with hearing impairment have greater difficulty coping with noise than those with normal hearing ability. In order to reach alleviate tinnitus, Hiller and Haerkotter [20] recommend medicamentous therapy combined with relaxation, rehabilitation, autosuggestion, biofeedback, hypnosis, and acupuncture as an alternative therapy method. They try to improve life quality psychologically and socially so a person can fully participate in work and social life, while not being limited by health issues.

Aim

The aim of this research performed in 2014 was to verify the connection between tinnitus and hearing disorders and identify factors that affect tinnitus. When performing the measuring, we also verified the efficacy of hearing protection measures of persons in hazardous working environments.

Design

Quantitative, cross-section, observation study

Methodology

In order to gain input data, two research methods were used. The first was audiometry with overall hearing loss evaluation (CSS) according to Fowler. Measuring procedures were performed in an audiological outpatient department as part of preventive examinations of employees who had been exposed to noise. An MA31 type clinical audiometer was used. Measuring was performed by a nurse who was a member of a work-health service team with a second degree of university education and a certificate in audiometry. When evaluating audiometry results, the nurse takes into consideration the client's age and period of noise exposure. The research took place from March 2014 through August 2014 at the outpatient department in Žiar nad Hronom.

The second method used was a non-standardised questionnaire of individual structure, designed for clients who reported tinnitus during CSS measurement. Individual questionnaire items were focused on better specification of the audiogram in individual clients. The completed questionnaire was subsequently allocated to the audiogram results. Significant interaction of quantitative variables was evaluated by Pearson's correlation coefficient (r).

Characteristics of the group

Selection of the respondents was deliberate and targeted. The respondents work in the industrial park in Žiar nad Hronom (the SR), in various operations with permissible noise risk of categories II, III and IV. The examinations were performed during periodical and initial preventive examinations relating to noise exposure in the workplace. The overall number of audiometric examinations performed was 1,687. 140 respondents also mentioned tinnitus sensation during the audiogram. Hearing impairment of various degrees was found in 125 respondents. Tinnitus without proven hearing impairment was found in 15 respondents. We continue working in the research with 140 respondents. The respondent group consisted of 17 women (12.15%) and 123 men (87.85%). The respondents' age ranged from 20 to 64 years. The average age was 49.97 years. The men's average age was 50.44 years, while the women's average age was 46.52 years.

Results

We interpret the results by analysing the number of years that respondents had been exposed to noise and overall hearing impairment in the form of tables with absolute and relative totals (Tab. 2, 3)

Table 2. The period worked while exposed to noise

Noise exposure period in years	n	%
<5 > 10	41	29.28
<10 >19	79	56.43
< 20	20	14.28
Total	140	100

Table 3. Hearing disorders (CSS according to Fowler)

Hearing disorders	n	%
Without hearing impairment	15	10.71
Slight	53	37.85
Medium	66	47.15
Severe	6	4.29
Total	140	100.00

Interdependency between hearing disorder and tinnitus has not been proven in the monitored group ($r = -0.014$)

Table 4. Tinnitus duration

Tinnitus duration	n	%
< 3 months	18	12.86
< 6 months	38	27.14
> 12 months	39	27.86
<12 months	45	32.14
Total	140	100.00

Most respondents had experienced tinnitus for longer than 1 year (Tab. 4).

Table 5. The period from tinnitus onset to visiting a doctor

Period length	n	%
> 3 months	31	22.14
> 6 months	9	6.43
> 12 months	96	68.57
< 12 months	4	2.86
Total	140	100

The highest number of respondents visited the doctor for treatment within 6 to 12 of tinnitus onset (tab. 5). Within the monitored group, most respondents are being treated (129 respondents), of whom 126 (90%) experience tinnitus irregularly. 14 (10%) respondents experience tinnitus continuously. According to the results, they are mostly non-treated patients (11 respondents).

Table 6. Factors worsening tinnitus

Factors worsening tinnitus	n	%
exposure to noise	103	73.57
illnesses	28	20.00
stress	9	6.43
weather	0	0
and others	0	0
Total	140	100

Respondents in the largest group think that exposure to noise is a factor that worsens tinnitus (Tab. 6).

Table 7. Factors alleviating tinnitus sensing

Factors alleviating tinnitus	n	%
television and radio	107	76.43
Sport	13	9.28
Music	20	14.29
and others	0	0
Total	140	100

Most of the respondents consider television and radio to be a factor that alleviates tinnitus (Tab. 7).

Table 8. Method of relaxation

Method of relaxation	n	%
Passive	94	67.14
Active	46	32.86
Total	140	100

The majority of respondents, 94 (67.14 %), relax passively (wellness, massage, books, music, etc.) and 46 (32.86%) of respondents prefer active relaxation (swimming, tourism, working in the garden, etc.) (Tab. 8).

Table 9. Activities affected by tinnitus

Activities affected by tinnitus	n	%
sleep and relaxation	136	97.10
working	2	1.45
non-working	2	1.45
and others	0	0
Total	140	100

According to the respondents, the activity that is most negatively affected by tinnitus is sleeping (Tab. 9).

Discussion

Tinnitus is a very unpleasant symptom that markedly worsens life quality of the person affected. In his study, Hiller [20] states that one third of the population has some experience with tinnitus during their life.

The aim of the research was to assess hearing condition and find a connection between tinnitus and hearing disorders in the group of 140 respondents who had been exposed to noise. The average age of the respondents was 49.97 years. According to Šuchová [21], every second individual suffers from tinnitus in the age category of 60-65 years. In this category, there are more men than women. The authors Roth, Hanebuth, Probst [22] and Agraval, Platz, Niparko [10] came to the same conclusion; increased hearing loss in men is more common than in women. Particularly, 30% of men and 20% of women in Europe have 30 dB hearing loss at the age of 70, and 55% of men and 45% women at the age of 80. In the group monitored by us, there was prevalence of men. However, this composition was influenced by the selection of respondents and their work scope, which is typical for men. Tinnitus incidence rises among adults with hearing impairment to 70-85% [21]. According to experts, tinnitus does not necessarily have to be a sign of a hearing disorder. According to Rečičárová [3], there was no connection between hearing disorder degree and worsening of tinnitus. Interdependency between hearing disorder degree and tinnitus was not confirmed even in the group being monitored by us ($r = -0.014$) (Tab.3). These findings are also confirmed by tinnitus occurrence overview in combination with hearing disorders based on examinations in the ORL outpatient department in Žiar nad Hronom in four monitored years (Tab.1). Out of the total number of examinations performed, hearing disorders were found in 25.43% of individuals, while tinnitus was recorded only in 18.68%, with a slight prevalence of tinnitus in men.

To a great extent, the decreasing incidence of hearing disorders is the result of legislative measures focused on health protection at work (Act No. 124/2006

of Coll. on safety and health protection at work) and legislative compliance to regular preventive examinations of respondents exposed to noise. According to an Italian study, in addition to genetic predisposition, environmental factors also have an impact on hearing disorders, especially noise exposure duration in the workplace [23]. In the group being monitored by us, more than half of the respondents (56.43%) had been exposed to noise from 10 to 19 years (Tab.1). Based on audiological examinations performed with CSS calculation according to Fowler, the respondents were divided into groups with slight hearing loss (25 to 40 dB), with medium hearing disorder (41-70 dB), and severe hearing disorder (71-90 dB) (Tab. 2).

Most respondents had experienced tinnitus for longer than 1 year (Tab. 4). The respondents most often decided to be treated within 6 to 12 months of the onset of tinnitus symptoms (Tab. 4). Respondents studied by Kučerová [24] decided to seek a doctor sooner. 41 respondents (60%) visited a doctor within 3 months of tinnitus onset (Tab. 5). Respondents who visited a doctor and received treatment have less severe tinnitus that is not continuously experienced.

Exposure to noise was specified as a factor that exacerbates tinnitus by 103 respondents (73.57%) (Tab. 6)

Watching television and listening to the radio were specified by 107 (76.43%) respondents as a factor that alleviates their tinnitus. Kučerová [24] came to comparable findings in her research. Music and watching television help alleviate tinnitus. Psychotherapy and relaxation also help alleviate these problems. By eliminating stress, it is possible to expand narrowed veins and thus reduce symptoms. The majority of respondents, 67.14%, relax passively (wellness, massages, books, music, etc.) Almost 33% of the respondents prefer active relaxation (swimming, tourism, working in the garden, etc.) (Tab. 8).

According to respondents, the activity that is most negatively affected by tinnitus is sleeping (Tab. 9).

Kučerová [24] also found that most respondents (46.9%) stated sleep and relaxation in their answers.

Conclusion

Life quality of a person, family and community is provided by community nursing by “physical, mental and social life sustaining and support in compliance with social and ecological environment together with nursing care provision concentrated on the quickest possible gain of independence and self-sufficiency” [25].

Employees' health protection and support is a part of a community nurse's competence regarding health protection at work. However, although tinnitus is not a symptom that endangers human life, it does worsen it. In tinnitus, a primary role is played by involuntary limbic and vegetative systems. A patient cannot influence his or her tinnitus. They cannot decide whether they do or do not want

to sense it. Concentrating on tinnitus results in negative emotions, leading to concentration disorders, sleeping disorders, loss of joy in life, and consequently in depression and reduction or loss of life meaning. Frequency and loudness of tinnitus itself do not play any important role. Timely detection and subsequent treatment of this symptom are important.

Within the research performed in the group of 140 respondents with tinnitus, we verified a dependency between hearing disorders and tinnitus. A statistical dependency between quantitative variables was not proven. We did not find that hearing disorders are worsened by long-term exposure to noise in the working environment. These findings prove the efficiency of the preventive measures put in place. Regular preventive examinations in CSS increase by over 1% every second year and employees are removed from noise exposure risk to prevent occupational hearing disorders. In the group of respondents, hearing disorders and tinnitus were more frequent in respondents who perform physical work than those who had desk-based jobs.

The respondents who visited a doctor within 12 months of first symptoms and are being treated do not continuously experience tinnitus. For them, the course of tinnitus is more favourable as they experience periods without tinnitus. Prevention and timely detection of hearing disorders with subsequent medicinal and alternative treatment of these disorders is important. The aim is complete and appropriate integration of a person in work and social life without limitations caused by health issues.

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Wykorzystanie wspomnie i biografii w opiece nad osobami cierpicymi na demencj w řrodowisku domowym

Use of Reminiscence and Biography in Care of People Suffering from Dementia In Home Environment

Abstrakt

Wstp: Starzenie si ludnořci staje si oglnořwiatowym problemem naszych czasw. Starzenie wřród populacji czeřkiej po roku 2010 jest jeszcze szybsze. W parze z rosnc liczb osb starszych i dluęořci Źycia pojawia si rwnieę demencja. O demencji moęemy dzisiaj mwci jako epi-demii XXI wieku. Praca skupia si na wykorzystaniu wspomnie i autobiografii ludzi z demencj w řrodowisku domowym.

Metody: Praca omawia innowacyjne podejřcie do opieki nad osobami starszymi z demencj, z wykorzystaniem wspomnie i autobiografii. Niniejszy dokument ma charakter dyskusyjny.

Cel: Celem niniejszego artykułu jest zwrcenie uwagi na korzyřci i moęliwořci stosowania terapii wspomnie i modelu autobiograficznej opieki, w praktyce, tak aby pacjent uzyskał maksymaln korzyřci.

Zawartořci: Demencja stanowi stosunkowo duę grup chorb o rżnej etiologii i stopniu zaawansowania. Chociaę osoby z demencj trac niektre z cech ich osobowořci i kontaktu z samym sob, chory jest zawsze człowiekiem i ma prawo do poszanowania i wciwej opieki, dlatego konieczne jest, aby odeřci od dogmatu, że osoby z demencj s niekontaktowe, a opieka nad chorymi bardzo trudna. Obecnie, poczynia si starania, aby opiek nad chorym przenieř do řrodowiska domowego, w ktrym wykorzystuje si dobry wplyw znanego choremu otoczenia oraz rodziny.

Wnioski: Głwnym celem społeczeřstwa powinna by poprawa jakořci Źycia wszystkich osb z poszanowaniem etycznych aspektw opieki. Jedn z moęliwořci godnej opieki nad pacjentami z otępieniem jest moęliwořci wykorzystania wspomnie i biografii.

Słowa kluczowe: Biografia, otępienie, wspomnienie, rodzina, řrodowisko domowe

Abstract

Introduction: The aging population is becoming a worldwide problem of our time. Even the Czech population began to age faster after 2010. Together with the increasing number of seniors and longer life expectancy, dementia is also on the rise. Dementia is an epidemic of the 21st century. Our paper focuses on personal stories of people with dementia at home. **Methods:** The text discusses an innovative approach to caring for elderly with dementia with the use of personal histories and has rather a discursive character.

Goal: The aim of this paper is to highlight the advantages and choices of the application of reminiscence therapy and autobiographical care model to bring patients with dementia maximum benefit.

Contents: Dementia represents a relatively large group of diseases with different causes and extent. Although people with dementia lose some attributes of their personality and contact with themselves, they are always human beings and are entitled to respect and adequate care. It is necessary to depart from the dogma that people with dementia are uncommunicative and that caring for people with dementia is very hard. At present, there is effort to move the care of these patients to the home environment in order to maximise the potential of the known environment and the family.

Conclusion: The main goal of society should be to improve the quality of life of all individuals and respect ethical aspects of care. One way to offer dignified care to patients with dementia is the use of reminiscence and biography.

Key words: Biography, dementia, reminiscence, family, home environment

Introduction

It is widely known that the process of aging and old age brings with it many changes that are considered and perceived as negative or annoying by both seniors themselves and younger people. It is important to realize that the process of aging is inherent in the life of all living beings, including humans. The notion of dementia is a combination of the Latin words *de* (free) and *smaller* (the mind, consciousness, mind). Dementia is a syndrome and a result of brain disease. Usually, a chronic or progressive disease is defined by a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, reasoning, learning ability, language and judgment, i.e., cognitive functions. Consciousness is not clouded. Cognitive impairment usually accompanies and sometimes precedes deterioration in social behaviour, emotional control, or motivation [1]. Secondly, it leads to collapse of non-cognitive functions. In recent years, society has undergone many changes that have greatly influenced the development of care for the elderly and nursing, geriatrics and gerontopsychiatry. Population aging is a very hot topic and we can expect a higher demand for specialised care for seniors in the future. Significantly, the role of the family is becoming predominant, as is rehabilitative nursing care and the requirement to ensure the highest possible quality of life. When offering optimal conditions after stabilising the health status of an individual, follow-up care may be provided in a patient's home environment [2]. However, it is necessary for patient and family to cooperate. Nursing, like medicine, is currently enjoying rapid development. Even at home, it uses new knowledge from research and practice, meaning care

is becoming more efficient and, above all, has a favourable effect on the patients themselves. Patients are viewed holistically, meaning that bio-psycho-social unity is important and care is not only focused on the somatic side, but also on the psyche of the patient. This trend is reflected in the care of patients with dementia. It is relevant to inform family members about new, non-pharmacological approaches for patients with dementia. In the last few years, some of these ways of care have become increasingly important, such as basal stimulation, reminiscence, and biography.

The importance of family in care of patients with dementia

"The family is a universal group which offers significant sociopsychological phenomena to the life of an individual, such as motivational volitional characteristics, the ability for him to create confidence in himself, his attitude to himself, strong social bonds and emotionally reciprocated relationships" [3, s. 303]. In recent years, the number of families in which the partners (parents) are not married has risen. This coexistence is described as *"two adults of the opposite sex in a casual relationship who cohabit (with or without children) for a minimum of fifteen years"*. The number of single families is increasing [3]. All these attributes certainly influence decisions concerning the care of loved ones with dementia at home. The majority of family members react with shock to the initial dementia diagnosis, but there is also a kind of relief. It is best for the patient if the family decides to take care of them at home, because these people are hard to adapt to new and unfamiliar surroundings. The family of the patient knows most of his habits, needs and background. However, family members should realise that they need to devote time and attention to their own personal needs including leisure activities, professional growth, and financial security of their families. It is also important to change ourselves when we care of the sick. Family members should be educated about caring for the sick and the possibilities of social assistance and respite services that can be provided by health professionals, especially nurses and the patient's attending physician. It should be explained to care givers that the use of professional help does not reflect the inability of the family, but improves the quality of care provided. Finally, it is necessary to educate the family about how easily these techniques that contribute significantly to maintaining the patient's self-sufficiency may be applied [4].

Reminiscence

The notion of reminiscence is synonymous with the Czech words recollection or remembrance. For a patient with dementia this means regaining experienced events that enrich everyday life, with the main purpose being to fill time, improve social inclusion, establish psychological well-being, and strengthen self-express-

sion and self-esteem [5]. This technique deliberately recalls memories maintained in long-term memory, even in the advanced phase of dementia. The principle of this technique is that a sick person is in an environment that raises his confidence and trust [6]. This therapy may be quite easily integrated into home care for the sick. The home environment should be changed as little as possible so as not to scare or confuse the patient. Reminiscence activities involve conversation with the patient about his present life, his past activities, events and experiences. Commonly used are old photographs, objects, instruments, music, movies, etc. It is important that family members learn not to deprive seniors of old items that they consider to be no longer needed, but to use them for reminiscence. Indeed, they may be of great importance for a patient with dementia. It is not advisable to renovate housing and change the furniture unless necessary, so dementia sufferers feel safer. Also telling old stories and remembering events are part of reminiscence. Here, the family has the opportunity to come together listen to old stories and songs. It is not appropriate for family members to make it clear that the story has been heard many times. The lives of seniors are full of events that are important and should be communicated to others. Seniors employ memory and thinking and affirm their own identity and continuity in their lives by relating their memories. The act also addresses the need to transfer experience to the younger generation and thus contribute to the continuation of life. Group meetings are of great importance as they allow people to reminisce together. Recollection allows balancing [7]. Reminiscence activities are one of the keys to successful acceptance of aging that help seniors cope with this difficult phase of their lives. Family members can often be enriched with new information that offers them the opportunity to understand better the life of their loved one [4].

Biography

In relation to the care of a person, the notion of biography can be defined as a set of information about an individual who is actively involved in its creation. In this case, we are talking about active biography. However, we can also create a biography based on other sources of information, such as family, friends, acquaintances, documentation, and nursing staff. In this case, a biography is passive. In terms of content, we can divide biography into several parts, one of which is autobiography, which contains an active narrative of the patient. Story biography is used for writing biographical data about patients with symptoms of dementia who already can't remember their memories. Activation of senses with biography is based on basal stimulation and is a summary of information when everything is classified according to individual sensory areas such as taste, touch, smell, etc. Another method that can be used is called *biographic anamnesis*, which involves relating information about the life of the patient in the form of a story. Biography can be divided into thematic units, *childhood, youth, adulthood and*

old age. Biographies can even be used as institutional devices that are recorded in a biographical client record. The introduction section contains client identification information (name, place of birth, names of father and mother, and professions). The *childhood* section typically contains data about siblings, friends, favourite toys and foods, home responsibilities, relationship to school, etc. *Youth* is focused on career choices, the patient's role models, first responsibilities, first love, etc. *Adulthood* contains information on job, marriage, children, health problems, and successes and failures. In the *old age* section, we ask seniors about retirement and its effects in terms of new responsibilities, roles, plans, peculiarities, and health difficulties, and the patient is asked to judge their life or recall the happiest or most difficult periods. In this context, we must recall Professor Erwin Böhm's psychobiographical model of care that is especially commonly used in German-speaking countries and is suitable for patients suffering from dementia and other disorders of communication and orientation. This model promotes understanding between generations and between caregivers and care recipients. It is a singular biography with an emotional subtext. Historical biography reflects the socio-cultural and regional aspects of time, as each region is unique (dialect, customs, habits) [8]. In practice, the attitudes of staff and families are changed and they better understand the client and provide improved care. In his model, Böhm focuses on people and their changed psyche. When he used his psychobiographical model in practice, he forced care providers to think and look for ways to give maximum encouragement to clients in terms of their self-sufficiency, use of familiar things, habits, and rituals. The principle is to respect the lifelong habits of seniors. It is necessary to understand the life history of the patient, because therapy is life itself. The main aim of nursing care according to Böhm is "*revival of the soul*" of the old, which he describes as a human soul energy called also "elen vital", the aboriginal source of energy that people use when they do something which is also a source for motivation in life. According to the author, all other care is secondary, because if a person does not have a will to live (does not have "elen vital"), or does not feel like doing anything, then there is a deficit of self-care. Another goal is to promote the professional interest of care providers and improve their skills. In many cases, this treatment maintains patient mobility, is not expensive, promotes teamwork, encourages self-care of patients, prevents burnout, and especially strengthens cooperation between family and staff and shows that what we do really makes sense [9]. Working with the biographies of seniors offers the feeling that caregivers are interested, thereby increasing the recipient's sense of confidence and security.

Discussion

Reminiscence and biography are techniques that can be easily applied in nursing care of patients with dementia, both in institutes and at home. Abroad, these

techniques are used far more often than here in the Czech Republic. However, in recent years professionals and the public in our country have become more aware of these techniques. It is worth mentioning research by Marková and Jedlínská [5], whose results were published in the journal *Florance*. The aim of this research was to assess the attitudes towards aging among seniors who live in institutions and describe the importance of reminiscence activities for the life of the elderly. Qualitative investigation of these authors' research and the results of many studies that took place in 2005-2007 at the Geriatric Centre in Prague, indicate the positive effect of remembrance for clients who attended group meetings in terms of improved mood, behaviour, thinking and memory. Overall, remembering increases seniors' satisfaction with life and improves adaptation to new environments [5]. Ing. Bc. Hana Vojtová [10], Director of Master Kristan's Home of seniors in Prachatice, put into practice the concept of sensory activation in older adults when talking about the biography of a person as follows: *"We can have the same name and surname, we can be physically very similar, and yet we do not live the same life, we do not read the same books, we do not eat the same food, and we live lives which are different to one another's."* Vojtová further states that biographical information is not retrieved out of curiosity, but because we want to better know and understand the patient in order to offer him activation techniques that are relevant to him [10]. Psychiatrist MUDr. Vanda Franková [11] thinks that reminiscence should be considered as comprehensive care for seniors with dementia, as this technique promotes self-sufficiency and enhances the quality of life not only for patients with dementia, but also for their family members [11]. This opinion is also held by other leaders in the field of gerontopsychiatry such as MUDr. Holmerová, MUDr. Tošnerová, and many others who agree unequivocally that these procedures should be inherently included in the care support methods of patients with dementia.

Conclusion

There are many activation techniques for patients with dementia. In our paper, we address two techniques that in our opinion are very applicable in a domestic environment. They are easy to understand, inexpensive, and available for family members who care for their loved ones with dementia. The care approaches that we describe can involve virtually everyone. An important prerequisite for the success of care is a very human and ethical approach to the patient. This reduces the attractiveness of irrational and ineffective procedures that may harm patients in many ways. Dementia cannot be cured, but with the use of non-pharmacological methods such as reminiscence and biography, it is possible to slow the course of disease and spend time with the patient to the benefit of all concerned. We believe that this type of care respects the dignity of the individual, as the client is perceived primarily as a person who has a past, present, and some idea about the future. This innovative approach undoubtedly increases quality of life.

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