IMPORTANCE OF VARIABILITY OF LABORATORY PARAMETERS AND UNCERTAINTY OF LABORATORY EXAMINATION METHODS IN CLINICAL PRACTICE

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Abstract
The methodology of laboratory examination methods is also influenced by the biological variability of the determined parameter and by the uncertainty of the methodology used for its determination in the laboratory. At the model example of the dynamics of the concentration of the Ca15-3 tumor marker, we have demonstrated the limits of the informational contribution of laboratory analyzes. We note that the value of laboratory examination methods is significantly multiplied with other diagnostic methods, especially imaging techniques. Their common informational power thus makes it possible to reach the right diagnostic decision at an earlier time, which increases the success rate of patient therapy.

Key words: Variability. Reference limit. Coefficient of variation. Tumor marker.

1 Introduction

Laboratory examination methods in healthcare must be a reliable source of data, which are necessary for correct differential diagnostics and the whole treatment-preventive process. In the recent decades, we have witnessed the tremendous development of this branch of biomedical industry. It has been resulted in hundreds of different laboratory parameters that allow us to control and monitor a large variety of biochemical-metabolic processes. However, there is also great variability in the methodological palette of examinations. A given parameter can be determined using enzyme immunoassay, chemiluminescence, photometry, radioimmunoassay, electrochemi-luminescence, etc. However, this variability also poses a risk and challenge to further improve laboratory investigative techniques and methodologies [1].

2 Requirements of physicians

From the point of view of patient´s care management, it is crucial for the physician and nursing staff to have a reliable and veracious outcome of the ordained parameter. Their clear requirement is that the results are to be delivered in a explicit format and, in the case of quantitative numerical data, with a clearly defined biological reference interval for the parameter. The patient sample must be received and laboratory processed within the appointed time limit. In fact, this simple set of conditions conceals the complex machinery of processes [2].

3 What physicians don't see?

However, there is also information that doctors do not see in the patient's result sheet. They are not given, because they mainly indicate the degree of variability and inaccuracy of the laboratory results.
They belong here:

Parameters of a particular examination method: detection limit, determination limit, linearity region, analytical specificity of the method, measurement accuracy, measurement preciseness, and robustness of the laboratory method.

Above all, *quality control* should be mentioned. It is a process where a sample with a known concentration of the analyzed parameter is added to a series of unknown samples. If a laboratory determination shows a result within a tolerated interval around the indicated value, we assume that this parameter is determined correctly also in unknown samples. External quality control and interlaboratory comparative tests have a similar control function [3, 4].

Interferences: The presence of some substances and molecules affects the test results. In the case of bio-chemical parameters it is usually icterus, hemolysis and lipid content. Therefore, interferences must be taken into account and their presence and influence monitored.

Measurement uncertainty: The laboratory investigative methods of each parameter consist of a sequence of steps, each of which contributes a certain error to the final value. We try to quantify the sum of all possible inaccuracies and errors by calculating the so-called extended combined uncertainty U_c, which quantifies the contribution of all the uncertainties of all individual steps and actions [5].

Biological variability: is caused by the characteristics of the living systems themselves in combination with the environment in which they are found and includes factors such as age, race, pregnancy, menstrual cycle, menopause, genetic predisposition, eating habits, etc. Biological variability from the individual's point of view is divided into intraindividual and interindividual [1 ,6].

All these factors, to a greater or lesser extent, affect the specific outcome of the patient's laboratory examination. The question is to what extent this information is also important for physicians.

3 Aim

On the results of selected laboratory parameter Ca15-3 verify the significance of information on its variability for the decision-making process in clinical practice.

4 Material and Methods

We had a time series of examinations of the Ca15-3 tumor marker in a patient who was treated with a breast cancer diagnosis and subsequently followed up with regular mammography and tumor marker determination intervals. No other co-morbidities were present in the patient. All processed data have been de-identified in order to guarantee patient privacy.

The tumor marker Ca15-3 was determined by the electrochemiluminescence method based on ruthenium complex excitation. The biological cut-off value of Ca15-3 for the Caucasus population of the catchment area of the laboratory was 35 kU/l. Intraindividual variability of the determined parameter is given at the coefficient of variation CVi=6.1%. The expanded combined laboratory method uncertainty was U_c=5.2%.

5 Results and Discussion

In our patient, the Ca15-3 parameter was determined 17 times in total. The results are shown in Table 1. Tumor extirpation was performed in the period after the second tumor marker determination. This was followed by a gradual decrease in its concentration, which confirmed the causal relationship between its concentration and the removed neoplasm mass. The results are shown in Figure 1. The fifth assay has already verified the achievement of a biological limit of 35 kU/l, followed by a further decrease (Table 1, Figure 1). The development shown is a typical example of a laboratory image of successful tumor therapy.

Table 1 *Results of the tumor marker Ca15-3 examinations.*

Examinations sequence	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**
Ca15-3 (kU/l)	101.2	107.3	60.4	40.2	30.9	27.1	21.1	20.5	19.8	15.6	14.9	19.9	15.4	14.7	16.4	15,2	27.9

However, the following dynamics of change is no longer as simple as it would seem. The patient was clearly in remission, with an average Ca15-3 concentration of $\bar{x}$=17.35±2.62 kU/l over the 7th to 16th determination period, with a coefficient of variation of Vk=15.12% (Figure 2). This coefficient of variation is higher compared to the given parameter of intra-individual variability of Ca15-3 (CVi=6.1%). The reason may be the biometabolic constitution of the organism, as well as the fact that it is not a healthy individual but an individual in whom the cancer has been treated. Measurement values no. 7-16 are an example of an ideal state of tumor marker concentrations in a long-term monitored patient in remission. Extended combined uncertainty of laboratory method U_c=5.2% guarantees accuracy and feasibility of provided data.

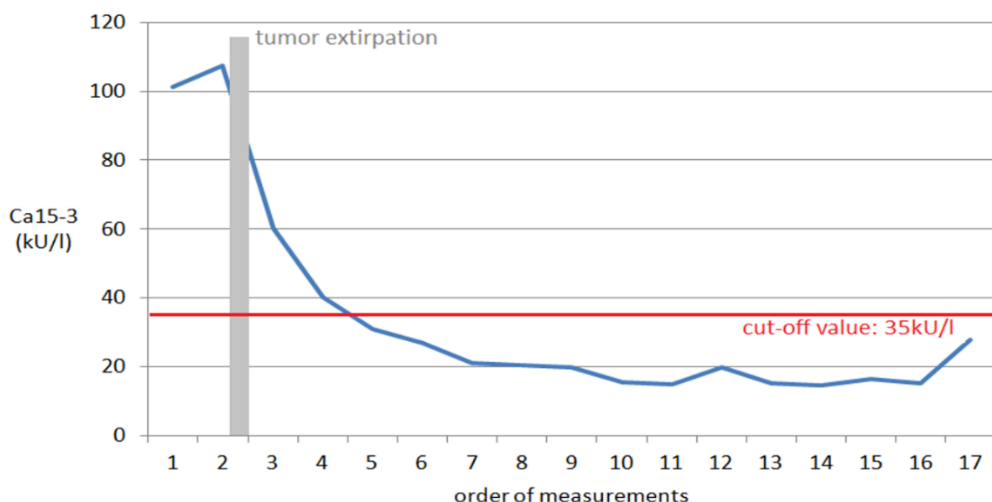

Fig. 1 *Time dynamics of decrease of Ca15-3 tumor marker concentrations*

The last 17th value of Ca15-3 determination (27.91 kU/l) appears to be very problematic, although it is still below the 35 kU/l limit value. Its magnitude already exceeds the interval of three times the standard deviation value (±3*sd*=7.66) of the observed arithmetic mean of the stabilized values of Ca15-3 concentrations in remission. And exactly at this moment, laboratory diagnostics alone is becoming insufficient. The question is what factor caused the observed increase in the concentration of the monitored parameter. If we would to rely solely on the monitoring of the laboratory parameter, further examination would necessarily follow at a defined time interval. If this following examination also showed a tendency to increase Ca15-3 concentration, it would most likely be a recurrence of the disease. If the following examination showed a return to the original stabilized range of numerical values, other effects (mastitis, trauma, etc.) would probably be the cause. In this respect, therefore, the focus is shifted to imaging techniques, especially to the mammography and ultrasonography, which are able to eliminate non-malignant processes immediately after detection of increased concentrations of the endpoint and thus speed up the diagnostic conclusion, which is crucial for further development of the patient's health condition.

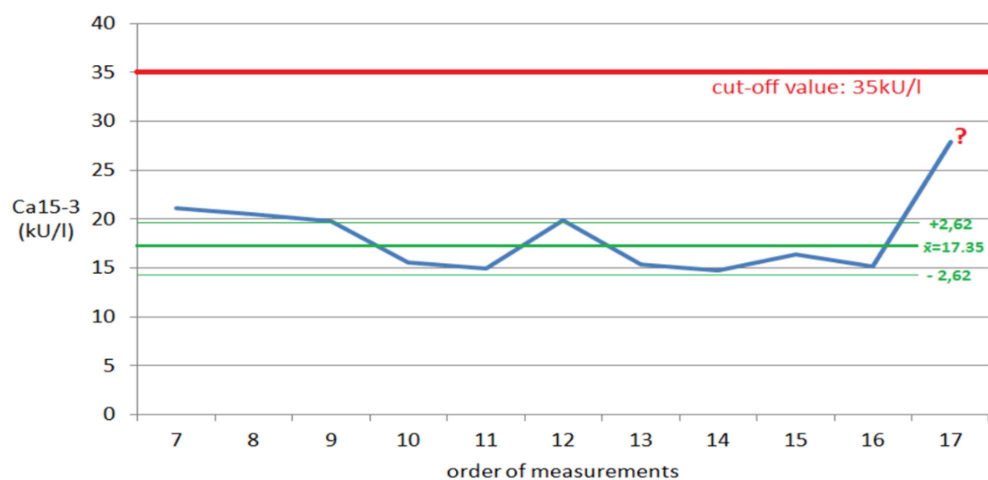

Fig. 2 *Variability of Ca15-3 tumor marker during remission*

6 Conclusion

In clinical practice, the multispectral informational palette of data variability of laboratory parameters and uncertainty of laboratory examination methods is significantly reduced. The result is a final value of the parameter concentration along with the indication of its biological reference interval. Other information, in particular data on the uncertainty of the laboratory examination of a particular parameter by a particular method, is not included in the results sheets. While they represent an information benefit, from the point of view of the dichotomy of decision algorithms in the process of differential diagnostics, they mean some confusion of information. Therefore, the partial results of laboratory diagnostics should be compared and aligned with the other results of other biomedical and laboratory components.

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PATIENT SATISFACTION WITH INPATIENT HEALTH CARE IN THE HOSPITALS OF THE SELF-GOVERNING REGION OF TRENČÍN

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Abstract
Background: The assessment of patient satisfaction with institutional health care is becoming an important element in assessing the quality of this care.
Goal: The purpose of this pilot study was to determine the level of satisfaction of patients with hospitalization in the hospitals of the Self-Governing Region of Trenčín (SGRT), followed by putting into practice the final form of the satisfaction questionnaire.
Methods: Determining the satisfaction of patients with hospitalization was carried out by the questionnaire of satisfaction of own construction. The questionnaire contained 40 questions and consisted of a total of 6 parts: a demographic, socio-economic, anamnestic, pre-hospital, hospital (26 questions) and a quality of life part. The results were evaluated by descriptive statistics methods in Excel 2013.
*Results:*The care of medical doctors (a), nurses (b), and disease awareness (c) was rated on the scale of 1 to 5 (1 - best, 5 - worst) as follows: a, 1.4-1.6; b, 1.3-1.7; c, 1.7-1.96. So called hotel services were also rated on a scale of 1 to 5 (1 - best, 5 - worst): d, media availability: internet: 1.7-4.3; e, cleanliness (floors, toilets, bathrooms and so on): from 1.65-2.35; f, food quality, quantity, dining culture: 2.0-2.3. On a scale of 0 to 10 (0 - worst, 10 - best) were rated: g , overall satisfaction with the stay: 8.15-8.9. The overall quality of the provided institutional care was evaluated as a measure of improvement of one's health condition at the beginning of hospitalization and before discharge from the ward: NsP Považská Bystrica improved by 2.9, NsP Prievidza by 2.8, and NsP Myjava by 3.76 (rated from 0 to 10).
Conclusions: The survey of patient satisfaction with hospitalization in SGRT hospitals yielded valuable results in the pilot phase. Slightly critically were evaluated the so-called hotel services such as cleanliness in the department and food. The care of doctors, nursing care and awareness of the disease was evaluated highly . A high level of satisfaction was also achieved in the summary evaluation of the stay and the quality of the health care itself.

Key words: Patient satisfaction. Hospitalization. Self-Governing Region of Trenčín.

1 Introduction

Health care assessment is a long-term object of interest of healthcare professionals, researchers, economists, sociologists and politicians. Although the subject is clearly defined, various methods of investigation are used in practice and studies have varied theoretical assumptions. However, this diversity in research does not mean that the study in question does not provide valuable results applicable to practice [1].

Institutional health care is an important area of health care, both from a qualitative point of view, as the reason for such is usually a more serious illness, as well as from a quantitative point of view, as evidenced by data on the number of hospitalizations. In 2018, inpatient health care facilities in the SR recorded 1,189,662 terminated hospitalizations (each in a ward by discharge, death or transfer to another ward). The mean age of the hospitalized patient was 49 years and the mean treatment time was 6.4 days [2].

Similarly, in assessing the volume and cost ratio, institutional health care shows significant values (years - costs): 2017 - 1,276 mil. €, 2018 - 1,312 mil. €, 2019 - 1,466 mil. € and the proposal for 2020 - 1 508 mil. € (which represents about 30.3% of all health care costs covered by public health insurance) [3].

Given the facts, there is sufficient reason for the quality of the provided institutional care to be evaluated not only by experts, but also by the patients themselves.

2 Evaluation of patient satisfaction in institutional health care facilities of the SGRT

At its session on 26 November 2018, the Assembly of the SGRT by resolution no. 151/2018 in point III. C recommended the President of the SGRT to set up a task force on health as an advisory body to the President of

the SGRT. On 1 February 2019, Ing. Jaroslav Baška, the President of SGRT, created the Task Force for Health Care (TFHC) as his permanent advisory body for the purpose of preparing materials, assessing and submitting opinions on materials related to health care issues within the SGRT. Among the main objectives of the TFGHC was the improvement of the provided institutional care.

3 File and methods

One of the indirect tools for assessing the quality of healthcare is patient assessment. The patient reported outcomes (PRO-s) method is an internationally recognized method. This method was also used in the satisfaction survey of patients hospitalized in SGRT hospitals. Patient Satisfaction Questionnaire created in the TFHC and endorsed by the TFGHC 17.6.2020 in the final working pilot version of the survey, which was carried out after thorough preparation in all hospitals of SGRT in June and July 2020. Patients were surveyed by an educated nurse-interviewer, the reason for the 100% "return" of the questionnaires. The representativeness of the survey was ensured by a consecutive way of addressing patients.

A total of 509 questionnaires from 509 patients were evaluated, of which 201 were men and 308 women. Hospitals were represented by the following files: NsP Myjava - 124 patients, of which 33 were men and 91 women; NsP Považská Bystrica - 138 patients, 69 men and 69 women; NsP Prievidza based in Bojnice - 247 patients, 99 men and 247 women.

The questionnaire had 40 questions and a total of 6 parts: a) demographic part (4 questions), b) socio-economic part (1 question, 2 sub-questions), c) anamnestic part (2 questions), d) pre-hospital part (5 questions, e) hospital part (26 questions), f) quality of life part (2 questions).

The survey was carried out mainly in June and July 2019. In most cases, the planned number of 20 completed questionnaires in each department was achieved. Questionnaires in gynecological and obstetric wards are currently being supplemented so that gynecological and maternity patients can be assessed separately.

The following departments were involved in the survey:

Hospital Považská Bystrica (8 departments): Internal department, Surgical department, ODCH (Long-term patients department), Dermatology department, Neurology department, Orthopedic department, Palliative care department, Psychiatric department.

Hospital Prievidza based in Bojnice (11 departments): Department of Geriatrics, Surgery department, Internal department, Dermatology department, Neurological department, ODCH (Long-term patients department), ORL (Oto-Rhino-Laryngo department), Orthopedic department, Psychiatric department , Traumatology department, Urology department.

Hospital Myjava (6 departments): Internal department, Surgical department, Department of Anesthesiology and Intensive Medicine, ODCH (Department of Long-term Patients), RHB (Physiotherapeutic rehabilitation department), Gynecology and Obstetrics department.

4 Results

In general, the group can be characterized by older age (on average over 60 years) with increased morbidity rate, as evidenced by the need for 6-32 visits to outpatient clinics of various medical specialties over the past 12 months. Hospitalization of patients is unplanned in more than half of the cases. The average length of stay ranged from 9.5 to 11.9 days, which was influenced by the fact that wards with longer stays of patients were also included in the evaluation, such as e.g. long-term sick or psychiatric ward.

The main assessed parameters , which have an impact on the overall satisfaction of hospital patients, have yielded the following results:

The time from coming to the admission ambulance to bed in the ward was very good: lasted 1.1-1.4.

Physician care (rated on a scale: 1 - best, 5 - worst) was rated very positively: 1.4-1.6. Nurse care (rated on a scale: 1 - best, 5 - worst): was also rated very positively: 1.3-1.7.

In media offered (magazines, books, television, etc.), patients were relatively critical of the unavailability of the Internet (rated on the scale: 1 - best, 5 - worst): 1.7-4.3. The cleanliness of the environment (floors, toilets, bathrooms, etc.) was rated slightly critically (rated on the scale: 1 - best, 5 - worst): 1.65-2.35. The quality of the food, its quantity, dining culture was also evaluated slightly critically (rated on the scale: 1 - best, 5 - worst): 2.0-2.3.

Awareness of the disease was assessed very well (rated: 1 - best, 5 - worst): 1.7-1.96.

The overall satisfaction with the stay in the ward was also rated very well (rated on the scale: 0 - worst, 10 - best): 8.15-8.9. The overall quality of the institutional care provided was very well assessed, with patients assessing the rate of improvement in their health in relation to their quality of life at the beginning of hospitalization and before discharge from the ward (rated on the scale: 0 - worst, 10 - best): a, Hospital Považská Bystrica 5.2 vs

8.1, ie. improvement of 2.9. b, Hospital Prievidza: 5.6 vs 8.4, ie. improvement at 2.8. c, Hospital Myjava: 4.25 vs 8.0, ie. improvement at 3.76.

These results are shown in the tables 1, 2 and 3.

Table 1 *Parameters (file I.)*

Hospital	Parameter				
	Age	Number of doctor appointments in the last year	Unplanned hospitalization (%)	Average stay (days)	Arrival to admission - taken to one's room (hours)
P. Bystrica	43 - 74	7,4 - 32	57.4	9.5	1.3
Prievidza	49 - 74	6 - 32	51.0	10.6	1.4
Myjava	59 - 76	5,8 - 26	61.0	11.9	1.1

Table 2 *Parameters (file II.)*

Hospital	Parameter				
	Care (1 - best, 5 - worst)		Internet connection (1 - best, 5 - worst)	Cleanliness (1 - best, 5 - worst)	Food (1 - best, 5 - worst)
	Doctors	Nurses			
P. Bystrica	1.4	1.4	4.3	1.65	2.3
Prievidza	1.4	1.3	3.9	1.85	2.0
Myjava	1.6	1.7	1.7	2.35	2.1

Table 3 *Parameters (file III.)*

Hospital	Parameter			
	Disease awareness (1 - best, 5 - worst)	Overall stay satisfaction (0 - worst, 10 - best)	Quality of life at admission (0 - worst, 10 - best)	Quality of life at discharge (0 - worst, 10 - best)
P. Bystrica	1.96	8.15	5.2	8.1
Prievidza	1.7	8.9	5.6	8.4
Myjava	1.95	8.7	4.25	8.0

Patient satisfaction is perceived particularly sensitively in the case of the assessment of satisfaction with the stay in the maternity wards. In our survey, we evaluated this satisfaction collectively in all patients. Physicians' care reached the range of 1.15 -1.45; nurses' care: 1.30-1.40; disease awareness: 1.55 -1.60; overall satisfaction with the stay: 9.10-9.60; quality of life on admission: 8.20-9.10, and quality of life before discharge: 9.20-9.40.

5 Discussion

Patient satisfaction with hospitalization is usually examined as one of the parameters of the hospital's quality assessment. In the evaluation, the Institute of Economic and Social Reforms (IESR) used the deviation from the average on a 5-degree scale: significant plus deviation, slight plus deviation, average (no deviation), slight minus deviation and significant minus deviation. In the evaluation of hospitals for the year 2019 in the category of general hospitals, in the category of patient satisfaction with hospitalization they ranked as follows: NsP Prievidza based in Bojnice - no deviation, NsP Myjava - no deviation, NsP Považská Bystrica - slight minus deviation [4].

Health insurance companies have also been assessing patient satisfaction with hospitalization for several years. Dôvera, Health Insurance Company a.s. (Dôvera, zdravotná poisťovňa, a.s.), uses optical evaluation in categories: best (satisfaction), average (satisfaction) and worst (satisfaction). The evaluation for 2019 evaluated more than 6 500 questionnaires. NsP Považská Bystrica was rated as "best", NsP Prievidza based in Bojnice as "good" and NsP Myjava as "worst" [5].

Generel Health Insurance Company a.s. (Všeobecná zdravotná poisťovňa, a.s.), uses similar optical ratings in satisfaction surveys in the categories: best (satisfaction), average (satisfaction) and worst (satisfaction). During the evaluation for 2019, more than 17,000 questionnaires were evaluated. NsP Považská Bystrica was rated as "average", NsP Prievidza based in Bojnice as "average" and NsP Myjava as "average" [6].

Evaluation from a similar survey by the UNION, Health Insurance Company a.s. (UNION, zdravotná poisťovňa, a.s.) could not be obtained from publicly available sources [7].

The results are based on a simple evaluation of satisfaction, without the possibility of a more detailed analysis in relation to the defined parameters. Therefore, they cannot be considered as valid enough. Equally, their voluntary and anonymous nature is a limitation, in particular in regards to age, diagnosis and identification of the ward in which the patients were hospitalized. The Ministry of Health is working on the final version of the questionnaire for patient satisfaction with hospitalization, which is intended for all institutional facilities

in Slovakia. This approach would allow a relevant comparison of satisfaction. The SGRT considered it appropriate to use its own questionnaire in the current situation, which considers to be valid enough that its results can be used to analyze the provision of institutional health care and also to design and implement measures that could increase its quality.

Unfortunately, it is necessary to state that in the official inclusion of satisfaction questionnaires as a tool for determining the measurement of the quality of institutional care, the Slovak Republic is lagging behind the European reality. E.g. in Germany, measuring satisfaction has been required since 2005 as an element of quality management reports and since 2002, the Department of Health (DOH) has launched a national survey program in which all NHS trusts in England have a patient satisfaction survey on an annual basis and report the results to their regulators [8, 9].

6 Conclusions

The survey of patient satisfaction with hospitalization in SGRT hospitals yielded valuable results in the pilot phase. Patients get to bed relatively quickly, although more than half of the income is unplanned. Slightly critical were evaluated the so-called hotel services such as cleanliness at the department and food. The care of doctors, nurses and awareness of the disease was highly evaluated. A high level of satisfaction was also achieved by the summary evaluation of the stay (as a control parameter of satisfaction with partial parameters). The quality of care provided was very good, which patients indirectly assessed on the increase of 28% to 37.6% in quality of life before discharge from the ward compared to the condition on admission to the ward.

The contribution of the survey was also assessed by the SGRT Council at its regular session on 25 November 2019, when it discussed and approved the introduction of a uniform patient satisfaction questionnaire in hospitals in the founding authority of the SGRT from 1 January 2020 onward, which was imposed as obligatory to hospital directors in the competence of the SGRT.

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THE CONDITION AND PROSPECTS OF WELLNESS TOURISM IN THE SUMY REGION

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Abstract
Introduction: Wellness tourism is a quite new concept that has emerged relatively recently and has become another consequence of globalization. However, every year, wellness tourism is gaining momentum and more and more people around the world are discovering new opportunities. In the Sumy region, there are all prerequisites and factors for development of health (wellness) tourism, but this area is not yet sufficiently researched and analyzed. It is this complexity and lack of studies on the topic that determined the choice of research subject and confirmed its relevance.
Objectives: The aim of this article was to investigate the situation and identify the prospects for development of health tourism in Sumy region of Ukraine.
Methods: During literature review for this work textbooks, scientific manuals, works of domestic and foreign authors, articles, as well as publications in periodicals, electronic publications and the World Wide Web were used. The data and materials provided by the studied entities (sanatoriums), travel agencies, medical centers) were analyzed. In the process of research and analysis of the health tourism market of Sumy region of Ukraine various methods of research were used, such as: observation method, comparison method, abstract-logical method (theoretical generalizations and formulation of conclusions), questionnaires and sociological studies.
Results: The result of our study is formulation of the theoretical foundations of wellness tourism; research of the factors that form the prerequisites for the successful development of health tourism in Ukraine; research of the health tourism market in Ukraine in general and Sumy region in particular; searching for ways to overcome the problems that exist in the sphere of health tourism in Sumy region, as well as developing recommendations for improving the current state of tourism.
Conclusions: In general Ukraine, and in particular Sumy region, have significant medical and recreational tourism potential, but the level of development of health tourism is unsatisfactory. For health tourism to become a full-fledged part of the tourist space of the region, it is necessary, at the state as well as at the regional level, to focus efforts on solving the tasks listed in these articles.

Keywords: Health tourism. Sumy region of Ukraine. Inbound tourism. Resorts. Medicine and treatment.

1 Introduction

Today, in this fast-paced and taxing time, any adult needs a break from stressful situations to maintain their physical and mental health. Consequently, health tourism is one of the most popular types of recreation. This is due to its accessibility to virtually all age groups, as well as the undoubted health benefits from visiting resorts and health resorts. Wellness tourism is also becoming increasingly popular trend in the development of world tourism. Medicine plays an important role in the international tourism industry.

According to World Tourism Organization estimates, treatment and rehabilitation are among the most important motivations for tourism. Over the last 15 years, the number of trips for health and treatment purposes has increased by 10% worldwide. Wellness tourism is gaining global popularity because its flows have spread across all the continents of our planet. This form of tourism is the most stable, year-round, in-demand and promising [10].

The problems of medical tourism are covered in the works of many Ukrainian scientists, such as A. Babkin, V. Bogolyubov, Yu. Bezrukov, A. Vetnev, I. Kozlov, O. Lyubitseva, M. Malska, E. Stepanov, E. Sukharev, N. Fomenko, I. Shalkovskaya and others in different periods of time.

Wellness tourism is a fairly new concept that has emerged relatively recently and became another consequence of globalization. But every year, wellness tourism is gaining momentum and more and more people around the world are discovering new opportunities. Thus, first and foremost, this type of tourism performs important social functions related to treatment and prevention of diseases, as well as promotes various activities aimed at protecting health of the population. From the economic point of view, for the state introduction of new types of tourism enables new markets for tourist services to be introduced and, accordingly, to generate higher revenues [7].

However, despite the fact that in Ukraine, and in particular in Sumy region, there are all prerequisites and factors for the development of health tourism, this area is not yet sufficiently researched and analyzed. It is

this complexity of the topic and its lack of study that has determined the choice of research that confirms its relevance.

Therefore, the aim of this article was to investigate the situation and identify prospects for development of health tourism in Sumy region of Ukraine.

2 Materials and methods

Wellness trips have a long history. Even the ancient Greeks and Romans used healing springs and places with favorable climates to improve their health. Times have changed, but the motivation for traveling has remained the same. The healing properties of natural factors continue to attract patients to resort areas. The flows of tourists traveling for medical and recreational purposes are not as plentiful as those of tourists who want to relax and have fun, but they are growing rapidly, their geography is expanding [1].

In modern tourism terminology, the most popular and accurate definition of the concept of "wellness, health or medical" tourism is the following: health and wellness tourism involves the movement of residents and non-residents within state borders and beyond them for a period of no less than 20 hours and no more than 6 months for health purposes, for the prevention of various diseases of the human body. According to the index of person-days of stay, health tourism occupies less than 1% in the global tourist turnover, and more than 5% in the income structure, makes it one of the most profitable branches of tourism. Around the world, leisure industry theorists are busy searching for the most exotic entertainment, but the opportunity to restore health during exciting tours is the most appreciated [2].

Health tourism is based on balneology. Balneology is a medical scientific discipline that studies the healing properties of natural climatic and physical factors, the nature of their effect on the human body, the possibility of their use for treatment and prevention of diseases, as well as for the purpose of health improvement [6].

Health tourism has a number of distinctive features. First, the stay at the resort, regardless of the type of the latter and the disease, should be long-term, at least three weeks. Only in this case the desired health effect is achieved. Secondly, treatment at resorts is expensive. Although relatively cheap tours have recently been developed, this type of tourism is mainly aimed at affluent clients who are increasingly focusing not on a standard set of medical services but on an individual wellness program. Another feature is that the resorts are visited by people of the older age group, when chronic diseases exacerbate or the body weakens and is unable to cope with daily stresses at work and at home. Accordingly, these tourists choose between resorts that specialize in treatment of a specific disease, and resorts of mixed type, which have a positive impact on body and contribute to recovery [8].

Recently, the health tourism market is changing. Traditional sanatorium resorts are no longer a place of treatment and recreation for the elderly, and are becoming multifunctional wellness centers designed for a wide range of consumers. Modern transformations of resort centers are caused by two circumstances. First of all, the change in the nature of the demand for health services. Healthy lifestyles are coming into fashion, and there is a growing number of people around the world who maintain good physical fitness and need for anti-stress programs. Mostly middle-aged people who prefer active rest and are often limited in time. According to many experts, consumers of this type of services will be the main clients of health resorts and guarantee the prosperity of health tourism in the XXI century.

The second reason for the reorientation of resorts is that their traditional support, including financial support, from municipalities and the state is diminishing. Health resorts have to diversify their product to reach new segments of the consumer market and attract additional customers. Keeping wellness function, resorts make a more diverse program of patient stay, conduct cultural and sports activities. They offer a wide range of wellness services. Thalassotherapy is very popular in seaside hotels lately, and the programs such as "Anti-cellulite", "Phyto-Beauty-Rejuvenation" are in high demand. The duration of treatment and rehabilitation courses becomes more flexible [1].

Health tourism is divided into many categories: speleotherapy, phytotherapy, aerotherapy, thalassotherapy, spa-therapy and many others. Its main directions are climatotherapy, balneotherapy and mud treatment - the same categories are widely represented in our country.

Ukraine has all the necessary resources for development of wellness tourism. It is the richest country in Europe in terms of quantity and quality of natural factors - mineral waters, therapeutic muds and climatic conditions.

Ukraine has huge reserves of medicinal mineral waters, namely, mineral waters of almost all major balneological groups. Consequently, balneotherapy is developing. Likewise, huge reserves of therapeutic muds on the territory of Ukraine contribute to the development of mud cure. The natural conditions of Ukraine also contribute to the development of climate treatment. Nowadays seaside, mountain and plain climatotherapy is developing on the territory of Ukraine.

Table 1 shows the distribution of resources used by health tourism by regions of Ukraine.

Many regions of Ukraine, despite their significant therapeutic and recreational potential, including the availability of various natural healing resources (mineral waters, mud deposits, recreational forests, etc.), are underdeveloped tourist regions. These include and Sumy region, located in the north-east of Ukraine, which has

Table 1. *Wellness tourism resources by regions of Ukraine*

Administrative units (regions)	Wellness tourism resources		
	Types of mineral waters	**Types of therapeutic mud**	**Types of climate**
Vinnytsia Oblast	Radon	Peat mud	Flat forest steppe
Volyn Oblast	Sodium chloride	-	Flat forest
Dnipropetrovsk Oblast	Sodium chloride	-	Plain steppe
Donetsk Oblast	Sodium chloride, sulfide	Mainland silt	Flat forest steppe
Zhytomyr Oblast	Radon	-	Flat forest
Zakarpattia Oblast	Carbon dioxide; hydrogen sulfide;arsenic	-	Mountain forest
Zaporizhia Oblast	Sodium chloride, sulfide	Seaside silt	Plain steppe, seaside steppe
Ivano-Frankivsk Oblast	Hydrogen sulfide	Peat mud	Mountain forest
Kiev Oblast	-	-	Flat forest
Kirovohrad Oblast	Radon	-	-
Luhansk Oblast	Sodium chloride	-	Flat forest steppe
Lviv Oblast	Sodium chloride	Peat mud	Flat forest steppe
Mykolaiv Oblast	Sodium chloride	-	Seaside steppe
Odessa Oblast	Sodium chloride	Sulfide seaside silt	Seaside steppe
Poltava Oblast	Sodium chloride	Peat mud	Flat forest steppe
Rivne Oblast	Sodium chloride	Peat mud	Flat forest
Sumy Oblast	Sodium chloride	Peat mud	Flat forest steppe
Ternopil Oblast	High content of organic matters	Peat mud	Flat forest steppe
Kharkiv Oblast	High content of organic matters	-	Flat forest steppe
Kherson Oblast	-	Sulfide seaside silt	Seaside steppe
Khmelnytskyi Oblast	High content of organic matters	-	Flat forest steppe
Cherkasy Oblast	Radon	-	Plain moderate forest-steppe
Chernihiv Oblast	Iron	-	Mountain forest
Chernivtsi Oblast	Sodium chloride	Peat mud	Flat forest

significant therapeutic and recreational tourism potential (sufficient number of sunny days per year, healing mineral waters and mud, wellness forests and other resources). The territory of the region has a favorable geographical position, unique historical and cultural monuments, a wide network of nature reserves and, in a natural and climatic aspect, is favorable for the development of health tourism.

In Sumy region there are 37 sanatorium and resort establishments of different functional purpose, which serve more than 67.1 thousand visitors annually, among them 4.9 thousand are foreigners, about 16.2 thousand people are improving their health [4].

The area is located within two physical-geographical zones – Polesia and Forest-steppe. The climate of the region is temperate continental, with warm summers and moderately cold winters. More than 300 rivers flow through the region. They all belong to the Dnieper basin. The largest of them are: Desna, Seim, Sula, Psel, Vorskla. There are 33 large lakes and 1,660 ponds and reservoirs within the region. Sumy region has considerable potential for development of resort industry [4].

The territory of the region is one of the most ecologically safe zones of Ukraine, has excellent places for health improvement and rest.

3 Results

Our analysis of the sanatorium and health resort infrastructure of Sumy region, which can be used for the purpose of health tourism, revealed that there are 19 establishments in the region, incl. 4 - sanatoriums (3 of them are for children), 3 - sanatoriums-preventive health centers, 12 recreation bases. During 1990-2018 years the number of health resorts in the region decreased by 76.5%, and the number of beds (beds) in them by 71.8% [5].

Territorially in the Sumy region sanatoriums are unevenly distributed and concentrated in only 4 districts - Sumy, Shostka, Okhtyrka and Lebedyn.

According to existing classifications of resorts, they are divided into mud, climatic and balneological resorts, where clients are treated with natural mineral waters. Some sanatoriums offer several different health and wellness profiles, such as the Tokari sanatorium located in the Lebedyn district of Sumy region (oblast), where natural mineral waters, local peat mud and various medical procedures are used for treatment and rehabilitation [9]. That is, this sanatorium at the same time belongs to balneological, climatic and mud categories. It specializes in rehabilitation and treatment of people affected by the Chernobyl disaster, children and adults, war and labor veterans, people with disabilities and other people in need of health improvement. For balneological procedures the source of mineral water of chloride-sodium composition of type "Mirgorod" (water "Tokarevskaya") is

extracted from a depth of more than 1000 m. This water allows to treat diseases of the gastrointestinal tract, kidney and liver disease.

"Sosnovy resort Buimerovka on Vorskla" which is located in the Sumy region 6 km from Okhtyrka, on the bank of the Vorskla river can be classified as balneological and climatic type, it is popular not only in Ukraine, but also abroad [3]. This establishment opened in 2005 and provides visitors with tourist and health-improving services. Built according to RCI international standards, the resort offers various types of recreation: beach, SPA, sports, fishing, horseback riding, eco-tourism, mushroom and berry gathering, corporate leisure and conference tourism.

A separate category consists of children's sanatoriums, which can serve tourists of this age category. There are 3 establishments of this type in the Sumy region: the Lebedinsky Children's Multidisciplinary Sanatorium, the Antituberculosis Children's Hospital (Sumy), and the Shostka Regional Children's Antituberculosis Sanatorium. The combination of medical treatment with the recreational opportunities of the available forest recreational resources contributes to the development of these facilities as center of health tourism.

Also, during the study, it was found that in 2018 - 2019 there were 3 health resorts in the region. One of them is the "Oldysh" climatic sanatorium under sponsorship of JSC Sumykhimprom specializing in treatment of diseases of nervous, respiratory and musculoskeletal systems. To improve the health of the employees the sanatorium "Izumrud" functions under the patronage of Shostka state-owned plant "Star" and preventive clinic services JSC "SMNVO" (Sumy). However, the facilities of these establishments are not used as points of health tourism.

Our analysis also revealed that despite the presence of significant medical and recreational tourism potential in the region, the level of development of this type of tourism is unsatisfactory. The reasons for this are the lack of support from state bodies of local self-government, insufficient funding, lack of investments, advertising, shortcomings in the territorial organization of the sanatorium and resort economy, etc. Also, health resorts of Sumy region are absolutely uncompetitive in the world market due to lack of modernization, introduction of new technologies, improvement of service level, medical care and promotion.

In the study of the tourism market, it is also important to analyze the activity of tourism companies. In order to study the place they occupy in the functioning of this area, we have developed a number of questions and conducted a survey among a number of tourist companies of Sumy region of Ukraine. The survey revealed that wellness tourism in Sumy region market is actually in its infancy, and to transform it into a developed industry, it takes a lot of effort and time on the part of all relevant entities that seek to develop it. Initiatives and appropriate measures for the promotion of health tourism should come from those entities that are interested in profit from the industry. We are talking about private tourism companies, as well as health resorts, which form the market for health tourism. And upon researching the market, study trends and customer requests, it is possible to see that health tourism is a very promising service industry. However, this niche of the market today is virtually unfilled and undeveloped.

4 Discussion

The sanatorium and spa industry will be able to actively develop in the direction of health tourism and bring significant profits to the Sumy region, provided that the authorities support entrepreneurial initiatives. For this purpose, it is necessary to modernize the material and technical base of the existing resort and sanatorium establishments and planning of their territories, to attract investors, including, but not limited to foreign ones, to expand recreational services and leisure activities, to improve the skills and wages of service personnel of institutions of this type.

To attract the attention of foreign tourists, resorts of Sumy region of Ukraine need to solve a number of problems related to their financing, management and modernization. The foundation for development (design) of health-improving tourist product of Ukrainian resorts should be based on the latest SPA-technologies that improve the quality of rest and health. For this purpose, it is necessary to develop fundamentally new approaches to activity of sanatoriums on the basis of borrowing experience of market management of the international resort sanatoriums-hotels; to fully meet the needs of consumers in recreation, treatment, relaxation and wellness during their stay at a particular resort.

Also, at the moment, the state of legislative support for development of health resorts is a current problem, as tourist activity is a complex subject of legal regulation, and often is regulated by both traditional and special normative acts.

The modern development of health resorts should be based on a comprehensive and simultaneous combination of health, recreational and leisure services, which directly determines the need to create an appropriate optimal market infrastructure that serves such territorial tourist and recreational complexes. However, the tax system, as one of the elements of the economic mechanism, does not properly stimulate the development of recreational activity in Ukraine as a whole and in Sumy region in particular.

We believe that the material and technical base of tourism in the Sumy region should be significantly strengthened in the future, and the comfort at the hotel industry should be improved. The most promising types

of recreational activity in the region should be: long-term rest, sanatorium and recreational health improvement; sports and health tourism, leisure, recreation (85% of the total population of tourists). In order to promote health tourism in Sumy region, various presentations, exhibitions and negotiations with representatives of foreign countries should be held in regards to possible cooperation.

5 Conclusions

Summarizing all of the above, we can conclude that the Sumy region has a significant medical and recreational tourism potential, but the level of development of health tourism (wellness) is unsatisfactory. There is absolutely no support of state bodies of local self-government, insufficient funding, lack of investment, advertising, shortcomings in the territorial organization of the sanatorium and resort economy, etc. Also, health resorts of Sumy region are absolutely uncompetitive in the world market due to lack of modernization, introduction of new technologies, improvement of service level, medical care and promotion.

For health (wellness) tourism in Ukraine as a whole and in the Sumy region in particular to become a full-fledged part of the tourist space, it is necessary, at the state and regional level, to focus efforts on the following tasks: creation of a system of effective incentives for development of domestic medicine, modernization and development of spa treatment, increase in sales of relevant services, retraining and advanced training of staff of sanatorium and resort establishments, creation of an appropriate material and technical base; substantiation of real sources of financing, cooperation with the institutes of power and public organizations on the issues of solving problems in the development of wellness tourism, launching the new product of health tourism in the international market.

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INFORMAL LONG-TERM CARE FOR THE ELDERLY WITH DEMENTIA IN SLOVAKIA

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Abstract
Background: Dementia is one of the key reasons of disability and cause of the dependency of the elderly on another person. An elderly with dementia needs assistance in every aspect of their lives and their family members hold an important role as informal care givers. The complexity of the diseases and a wide range of life changes associated with long-term care in their homes provides a variety of physical, psychological, and also social and economic demands for them to cope with. Specific requirements and demands associated with dementia, high rates of workload carers, provided support and assistance from professionals are the factors that directly affect the quality of nursing care and thus the quality of life of the elderly with dementia.
Objective: The main objective is to provide a comprehensive perspective at the theme of long-term care for the elderly with dementia in their home environments. We focused on the quality of informal care provided by the closest relatives to people with special needs.
Method: The research method was a questionnaire of our own design. The part of it was a short knowledge test for informal carers and a test to assess the sufficiency of the elderly in ADL and IADL.
Sample: Research sample consisted of 96 respondents who took care of their loved ones in their social environment.
Results: Based on the analysis of the research results it is evident that the quality of long-term care in the social environment is relatively low. Informal care givers lack the theoretical knowledge and practical skills that are necessary for the implementation of quality and specific care for the elderly with dementia. There is not an integrated cooperation of experts from the health, social and legislative sectors, which would help them to improve the quality of informal care.
Conclusion: Providing informal care to people with dementia at their home environments is difficult, and evolving process. Physical demands and mental stress of everyday care elicit a high degree of congestion of informal carers. Management of long-term care in the social environment is weak and ineffective. There we need team, multidisciplinary and various spheres in the care of professionals who significantly affect the quality of informal care.

Keywords: Dementia. Elderly. Informal care. Long-term care (LTC). Quality.

1 Introduction

Dementia is such a serious problem that the WHO and other international organizations that deal with neurological diseases and mental health have developed several action programmes, strategic plans and recommended interventions to cope with it. According to the WHO, there are 47.5 million people with dementia in the world. An increase of 7.7 million new cases per year is estimated. Despite numerous clinical studies, there is currently no causal treatment to stop or reverse the development of dementia. There is only the care focused on its progressive course and on ensuring the maximum possible quality of life [1].

Most people with dementia live at home, and their family members are the key informal care givers. A quality care in the home environment is very demanding and difficult to assess. Different quality indicators are used in institutions, but in the home environment the use of these indicators is inappropriate and hardly used. Caring for people with dementia is very demanding and long-term in all aspects. The demands of daily care get informal caregivers beyond their physical and emotional burden.

The main objective of our study is to focus on the issue of long-term care for people with dementia provided by informal care givers in the natural environment of patients. A complex view of long-term care and its quality was reached by an analysis of research results, which was aimed at obtaining information on the current and real situation of care from the perspective of an informal care giver.

2 Informal care

Informal care is currently seen more as a substitute than as a complementary part of a holistic approach in LTC. This is often a gap filling or an emergency solution where the LTC service is not provided. Informal care is not free from a societal point of view. Some research has already confirmed that its costs are very high, sometimes

unbearable, if we add all hours devoted to care, deteriorated quality of life and health of care givers, or difficulties connected with work and social employment in the long term [2].

Informal care is defined as *"care provided to persons who depend on the help of another person for normal daily activities due to severe disability, mostly by immediate family members in the home environment or by other persons living with the same household as a dependent person"* [3, p. 28]. The European Association for Care Givers EUROCARERS defines a care giver as *"a person who, outside a professional and formal framework, provides unpaid care to someone who has a chronic illness, disability or other long-term health or the need to be cared for"* [3, p. 11]. In our country the care givers are divided into formal and informal ones according to whether they receive a salary for their care. Unpaid care givers are family members who take care of their closest relatives most often are based on their close family relationships. Their care is provided without expectation of remuneration, in some cases they may receive social benefits as a compensation for the loss of income. In practice there are also informal carers who are not in a family relationship to a sufferer. In such cases, it is most of all a close friendship with the cared for person [3]. Many studies have shown that the most common group of informal carers is women aged 55, and this group is particularly vulnerable to a high risk of burnout, the possibility of abuse and social isolation [4].

The services provided by informal care givers can be divided into three main groups in terms of the intensity and extent of meeting the needs of a person with dementia: The first group is subsidiary care, which is physically and mentally relatively undemanding care including provision of repairs in households, accompaniment to the family doctor, or handling various official matters. The second group is referred to as impersonal care and includes activities that are mainly related to household care such as cooking, cleaning, and washing. The third group is considered the most demanding and is referred to as a personal care aimed at maintaining independence, autonomy and satisfying the needs of the cared for person [5].

3 Long-Term Care and its Impact on Informal Care Givers

According to the research made by National Family Caregiver Alliance, the common denominator of informal care is the emotional impact that it has on care givers. Informal care givers often deal with intense sadness and pain, often longing for a miracle and a normal life. They struggle with frustration at the changing family dynamics. They are disappointed by the lack of understanding from people who do not care about anyone. They suffer from social isolation due to stigmatism and deviation from the norm. An increased responsibility causes long-term stress and loss [6]. Prolonged physical, emotional, social, but also financial burden causes the overall burden on care givers. In their study Tabakova et al. define 5 most common areas that characterise the overload on a care giver overload as follows: Poor sleep, fatigue, lack of time to meet personal needs, stress, and depressed mood [7].

Pearlin et al. [8] list four areas of stressors that affect the care givers. The first area is the so-called background of the context to which belongs for example the level of support and the impact of other life events. The second area are the specific requirements of care referred to as primary stressors, which include the time devoted to care, the extent of care, the diversity and intensity of behavioural, cognitive and psychological symptoms. The third area are secondary stressors such as the secondary role of the care giver – childcare, work and career, caring for one's own household, family relationships and conflicts, but also social life. The fourth and last area includes intrapersonal stressors – the personality of the care givers, their competencies and roles [8]. Many studies show that family care givers are particularly prone to affective disorders such as depression and anxiety, with women being more prone to these disorders. The risk to develop affective disorders persists for many years during care and even after the end of care provision [1].

Many studies and research show that informal car givers who care for people with dementia are at greater risk of serious illness, general mortality. They have also been shown to be at higher risk of metabolic syndrome and cardiovascular disease, higher incidence of obesity and smoking, more likely to drink alcohol, more frequent sleep disorders, higher levels of stress hormones, impaired immunity, poorer vaccine responses, slower wound healing, more frequent over-the-counter medications, less interest in prevention and care for one's own health, but also loss of cognitive functions [8].

Care givers often lack social contact and support from their friends, neighbours, family members and they experience social isolation. They lose social contact especially after the decision to leave their jobs and devote their free time to caring for their closest relatives. Care givers tend to sacrifice their free time activities and hobbies, limiting their time spent with family and friends. It has been proven that care givers who have maintained their social contacts and continue to maintain various social interactions have lower negative psychological symptoms [8].

In addition to the impact on physical and mental health, informal carers also must deal with financial problems. The provision of care can become a full-time job without adequate financial support. It often happens that a family member must leave his or her job or find a less demanding one, but worse paid job, which is calculated as an indirect cost [1]. The direct payments for provided health and social services such as consultation with a doctor, emergency treatment, co-payments for medicines, or the purchase of over-the-counter medicines and various medical devices, fees for respite care in sanitary facilities are a huge burden for the budget of every household.

Despite the complexity of informal care, many care givers are motivated by several factors. Some caregivers feel proud of their role and can find many positives in their duties, such as feeling of importance and self-realization, feeling of love and reciprocity, spiritual fulfilment, and the sense of duty [8].

4 Support to Informal Care Givers

Informal care givers cannot be considered a natural source of care. Caring for people with dementia is demanding and requires a lot of time, and energy and often significant physical effort from care givers [2]. The risk of overload on the side of care giver increases if all care and responsibility is laid on exclusively one person. In their work, Tina and Karen point out the existence of the so-called triple model of nursing care. They emphasize that in LTC it is a mutual relationship of three active components – the care giver, the person that they are cared for and the public or private programme [9].

The support and assistance of carers by professionals, lead to a significant reduction of the burden, which is essential for them to be able to provide care for their loved ones for as long as possible. Support for informal carers must be complex and it should cover all the areas where problems occur such as the information to support understanding of dementia, the acquisition of skills needed to provide general care, relief services, but also financial support and legal aid.

Counselling and crisis intervention form the basis of psychosocial assistance. It is a long-term and permanent process in which a professional provides a care giver with guidance and support focused on their life goals and needs. They solve various problems and pass on information focused on the expertise and communication skills needed in day-to-day care. Telephone crisis intervention also has an important role in psychosocial support. It is easily accessible to informal care givers without having to leave a loved one. It offers fast help and support to informal care givers when they are in stress or mental discomfort [10].

Respite care is not often utilised service in Slovakia. However, there will always be time left when care givers need the help of formal services. Respite care includes a whole range of relief services, which can take place in the home environment, in day centres, but also in institutional care. The relief service may also vary in duration, where the services may be short from several hours to several weeks. Relief services can be planned, unplanned or emergency. The goal of respite care is to provide care givers with a break from his care responsibilities to such an extent that his stress, exhaustion, and also frustration and social isolation are removed. Of course, relief services should also benefit a person with dementia [1].

Certain form of support for care givers is provided by self-help groups. They are made up of informal care givers who meet at regular intervals under the guidance of an expert. They share their experiences in caring for their loved ones. Relationships between them are very important. They give each other hope, cohesion, provide each other with psychological support and share experiences with each other. Support groups are considered a form of support that significantly reduces the stress and overall burden of informal care givers [10].

Support for informal care givers should be ongoing, well-coordinated and multi-level with all stakeholders. And since people with dementia and their carers often have the most experience and unique views on dementia-related problems and needs, quality of life, and the overall burden of the disease, they should be involved in formulating policies, strategic plans, laws and services [1].

5 Quality of Services Performed by Informal Care Givers

Older persons who rely on LTC services have the right to an adequate degree of personal control over the care provided in terms of its scope, quality, financial demands, but also safety. In order to ensure the quality of LTC services, coordination and integration of individual services focused on the individual needs of a dependent elderly person must work. Informal care is traditionally considered a private matter in Slovakia, and therefore no special qualification requirements are expected for this performance. Some informal care givers undertake a nursing course and some of them receive, in a broader sense, professional instruction from health professionals [3].

6 Research Problem and Objectives

Based on theoretical knowledge, we formulated the following research problem:

"What is the level of quality of care for people with dementia provided by informal caregivers in the home environment?"

The main research objective was to obtain the most comprehensive view of the issue of healthcare provided for a person with dementia from the perspective of an informal care giver.

Partial objectives:

- Assess the complexity of care givers for the persons with dementia who live in their home environment and have the different stages of dementia.
- Determine whether informal care givers have sufficient theoretical knowledge and practical skills needed to care for people with dementia.
- Find out if informal care givers have the possibility of support and help and they cooperate with experts.

7 Methodology

The research method is a self-designed questionnaire that consists of 34 items that are divided into 5 sections. At the beginning of the questionnaire, the items focus on the demographic characteristics of the respondents – informal care givers. Other items focus on the issue of informal care. The third set of items focuses on care recipients. The fourth set of items consists of items focuses on the specifics of the care for elderly with dementia. At the end of the questionnaire, the items are aimed at supporting informal carers. The questionnaire includes a short knowledge test focuses on the theoretical knowledge of the respondents and a test to assess the self-sufficiency of the person in common daily activities and instrumental daily activities (ADL and IADL). Data collection took place from January to March 2017. The participation of respondents was voluntary. 100 questionnaires were distributed to direct and indirect contacts. 96 completed questionnaires were returned, which is a 96% return.

8 Sample

The research sample consists of 96 respondents addressed by deliberate selection. They are informal care givers who cared for their loved ones suffering from dementia in their natural environment. There is no restriction that would condition the age category of the respondent or the length of provided care.
The youngest respondent is 19 years old and the oldest 84 years old. The most frequent respondents are 47 years old (7.3 %). The median was 51 years old. In the examined group there is 10 (10.4 %) respondents in the age category over 65 years. Of the total number of the examined group, 74 (77.1 %) are women and 22 (22.9 %) men. The ratio of women to men is 3.36:

- Children (a daughter, a son) took care of their loved one most often. They are the largest group with 44 (45.8%) of the total number of respondents.
- The second group are grandchildren (a grandson, a granddaughter) with 16 (16.7 %) respondents.
- The third group consists of partners (a husband, a wife) with 14 (14.6 %) respondents.
- Siblings (a sister, a brother) and neighbours (a neighbour) form equal and quite large groups with 5 (5.2 %) respondents.
- In terms of housing conditions of the cared for person, up to 58 (60.4 %) respondents live in the same household as their close person, whom they care for.

9 Results and Discussion

In our study we present the perspective of an informal care giver who cares for a person with dementia in the home environment. We focus on the level of quality of care based on several indicators that are generally valid in the provision of services in LTC. The quality of services provided in LTC is extremely different. Many surveys and reports show great dissatisfaction and point out the shortcomings identified. The quality of services provided in LTC is not easily assessed. It is a challenging task in health or social care facilities and in their home environment it is almost impossible because there are no uniform mechanisms to assure quality and standard quality indicators are unsuitable for informal care [11].

Age and gender are a certain indicator of the quality of provided care. The average age of the respondents is 51 years. The oldest respondent is 84 years old. As many as 10.4 % of respondents are of retirement age (over 65 years). Repková states that family carers are aging, as demonstrated by the research project "Informal care givers in the long-term care sector" from 2008. This is confirmed by the results where up to 20 % of care givers receive a retirement pension, 47 % of care givers are aged between 51 to 64 years. In our research, women significantly outnumber them (77.1 %), while the group of men is represented only by 22.9 %. Similar age characteristics are mentioned in her research project by this researcher who reports 82 % is the participation of women in family care and only 18 % of involved in this kind of care are men [3].

Reconciliation of work, family and care responsibilities is another factor that directly affects the quality of care provided. Not only the time and physical demands of all responsibilities, but also the conflict of secondary roles of the care giver plays an important role in the care for a close family member. At the time of our research, up to 44.8 % of care givers took care of their close relatives and at the same time went to work full time. It is necessary to point out 12.5 % of this group of care givers who cared for their loved one in an advanced stage of dementia, when caring for these people is physically and emotionally exhausting. At the time of our research, 5.2 % of care givers had part-time work and 5.2 % of them were in the position of self-employed. 9.4 % of care givers were unemployed at the time of the research and 24 % of care givers were retired, so they could devote their time mainly to the care for their loved ones. This more flexible variant is also pointed out by Repková, who perceives the self-employed person as a care giver in up to 26.3 % of representations and the unemployed in up to 45 % of representations [3]. Care for close relatives represents a high degree of overload for the informal care giver due to the emotional bond, but also the time required. This is also proved by the results of our research, where caregivers stated in 77.1 % of cases that another person helps them in to care for their loved ones. 15.6 % of respondents stated that 3 or more people help them to care for their loved ones.

The complexity of care for persons with dementia is directly related to the progression of dementia and its individual manifestations. As many as 39.6 % of care givers cared for their loved one who had an advanced stage of dementia. Intermediate stage of dementia was reported by 32.3 % of care givers for their loved ones and the early stage of dementia by 16.7 % of care givers. From the stage of dementia, the dependency of the care for a person in the ADL and IADL also develops. That is also related to the time required to a provided care. According to our research results, up to 75.0 % of care givers provided seven-day care for their loved ones. The complexity of the care associated with the progression of dementia reflects the number of hours that informal carers spent with their loved ones. While less than 6 hours of care were sufficient for people with early-stage dementia, people with advanced dementia required 24-hour care.

The extent of burden of the care provided for persons with dementia is also confirmed by our results, which describe the scope and area of assistance that care givers should provide to their loved ones. The scope of care is mostly a “full help”, as expressed by 33.3 % of care givers. After reassessment the extent of dependency of the nursed persons in the ADL, we found that up to 41.2 % of care givers cared for a person with a “high dependence on another person” and 37.6 % of care givers provided care for their close relatives with a “mild dependence”. Similar results were obtained after reassessment the extent of dependency of the nursed persons in the IADL, where up to 54.1 % of respondents cared for their close relatives with a degree of burden “dependent on help from another person”. When assessing the intensity of care provided to the nursed persons, a certain degree of burden in the provision of care was demonstrated, as care givers had to apply daily interventions in almost all ADLs and IADLs.

Informal care, especially the care for a close relative with emotional attachment, is a great emotional burden. The irreversible progression of the disease is connected with specific manifestations that significantly affect the life of the whole family and represent various problem situations that they have to cope with. Behavioural and psychological symptoms (BPSD) are the main cause of emotional as well as social burden of informal care givers and become a decisive factor when home or institutional care comes to consideration [12]. As many as 78.1% of care givers assessed BPSD as a challenging situation. Of all the forms of BPSD, they most often encountered Sundowner's syndrome, in 42.7 % of respondents. Total of 29.2 % care givers described wandering and aggression as a challenging situation and 25 % of them considered hallucinations difficult to cope with. A frequently called as a “problem situation” for care givers was the replacement of the incontinent pad, which was reported by up to 27.1 % of care givers and the administration of medicines orally, was reported by 21.9 % of care givers.

Provision of help and care to close relatives at a time when they are no longer able to take care of themselves is a huge and long-lasting burden. This is also confirmed by the results of our research. 31.3 % of carers describes this care as “quite exhaustive” and 25.0 % of them as “maximum exhaustive”.

The quality of theoretical knowledge of dementia on the side of care givers is important when they care for people with dementia. As long as care givers perceive dementia as a hopeless situation, people with dementia will be very vulnerable. According to experts in the care of people with dementia, it is not possible to provide a high quality LTC without adequate and good theoretical knowledge and practical skills. Just understanding what is going on in the brain with dementia will help to manoeuvre the behaviour and the individual symptoms of the disease. With good knowledge our care can have impact and by proper responding to the needs of our close relatives, we can fundamentally improve their quality of life [13]. Therefore, we focused on the provision of professional information to informal care givers. Our results show that the vast majority (83.3 %) of informal care givers are provided with professional information necessary in the care for people with dementia. The family doctor was most often mentioned as the source of professional information (50.0 %). The second most common source of professional information was the Internet (30.2 %) and books from nursing practice (20.8 %). Based on a short knowledge test, we found out that more than a half of care givers has insufficient knowledge about dementia and the care for people with dementia. Only 7 care givers were assessed in the test for excellent knowledge and the knowledge of another 7 care givers were assessed as very good. 14 care givers had the good level of knowledge and 16 care givers reached only a sufficient level of knowledge.

In the care of persons with dementia, it is important to protect their cognitive performance from rapid decline, prevent their social isolation, ensure they have adequate social contact, and support their self-service skills in everyday activities at the maximum possible level. This requires great determination, strength, endurance, love, and also cohesion and empathy not only from the informal care giver, but from the rest of a family. Take hold of the role of an informal care giver changes the life habits, rituals and priorities of the whole family. As dementia progresses, care becomes more physically and mentally demanding [12]. Our results show that informal care givers lack the help and support of professionals. In seeking help and cooperation from experts, we found that the doctor who most often diagnosed dementia in a person was a neurologist, as stated by 39.6 % of care givers. However, we know from nursing practice that long-term care for persons with dementia is taken over by a psychiatrist. In practice, there is the lack of activity on the part of experts who focus on prevention, test cognitive functions, educate care givers and integrate cooperation with other experts. 56.3 % of care givers said they were not provided with the necessary information about the support. They also lack the help in sudden crisis. As many as 65.6 % of care givers stated that they have the opportunity to contact professional help, but at the same time we found out

that it was their doctor's consultation, ambulance service, a first aid service and the intervention of a nurse from Home nursing agency. Park et al. states that the institutionalisation of a person with dementia was delayed by up to 329 days when the informal carer cooperated with an intervention group of professionals compared to persons whose care giver did not receive this help and support. Cooperation with support and self-help groups has been shown to improve caregivers' well-being, reduce their feelings of depression, and also burden and the overall impact of care [12].

Continuous and efficient help and targeted support provided by professionals is essential to eliminate the negative factors that cause overload for care givers. Fertaľová et al. state that the financial contribution for care and nursing service as the most frequently used form of support in the provision of care. It is also confirmed by the statistics of the Centre for Labour, Social Affairs and the Family. Another form of help and support that informal care givers are interested in is the care service provided by nursing professionals. According to other existing statistics, the social service in the day hospital is used only to a minimal extent in Slovakia [12].

The results of a special Eurobarometer from 2007 show that Slovak people prefer long-term care for their close family members at home and they rely less on professional social and health services. At present, there is also a network of various support services for dependent persons and informal care givers in Slovakia, but the problem is the lack of information about the possibilities of their use [12]. Our results also point to the lack of information about support and options for informal care givers. As many as 84.3 % of care givers use the help and support from professionals, but from all care facilitation services, care givers use food service (20.8 %), home nursing agency (18.8 %) and doctor's visits at home (16.7 %). Another problem that informal care givers must deal with on their own are compensatory aids. As many as 57.3 % of care givers depend on the use of compensatory aids to facilitate the care of their close relatives. The most frequently used compensatory aids are a shower chair, commode, positioning aids and a mechanical transfer device – a trolley. Only 39.6 % of care givers receive compensation aids through a contribution through Ministry of Labour, Social Affairs and Family of the Slovak Republic or a voucher from a health insurance company. 25.0 % of care givers buy the compensatory aid by purchase and 7.3 % of caregivers borrow it from their acquaintances [14].

The space we left at the end of the questionnaire to the observations, comments and suggestions of the respondents indicates that there in Slovakia care givers lack a satisfactory level of help and support from experts and the state. The requirements placed on them are too high and demanding to provide quality long-term care in home environment. The care and overall interest in informal care givers is also critical, mainly because of their burden and overall management of long-term care.

When we do not consider dementia to be a life-limiting condition, we do not provide adequate care to focus on the quality of life. Quality services and evidence-based care are the only key basis that reflects quality of life. Research shows that the quality of life of persons with dementia is threatened by the number of factors because informal care givers are unable to access services and needs adequately. In addition, the lack of understanding and stigma of society leads to what experts call the "social death of the family and carers" [13].

10 Conclusions and recommendations

Dementia is one of the most common and dreaded diseases of the elderly. It is a serious problem not only for individuals or families, but for our society. It is becoming a major threat and Slovakia does not have a National Plan to combat dementia, although the European Union has taken measures to combat neurodegenerative diseases since 2008. In our study, we point out the problems of informal care givers and their irreplaceable place in the long-term care system in the home environment. We assessed the complexity of care for persons with dementia and emphasised the specific problems that informal carers face on the daily basis.

Based on the theoretical background and evaluation of research results, we propose the following recommendations for practice with a focus on the following:

- Improve public awareness, amend legislation, set up support groups, improve awareness of the specific needs of persons with neurocognitive disorders in secondary and higher education (health, social work, and education), and implement programmes aimed at active aging and the age-friendly environment.
- Provide respite care services for informal care givers.
- Create an "informal care giver"" identity card, on the basis of which the care giver can use various forms of social assistance, support, relief, bonuses focused on the rest and relaxation (recreation, holidays, wellness, massages, season tickets for gym access, swimming pool).
- Make the form of "low-threshold help and assistance" [4]. A trained volunteer or employee will be able to support and supervise an assigned person with limited life abilities in performing his or her leisure activities. The day-to-day supervision of the informal care giver in social life of a dependent elderly person will be relieved and his role will be replaced by the so-called "Everyday companion" (for example a visit to a museum, theatre, board games, walks in the park), which will increase the quality of life of the dependent person. In cooperation with an expert, it will be possible to make a "biography" of a dependent elderly person (detailed CV describe the life story, highlight positive and negative events that significantly affected his life, define personal needs, rituals, daily routines). The care provided will be made and its quality can be

controlled. It will allow the interested to better plan leisure activities, services provided and care. Personal documentation will be applicable even in the case of placement in an institution.

- Organise free training of informal care givers for general public (personal participation, e-learning) to understand dementia as a disorder of brain function – training from the beginning – anatomy and physiology of the human body with the focus on the brain and nervous system, describe pathological conditions and their manifestations and context [13].
- Establish the "Palliative Care Letter", the so-called "Living will", where all attitudes, opinions are listed, the wishes of the persons being cared for at a time when he or she is still able to think and be concise, and can decide on themselves, on their lives, and finally on treatment and cure. If necessary, it will be possible to consult the individual decisions of the person with dementia, with an expert (doctor, nurse, and counsellor → individual alternatives, negative or positive consequences). The "Palliative Care Letter" will leave decisions and instructions that will be guided and defended in the future by an authorised legal representative for the benefit of the person with dementia (in case they refuse hospitalisation, refuse autopsy, and refuse artificial life extension).
- Select a legal representative, care giver (so-called third party) authorised to act in the field of health care. Based on the free decision of the guardian, a person will be elected to act on behalf of and defend the interests of the guardian when he or she is no longer able to verbalise his or her wishes and opinions (for example informed consent, refusal of examination, initiation of treatment). This will prevent ethical conflicts in problem issues, relieve the psychological burden of the care giver in decision-making in problematic situations [4].

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CONTEMPORARY COMMUNITY NURSING CARE FOR CHILDREN IN PROFESSIONAL FAMILIES IN SLOVAKIA – CHALLENGES AND PARADOXES

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Abstract
Theoretical Background: In Slovakia there is no functional model of community nursing care for children in professional families that is why the authors focus on the creation of a community nurse in this specific area. Preventing traumas and supporting children to heal from adverse childhood experiences promotes and protects health throughout life.
Objective: To examine the possibilities of community nursing to improve nursing care for children in professional families.
Method: We applied the method of a semi-structured interview with professional parents. An important source of information was the categorisation of their statements according to three exploratory questions.
Sample: Four professional mothers aged from 26 to 46, selected by deliberate choice. The main criterion was their professional experience as a professional parent, willingness to cooperate, openness to provide information, consent to a personal meeting and processing the information in accord with the ethics of research and privacy.
Results: We summarised the beneficial and questionable factors in nursing care for children in professional families. The interviews with professional parents show that a community nurse is needed in professional families in Slovakia.
Conclusion: Even if community nursing focused on childcare in a professional family does not exist there in Slovakia, there is a possibility for the job of a community nurse in our country. The core goal is raising awareness about this theme in our society. It is important to make an investment in high-quality community nursing care for children, with the greatest impact on increasing the health literacy of Slovak population.

Key words: Attachment. Childcare. Community nursing. Health condition. Professional family.

1 Introduction

The meaning of the concept community from Latin origin *"communitas"* can be understood as kindness, the sense of community or communion. The prospering community has at its core feature an open and effective communication between individual members who, through their mutual openness, strive to reach common goals for the common good of each other. Within this space everyone can receive emotional support, appreciation and practical help in everyday life [1]. **Community nursing care** is defined as the care provided in a particular community, such as the care for sick people, prevention, and health promotion, educating the population about health care and to identify individual needs, elimination of difficulties. The work of a **community nurse** requires independence, expertise and the ability to make the right and timely decisions about the interventions s/he uses within a community. Working in a community enables nurses to effectively design interventions towards health prevention and elimination of risk factors [2].

The childcare in the family is a necessity to ensure the healthy development of a child in terms of cognitive, emotional and social development, safe housing, and healthy nutrition. In case of improper functioning of the family, the withdrawal of a child by the court and the order for institutional care come next. This may be present in the following facilities: A children's home, an orphanage for unaccompanied younger aged children, a crisis centre, a re-socialization centre for drug addicts, and other facilities to implement measures. *"By a child we mean any human being under the age of eighteen unless, under the law applicable to the child, the age of majority is reached earlier"* [3, article 1]. In case the family is not functioning well, according to Family law no. 36/2005 Coll., the court may order the placement of a younger-aged children in institutional care only if their upbringing is seriously impaired and the child cannot be placed in alternative personal care or foster care [4].

In 1993, the concept of **professional care** was for the first time mentioned as professional substitute education in Act No. 279/1993 Coll. on school facilities as *"the mission which provides temporary or long-term care to a child from a substitute education facility or another special educational facility or special boarding school."* Maximum 3 children can be placed there, except for siblings. A person who provides professional alternative care is an employee of Family Foster homes (further FFH) [5]. Škoviera claims that professional substitute education in the family has gradually transformed into a professional substitute family and in 2005 to a professional family, which is understood as the form of de-institutionalisation of family foster home [6]. However, the original intention was to provide specific form of childcare for a child who is severely emotionally disturbed and needs safe home

environment. Due to the content of the work of the substitute educator with specialisation on nursing, the structure of the staff has also changed. The proportion of men decreased significantly, with 9 professional educators pertaining to one educator. The impact of transformation was also reflected in the perception of the status of a professional parent or educator as professionals who lose their respect and esteem in the eyes of staff or children. Towards 31 December 2017, 1373 children were placed in professional families with ordered institutional care in Slovakia [7].

A child placed in a professional family has a better chance of experiencing family and real life. The individual approach of professional parents affects the development of the child's personality, which is not compelled to compete and gain the adults' attention among other children in FFH. They learn to create emotional bonds and build relationships [8]. Bowlby, on the basis of aforementioned, developed the theory of **attachment** – relational bond, which is based on the instinctive tendency in the child to bind to the mother. This tendency is arranged via six primary emotional reactions of a child: *Crying* and *smiling* of a child have the task of bringing the mother to the baby and keeping her close to him or her. *Ensuing* and *holding* have the opposite function – they keep the baby close to the mother. The fifth reaction is *sucking* and the sixth *calling* [9]. Since the mission of a professional parent is to provide safe home to a child, there is an emotional bond, a relationship at the level of attachment. And there in the core of our law there lie the following five paradoxes.

2 Attachment

- **The first paradox** is that *the mission of professional parenting*, as defined in Act 317/2009 coll., remains unchanged. It reads as to *keep the distance from a child* [10]. In addition to attachment and creating an emotional bond with an entrusted child, there are other aspects that a professional parents should take into account and consider that she or he is a human being with certain needs.
- **The second paradox** is the existence of so called *phenomenon of a stranger child* in a family where a stranger child becomes a part of the family, and the professional parent is not always able to express love to the same extent as to his or her biological children.
- **The third paradox** is the *loss of family intimacy*. Last but not least is difficulty for children to *alternately live with their professional family* and *to keep in touch with their biological parents*, and different approaches to the management of children's homes towards professional parents. This can may ultimately undermine the stability of the original family. [8, p. 22-24]. An American psychologist Carl Rogers [11] emphasises that the acceptance of others is important factor in personality shaping and in preserving their children's mental health, because it leads to a sense of safety, awareness of self-worth and formation of their trust to the world.
- **The fourth paradox** is *alternating the child's environment by maintaining a prescribed contact with biological parents*. Frequent alternation of the environment makes the child feel uncertain, unsafe and it creates the feeling that "he has no place in a family". It is important to approach the contact of children with their biological parents individually. It needs to be taken into account if it is in favour of the child or is not.

The research studies show that mother's stress during her pregnancy causes the release of stress hormones that pass on to her child. When a mother gives up her child, even if it is a choice and adoptive parents are present at the birth and a child is placed in their arms as a newly born, an infant has still experienced an **enormous loss**. Every infant is attuned to his or her mother's voice and rhythms and thus in an emotional memory a deep sense of abandonment creates insecurity for the child. This loss is real even if there have been no other *adverse childhood experiences* (ACEs) and *traumas* [12].

Adverse childhood experiences (ACEs) are traumatic events that occur in childhood (0-17 years) such as abuse or neglect, aspects of the child's environment that can undermine their sense of safety, stability, and bonding such as growing up in a household with substance misuse, mental health problems, or instability due to parental separation or imprisonment of a parent, sibling or other member of the household [13]. The length of childcare in a professional family is individual. Letting a child go from a professional family back to a biological family or an alternative family is another serious trauma for children. The alarming fact is that with a neglected diagnosis of the child's family environment and uncritical aspiration to return the child back to the biological family as soon as possible, the child returns to the dysfunctional family. The child thus alternates between stays in various professional families. Instead of ensuring the child's well-being and safety, any exclusion and placement is another serious trauma in his or her life [6]. Traumatic events in childhood can be emotionally painful and can have negative lifelong effects. Factors such as the nature, frequency and seriousness of the traumatic event, prior history of trauma, and *available family and community supports* can shape a child's response to trauma [14].

Trauma affects *how we* – human beings *feel about ourselves*. The child in general takes things personally. When bad things happen, children believe it was their fault, so they have a *lifelong sense of shame*. Trauma affects brain development, and the brain circuits that regulate emotions, stress, body modulation, social relationships, insight, self-regulation, and impulse control. These circuits physiologically are distorted in their development under conditions of trauma. Trauma also gives a person a *sense of a world where* they don't not belong, where *they are not safe* and do not trust other people or

they trust some people too much when they shouldn't. So it distorts development in multiple ways. And these effects can be lifelong and they can lead to *physiological and mental illness* [15].

Adoptive parents with their best intention start caring for a child who is already filled with unconscious awareness that the world is unsafe and he or she is not worthy. For professional or adoptive parents, the good news is that these unconscious beliefs, and the ways the nervous system is programmed are not fundamental to who we are. What their child has learned about the world *can change*. The most important for healthy development of every child is to *feel loved* – not to be loved. They need to feel it [12, 16].

3 Community nursing care

- **The fifth paradox** is that although at present there are more than a thousand children growing up in professional families in Slovakia, **community nursing care** is not a common standard for children in FFH and professional families. The professional team that provides assistance to professional parents consists of a FFH manager, a psychologist, a social worker and a special pedagogue. Neither of these professionals graduated medical school. Professional parents thus agree that there exists the *need of centre to guide* them in the care of their sick children.

The American Academy of Paediatrics (AAP) reports that the prevalence of health problems among children placed in foster and professional families has increased over the past 30 years. These children are classified as children with specific medical needs. It states that between 30 % and 80 % of children placed in foster families have at least one health problem and one third of them have at least one chronic disease. However, despite these alarming figures, it is common for the disease not to be diagnosed and treated until the child is placed in alternative care. Up to 80 % of children in FFH have specific mental health needs. Approximately 60 % of children under 5 years of age have specific developmental problems and more than 40 % of children in school age experience learning difficulties. They often have special curricula and repeat the same grade at least twice due to the lack of mastery of study requirements [17].

As there is no functional model of community nursing care for children in professional families in Slovakia, we can draw inspiration from Great Britain. Since 1987 there exists Community Children's Nursing (CCN) that serves to support, maintain and develop the provision of quality nursing care for children according to their needs. CCN is able to respond effectively to the current needs of childcare and appeals to the necessity of nursing education.

5 Objectives, methodology, sample and organization

The objective of our survey was: *Examine the significance of community nursing for better quality of nursing care for children in professional families*.

Our partial objectives were the following:

- Examine the children's health and wellbeing as described by their professional parents during the stay in a professional family.
- Sum up the opinions of professional parents about the work of a community nurse in the care for children in professional family.
- Examine the assessment of the factors beneficial to professional parents in childcare.
- Examine the assessment of the factors questionable to professional parents in childcare.

We used the method of oral semi-structured interview with four professional parents, which we focused on the healthcare provided to children placed in professional families. One interview lasted 60 minutes. All parents agreed that children would be the part of our survey. The written communication from all semi-structured interviews written down in the form of transcripts. We asked professional parents 9 survey questions.

The survey sample consists of four professional parents aged from 26 to 46 who care for children in a professional family aged from 0 to 15. Their experience with childcare as professional parents is from 2 to 11 years. All the respondents were selected by deliberate selection, the criteria for selection were practical experience in the profession of professional parent, willingness to cooperate, openness to provide information, and the possibility of personal meeting (table 1).

Table 1 *Sample – professional parents*

Respondent sex	Age	Period of employment	Number of children in professional care
Female	34	5 years	6
Female	26	2 years	4
Female	46	10 years	20
Female	40	11 years	19

We started the research with semi-structured interviews with professional parents in February 2019, in respondents' homes. The duration of one interviews was approximately 60 minutes. During the session we obtained the information about health condition and manifestations of individual children, which were categorised and evaluated.

5 Results

The individual parameters in the interviews with professional parents were based on our survey objectives. The obtained results (table 2) indicate the demand of professional families to turn with their questions and uncertainties about health condition and childcare to professional community nursing.

***Table 2** Brief overview of the results of interviews with professional parents*

Parameters	Results
Information of the child's health condition obtained by a professional parent	Superficial information in three parents of four – performed only basic screening. Inconsistent investigation of drug and toxin effects, Fetal Alcohol Syndrome (FAS). Absence of examinations despite symptomatology, for example in an epileptic seizure. Child neglect. Revaluation of psychiatric care. Need to handle multiple medical examinations due to inconsistency of FFH staff. Deliberate concealment of information on the child's health and behaviour. Indifference in the diagnostics in proven manifestations such as reflux. Nameless problems. In one case of four, sufficient information was provided about the child's health condition (Jaundice type C).
Meeting the needs of a child during care in a professional family	Complexity, respect for individuality (*How* – not only – *What*). Biological needs (nutrition, sleep, excretion, and hygiene). Mental needs (love, belonging, self-esteem, and self-acceptance). Social needs (to belong somewhere, to have a place).
The opinion of a professional parent on community nursing	Absence of a specific concept of a community nurse in one of four cases (giving priority to medical assistance). Certainly in two out of four cases. Nurse as the part of a preparatory team in one of four cases.
Area of community nursing through the perspective of professional parents	Education and management of risk situations. Help with specific diseases. Professional information about child development. Visiting service in professional families. Help and support for professional parents. Group counselling for professional parents. Provision of comprehensive information to unexperienced parents, for example about sudden death syndrome of new born, understanding of the behaviour of a child with withdrawal symptoms, traumatised children due to non-admission, rejection, hyperactivity (ADHD).
Assessment of the child's prosperity by parents due to the professional family	The longer the stay in a professional family, the better for the prosperity of a child. The importance of long-term stay in a professional family also lies in establishing a relationship. The proper time to establish a relationship is from 3 to 4 years. Stabilisation of a child's health. For some children, progress in the professional family is visible after three months, in other cases after two years (in the case of a mature professional parent, the shift is being noted after 1 year). Expression of a child's personality is present within 1 year of a stay in a professional family. Cognitive growth in a child is positively evaluated. The shift is always visible depending on the severity of the damage: Child with withdrawal symptoms – the adaptation within a few weeks. Child with FAS – adaptation within a few months.
Factors assessed by professional parents as beneficial	Respect to the needs and habits of the child that have impact on the adaptation in a professional family. Meeting the need for safety and security with respect to family environment, daily routine, and relationship. Understanding the causal relationship between behaviour and consequences of a child, training of patience, mutual consensus and child stabilization. Efforts to adequately manage risks – help with specific diseases (asthma, laryngitis, and kidney disease), self-harming, withdrawal symptoms, FAS, injuries, sudden deterioration of mental status.

Factors assessed by professional parents as questionable ones	Fragmented care – incomplete and missing information, alternation of caregivers, automatic pedopsychiatric care, absence of systemic child guidance, indifference of supervisors. Legislation – repeated contact of a child with risky environment, lack of experience with the community nurses, absence of the mother is replaced by pedopsychiatry, the medical doctor is perceived as a guarantee of "quality" care, addressing the child's inadaptability by premedication. Failure to cope with problem situations – self-harming to attract attention, encopresis to attract attention, nightmares, wetting, sadness and fear in children.
Specific steps in the care of children by professional parents	Create natural family conditions, lead children to independence. Complement the awareness of a child's health, better diagnostics of child's health problems, better understanding of individual specifics in meeting the needs of a child, assistance during learning and promote socialisation.
Need for support and assistance for professional parents	Encouragement, management of emotionality (rationality), supervision, the network of professional parents, motivating attitude of superiors, community nursing.

Source: Our own research results

In the following chapters from 3 to 7 we present our survey findings in the agreement with given objectives.

5 Quality of information about children before their stay a professional family

The results indicate that parents perceived the information about the child's health condition before their stay in a professional family as incomplete. They lacked information about:

- social background of the child like drug abuse, alcoholism, abuse, neglect;
- genetic burden such as mother's epilepsy;
- children's home adaptation process;
- special habits and needs of the child; and
- if respectively when a child overcame fetal alcohol syndrome (FAS) or other chronic diseases.

Despite the symptomatology, the parents consistently claimed that the child had not been diagnosed in his or her early stages in certain diseases. Basic screening of children was made across-the-board that may not have been sufficient to diagnose child-specific diseases in FFH. From the parents' perspective, automatic pedopsychiatric care was often indicated.

7 Child's progress from the perspective of professional parents

Positive prosperity of the child due to the professional family results from the testimony of all professional parents. It is clear from their testimony that a longer stay in the family had a greater impact on the child's health and development. The progress was conditioned by the degree of the damage to a child, the length of family stay and the quality of care provided by the professional parent.

8 Professional family – added value to a child development

Professional parents regarded among the factors that support the healthy development of a child in a professional family in particular the following:

- Promotion and respect of a child's individuality;
- satisfying the need for safety in the sense of *belonging – having his/her own place to live";*
- encourage children to perceive the relation between cause and consequence of their behaviour;
- leading children to independence; and
- good risk management techniques and dealing with sudden situations.

Based on our observations, the right choice of family with regard to the needs and health condition of a child, the age and maturity of the professional parent, his or her readiness for the role of the parent, experience, responsibility and responsiveness to the specific needs of the child are very important personal characteristics.

9 Barriers to quality childcare in professional families

Professional parents consider the following to be questionable factors in their work:

- Insufficient support or indifference by superiors (FFH management)
- too fragmented care – frequent child rotation between families families, the transfer of a child from their professional family to biological family and vice versa,
- legislative loopholes regarding the repeated contact of children with the risky environment from which they were excluded,

- failure to cope with acute and problematic situations in children, such as self-harm, deception, aggression and others,
- lack of system access.

Too fragmented childcare led to the provision of incomplete information to professional parents about the child from healthcare professionals. The fact that the child did not have one stable person to take care of him or her, led to fragmented childcare and biased assessment of the child's health condition, which was worked out as an automatic pedopsychiatric childcare. In this context, we were intrigued by the fact that in every interview with professional parents every child in FFH was dispensarised.

10 Creating the role of a community nurse

The opinion of participants on community nursing were not explicit. They believed that the role of a community nurse is to provide them necessary help in their childcare especially for ill children:

- Provide necessary information of a child's health condition and of developmental specificities.
- Visitor service in professional families.
- Education and management in dangerous situations.
- Individual and group counselling.
- Provision of comprehensive information to parents with no experience for example about traumatized children and hyperactive children with ADHD.

We attribute it to their lack of experience in this type of care. The best vision for the work of a community nurse had older and more experienced professional parents. According to professional parents, a community nurse should provide individual education, group counselling and visitor service.

11 Conclusion and recommendations

The need to utilize community nursing in Slovakia has been increasing. In Slovakia there does not exist the job of **a community nurse** in a professional family. This is mainly due to changing social conditions. However, community nurses are required to provide specific nursing care. The community is also a professional family. Placing a child outside of his or her biological family should primarily be associated with a high level of professional responsibility [18]. It is important for professional parents to be aware of the magnitude of what they take on, because children are not a blank sheet of paper nor parents are. They need to be very patient and dedicated, not expecting anything from their children in regards to expecting them to take good care of their children's needs.

Preventing adverse childhood experiences (ACEs) by supporting children and their parents to heal from ACEs and their impact, already promotes and protects health and well-being now and in the future. Relational bond in the very early years is crucial for healthy development of every human being. Gabor Mate believes attachment is amenable to positive intervention – the power of relationship in healing and the neuroplasticity of the brain. Good and healthy relationships support healthy development throughout human life [12].

Community nursing has a relatively wide field of activity in the field of childcare in professional families. Based on our survey results, we found it very important to complete the information about the child as soon as he/she was placed in a professional family. It is important for parents to know the information of child's health condition, genetic burden, overcoming withdrawal syndrome after the childbirth, their specific habits, adaptation problems and specifics in meeting his/her needs. Community nursing can have a supportive effect on satisfying the child's safety and security needs by monitoring the family environment and providing support to professional parents. A well-informed and educated professional parent has the potency to prevent risks. For professional parents can be helpful a community nurse who, based on her competencies, can provide specific nursing care for children with various health problems; she can educate, support professional parents and provide visitor service in their professional families. A community nurse can provide professional parents with information related to childcare – meeting the children´s needs depending on their development stage, and specific health issues. She would also be in charge of risk and problem management. She could support professional parents in specific diseases that require the provision of professional nursing care. Another area where a community nurse could work is a group counseling for novice professional parents. According to professional parents, the community nurse should provide comprehensive information related to the following: Sudden neonatal death syndrome, with an understanding of a child with withdrawal symptoms, traumatized children due to non-admission, rejection and ADHD children.

Based on the results of our qualitative study, we suggest the following **recommendations for community nursing practice** and the work of a community nurse in the field of childcare in family foster homes (FFH) and professional families:

- Implement and document an assessment of a child's health condition and specificities in meeting the needs of a child before being he or she is placed in a professional family. Provide parents with complex information related to the specifics of childcare.
- Assess the professional parent's readiness for childcare of a child with specific needs.
- Provide professional parents with support and advice in the childcare of children with specific needs.
- Provide parents with emergency counselling in emergencies.
- Realize a visitor services in professional families to examine the environment, childcare and provide supervision to professional parents.
- Attend educational courses to improve the knowledge of professional parents that can make a significant contribution to the better quality of childcare in a professional family.
- Spread awareness about the benefits of community nursing in a professional family.

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HEALTH PROBLEMS OF PROFESSIONAL MUSICIANS AND MUSIC STUDENTS

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Abstract
The article focuses on various health problems of professional musicians. Based on the literature, it briefly describes Playing related musculoskeletal disorder (PRMD) and the most common auditory problems, and it outlines the possibilities of preventing them. It stresses the need to conduct a research among Slovak musicians. In addition, it brings preliminary results from a pilot questionnaire distributed to music students at the Academy of Arts in Banská Bystrica. The aim of the article is to highlight the importance of musicians´ health problems, and the need to create a preventive or intervention program for music students.

Keywords: Musician. Playing related musculoskeletal disorder. Hearing disorder. Intervention.

1 Introduction

Preparation for a career of a professional musician requires quantum of hours spent practicing the instrument (which includes repetitive movements), listening to music and performing for the audience. These activities often result in various health problems. Musicians report on different Playing related musculoskeletal disorders (PRMD), hearing disorders and psychological difficulties. Considerable attention has been paid to their physical health, and many researches have shown that these problems occur in professional musicians all around the world. Moreover, they start to show during studies, sometimes even in early childhood. It is necessary to pay attention to this topic also in Slovakia. The musicians´ health should be examined and accordingly, effective prevention/intervention programs for music students, resp. occupational therapy for active professionals should be suggested.

2 Demands on musicians and their health

Nowadays, great pressure and demands are placed on most professions, including musicians – performers. Although, on the stage, the artists often create the impression of stable, determined, confident, somewhat egocentric and passionate people, they face a number of obstacles, and sometimes, their real life is miles away from the one that audience sees in the stage spotlight. Behind their success, dozens of failures, and also disappointments and hours of self-denial could stand. In no way we want to claim that musicians are unhappy and that they internally suffer under the mask of satisfaction, but we want to pay attention to the problems that many of them encounter in their professional careers.

The profession of a musician could be very demanding and exhausting. Being a successful performer requires musical talent, number of hours spent by practicing, excellent interpreting skills, the ability to perform precise movements, excellent perceptual-motor coordination, etc. Furthermore, personality traits such as stress resistance, psychological stability, sociability, low psychoticism, etc. are essential for success. Moreover, there are also requirement regarding actual psychological and mental condition because any performance is influenced by musician´s health, which is at risk for many reasons.

Various aspects of both, physical and psychological health of professional musicians are subjects of much research, especially abroad. Unfortunately, Slovak science in this area lags far behind foreign ones, and there is currently no complex domestic scientific literature describing the health problems of Slovak musicians. However, foreign literature brings a quantum of information in professional journals, conference papers, books, or other online sources. The latest research shows that musicians cope with number of problems.

Primarily, the musicians´ workload is reflected in their physical health. The most common difficulties are musculoskeletal disorders. Their essence depends on the specific musical instrument on which a musician performs. Great deal of research is devoted to orchestra players. In the Australian orchestras, for example, participants from 8 orchestras were examined in the research by Ackerman et al. [1]. Up to 84 % of them reported on pain or former injuries, which resulted in ceasing participation in routine rehearsals or interfered with playing their instruments, and up to 50 % reported pain or injury at the time of the research. Less than 50 % of participants mentioned complete recovery. *"The most common broad sites affected were the trunk (primarily the back), the right upper limb and neck, the left upper limb and neck, and the neck alone, but the relative proportions varied by instrument"* [1, p. 181]. In 2017 *"worldwide studies have shown a high prevalence of PRMD among orchestral musician sometimes exceeding 80 %"* [2, p. 27]. Repetitive hand movement in musicians plays significant role in developing specific movement disorder, focal hand dystonia, which often manifests itself by loss of control in fast passages while playing, and the decrease in the precision of performance. In serious conditions, the fingers start

curling and involuntary flexion and contraction of muscles involved in the play appears (e.g. bowing thumb). Sometimes the spasms are associated with tremor. According to Zeuner & Molloy (2008), *"Musicians are said to be at particular risk for dystonia, especially pianists, guitarists and woodwind players"* [3, p. 1]. Eckart Altenmüller, the vice President of the German Society of Music Physiology and Musicians' Medicine in Hannover found that *"...prolonged practice and pain syndromes caused by overuse can precipitate dystonia, which is developed by approximately 1 % of professional musicians and usually ends their career"* [4, p. 530]. Intense training might be also related to physiological tremors. Findings by Lee at al. [5] *"...corroborate the notion that physiological tremor is related to motor dexterity through intense training (Deutsch et al., 2011) and manifests itself at the peripheral level as an increased tremor amplitude in musicians as compared to non-musicians"* [5, p. 7].

3 Instrument played and specific health related problems

Literature also mentions many other problems related to the artist's work in the field of musical art. Their nature depends on the instrument played. Typical PRMD differ in violinists, accordionists, pianists, saxophonists etc. However, some problems are common to multiple performing groups. As described by P. Drbal [6], musicians often suffer by diseases such as De Quervain's disease (inflammation of two tendons controlling the thumb movements and tendon sheath), ganglions (softer or harder lumps usually on dorsum manus, on the wrist), arthroses (degenerative disease of joint cartilage and bone), tennis elbow (series of micro-cracks, tiny tears or inflammations developed in the elbow tendons), or shoulder impingement syndrome (impingement of shoulder tendons or bursa from bones of the shoulder) [6].

Besides musculoskeletal problems, musicians often experience various auditory disorders. Long-term exposure to excessive sound levels causes hearing disorders such as hearing loss and tinnitus to appear frequently among musicians' health problems. In 2014, Tania Schink et al. found that, among German musicians, there was *"almost fourfold higher adjusted HR* (Hearing loss) *for NIHL* (noise-induced hearing loss) *and a 57 % higher adjusted HR for tinnitus for professional musicians in comparison with the general population"* [7, p. 472]. E. Králová [8] described tinnitus as follows: it *"...is also referred to as rustle in the ear and it frequently occurs in the connection with shortage of hearing"* [8, p. 42]. Further, she mentioned possible treatment in musicians: *"In the vast majority of cases its origin and cause is unknown. Treatment of tinnitus is mostly symptomatic. In these cases, auxiliary treatment is used, which, although it does not remove the cause of the troubles but reduces the symptoms"* [8, p. 44].

Various health problems in musicians appear already in the early stages of their music training. Research by Anna Cygańska et al. [9] showed that in children who played violin, body posture lead to *"some changes in parameters characterizing anteposterior spinal curvatures in the sagittal plane"* [9, p. 176]. It can be assumed that similar changes would be caused by playing other instruments that require unnatural body position and movements. Above mentioned leads to the idea of considering the possibilities of early prevention, resp. intervention for young musicians. The easiest way would be to include preventive and/or intervention activities in the education, i.e. in the musicians´ training. Undeniably, this idea is not new, and is currently being applied in many European countries, such as Norway, Germany, France, Spain, Russia, etc. In Norway, in 1982, the doctor Crispin Spaulding taught the subject of musical physiology, in which she taught anatomy, physiology, ergonomic education, stress processing, etc. In Germany, the Curriculum Musikphysiologie an Musikhochschulen was issued in 2001, with a recommendation for the introduction of a two-semester seminar in musical physiology. In Switzerland, Schweizerische Hochschulzentrum für Musikphysiologie was founded in 2005-06, working with music schools at university level. The 2007 report of the Association Européene des Conservatoires, Academies de Musique et Musikhochschulen suggests the establishment of musical physiology field, etc. [10].

.4 Projects and programs supporting healthy development of musicians

There is number of organizations in the world dedicated to prevention, intervention, and diverse musicians´ support, which are also supporting projects dedicated to the healthy development of musicians. For example, in Germany since 2003, Kapfenburg Castle Foundation, foundation that *"runs a broad range of projects which are addressed to all people who make music, are undergoing an instrumental training or teach music, while they also get in touch with musicians in a medical and psychological way or work at music schools"* [11]. The nearby Czech Společnost pro hudební fyziologii a medicínu hudebníků (Society for Music Physiology and Medicine of Musicians), which is led by the President MUDr. Pavel Drbal, can also be taken as an example. The organization cooperates with music schools at all levels and artistic ensembles, is engaged in educational and preventive activities, coordinates research in the field of music physiology and pathophysiology, provides counselling and information services for patients, all in order to *"serve music that is an important part of our intangible cultural heritage and improve the working conditions of artists"* [12].

The seriousness of health problems and the consequent need to address them are also highlighted by some foreign universities. For example, the Music School at Arizona State University, due to requirements by the National Association of Schools of Music, notifies *"students, faculty and staff of the health and safety issues,*

hazards, and procedures inherent in music practice, performance, teaching, and listening both in general and as applicable to their specific specializations. This includes but is not limited to basic information regarding the maintenance of hearing, vocal, and musculoskeletal health and injury prevention" [13].

A well-thought-out preventive or intervention program must reflect the current situation in the targeted group. Since Slovak musicians get education in local schools and they work in specific conditions, their health problems can be slightly different from the problems of musicians in other countries of the world. Therefore, it would be advisable to examine the Slovak population of musicians as well. Based on the problems identified, on understanding their perception by musicians, and on the analysis of verified effectiveness of existing prevention/intervention activities, it would be possible to establish an appropriate preventive and/or intervention programs for future Slovak professional musicians. The programs could aim at preventing or minimizing the consequences of long-term active interpretation, not exclusively in the physical domain but also in the mental health and well-being. A prerequisite for proposing such a program is the identification of the current situation. This is where the difficulties about diagnostic tools arouse. There is a small number of validated instruments to detect musculoskeletal pain. Psychometrically tested were only few of them, e.g. long and short form of McGill Pain Questionnaire (LF-MPQ, SF-MPQ) by Melzack, and the Brief Pain Inventory (BPI) by Daut et al., Cleeland and Ryan. Especially for musicians, Musculoskeletal Pain Intensity and Interference Questionnaire for Musicians (MPIIQM) was developed and validated by Patrice Berque in 2014. It is designed to measure musculoskeletal pain intensity and pain interference in professional orchestra musicians [14].

5 Pilot survey – research focusing on physical and psychological health of musicians

In order to create a preliminary picture on the situation between musicians and music students in Slovakia, we plan to conduct a research focusing on both physical and psychological problems related to musicians´ work.

In the beginning, we created questionnaire, which we distributed in the school year 2019/20 to performing arts students at the Academy of Arts in Banská Bystrica (Slovakia). In our pilot survey, we used a questionnaire designed in cooperation with experts in the field of physical education and physical health – Mgr. Juraj Kremnický, PhD. and Mgr. Soňa Kremnická, PhD., who has multi-year experience with young musicians (currently, she teaches the subject Physiology and hygiene of the voice/playing apparatus at the Conservatory). We divided the self-reported questionnaire into two parts. In the first one, we focused on any pain, tension and stiffness of muscles while playing (now and in the past), and in the second part, we surveyed consequences of these difficulties, such as quitting playing or taking various measures (e.g. visiting a doctor, studying literature, etc.). 15% of our respondents reported they did not feel pain in any parts of their bodies at the time of the survey, nor did they before. 85% responded that they felt the pain while playing either often or almost always. As much as 52% of students sought a doctor help. Subsequently, of these, one respondent underwent surgical treatment, 41,2% took medication treatment, 76,5% underwent the rehabilitation. Of all students, many also reported "self-treatment" or taking other measures, such as doing exercise (6% strengthening, 12,1% yoga or stretching, 12,1% relaxation, 15% swimming), taking self-medication by applying ointments (9,1%), taking nutritional supplements (3%), having massages (6,1%). Further investigation is needed to confirm psychometric characteristics of the questionnaire.

We consider the results or the survey to be alarming. If about half of musicians experience pain while playing to such an extent that they seek medical help during studies, i.e. before starting a full professional career, it is necessary to consider including an intervention/prevention programs in their training.

In the future, we would suggest addressing this issue in more detail, extending the research to examine auditory dispositions (there is an empire-based concern that students might also suffer from hearing problems such as tinnitus), the psychological problems, resilience of students and their well-being. Based on the results obtained, we would propose to create both intervention and prevention programs. The seriousness of the topic is intensified by the fact that health discussions with professional musicians *"revealed a complex link between health and performance, including the dramatic impact of potential or actual health problems on musical careers"* [15, p. 129]. *"Only those who feel comfortable in their body can also play or sing expressively. For this, music students already need a basic knowledge about stress management techniques, balance through movement and a physiological posture at the instrument"* [16]. Further, scientists recommend *"that a music health curriculum, including body awareness programs such as Alexander technique, regular hearing tests, advice on hearing protection, noise level monitoring, performance anxiety counseling, as well as training in injury prevention and management, be implemented and made available to students"* [17, p. 158]. All of these can be addressed in the intervention and prevention programs throughout the music studies.

6 Conclusion

A quantum of world research documents various health problems in musicians. There is a lot of evidence that repetitive movements while playing instrument often result in PRMD. Furthermore, the scientific literature provides evidence of hearing disorders in musicians related to their work and excessive exposure to high noise levels, and of psychological issues linked to the specific character and demands of musicians´ professional activities.

Similar comprehensive studies in recent decades have been completely absent in Slovakia. Therefore, we find it important to address this problem and to create a team of scientists who would be able to evaluate not only musculoskeletal disorders, but also hearing disorders and psychological problems. We assume that the difficulties start emerging before students start their active career of a performer. Therefore, an effective and sophisticated intervention and prevention program should be provided to music students. Ideally, preventive activities could be included in the curriculum in the form of physical exercise, educating students about various ways to prevent the health problems, psychological counselling etc. We could take the example of many European countries where similar programs have already been put into practice.

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