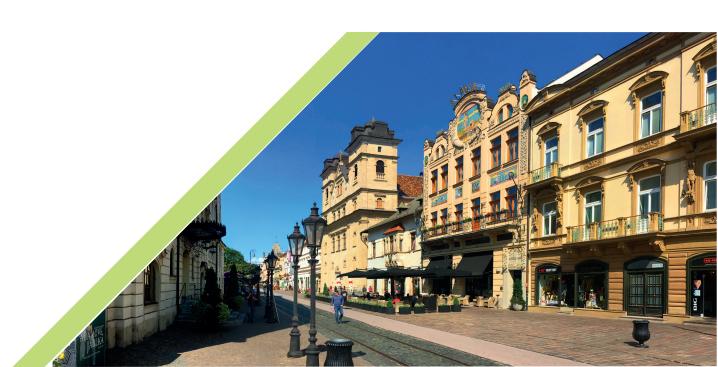
Iveta Nagyova, Zuzana Katreniakova (eds.)

**Reviewed Book of Proceedings** 

# Chronic Diseases and Integrated Care: Rethinking Health and Welfare Systems

Kosice 2020 Slovak Republic

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Iveta Nagyova, Zuzana Katreniakova (eds.)

### **Chronic Diseases and Integrated Care: Rethinking Health and Welfare Systems**

Reviewed Book of Proceedings

#### Statement of review

All papers published in these proceedings have been independently reviewed by the members of the conference International Scientific Committee\*. Note: The complete list of reviewers can be found on page 5.

Papers published in this reviewed boof of proceedings were presented at the International Conference on Chronic Diseases and 6th SAVEZ Conference held on 24-25 October 2019 in Kosice, Slovakia.

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### INTRODUCTION

Ageing populations with rising chronicity, fragmented services delivery resulting from split management of health and social services, provider dissatisfaction over the standard of care for elderly patients, and vulnerable population groups are amongst the major health challenges throughout Europe. To add to this, there are great disparities between the EU regions. The indicator of population healthy life years in new EU member states has been ten years below the EU old member states average. The existing hospital-centric model of care, weak gatekeeping at the primary level, and fragmented delivery of services with limited continuity of care for patients with chronic conditions are the critical contributors to below the average health outcomes in these countries.

The complexity of needs arising from having multiple chronic conditions, in combination with ageing population, requires urgent changes to models of care that drive:

- A shift in focus from a simple extension of life to improved functioning, well-being, and quality of life.
- A shift towards an environment where health and social care are treated as a single unit bringing together a range of professionals and skills from both the cure (healthcare) and care (long-term and social care) sectors.
- A shift towards community-based health and social care and the need for people to coproduce a healthier population that has less need for acute services and takes more responsibility for its care.
- The priority toward prevention and support for self-management of health.
- The need for partnership and a cross-sectoral approach to innovation that has a significant potential to increase choice and control for European citizens and support a necessary transformation in health and social care services.

This book of proceedings contains academic texts whose main purpose is the presentation and sharing of knowledge in the prevention and management of chronic diseases with a particular emphasis on implications for people-centered integrated models of care. All papers are made available to professionals and the general public via OpenAccess.

The International Scientific Committee\*, comprising experts from several universities and non-state actors, believes that the book of proceedings will stimulate further scientific discussions, research, and interdisciplinary development.

Editors Iveta Nagyova, Zuzana Katreniakova

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# SECTION 1

# Prevention and management of chronic conditions: Life course-approach

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### DETERMINANTS OF HEALTH-RELATED QUALITY OF LIFE IN PATIENTS WITH OSTEOARTHROSIS

#### Julius Evelley<sup>1</sup>, Martin Vicen<sup>2,3</sup>, Peter Polan<sup>2,3</sup>, Iveta Nagyova<sup>1</sup>

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**BACKGROUND:** Osteoarthrosis (OA), as one of the most common consequence of arthritis of the knee and hip joints, is considered as main course of musculoskeletal pain and incapacity for work. OA is also often associated with decreased health-related quality of life (HRQoL). The main aim of the study was to explore sociodemographic, clinical, and psychological factors related to HRQoL.

**METHODS:** The sample consisted of 146 OA patients (64±9 years old, 51% males). Data collection was carried out one day before total knee/hip arthroplasty. Physical (PCS) and mental (MCS) components of quality of life were measured using SF-36. Functional status was assessed with KOOS/HOOS, and psychological well-being with GHQ-28. We analysed data using correlations and multiple linear regressions.

RESULTS: Total explained variance for PCS was 45%. In the final model only restrictions in daily activities were significantly contributing to total explained variance ( $\beta$ =.63, p<0.001). In MCS total explained variance was 43% and OA symptoms, activities of daily living, and pain were significantly associated with MCS. However, when psychological factors were added into the model, only anxiety remained significantly associated with mental component of quality of life ( $\beta$ =-.54, p<.001).

**CONCLUSIONS:** Clinical and psychological factors were found to be related to both physical and mental components of HRQoL, however restrictions in activities of daily living and anxiety appears to be the most important factors associated with overall well-being of OA patients. These results can find implications in patient educational and pre-surgery preparatory programs.

Key words: osteoarthrosis, arthroplasty, health-related quality of life, activities of daily living, psychological factors

#### Introduction

Osteoarthrosis (OA), as the most prevalent chronic musculoskeletal condition worldwide, has significant consequences for the society. Due to ageing population, lack of the physical activity and high obesity rates, it is expected that the prevalence of the OA will increase by 40%, up to 2025. Joints, knees, hips, hand, foot, and spine are the most common areas of development of OA. Knee OA is however the leading cause of disability in older population. OA is characterized by joint pain and disability as a result of loosening of the articular cartilage, bone hypertrophy, consequent formation of osteophytes and bone sclerosis (Cui et al. 2020, Srivastava et al. 2017, Cavalcante et al. 2014, Farr et al. 2013). Total hip and total knee arthroplasties (THA/ TKA) are highly frequent, successful, and cost-effective surgical procedures for patients with end stage of symptomatic osteoarthrosis. More than 1 million arthroplasties

are carried out every year worldwide and this number is projected to double within the next two decades. Total knee replacement results in significant intermediate and long-term benefits, especially diminishing the pain and improvements in daily functioning (Goodman et al. 2020, Bahardoust et al. 2019, Shan et al. 2015, Pivec et al. 2012).

Untreated OA negatively impacts the quality of life, with its restriction of ability to perform work and family roles (Wysocka-Skurska et al. 2016). Limitations in walking, stairs climbing, and squatting are common patient complaints that greatly interfere with activities of daily living. In elderly population functional status is impaired by pain, stiffness, muscle atrophy, and crepitus of the affected joint (Srivastava et al. 2017, Cavalcante et al. 2014). During the 2 years waiting period for THA/TKA a significant increase in disability and decline in functionality has been demonstrated by Ho et al. (2021).

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Mental health deterioration and impairment have been shown to be one of the major contributors to the increased disability in OA. Duivenvoorden et al. (2013) found high prevalence of anxiety and depressive symptoms in population with end-stage of OA (higher in hip OA patients). Perneger et al. (2019) reported similar associations of determinants of health-related quality of life (HRQoL) between hip and knee OA patients. The association between various determinants and HRQoL in people are yet studied insufficiently. More research is needed to fully understand the associations between determinants of HRQoL, such as pain, disability, physical performance, and psychological factors in severely impaired individuals with OA (Lowry et al. 2017).

Thus, the main aim of this study was to examine sociodemographic, clinical, and psychological factors related to HRQoL in patients with end stage of OA, before total knee and hip arthroplasty.

#### Methods

#### Sample and procedure

Sample of this cross-sectional study consisted of consecutive patients with end stage of OA. Data collection was carried out one day before THA and TKA at the Department of Musculoskeletal and Sports Medicine, Kosice-Saca Hospital in the period from 03/2019 to 09/2019. The medical examination was followed by the structured interview where patients completed self-reports to assess quality of life, functional status, depression, anxiety and baseline socio-demographic data. Procedure lasted for a total of approximately 20 minutes. Patients participated in the study voluntarily, after signing the informed consent. All collected data were anonymized. Research was approved by the Ethics Committee of the 1st Private Hospital Kosice Saca (Approval No. 03-2019).

#### Measures

Quality of life. Health Survey Short form–36 (SF-36) is a generally accepted quality of life questionnaire. The 36 items are divided into 8 subscales: bodily pain, physical functioning, physical role limitations, general health perceptions, vitality, emotional role limitations, mental health, and social functioning. These subscales are

combined Physical Component Summary (PCS) and Mental Component Summary (MCS). Scales run from 0 to 100, with the higher value indicating better HRQoL (Ware & Sherbourne 1992).

Functional status. The Knee/Hip Injury and Osteoarthritis Outcome Score (KOOS/HOOS) was used to assess patients' functional status. KOOS/HOOS is a valid and reliable extension of Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) for assessment of patient-relevant outcomes in elderly subjects with advanced OA (Roos et al. 2003). Subscales Pain, Symptoms, Activities of daily living, Sport and recreation was included. For each item five answer possibilities are available (Likert scoring, 1-5). Higher score means worse functioning.

**Psychological well-being.** Subscales of Anxiety and Severe depression from the General Health Questionnaire 28 were used to asses psychological well-being. GHQ-28 is a valid and reliable self-administered screening instrument which aims to detect those with diagnosable psychiatric disorders. For each item four answer possibilities are available (Likert scoring, 1-4). Higher score means higher psychological distress (Goldberg & Hilier 1979, Sterling, 2011).

#### Statistical analyses

We analysed data using descriptive statistics (mean, frequencies, standard deviations, range). For analyses of associations between dependent variable HRQoL (PCS/MCS SF-36) and independent variables functional status (HOOS/KOOS) and psychological well-being (GHQ 28), correlation and multiple linear regression analyses (Enter method) were used. To perform analyses, we used IBM SPSS 25.0 Windows (IBM, Chicago Illinois, USA). The level of significance was set at p<0.05.

#### **Results**

During the 7-month period, data from 146 patients with end stage of OA, one day before THA (45.2%) and TKA (54.8%) were collected (response rate 95%). Table 1 displays descriptive characteristics of the study sample. Mean age of the sample was 64.6 years with standard deviation 9.2 years, and 50.7 % was males. The majority of the patients attained secondary education, were married, and were retired or disabled.

**Table 1** Descriptive characteristics of sample (n=146)

Variables	n (%) or mean ± SD
Age	64.6 <b>±</b> 9.2
Disease duration (years)	$9.8 \pm 10.3$
Diagnosis	
Hip	66 (45.2)
Knee	80 (548)
Gender	
Male	74 (50.7)
Female	72 (49.3)
Education	
Elementary	13 (9)
Secondary	86 (59)
University	47 (32)
Family status	
Unmarried/Divorced/ Widowed	40 (27.4)
Married	103 (70.5)
Working status	
Retired/disabled	96 (65.7)
Employed	47 (32.2)

Correlation analyses (Table 2) revealed significant negative associations between PCS and gender, positive associations PCS with symptoms, activities of daily living and sports activities. MCS significantly negatively correlated only with anxiety and depression. Total explained variance of PCS was 45% (Figure 1). In the final model only restrictions in daily activities were significantly contributing to total explained variance ( $\beta$  =.63, p<0.001) (Table 3). For MCS, OA symptoms, activities of daily living, and pain were significantly associated with MCS; however, when psychological factors were added into the model, only anxiety remained significantly associated with mental component of quality of life ( $\beta$ =-.54, p<.001) (Table 3). Total explained variance was 43% (Figure 2).

**Table 2** Bivariate correlation coefficients

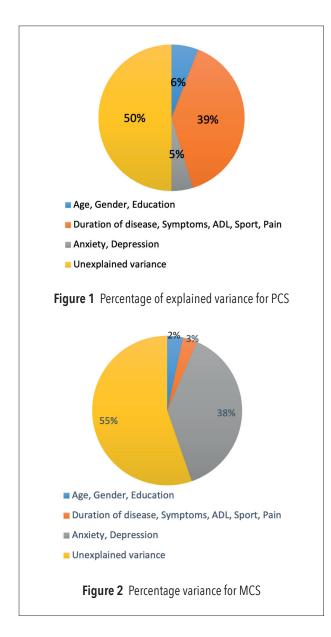
	SF-	-36
	PCS	MCS
Sociodemographic		
Age	14	07
Gender	22*	.05
Education	.14	.13
Clinical		
Disease duration	.14	04
Pain	06	.15
Symptoms	.28**	08
Activities of daily living	.60**	.15
Sport activities	.18*	.05
Psychological		
Anxiety	07	59**
Depression	10	48**

PCS-Physical Component Summary, MCS-Mental Component Summary;  $^*p<0.05, *^*p<0.01$ 

**Table 3** Multiple linear regression analyses: Beta coefficients for the final PCS and MCS models

	SF	-36
	PCS	MCS
Sociodemographic		
Age	10	.01
Gender	09	.05
Education	.06	05
Clinical		
Disease duration	01	06
Pain	.03	25
Symptoms	09	17
Activities of daily living	.63**	.12
Sport activities	.07	.07
Psychological		
Anxiety	.05	55***
Depression	.01	11

PCS-Physical Component Summary, MCS-Mental Component Summary; \*p<0.05, \*\*p<0.01



#### **Discussion**

The main aim of this study was to examine sociodemographic, functional clinical, and psychological factors related to HRQoL in patients with end stage of OA, before TKA/THA. Our results demonstrated that clinical and psychological factors were related to both physical and mental components of HRQoL, however restrictions in activities of daily living and anxiety appears to be the most important variables associated with overall HRQoL of OA patients.

The univariate correlation analysis of sociodemographic variables showed that only gender was significantly associated with PCS, what means that being female results in worse PCS. However, these findings were not confirmed in multivariate analyses. Our results are partially in line with findings of other authors (Vitaloni et al.

2019, Wysocka-Skurska et al. 2016, Srivastava et al. 2017). We found no more significant associations between sociodemographics and HRQoL, which is in contrast with outcomes of a study by Vitaloni et al. (2019) who reported that educated and younger patients mostly perceived better HRQoL. On the other side, Wysocka-Skurska et al. (2019) reported weak associations of age with both PCS and MCS.

From clinical variables only symptoms, restriction in daily activities, and sports were significantly associated with PCS in univariate correlation analyses. These findings suggest that with worsened symptoms and performance in activities of daily living and sports, patients also perceived worsening in PCS. In further multivariate analyses, only restrictions of in activities of daily living were significantly contributing to total explained variance in PCS. Pain was no longer associated with PCS. As to MCS there was no correlation with clinical factors, but in regression analyses symptoms, activities of daily living, and pain were significantly associated with MCS. However, when psychological factors were added into the model, only anxiety remained significantly associated with MCS. These results are partially in concordance with Duivenvoorden et al. (2013) who found that both depression and anxiety predicted HRQoL preoperatively in hip/ knee OA patients.

Further research is needed for better understanding of pre-operative correlates of HRQoL. As Duivenvoorden et al. (2013) stated, treating patients with anxiety and depressive symptoms therapeutically before arthroplasty may lead to better outcomes after THA or TKA.

Understanding pre-operative patients' characteristics can improve educational preparatory programs and effectiveness of pre/post-surgical management of patients undergoing TKA/THA. The main limitations of this study included data collection carried out in single hospital. Another limitation might be that a study was carried out one day before surgery. TKA/THA may be for some patients a stressful event what can impact outcomes especially in psychological characteristics. Nevertheless, the results of our study can be used to support pre-operative preparation programmes and educational and rehabilitation programs after surgery (Lowry et al. 2017).

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# PROFILE AND PLACE OF PATHWAY COORDINATOR FOR COMPLEX PATIENTS

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**BACKGROUND:** the return home of elderly patients hospitalized for chronic heart disease at the University Hospital of Martinique remains a major organizational challenge. Lack of coordination between the actors involved translates into long, costly and inappropriate hospitalizations. The goal of the study is to identify the required skills of a complex pathway coordinator in this setting.

**METHODS:** To do so, we traced the evolution of the hospital coordination team over the last 10 years. We conducted also a survey on the skills expected from a health pathway coordinator, using questionnaires distributed among different care providers and patients.

**RESULTS:** We observed that the coordination team has centered around two missions: bed manager and in-hospital pathway coordinator. However, operational objectives and timely evaluations have been lacking. The survey shows that the candidate profile fits best with caregivers, and to a lesser degree with physicians and administrative staff. We also identified three underestimated tasks: identification of bed-blocker patients, psychosocial assessment of the patients, and building of coordinated pathways for the most complex patients in collaboration with primary care settings.

**CONCLUSIONS:** In conclusion, a pathway coordinator at the University Hospital of Martinique must have specific managerial skills, and overt support from the Hospital Board.

Key words: coordination, pathway, caregiver

#### Introduction

The Health care pathways are established by each medical staff division. This presents a problem for patients followed for chronic disease. Most of them are elderly people with several chronic diseases, comorbidity and usually precarious, which will require complex journey. The University Hospital of Martinique, located in the French West Indies, answers therapeutic needs in acute phases and provides specialty medical follow-up. Our thinking about taking over cardiological care for chronic patients in heart failure is evolving, is going further than care delivered in cardiology services (HAS 2014).

Heart failure is a predominant cause of hospitalization. Many guidelines are known in this cardiology and recommend longitudinal and multidisciplinary care. But a few studies such as REZICA (Deker 2017) show a high rate

of readmissions and difficulties in continuing home care. After entering the emergency department with heart failure, 28% of patients are discharged and sent back home, while 72% are discharged to hospital or partner services. However, we can see a rate of 35% of re-hospitalization in Martinique, similar to the rate in mainland France, but an average length of stay that is superior to the national rate in Martinique. This data is actually challenging and questions the conditions of returning home and staying there safely. Moreover, certain Martinican characteristics add to this chronic cardiologic disease management: ageing, social and family isolation, precariousness and an important prevalence of obesity and diabetes. All of this suggests the need for an improved coordination of a patient health pathway, in connection with the current national program Ma Santé 2022 (ARS 2020) with transversal care, against rehospitalizations and in a spirit of better quality of life.

Nowadays there are two lines of thought: interprofessional disease management inside the hospital or a case management approach to improve the course of life with a care pathway. They both apply to therapeutic strategies for patients with chronic heart diseases but the second option is a personalized longitudinal view. The concept of a continuous healthcare circuit is far more global than medical care and embraces the medical, psychological and social aspects of a situation. The fact is that psychosocial and supportive needs are not sufficiently addressed by the current care. With continuous improvement, we are seeking to build a safe and personalized plan to return home as early as possible during hospitalization, reflecting all medico-social items. Each health course must be designed to limit readmissions and maintain outpatient follow-up. Who would be the best person available to imagine such a global pathway with the medical team and patients?

This study aims at defining the use of the existing coordination platforms and finding who is most is best placed to organize the care coordination for each patient (ARS 2018).

#### Methods

First, we conducted a retrospective observation on the organization of the coordination team from 2008 to 2018, at the hospital. Then, we conducted a study to identify a typical profile of a path coordinator from June to August 2018. A questionnaire was created, adapted from the Likert Scale Technique for the Measurement of Attitudes. This consists of a series of statements in which the subject must indicate his/her degree of agreement in skills, know-how and initial training. The last question was open on the added value of a person dedicated to the fluidity of the courses.

As part of our investigation, we oriented our choice on 2 groups:

- the public: doctor, carer, user
- the place of practice: hospital and primary care

Then we distributed 60 random questionnaires to users and professionals in June 2018 with a re-launch in August 2018. Multiple answers were possible.

#### **Results**

The coordination team has had two missions since its beginning in 2008. Historically, the coordinators were bed managers nurses. Over time, they have been experimenting with new profiles to work on health pathways with nursing assistants, nurses or social workers. They accompany citizens with social characteristics who become bed-blockers. They deal with the admission to and discharge from the hospital services, mostly from the Emergency department. However, many services, mainly cardiology, do not call for coordination due to lack of knowledge of how it works.

The survey to identify a typical profile of a coordinator was distributed to 60 (100%) people including 14 (24%) patients, 15 (35%) doctors, 21 (35%) nurses and 10 (19%) care managers. After a re-launch in August 2018, 53 (88%) responses were analysed.

Qualities required for knowledge are caring and compassionate relationships (58%), initiative (52%), speed and efficiency (49%). The expected skills are organizational and regulation know-how (64%), transfer of knowledge (55%) and capacity of analysis and synthesis (52%) (Table1).

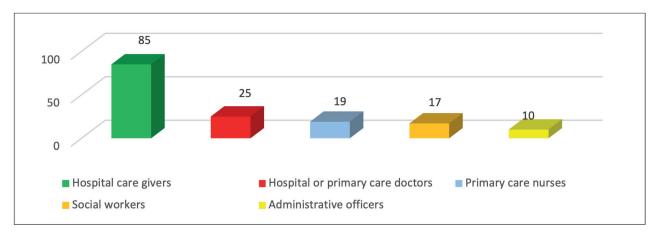


Figure 1 Initial training of the coordinator

Table 1 Survey results: Typical profile of a coordinator

SURVEY: TYPICAL PROFILE OF A COORDINATOR					
	Totally agree	Enough agree	Do not know	Disagree	Totally disagree
		K n o w - h o v	V		
Diplomat, médiator	25	4		1	
Benevolent, attentive	31	1			
Volunteer, dynamic	23	4	1		
Neutral	16	8	1	2	
Fast, effective	26	8			
Initiative	28	5	1		
Ability to take risks	11	6	5	3	
Strong adaptibility	25	8	1		
Respectful of rules	24	5	1		
		K n o w - h o v	V		
Organize, regulate	34				
Plan, manage	26	3	1		
Négociate	24	7	1		1
Control	22	11	4		
Transmit	29	4			
Analyze	28	4			
Synthesize	24	6			
	k	(now-initial tr	aining		
Hospital doctor	13	5		4	1
Primary care doctor	13	6	2	2	2
Hospital caregiver	45	11	1	1	3
Primary care nurse	10	9	1	4	2
Administrative officer	6	7	1	3	5
Social worker	9	13	2	2	2

The results show that in terms of knowledge, hospital care givers are clearly ahead (85%), compared to Hospital or Primary Care doctors (25%), Primary Care nurses (19%), social workers (17%) and administrative officers (11%) (Figure 1). Most of questions were about the choice of the Care Giver and his/her spheres of competences. The floor remains open for general and polyvalent skills or specific knowledge, cardiologic expertise for example.

This survey is able to identify a profile of a coordinator, who must be a hospice caregiver with skills in terms of being knowledgeable as a diplomat, benevolent, having a strong spirit of initiative and know-how in organizing, analysing and -transmitting information.

#### **Discussion**

The expected added value of a care coordinator is to identify the rupture points in the medical pathways which represent failures both for the nursing staff and for the patients. Unplanned re-hospitalizations disrupt care services

and question the links between Hospital and Primary Care. The identification of a bed-blocker patient allows the optimization of the quality of live, breaks the social and family isolation because of the long stay in Hospital and creates consistency in longitudinal follow-ups. They are an example of practical guidelines for the determination and assessment of activity for the coordination team. This platform needs annual targets with performance analysis. However, we saw a transversal team with diverse and targeted skills. Bed managers are an important pillar in the emergency department flow system during the acute phase (ANAP 2016). Differently, people in charge of the health pathways facilitate the cohesion of governance with complex patients. In cardiology, it would be possible to identify readmissions and organize Hospital-City-Hospital links for longitudinal follow-up. It should be an answer to the policies put in place by the last guidelines Ma Santé 2022. Since 2019, the cardiology department developed a flowchart to create an active queue of outgoing patients. In the future, we look forward to a partnership

with the coordination platform and Primary Care. Are we now thinking of using this process channelled by specialty, which involves specific coordination, or channelled by polyvalent systemic and non specific coordination? The platform agrees to innovate in order to be as close as possible to the needs of the Hospital. The care givers could work *outside the walls* at the interface between Hospital and Primary Care. Patient follow-up would be less dispersed, closer to complex therapeutic orientations and procedures governing the return to the patient's home with optimized medico-social transmissions (Has 2013, Kuhn-Lafond & Broussy 2019).

Such obstacles can be tackled with partnerships that now need to be encouraged by all institutions and managers. This training will have to focus on acquiring knowledge in management, human resources and in the way in which providing care is expected. These new working professionals will have to imagine efficient and proactive channels of communications between co-workers from different divisions, on an information sharing level as well as on a care-planning level (ANAP 2019, Giroud 2010). This experience should focus on the acquisition of knowledge in case management, human resources to optimize the expected transversal management. The survey made health professionals aware of the comprehensive and territorial care. Here the cardiological orientation takes place in the holistic support. Caregiver are trained to clinical and biological warning signals related to heart failure. They practice therapeutic education and lifestyle in conjunction with hospital cardiologists. The goal is to prevent cardiovascular complications and anticipate rehospitalisation.

#### Conclusions

We need real and direct communication between Hospital and Primary Care. Over these last 10 or 15 years, we have stepped from curing acute diseases to caring chronic non-communicable diseases. Indeed, we work with an ageing population who tends to be less autonomous and suffers from several pathologies at the same time. A caregiver is the challenge to follow complex patients, in the right to his self-determination and multiple therapeutics. This care system will ensure, for every single person, a continuous care circuit from the home to the hospital and back home. It means that all of this requires that we shift to new sight in reception and in multidisciplinary care of people, such as a coordinator caregiver.

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# CULTURAL DIFFERENCES IN NEEDS AND TREATMENT PREFERENCES IN RHEUMATOID ARTHRITIS PATIENTS

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**BACKGROUND:** Despite advancements in pharmacological treatment rheumatoid arthritis (RA) patients suffer from many (health) problems and diminished quality of life. This study aimed to identify needs and preferred non-pharmacological interventions in RA patients.

**METHODS:** The sample comprised 197 patients: 102 from Slovakia (SK) (82.4% females, mean age 55.42±13.33 years), 51 from Greece (GR) (62.7% females, mean age 52.32±14.21 years) and 44 from the United Kingdom (UK) (79.5% females, mean age 53.75±12.69 years). Structured interviews were used to collect data. To examine data CIA analyses were used.

**RESULTS:** Among the patients' needs was found a strong preference for spending extra time with the rheumatologist. The more preferred source of health information were books or leaflets. Over half of patients wanted to have a companion for medical check-ups. The most preferred non-pharmacological intervention was physical exercise. Patients were not in favour of group non-pharmacological interventions.

**CONCLUSIONS:** The results yielded market differences between countries. The biggest difference was in time spent with physicians; UK and GR patients would like to spend more time with their physicians. UK and SK more frequently than GR patients would like to have a companion during medical check-ups. Our results can help to design tailored disease management interventions for RA patients.

Key words: rheumatoid arthritis, patients needs, non-pharmacological interventions, cultural differences

#### Introduction

Rheumatoid arthritis (RA) is a long-term inflammatory condition that affects 0.3-1.2% of the population and is typically more common in women than men with a ratio of approximately 3:1 (Bijlsma and Hachulla 2018, Salaffi et al. 2010). This chronic autoimmune disease is characterized by systemic attacks of immune cells on the synovial tissue of the joints (Ryan 2014) which cause typical swelling, pain and tenderness. The condition is not curable, although drug therapy can reduce inflammation. Nevertheless, patients often experience daily symptoms of joint pain, stiffness, fatigue, and functional limitations (Mistry et al. 2020). RA is a significant burden to the patients with its symptoms affecting their physical, psychological, and social functioning. In particular, RA is affecting, for example, abilities to perform roles in the family, maintain various social roles, continue to fulfil duties in work or keep work performance at the same level, it can also lead to the loss of valued activities like hobbies or sports and overall

negatively affects the quality of life of the individual and his/her family (Katz et al. 2006). Patients may experience psychological challenges and implications of living with RA, including body image, sexuality (Hale 2020), and are more likely to suffer from depression (Nerurkar et al. 2019), low self-esteem (Filej et al. 2018), anxiety (Pu et al. 2018), psychological distress (Bacconnier et al. 2015), etc.

Medications are used to control RA, but the holistic patient-centered management of RA patients is in many countries still neglected. In addition, in literature many types of research about different therapies or non-pharmacological interventions (NPIs) (Santos et al. 2019) are reported, but few are used in daily practice. In Slovakia, for instance, RA patients are not getting any kind of physiotherapy or patients group meetings as part of their standard treatment in hospitals or outpatients clinic. In general, in the literature, there is a lack of information about patients' preferences and needs. Studies report on patient preferences regarding pharmacological treatment

(Chilton and Collett 2008) or recommendations regarding physical exercise (Metsiois and Kitas 2018, Cooney et al. 2011), but there is a scarcity of information on patients' preferences for management of RA in general and the choice of non-pharmacological interventions. This information is however crucial if we wish to design tailored disease management interventions for RA patients. Therefore, this study aimed to focus on RA patients' treatment preferences and needs, taking into account patients' cultural backgrounds.

#### Methods

The total sample comprised 197 RA patients from 3 European countries (Slovakia, Grece, United Kingdom). Structured interviews were used to collect data. Eligible patients were ≥18 years old and diagnosed with RA.

#### Treatment preferences and needs

In the interview were patients asked about disease duration and sociodemographic data- age, education, and employment status. Other questions, with answers yes or no, were asking about patients' preferences and needs in treatment. Patients were asked whether they wish to have more time to spend with their rheumatologist. Another question was whether they would like to have more booklets or leaflets about RA. The next question was if they prefer receiving information about RA and its treatment online (webpage with optional chat) or in person. After that, they were asked whether they would be interested in having a physical exercise program. They were also asked whether they would be interested to have group meetings with other RA patients as an extra part of the treatment to share information and get advice about their life with RA. The last question was about their preference to have a companion (family member, friend) for meetings with rheumatologists.

#### Statistical analyses

Descriptive statistics and CIA analyses were used to identify preferences for non-pharmacological interventions in RA patients. Data were analyzed by taking into account country, gender, age, disease duration, education and employment status. We performed all analyses using the Statistical Package for the Social Sciences (IBM SPSS 23).

#### Results

A basic description of the study population is given in Table 1 (n=197). The mean age of patients was  $54.25\pm13.42$  years, the mean disease duration was  $13.96\pm10.35$  years, and 76.6% were female.

From the Rheumatology Clinic of Louis Pasteur University Hospital in Kosice, Slovakia (SK) we had 102 RA patients (51.8%). Greek RA patients were from Konstantopouleio General Hospital in Athens, Greece (GR) with a total number of 51 patients (25.9%). From Queen Elizabeth University Hospital in Glasgow, Scotland United Kingdom of Great Britain and Northern Ireland (UK), we had 44 RA patients (22.3%). There were significant differences (p≤0.05) between countries in gender, education, employment status and disease duration.

Table 2 displays patients' preferences and needs. The most preferred non-pharmacological intervention was physical exercise - 47.7% of all countries together. One-fifth (21.3%) of RA patients preferred to spend more time with their rheumatologist, but there were marked differences between the countries - with almost 50% of UK patients as compared only to 3% of Slovak patients (UK 47.5%, GR 35.3%, SK 2.9%). The preferred source of health information was books or leaflets (almost 30%) compared to searching for information online (webpage with a chat ) - 22.3%. More than half of RA patients wish to bring somebody as a companion with them when visiting the rheumatologist or attending an intervention. Only 9.% of RA patients are willing to have a group meeting with another RA patient. All in all, there were significant differences between countries in every kind of treatment option, preference for NPIs or needs ( $p \le 0.05$ ).

Female patients in the UK wanted to spend more time with their rheumatologists than male patients. Furthermore, female patients in the UK were more open to having a companion during rheumatological visits. There were no significant gender differences found in Slovakia or Greece. Slovak younger patients wished to spend more time, compared to the UK older patients. Older UK patients also preferred to have physical exercise, a booklet with information, or a webpage with chat. There was no significant difference in age and patients' preference in Greeks. Lower education was significantly associated with a preference for companions present on rheumatological visits in Greek patients.

Table 1 Description of the study population (N=197)

	All countries together	Slovakia	Greece	United Kingdom	p-value
N (%)	197 (100%)	102 (51.8%)	51 (25.9%)	44 (22.3%)	
Age (years)					
Mean±Std.Deviation	54.25±13.42	55.42±13.33	52.32±14.21	53.75±12.69	n.s.
Range	22-80	22-76	28-80	29-76	
Gender					
Female	151 (76.6%)	84 (82.4%)	32 (62.7%)	35 (79.5%)	p≤0.05
Male	46 (23.4%)	18 (17.6%)	19 (37.3%)	9 (20.5%)	
Disease duration (years)					
Mean±Std.Deviation	13.96±10.35	20.21±10.06	8.08±5.56	7.14±6.13	p≤0.05
Range	1-57	6-57	1-20	1-26	·
Education					
Elementary	14 (7.2%)	3 (3%)	11 (21.6%)	0 (0%)	
Secondary	113 (58.2%)	75 (75.8%)	32 (62.7%)	6 (13.6%)	p≤0.05
University	67 (34.5%)	21 (21.2%)	8 (15.7%)	38 (86.4%)	
Employment status					
Employed	83 (42.8%)	32 (32.3%)	30 (58.8%)	21 (47.7%)	
Unemployed/household	27 (13.9%)	2 (2%)	10 (19.6%)	15 (34.1%)	p≤0.05
Retirement/disability pension	81 (41.8%)	63 (63.6%)	10 (19.6%)	8 (18.2%)	F
Student	3 (1.5%)	2 (2%)	1 (2%)	2 (2%)	

**Table 2** Patients' preferences and needs (N=197)

	All countries together	Slovakia	Greece	United Kingdom	p-value
N (%)	197 (100%)	102 (51.8%)	51 (25.9%)	44 (22.3%)	
Longer time with rheumatologist					
Yes	42 (21.3%)	3 (2.9%)	18 (35.3%)	21 (47.7%)	p≤0.05
No	155 (78.7%)	99 (97.1%)	33 (64.7%)	23 (52.3%)	
Physical exercise					
Yes	94 (47.7%)	35 (34.3%)	16 (31.4%)	43 (97.7%)	p≤0.05
No	103 (52.3%)	67 (65.7%)	35 (68.6%)	1 (2.3%)	
Booklet or leaflet					
Yes	59 (29.9%)	41 (40.2%)	13 (25.5%)	5 (11.4%)	p≤0.05
No	138 (70.1%)	61 (59.8%)	38 (74.5%)	39 (88.6%)	
Webpage with chat					
Yes	44 (22.3%)	30 (29.4%)	11 (21.6%)	3 (6.8%)	p≤0.05
No	153 (77.7%)	72 (70.6%)	40 (78.4%)	41 (93.2%)	
Patients group meeting					
Yes	18 (9.1%)	11 (10.8%)	7 (13.7%)	0 (0%)	p≤0.05
No	179 (90.9%)	91 (89.2%)	44 (86.3%)	44 (100%)	
Companion present on the rheumatologist visits					
Yes	109 (55.3%)	59 (57.8%)	16 (31.4%)	34 (77.3%)	- 10.05
No	88 (44.7%)	43 (42.2%)	35 (68.6%)	10 (22.7%)	p≤0.05

Next, we focused on analyses of selected sociodemographic and clinical factors that might play an additional role in RA patients' treatment preferences and needs (Table 3).

**Table 3** Detailed country comparisons by sociodemographic and clinical variables (N=197)

	Slovakia	Greece	UK
Gender			
Longer time spend with the rheumatologistww	.66	.17	6.08*
Companion present on the rheumatologist visits	1.87	.42	12.44***
Age			
Longer time spend with the rheumatologist	-60.52**	32.55	31.98*
Physical exercise	34.02	39.29	44**
Booklet or leaflet	40.87	39.61	32.42*
Webpage with chat	40.58	39.8	44**
Employment Status			
Longer time spend with the rheumatologist	.93	.72	6.38*
Education			
Companion present on the rheumatologist visits	8.72	6.8*	.45

<sup>\*</sup> $p \le 0.05$ ; \*\* $p \le 0.01$ ; \*\*\* $p \le 0.001$ 

#### Discussion

This study aimed to examine country differences in RA patients' treatment preferences and needs. The results showed marked differences between SK, GR, and UK RA patients.

The longer time spent with the rheumatologist was surprisingly preferred amongst younger SK patients, however, only 3% of patients reported this preference in total in Slovakia. On the contrary, nearly half of all UK patients (48%) wanted to spend more time with their rheumatologist, of which this percentage was highest among females and older patients. As to GR patients, 35% expressed their wish to spend more time with their rheumatologist, but there were no significant differences based on sociodemographic or clinical factors. The reason why so few SK patients needed a longer time with a rheumatologist may be caused by significantly higher disease duration (on average over 20 years) compared to UK and GR patients (on average 7.5 years). Also in our sample, SK patients were from a specific group of RA patients who were all on biological treatment, so they need to visit a rheumatologist at least once per three months, which means that they are more often in contact with their rheumatologist, compared to other groups who asked for more time (Russell et al. 2008, Ogden et al. 2004). Furthermore, biological treatment is used in cases when treatment with synthetic disease-modifying antirheumatic drugs failed (Lapcevic et al. 2017), so many SK patients have years of experience with how RA works and how to manage the disease.

Physical exercise programmes, as an addition to standard treatment, were sought after by nearly half of the patients in total, with the highest percentage in UK patients (98%) compared to approximately one-third (30%) in SK and GR patients. Specifically, older age had been a significant factor in the preference for physical exercise in UK patients. To include physical exercise programmes in the standard treatment of RA may help patients to manage pain, fatigue, and other common RA symptoms (Carpenter et al. 2020, Santos et al. 2019, Metsios and Kitas 2018). As such, it is important to teach and motivate patients to be physically active; and as the results of our study show in some countries (SK, GR) they might need 'a nudge' from the health care professionals in doing so.

As to preferences of source of educational information about RA, SK patients desired to have more booklets or leaflets in the highest percentage (40%), compared to 25% in GR patients and only 11% in UK patients. In the UK, booklets and also webpage was preferred significantly only by older patients. The results are surprising because we were expecting younger patients with lower disease duration, which means those with less disease experience, to show interest, specifically in webpages with chat (Wallin et al. 2018).

The analysis of patients' interests in group meeting programmes showed that RA patients, in general, are not very much interested in these types of programmes. None of the UK patients (0%) and only 10% of SK and 14% of GR

patients expressed their interest to participate in group meetings. It is not a surprising result, because the previous studies reported group interventions with chronic patients that do not always achieve the level of the desired effects (Baranowski et al. 1997).

In total, more than half of the RA patients would like to have a companion present on the rheumatologist visits, but we can see notable differences between the countries. The UK patients wanted a companion the most, i.e. over three-quarters (77%) of the patients with significant association with the female gender. As such, it would be interesting to study more in detail the social support of family/friends in future research in the UK. In SK patients, more than half (58%) preferred to have somebody with them during the rheumatology visit. In GR only one-third (31%) wished to have a companion present, and these were specifically patients with lower education. The need for a companion can be explained by a higher disability (Carpenter et al. 2020, Santos et al. 2019), but also by a need for psychological support, especially in patients of higher age, females, and those with lower education (Wolff and Roter 2011).

To our knowledge, this is one of the first studies examining patients' treatment preferences and needs for non-pharmacological interventions. Based on the results, we found that is hard to generalize which factor is significant in the process of how RA patients choose their treatment preferences or needs. Our limitation was a small sample size of RA patients from the UK and GR. Another limitation was that we collected the data in one rheumatology clinic in each country; and as such, the generalization of the results for whole populations should be done with caution. All in all, we hope that our study can initiate more detailed research on patients' treatment preferences and needs, that can be later considered and implemented in clinical practice.

#### **Conclusions**

In many countries, the focus of RA treatment is primarily pharmacological treatment, and physicians in their daily practice prioritize biomedical approaches over the bio-psycho-social model. Our results can help future research to focus also on patients' treatment preferences and needs with consideration of patients' cultural backgrounds. We can see that patients from different countries vary significantly in their treatment preferences and needs, and it needs to be reflected when non-pharmacological interventions are tailored for RA patients. These results could benefit clinical practice by helping to adapt

non-pharmacological interventions for chronic patients in different countries taking into account also socioeconomic and cultural factors.

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# SOCIAL AND COGNITIVE FACTORS ASSOCIATED WITH SELF-ESTEEM IN PEOPLE WITH MULTIPLE SCLEROSIS

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**BACKGROUND:** Multiple sclerosis (MS) is a chronic neurological, demyelinating disease with unpredictable course. Self-esteem is often impaired as a result of various changes in central nervous system. The aim of this study is to examine associations between factors that could possibly impair or protect self-esteem.

**METHODS:** Patients (N=158) performed Trail Making test versions A and B and were subjected to Paced Auditory Serial Addition test (PASAT). Patients also filled in questionnaires focused on perceived social support and social participation. Results were controlled for age, gender, education, functional disability, and disease duration.

**RESULTS:** Variance in self-esteem was significantly associated with social participation and social support in all three models. TMT A model explained 30.7% of variance, TMT B model explained 31.9% of variance, and PASAT model explained 29.1% of variance. Beta coefficients for social support were  $\beta$ =0.35;  $\beta$ =0.34, and  $\beta$ =0.33 respectively, and coefficients for social participation were  $\beta$ =-0.42;  $\beta$ =-0.42, and  $\beta$ =-0.44 respectively.

**CONCLUSIONS:** Both cognitive (visual attention and task switching) and social factors were significantly contributing to the self-esteem in MS patients. Patient educational programs and interventions focused on management of MS should focus on cognitive as well as social factors as a way to mitigate decline in self-esteem in patients with MS.

Key words: Multiple sclerosis, self-esteem, cognitive factors, social support, social participation

#### Introduction

Multiple sclerosis (MS) is one of the most common neurological diseases diagnosed in young adults (Murray, 2006). Typical symptoms of MS include weakness, mild to severe fatigue, movement problems, and gait instability. Psychological comorbidities include often depressive symptomatology and anxiety (Hansen et al. 2005). Visual, auditory and vestibular problems are frequently observed symptoms in people with MS, as well as postural instability, vertigo and dizziness. These sensory problems may be one of the sources of cognitive dysfunction in older MS patients. Those are manifested mainly in changed brain activity patterns, lowering of reaction time and problems in task switching. (Garcia-Munoz et al. 2020; Bonzano et al. 2020). MS as a heterogenous disease manifests itself in different clinical courses between the patients. Relapsingremitting (RRMS) is the most common clinical course, while primary progressive (PPMS) and secondary progressive (SPMS) are less common. Progressive forms of MS are much more likely to show substantial cognitive impairment and disability progression, due to cortical damage (Silva et al. 2020). Similarly to other symptoms, severity and time of onset of cognitive impairment may

vary between patients and may be present very early after diagnosis, as well as decades after first symptom (Moghadasi and Saharaian, 2020).

Whether the clinical symptoms of MS are predominantly physical, mental or sensory, the strain on daily functioning, quality of life and well-being is significant (Noormohammadi et al. 2019). Help and care of physicians, or family members may improve these characteristics and elevate well-being to the general population levels (Turcotte et al. 2018), the long-term nature of MS makes providing of constant care for people affected by MS, as too demanding task for either health system or family unit. Successful self-management strategies are thus the most efficient way to keep levels of well-being and quality of life as high as possible. Good self-management depends on mix of personal and environmental factors (Ghahari et al. 2019). While factors such as physical environment, social networks and community resources can be shaped by patient's needs only in a limited way, personal factors, like self-esteem, provides patient with greater manoeuvrable space in controlling of said factor (Mikula, et al, 2018). Self-esteem is vital resource for stress management (Ifantopoulou et al. 2015), improvement of physical and

psychological health-related quality of life (Dlugonski and Motl, 2012), and controlling of fatigue, which is one of the most common symptom of MS, present in majority of patients (Fragoso, et al. 2009).

Social factors, such as social support, seem to be of equal importance as self-esteem for well-being and quality of life in chronically ill people. Ability to maintain social relationships, join social and daily activities of peers, friends and family, is important predictor of these variables. Good levels of social support have also impact on heath functioning (Koutsogeorgou, et al. 2019). Some authors consider social support a key interventional target for optimizing patient care (Henry, et al. 2019). Symptoms of MS, including cognitive impairment and functional disability, social support, sociodemographic variables and self-esteem are interconnected in a complex way. The aim of the study is thus to examine associations between factors that could possibly impair or protect self-esteem, such as level of cognitive and motor impairment, and social support. Self-esteem was chosen as dependent variable, because it is variable most easily implemented into intervention programs out of those under study.

#### Methods

#### **Participants**

Out of 184 patients who met the McDonald criteria for diagnosis of MS (Polman, et al. 2005) were asked to participate in the study, 26 refused to participate (19 women and 7 men; response rate 85.8%). Data collection was carried out at the Neurology Department of the L. Pasteur University Hospital in Košice, Slovakia. Gender distribution of the sample was in line with general prevalence of MS (74.1% women). Mean age of the sample was 40.12±9.75 years. There were no statistically significant differences between respondents and non-respondents in terms of gender and age.

#### Procedure

This cross-sectional study consisted of a self-reported questionnaire, a semi-structured interview and a neurological examination. The invitation letter, the written informed consent form, the non-response sheet and the questionnaires were sent to participants' homes by postal mail. People in the study sample were reminded about the questionnaire by a phone call two weeks later. During this phone call, the interview and neurological examination were arranged. The same neurologist carried out the neurological examinations on all participants and a trained

interviewer conducted the semi-structured interview, acquiring information on age, gender, education and disease duration among other variables. Besides the interview, patients also underwent series of cognitive tests under the supervision of trained interviewer. Examinations took place at the Neurology Outpatient Clinic.

The local Ethics Committee approved the study in advance. Each person provided a signed informed consent to participate prior to the study.

#### Measures

#### Sociodemographic and clinical variables

Data on age, gender and education were retrieved via the interview. Information on disease duration were retrieved from medical records. Level of functional disability was measured by Expanded Disability Status Scale (EDSS) with score range from 0.0 to 10.0, with higher score indicating more severe disability (Kurtzke, 1983). This variable was assessed by a trained neurologist on the day of the interview.

#### Self-esteem

Self-esteem was measured using the Rosenberg Self-Esteem Scale (RSE) (Rosenberg, 1965). It consists of 10 items assessing global self-esteem. Examples of items include: "On the whole, I am satisfied with myself", or "At times I think I am no good at all". Five items are worded negatively and 5 positively in order to avoid response set; responses are then recoded during analysis. The score ranges from 10 to 40, with a higher number indicating a higher level of self-esteem. In our study self-esteem was treated as a continuous variable.

#### Social support

Social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS), which was designed to assess subjective perception of social support received from various sources like significant other, family, or friends (Zimet et al. 1998). The MSPSS is a 12-item questionnaire, with responses to the questions ranging from 1 to 7 on a Likert scale. The higher number indicates higher perceived social support in all of the items.

#### Social participation

This variable was measured using the Participation scale (P-scale). It includes 18 items and its use is intended for people in stigmatised or chronic conditions (Van Brakel, 2006). Each item includes two questions. The first question goes into some aspect of social participation in comparison with one's peers, for example: "Do you take part in as many casual recreational/social activities as your

peers?" If participants answer "Yes" or "Irrelevant\I don't want to, I don't have to" their answer is scored 0. If the answer is "Sometimes" or "No", the next question is: "How big a problem is this for you?" Participants then choose from four options: "No problem", "Small", "Medium" or "Large", which are scored 1, 2, 3 or 5, respectively. The summary score can range from 0 to 90; with a higher score indicating more restriction in social participation. (Van Brakel, 2006).

#### Cognitive functioning

Cognitive functions of people with MS were assessed by two tests: Paced Auditory Serial Addition Test (PASAT) and Trail Making Test versions A and B (TMT A, TMT B). PASAT is an auditory test focused on adding of numbers by patient in regular pace. This test measures speed and flexibility of processing of auditory information, as well as basic mathematical abilities. Version for MS patients

was adapted by Rao et al. (1989). During this test, patients listen to the series of numbers and their task is to add up currently heard number with the one administered before it. The interval between the numbers is 3 seconds. The final score ranges from 0 to 60, with higher number indicating better cognitive functioning (Rao et al. 1989).

TMT measures attention, psychomotor speed and visual search capability. TMT A contains 25 numerals randomly placed on a sheet of paper. The patient tries to combine these numerals from number 1 to number 2 up to 25 as quickly as possible. The time is measured in seconds. TMT B is made more complicated by adding letters, with the task being modified to switching between numbers and letters. The trail goes thus from 1 to letter A, continues to number 2, after that to letter B and so on (Bezdicek et al. 2012).

**Table 1** Results of linear regression models analyses

Model	Beta	Adjusted R <sup>2</sup>	F	Sig.
Model PASAT	20	0.29	5.57*	0.00
Age	0.18	0.2		
Gender	-0.04			
Education	-0.03			
EDSS	-0.06			
Disease duration	0.09			
PASAT	0.15			
Participation	-0.44*			
Social support	0.33*			
Model TMT A		0.30	5.93*	0.00
Age	0.17			
Gender	-0.02			
Education	-0.02			
EDSS	0.03			
Disease duration	0.07			
TMTA	-0.21*			
Participation	-0.42*			
Social support	0.35*			
Model TMT B		0.31	6.20*	0.00
Age	0.21*			
Gender	-0.02			
Education	-0.03			
EDSS	0.00			
Disease duration	0.08			
TMT B	-0.24*			
Participation	-0.42*			
Social support	0.34*			

<sup>\*</sup>p<0.05; PASAT - Paced Auditory Serial Addition Test; TMT - Trail Making Test; EDSS - Expanded Disability Status Scale

#### Statistical analyses

To assess the associations between self-esteem and models consisting of sociodemographic, clinical, psychological and cognitive measures, we used linear regression modelling. Total of three models were assessed, differing in cognitive test that was used. The statistical analyses were performed in program IBM SPSS 23.0.

#### Results

The statistical analyses showed that self-esteem was in the sample of patients with multiple sclerosis associated with result of Trail Making Test version A and Trail Making Test version B. PASAT, another cognitive test under study, was not significantly associated with self-esteem. Social factors (social participation and social support) have shown significant association with self-esteem in all three analysed models and the significance did not fluctuate depending on the type of cognitive test used in the model. The models explained 29%, 30% and 31% respectively of the self-esteem variance. The results of linear regression analyses are shown in Table 1.

#### Discussion

Based on the statistical analyses we conclude that self-esteem was in our sample associated with psychomotor speed, attention and visual search capability as measured by two versions of TMT test. Other tested cognitive functions of processing auditory information, do not seem to be associated with self-esteem. The reason for this may lie in mathematical nature of the test, where not psychological variables, but rather mathematical prowess and calculus experience could factor in the test results (Sandry et al. 2016). While the research in the field of psychological variables and cognitive functioning in people with chronic conditions is scarce, some studies found correlations between psychomotor speed and visual attention in such populations, like in the case of health related quality of life or depression (Park and Larson, 2015; Nie et al. 2019). The link between these cognitive variables and self-esteem is possibly useful for disease management and rehabilitation, as self-esteem seems to be affected by variety of interventions and can be thus improved, which may lead to partial improvements in cognitive functioning by enabling people to use their cognitive abilities to full potential (Saita and Acquati, 2020; Matsuguma et al. 2019; Richard et al. 2019).

According to our results, it also seems that the ability to seek and maintain social relationships and to participate in

social and daily activities is important for the self-esteem in people with MS. Social support and social participation yielded similar results in number of studies focused on health-related quality of life, well-being and similar psychological concepts (Koutsegeorgou et al. 2019; Henry et al. 46-51). Being able to draw support from family, friends, and significant other may build self-esteem of chronically ill people by convincing them, that they are worth of love and care, which in turn enables them to reciprocate social support and leads to positive mental health outcomes (Koelmel et al. 2017). Social participation similarly seems to be enabling factor to build self-esteem upon. Ability to socialize may provide feedback to patients that they are still able to be part of wider society and that limitations of the disease can be managed (Mikula et al. 2017).

#### **Conclusions**

Our results can be utilized in patient education by either physicians, nurses or psychologists as part of individual or group psychotherapy. Changes in self-esteem could be possibly achieved by focusing on enabling and encouraging social support and social participation in patients and their caregivers. The association between self-esteem and cognitive functions of visual attention and task switching could be also possibly modified by focusing on self-esteem, but causality of this association cannot be inferred without analysing longitudinal data. Thus the future research should focus on longitudinal analyses to determine causality of the associations.

#### Strengths and limitations

Since the MS affects women twice as often as men, results of this study apply more to women, since our sample reflected this fact. Another limitation is the nature of PASAT, where the mathematical abilities may play a role in determining the result of the test, even though the mathematical operations the patient has to perform are relatively simple (Sandry, et al. 2016).

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# A LIFE COURSE AND MULTIFACTORIAL APPROACH TO DEMENTIA PREVENTION

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**BACKGROUND:** In 2018, 50 million people lived with dementia and it is predicted its triple by 2050 worldwide. Dementia is likely to be a clinically silent syndrome that begins at midlife, and currently includes more than 100 types. The cognitive dysfunction, behavioural and psychological symptoms present devastating experience for patients, their families and other carers, as well as a whole society. The aim is to provide an overview on the latest recommendations for dementia prevention in a life-course perspective.

**METHODS:** Narrative review based on existing available evidence was done. Since 2006, three large studies were carried out in Europe including 6400 participants. A common benefit of these studies is the proposal of conditions for the implementation of the randomised controlled trials.

**RESULTS:** If pharmacological, psycho-social, and environmental interventions are implemented, people with dementia optimise their cognition, reduce agitation, depression or psychotic symptoms, and their carers' burden is reduced. Effective services should be available, scalable, and give value.

**CONCLUSIONS:** Recognised potentially modifiable factors present 35 % of all risk factors related to dementia and need to be tackled from early, through middle to late life period. The current estimates suggest that even a delay in onset of 1 year could prevent more than 9 million cases of dementia by 2050.

Key words: dementia, life-course approach, prevention, public health

#### Introduction

Worldwide, 50 million people live with dementia and it is predicted to triple by 2050 (ADI 2018). Dementia as a syndrome caused by a brain disorder currently includes more than 100 disorders. Alzheimer's disease (AD), being the most common form of dementia, is present in 50-60 % of all cases. Other forms of dementia (D) include, for example, vascular dementia, dementia with Lewy bodies, frontotemporal dementia, mixed dementia, and Parkinson's disease (ADI, 2018). The cognitive dysfunction, behavioural and psychological symptoms are huge burden not only for the patient, but as well as for informal and formal caregivers and for their community and society as a whole.

#### Risk and protective factors of dementia

At the forefront of scientific research on dementia there are factors that increase the risk of dementia (risk factors) and also factors that reduce its risk (protective factors). Currently, two major risk factors of AD are well recognized. These are age and specific genetic predisposition

and other potentially modifiable factors (Mistridis et al. 2017). Anstey et al. (2015) provided a detailed overview of about 25 risk and protective factors related to AD and dementia of various aetiologies and divided them into six areas - biomarkers, demographic factors, lifestyle, medical factors, pharmaceuticals, and the environment:

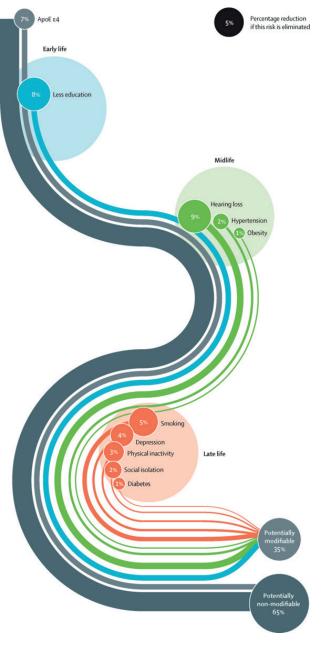
- 1. Biomarkers gene APOE  $\epsilon 4$  status has been found to be associated with high risk of late-onset AD (Wright et al. 2009).
- 2. Demographic characteristics age (the risk of AD and D strongly increases with the age), gender (in most countries of the world, the risk of AD and D is higher for women than for men), education (a low level of formal education increases the risk of AD and D), and ethnicity/race (it appears that for some race and ethnic groups there is a higher probability of selected risk factors associated with AD and D).
- Behavioural characteristics physical activity individuals with a physically active lifestyle are exposed to lower cognitive decline, decreased atrophy of the

brain and increased volume of hippocampus as compared to those with sedentary behaviour (Mistridis et al. 2017); diet - reduces the risk of AD and D to a certain extent. Mediterranean diet with a relatively low proportion of red meat, with an emphasis on whole grains, fruits and vegetables, fish, nuts and olive oil, or a combination of Mediterranean diet and a diet reducing hypertension, are supposed to reduce the risk of developing AD and D (Baumgart et al. 2015). Studies also have consistently demonstrated the relationship of low alcohol intake with the reduction of AD and D (Anstey et al. 2015); smoking - increases the risk of cognitive decline and, eventually, dementia. Quitting smoking may reduce the risk of developing AD and D to the level of those who do not smoke. A large multi-ethnic cohort study found that middle-aged heavy smoking doubled the risk of dementia at a later stage of life (Baumgart et al. 2015); cognitive activities - participation in cognitive stimulation activities (such as reading, playing puzzles, visiting museums and concerts) is related to reducing the risk of AD and D. The extent and type of cognitive activity is not reliably proven. For typical and normal aging, it is necessary to focus on reducing the risks and increasing protective behaviour, whereas for pre-clinical dementia or mild cognitive impairment it is important to focus on urgent risk control and reduction of modifiable health and behavioural risks (Anstey et al. 2015); and social engagement - a higher degree of social engagement, including family relationships, environmental adaptation, wider social networks, and sufficient number of different social interactions are related to reducing the risk of AD and D (Anstey et al. 2015).

- 4. Medical domain hypertension/hypotension, atrial fibrillation, stroke, diabetes and pre-diabetes, weight, cholesterol, traumatic brain injury, depression, and homocysteine 9 (Anstey et al. 2015).
- 5. Medications statins, anti-hypertensive, anti-inflammatory drugs, hormonal replacement therapy, and anticholinergics (Anstey et al. 2015).
- 6. Environment pesticides and air-pollution (Anstey et al. 2015).

#### Prevention and treatment of dementia

Preventive strategies and effective treatment of dementia is the greatest global challenge for health and social care in the 21<sup>st</sup> century. The WHO vision set out in the *Global Action Plan on Public Health Response for Dementia for 2017-2025* is aimed at a world in which dementia is prevented and people with dementia and their caregivers live well and receive the care and support they need, in order to fulfil their potential with dignity, respect, autonomy, and equality (WHO 2017).



**Figure 1** Life course model of contribution of modifiable risk factors to dementia. Source: Livingston et al. 2017

The evidence-based findings presented in several systematic reviews (Mistridis et al. 2017, Baumgart et al. 2015, Anstey et al. 2014) point to the currently unsuccessful treatment of dementia based on pharmacological medication and the importance of secondary prevention in relation to dementia. More than a third of cases of dementia might be prevented by nine potentially modifiable risk factors (Figure 1): less education in early life, hearing loss, hypertension, obesity in midlife, smoking, depression, physical inactivity, social isolation and diabetes in late life (Livingston et al., 2017). The aim of the paper is to present the newest evidence-based recommendations for prevention and care in a life course approach of dementia in the field of public health.

#### Methods

Narrative review based on existing available evidence based findings was carried out in June to August 2019. Since 2006, we identified in PubMed database three large-scale multi-component preventive intervention studies, which were carried out in Europe and included 6400 participants.

#### **Results**

MAPT (Multi-domain Alzheimer's Preventive Experiment) has been proposed as an approach to study the effect of isolated omega-3 fatty acid supplementation, isolated multi-disciplinary intervention (consisting of nutritional counselling, physical exercise, and cognitive stimulation) or a combination of two interventions to change the cognitive functions of a frailty subject over 70 years during the period of 3 years (Andrieu et al., 2017).

The goal of the Dutch PreDIVA study (Prevention of Dementia by Intensive Vascular Care) was to reduce the vascular risk factors in dementia prevention in a 6-year multidisciplinary, nurse-led randomized controlled trial (RCT) carried out in primary care settings with a total of 3,526 participants aged 70-78 years. Smoking, nutrition, physical activity, weight, and blood pressure were monitored and individual counselling was provided according to the protocol, supported by motivational interviewing (van Charante et al., 2016).

FINGER (Finnish Geriatric Intervention Study on the Prevention of Cognitive Impairment and Disability), in which more than 1,200 participants (aged 60-77 years) received either multimodal intervention (cognitive training, exercise, nutrition, and monitoring of vascular risk) or general health counselling. The participants were subjects

at high risk of dementia and their cognitive performance was slightly lower than that expected for their age. The intervention was acceptable and safe and had positive results in primary outcomes: a small but beneficial effect on cognitive function was recorded already after 2 years after the intensive multi-domain intervention was performed in the group (Ngandu et al., 2015).

A common benefit of these large studies is the proposal for conditions for the implementation of the randomised controlled trials (Table 1).

#### Behavioural and psychosocial interventions

The goal of AD and D treatment is optimal psychological and physical well-being and the highest quality of social relationships despite the irreversible and progressive limitation of cognitive performance and daily living competencies (Kurz 2013). According to Finkel et al. (1996), two major groups of symptoms of dementia are recognized, they are namely symptoms of cognitive dysfunction and behavioural and psychological symptoms. 97 % of people with dementia suffer from behavioural and psychological manifestations of dementia. In their treatment, there is an increase in disability, premature institutionalization, increased financial costs, and burden on caregivers (IPA 2012).

Psychosocial intervention based on psychological or social-psychiatric mechanisms of action significantly complements the pharmacological treatment of dementia. Individual forms of psychosocial interventions in dementia seek to achieve the stated goal in various ways. Cognitive stimulation and cognitive training improve cognitive performance. To enhance emotional well-being, psychoeducation patient groups, planned activities, reminiscence therapy, validation and self-sustaining therapy has been reported to be beneficial. To alleviate behavioural symptoms, the interventions may be focused on behavioural management, snoezelen, aromatherapy, music therapy, simulated posture and pet therapy. Cognitive therapy and occupational therapies reduce functional abilities in everyday life (Kurz 2013). People with dementia are usually older than 65 years, often with co-morbidities, so they may also need help in coping with these co-occurring diseases (Livingston et al. 2017).

#### Dementia as a burden not only for the patient

Dementia is a burden not only for patients, but also for those who are involved in their care. Many of social services to reduce burden, improving the quality of their lives, and support of caregivers to provide domestic care for as long as possible (Etters et al. 2008). Factors influence

**Table 1** Proposal for conditions for future dementia prevention trials.

Target population	Age: 50-70 year community-based no significant cognitive impairment few exclusion criteria select subjects at increased risk
Intervention	Multi-component, pragmatic combined pharmacological and non-pharmacological flexible (different countries) adapt to population
Design	Randomised controlled trial randomised individuals or clusters open, single-blind, or double-blind
Primary outcome measure	Time to onset of dementia cognitive decline handicap or disability
Secondary outcome measure	Cognitive decline cardiovascular disease cardiovascular risk factors surrogate endpoints (biomarkers, imaging parameters) depression quality of life utilisation of health resources
Duration of intervention	Realistic: 4-8 years open-label extension possible
Duration of follow-up	4-8 years delayed outcome assessment for primary outcome can be several years after intervention has finished.

Source: Richard et al. 2012.

the experience of informal caregivers such as gender, relationship to the patient, culture, and personality characteristics. The aim of eliminating their burden is the availability of respite care. To live in a home environment prevents social isolation, because the loneliness leads to the progression of dementia. Many countries therefore strongly support community care focussed on care coordination after establishing the diagnosis, outpatient social services, long-term community care, and support for dementia-friendly communities (OECD 2018).

The desire to keep a family member or friend at home, proximity to a person with dementia, and duty to take care of a partner is the motivation for care by informal caregivers. Care is a huge challenge, especially in the areas of emotional and social wellbeing, physical health and employment (Alzheimer's Association 2017). Psychoeducation, relief strategies, and multi-component programs for informal caregivers represent three forms of psychosocial intervention (Kurz 2013). Prince et al. (2016) highlight the need for training, mentoring, and support for primary caregivers by professionals.

On the other hand, the level of health and long-term residential social services for people with advanced dementia

is low in many countries of the world. There are gaps in the knowledge of dementia among professionals regarding managing the behavioural and psychological symptoms of dementia. Graduate education and basic caregiving courses do not prepare sufficiently formal caregivers for the challenges of care for people with dementia. The 2018 OECD publication reports about innovative programs focusing on dementia, stress management, and prevention of burnout syndrome. Some, for example, are graded in terms of the level of education they have achieved and are suitable for all relevant care providers, especially professionals (nurses, social workers, caregivers, etc.) who come into contact with people with dementia (OECD 2018). A collaborative care model, which includes geriatricians, psychiatrists, nurses, health care assistants, can improve care coordination and prevent the hospitalization of people with dementia (Alzheimer's Association 2017).

#### Discussion

The study aimed to provide an overview of the latest recommendations for dementia prevention from a lifecourse perspective. Our main findings shed more light on two areas: i) future preventive interventions based on the modifiable risk factors for dementia in a life course, as well as ii) future research on the effectiveness of applied public health interventions.

The development of the criteria for the implementation of randomised controlled trials is a common benefit of largescale studies, such as those of Andrieu et al. (2017), van Charante et al. (2016), and Ngandu et al. (2015). Future research on dementia risk reduction should apply a multi-domain life-course approach and implementation of public health practices that enhance the brain health of entire communities (Anstey et al. 2020). Multi-component interventions usually combine two or more types of interventions with moderately positive evidence. Although, the debate about which components and in what combination are the most effective is still ongoing (Jackson & Browne 2017). On the other hand, lifestyle intervention trials focussed on one component such as physical activity or cognitive training, etc. have shown modest or short-term results (Solomon et al. 2015). Based on our findings, the relevant target population should be in range from 50 to 70 years according (Richard et al. 2012). However, the results of other authors point to the need for intervention from an early age and with a focus on specific topics. For example, in childhood it should be linked to 'de-stigmatizing dementia' or 'laying the foundation to dementia-friendly communities' (Baker et al. 2018) and in adult population trainings on 'person-centred care', 'communication', 'interaction and behaviour in dementia care, and 'dementia awareness' (Smith et al. 2019; Weiss et al. 2020).

In the domain of dementia prevention, low educational level achieved in childhood, hearing loss, hypertension, obesity, smoking, depression physical inactivity, social isolation, and diabetes present nine potentially modifiable risk factors at different stages of life. If these risk factors are eliminated or diminished, more than a third of cases of dementia in particular in older age might be prevented (Livingston et al. 2017). For example, at age 60, more frequent social contact was associated with lower dementia risk. The association between dementia incidence and social contact was driven significantly by contact with friends, and no association was found for contact with relatives (Sommerland et al. 2019).

Within the primary prevention, based on identified risk factors and risk reduction, cardiovascular risk factors are emphasized. Ongoing secondary prevention strategies for AD (Crous-Bou et al. 2017) and related dementias are based on early detection of the disease's symptoms and preclinical stage intervention.

Studies however also report that there are people with neurological brain changes who do not show symptoms of dementia (Holmerova 2018). This supports the importance of cognitive reserve concept in public health interventions. Cognitive reserve represents a certain characteristic of a given person, his resistance to the deterioration of cognitive functions. Cognitive reserve is also possible to influence with a lifestyle. If pharmacological, psychosocial, and environmental interventions are implemented, people with dementia will optimise their cognition, reduced agitation, depression or psychotic symptoms, and this will also lead to reduced burden in their caregivers (Richard et al. 2012, Livingston et al. 2017). Using of cognitive reserve based concept may also affect the onset of dementia.

#### **Conclusions**

Preventive public health services for tackling dementia should be available, scalable, and value-based. Professionals need to implement interventions that work and stop using interventions are ineffective. The multiple role of public health is manifested mainly in reduction of risk factors related to dementia and in raising awareness of evidence-based protective factors. Potentially modifiable factors present 35% of all risk factors and are applicable in a life-course perspective - from early life, through midlife and in late life phase. Pushing back the age of dementia onset would bring enormous benefits. It is estimated that even 1 year delay in onset could prevent more than 9 million cases of dementia by 2050.

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### INTIMATE AND SEXUAL FUNCTIONING IN MALE PATIENTS WITH OBSTRUCTIVE SLEEP APNOEA: THE ROLE OF MASTERY

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**BACKGROUND:** Sexual dysfunction represents common but under-recognised and untreated symptom of Obstructive Sleep Apnoea (OSA). The aim of this study was to assess whether mastery is associated with intimate and sexual functioning in male OSA patients when controlled for age, body mass index, OSA severity, sleep-related problems, and psychological distress.

**METHODS:** We included 98 male OSA patients (Apnoea-Hypopnoea Index  $\geq$  5; mean age 47.5 $\pm$ 9.5 years). All patients completed the Pittsburgh Sleep Quality Index, the Epworth Sleepiness Scale, the Beck Anxiety Inventory, the General Health Questionnaire-28, the Pearlin Mastery Scale, and the Functional Outcomes of Sleep Questionnaire focused on assessing intimate and sexual relationships. Multiple linear regressions were used to analyse data.

**RESULTS**: Mastery was found to be positively associated with intimate and sexual relationships when controlled for sociodemographic, clinical, and sleep-related variables ( $p \le 0.01$ ), anxiety, and severe depression (p < 0.05). No association between mastery and intimate and sexual functioning was found when controlled for somatic symptoms of emotional distress (p = 0.06) and social dysfunction (p = 0.69).

**CONCLUSIONS:** Enhancement of mastery over ones' life and circumstances may help to optimize intimate and sexual relationships in male OSA patients with sleep-related problems, anxiety, and severe depression. However, mastery may not be adaptive in patients suffering from somatic symptoms and social dysfunction.

Key words: obstructive sleep apnoea, psychological distress, mastery, intimate and sexual functioning

#### Introduction

Obstructive sleep apnoea (OSA) is a lifelong sleep-related breathing disorder characterised by numerous symptoms and clinical featurs ranging from snoring, breathing pauses, frequent awakenings, fatigue, daytime sleepiness to depressive symptomatology, personality changes, or heart disease (Manarino et al. 2012). Sexual dysfunction represents common but under-recognised and untreated symptom of OSA. OSA patients often complain of poor libido or erectile dysfunction (Liu et al. 2015, Walker 2017, Tramonti et al. 2017; Skoczyński et al. 2019, Andersen & Tufik 2020).

Continuous positive airway pressure (CPAP) treatment may be efficient in diminishing impaired sexual functioning in OSA patients (Zhang et al. 2016). However, despite the acceptance of CPAP as a standard OSA treatment, it may not aliviate all symptoms related to sexual dysfunction (Steinke et al. 2016, Pascual et al. 2018). Some recent studies could not determine conclusively whether CPAP is an effective stand-alone erectile dysfunction treatment

(Pascual et al. 2018), or is able to improve sexual desire in men (Steinke et al. 2016). Therefore, personalization of the OSA treatment (Martinez-Garcia et al. 2019), which includes treatment of impaired sexual functioning becomes important in current clinical practice.

Mastery over ones' life and circumstances refers to the belief about an individual's own ability to mitigate the adverseness of an event. It is conceptualized as the extent to which a person perceives himself/herself to be in control of events and everyday situations and reflects the perception of his/her ability to manage them (Pearlin & Scholer 1987). This strong feeling of control is important for psychological adjustment. Mastery has also been shown to facilitate adaptation under stressful life situations, including chronic conditions. Mastery may be associated with better pain and fatique management (Kurtz et al. 2008), higher level of overall health (Gallagher et al. 2019), lower level psychological distress (Nicolaisen et al. 2018, Gallagher et al. 2019), better functional status in OSA patients (Timkova et al. 2018), or improved sexual outcomes in cancer survivors (Tang et al. 2010).

However, so far, little is known about the association between mastery and sexual outcomes in OSA. Thus, the aim of this study was to assess whether mastery is associated with intimate and sexual functioning in male OSA patients when controlled for age, body mass index, OSA severity, sleep-related problems, and psychological distress.

#### Methods

#### Study design and setting

This cross-sectional study was conducted at the Department of Pneumology and Phtiseology, L. Pasteur University Hospital and the Medical Faculty of PJ Safarik University in Kosice, Slovak Republic. All patients who visited the Department for one-night polysomnography (PSG) between July 2013 and August 2016 and underwent PSG were eligible for the study. Each patient completed and signed an informed consent form prior to their participation in the study, which was fully voluntary and included no incentives for participation. The study was approved by the Ethics Committee of PJ Safarik University in Kosice (approval no. 115/2011).

#### Sample and procedure

Indication for PSG was based on a general practitioner referral form. OSA was diagnosed based on an overnight sleep examination conducted by a pulmonologist specialized in sleep-disordered breathing. Only male patients with OSA between 18 and 65 years of age were included due to possible functional changes, increased vulnerability and decline in abilities and performance related to age and gender specific issues. The study sample comprised patients with an Apnoea Hypopnoea Index (AHI; number of apnoeas+ hypopnoeas per hour of sleep) score of 5 or more (American Academy of Sleep Medicine, 2005), who had no previous CPAP therapy or other OSA treatment, were Slovak-speaking and had no major comorbidities. Out of 185 eligible male patients, 31 patients who underwent PSG refused to participate in the study, yielding a total response of 83.0%. Another 56 participants were excluded because of major comorbidities such as coexisting sleep-related disorder, cardiovascular diseases, pulmonary conditions, a history of cancer in the past twelve months, major psychological and neurological comorbidities in the medical record, and/or current usage of medications which may have effect on cognitive functioning. Screening for comorbidities was based on medical data and an initial clinical interview prior to data collection. Patients filled out self-report questionnaires at home.

#### Variables and measures

#### **Functional status**

Intimate and sexual functioning was assessed using the 4-item Functional Outcomes of Sleep Questionnaire (FOSQ) subscale (Weaver et al. 1997). To assess the level of intimate and sexual functioning, responses are averaged (excluding missing responses) to create a subscale score of 1 to 4, with higher scores indicating less effect of sleepiness on intimate relationships and sexual functioning. In our sample, Cronbach's alpha was 0.92.

#### Mastery

Mastery was measured using the Pearlin Mastery Scale (PMS) (Pearlin & Schooler 1987). The PMS scale includes 7 items that measure an individual's level of mastery, a psychological resource that has been defined as "the extent to which one regards one's life-chances as being under one's own control in contrast to being fatalistically ruled". The two negatively-worded items require reverse coding prior to scoring, resulting in a score range of 7 to 35, with higher scores indicating higher levels of mastery (Pearlin & Schooler, 1987). In our sample, Cronbach's alpha was 0.84.

#### Sleep-related problems

Sleep-related problems concerned night-time sleep quality and daytime sleepiness. *Night-time sleep quality* was measured using the Pittsburgh Sleep Quality Index (PSQI) (Buysse et al., 1989). The PSQI is a self-rated questionnaire to assess sleep quality and disturbances over a one month. The PSQI consists of 19 self-report questions. The overall score ranges from 0 to 21, with higher scores reflecting poor night-time sleep quality. Cronbach's alpha in our sample was 0.70.

Daytime sleepiness was measured using the self-report Epworth Sleepiness Scale (ESS), an eight-item question-naire assessing the tendency to fall asleep in various day-time scenarios. The score ranges from 0 to 24, with higher scores indicating greater daytime sleepiness. An ESS total score greater than 10 indicates excessive daytime sleepiness (Miletin & Hanly, 2003). Cronbach's alpha in our sample was 0.82.

#### Psychological distress

Psychological distress was measured using the General Health Questionnaire (GHQ-28) (Goldberg & Hillier 1979). The GHQ-28 was developed as a screening tool to detect those likely to be at risk of developing psychiatric disorders. To assess psychological distress we used a three separate GHQ-28 scales: somatic symptoms (items 1–7);

social dysfunction (items 15–21) and severe depression (items 22–28). Higher scores indicate a higher level of psychological distress. Cronbach's alpha in our sample was 0.84 for severe depression, 0.80 for somatic symptoms, 0.89 for social dysfunction. Anxiety was measured using the Beck Anxiety Inventory (BAI), which consists of 21 items defining the most common anxiety symptoms (Steer & Beck 1997). Scores range from 0 to 63, with higher scores indicating a higher anxiety level. Cronbach's alpha in our sample was 0.88.

#### Sociodemographic and clinical data

Information on age and marital status was obtained from patient records. The Body Mass Index (BMI; height and weight) was assessed by a health-care professional. PSG was used to determine whether the diagnosis of OSA was present and to identify the severity of the disorder. PSG consists of a simultaneous recording of multiple physiological parameters related to sleep and wakefulness, which directly monitor and quantify the number of respiratory events, related hypoxemia and arousals. OSA severity was determined using PSG and was based on an AHI (number of apnoeas + hypopnoeas per hour of sleep) score of 5 or more, according to standard criteria (American Academy of Sleep Medicine 2005).

#### Statistical analyses

All analyses were performed using the Statistical Package for the Social Sciences (IBM SPSS 23). Firstly we described the background characteristics of the sample and calculated means and standard deviations. Secondly, multiple linear regressions were used to examine the associations between mastery and intimate and sexual functioning, controlled for sociodemographic and clinical variables, anxiety, depressive symptoms, somatic symptoms, and social dysfunction. Using regression analyses we assessed the crude effects (i.e. associations unadjusted for the number of predictors) of each variable separately on intimacy and sexual functioning, and then we continued with multiple regression analyses. We applied the enter method in linear regression to identify the factors associated with summary scores of intimacy and sexual functioning. Multicolinearity was assessed using the variance inflation factor (VIF $\leq 2.0$ ).

#### Results

#### Sample characteristics

The mean age of participants was 47.5±9.5 years. The majority of patients had secondary education (52%) and had

a partner (71%). The mean score for intimate and sexual functioning was  $2.9\pm1.10$  (Table 1).

**Table 1** Baseline characteristics of the male patients with OSA with AHI  $\geq 5$  (N=98)

Characteristics	n (%)/ Mean±SD
Age in years	47±9.5 (27-65)
Marital status; single	28 (28.9%)
Education	
Elementary	3 (3.1%)
Secondary	51 (52.0%)
University	44 (44.9%)
Body Mass Index	30.65±7.9
Apnoea-hypopnoea index (AHI) in events/h	34.54±21.11
Night-time sleep quality (PSQI; 0-21)	9.06±4.17
Excessive daytime sleepiness (ESS; 0-24)	10.30±5.00
Anxiety (BAI; 0-63)	28.84±19.97
Severe depression (GHQ-28; 0-21)	4.89±3.88
Somatic symptoms (GHO-28; 0-21)	8.81±5.10
Social dysfunction (GHQ-28; 0-21)	9.16±3.95
Mastery (PMS; 7-35)	20.92±4.52
Intimacy and sexual functioning (FOSQ; 1-4)	2.90±1.10

AHI – Apnoea-Hypopnoea Index; OSA – Obstructive Sleep Apnoea; PSQI – Pittsburgh Sleep Quality Index; ESS – Epworth Sleepiness Scale; PMS – Pearlin Mastery Scale; FOSQ – Functional Outcomes of Sleep Questionnaire; Missing values: AHI (1.0%), age (1.0%), ESS (1.0%), PSQI (1.0%), social dysfunction GHO-28 (1.0%), severe depression GHO-28 (2.0%), somatic symptoms GHQ-28 (4.0%), mastery (1.0%).

#### Multiple linear regression

Multiple linear regression showed that mastery was found to be positively associated with intimate and sexual functioning when controlled for sociodemographic, clinical, and sleep-related variables (p $\leq$ 0.01), anxiety (p<0.05) and severe depression (p<0.05). No association between mastery and intimate and sexual functioning was found when controlled for somatic symptoms (p=0.06) and social dysfunction (p=0.69). We also found that social dysfunction was associated with poor intimate and sexual functioning in male OSA patients the most strongly (Table 2).

**Table 2** Mastery regressed on intimate and sexual functioning (FOSQ); controlled for age, body mass index, OSA severity, sleep-related problems, and psychological distress (N=98)

	Crude	Model a	Model b	Model c	Model d	Model e
Age	-0.01	-0.04	-0.06	-0.12	-0.05	-0.06
Body mass index	-0.03	0.15	0.16	0.14	0.13	0.10
OSA severity	-0.19	-0.24*	-0.22*	-0.15	-0.22*	-0.21*
Sleep quality	-0.51***	-0.45***	-0.37***	-0.24*	-0.32**	-0.18
Daytime sleepiness	-0.31**	-0.23*	-0.19*	-0.20*	-0.16	-0.12
Anxiety	-0.43***		-0.25**			
Severe depression	-0.62***		-	-0.35**		-
Somatic symptoms	-0.54***	-	-		-0.30**	
Social dysfunction	-0.67***		-			-0.49***
Mastery	0.39**	0.23**	0.17*	0.18*	0.16	0.09
F change		7.96**	4.62*	4.53*	3.54	1.34
Adjuster R <sup>2</sup>		0.47	0.51	0.52	0.50	0.55

Displayed values are beta coefficients. FOSQ:Functional Outcomes of Sleep Questionnaire; OSA: Obstructive Sleep Apnoea; BMI: body mass index; F Change: significance of prediction improvement in model fit; Adjusted R<sup>2</sup>: explained variance adjusted for the number of predictors in the particular model; Crude: effect of each variable separately on functional status; Beta: standardized regression coefficient; Model a: effect of age, BMI, OSA severity, sleep quality and daytime sleepiness on intimate and sexual relationships; Model b: effect of age, BMI, OSA severity, sleep quality, daytime sleepiness, anxiety and mastery on intimate and sexual relationships; Model c: effect of age, BMI, OSA severity, sleep quality, daytime sleepiness, somatic symptoms of psychological distress and mastery on intimate and sexual relationships; Model e: effect of age, BMI, OSA severity, sleep quality, daytime sleepiness, social dysfunction and mastery on intimate and sexual relationships; FOSQ: higher score indicates higher intimate and sexual functioning; \*p<0.05; \*\*p≤0.01; \*\*\*p≤0.001.

#### **Discussion**

We found that mastery over ones' life and circumstances was found to be positively associated with intimate and sexual functioning when controlled for sociodemographic, clinical, and sleep-related variables, anxiety, and severe depression. No association between mastery and intimate and sexual functioning was found when controlled for somatic symptoms of emotional distress and social dysfunction, however.

Our findings may lead to an assumption that mastery may help improve intimate and sexual relationships in male OSA patients with sleep-related problems, anxiety, and severe depression. These results support a previous findings of significant associations between sleep-related problems, depression, anxiety, and sexual dysfuction in OSA patients (Hammoud et al. 2011). Furthermore, previous research showed that sexual activity was found to have soporific effect and consequently improves sleep quality in general population (Pallesen et al. 2020). Thus, it may be assumed that adequate sexual functioning may also be beneficial in achieving better sleep quality in OSA patients.

Interventions focused on the enhancement of mastery over ones' life and circumstances may help to optimize

intimate and sexual relationships in male OSA patients. Mastery as a part of patient empowerment (Aujoulat et al. 2008) was also found to be associated with individuals' capacity to make decisions about their health-related behaviour and to gain control over various health-related aspects of their lives (McAllister et al. 2012). The healthcare professionals may for example, observe a consistent pattern of patients' behaviors indicating lack of confidence in ability and willingness to deal with the various responsibilities with regard to control over treatment adherence, sleep-hygiene, or healthy lifestyle regimens. Building on this recognition, healthcare professionals may encourage and empower the patient to help her/him to achieve more effective symptom control. Mastery may further be improved by relaxation techniques (O'Brien et al. 2012), or by chronic disease management programmes which have been found to be effective in patients with pulmonary disease (Rea et al. 2004).

Interestingly, mastery may not be adaptive in patients suffering from somatic symptoms and social dysfunction. Future research should therfore explicitly test the role of somatic symptoms of emotional distress and social dysfunction in the association with sexual dysfunction in OSA patients.

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# SECTION 2

## Obesity, Cardiovascular diseases, Diabetes

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# NONGENETIC CORRELATES OF TYPE 2 DIABETES MELLITUS AMONG HUNGARIAN ROMA AND HUNGARIAN GENERAL POPULATION: COMPARATIVE CROSS-SECTIONAL STUDY

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**BACKGROUND**: Globally Diabetes mellitus (DM) has been rising. The aim of our study was to investigate and compare the magnitude of type 2 diabetes mellitus (T2DM) and non-genetic determinants on it among adult Hungarians General (HG) and Hungarian Roma (HR) population.

**METHODS:** Community based comparative cross-sectional survey was conducted in 2018 with a sample size of 821 (HG: n=417 and HR: n=404). Both fasting plasma glucose (FPG) and glycated hemoglobin (HbA1c) were measured. Stratified multivariable logistic and linear regression analyses were conducted to identify factors.

**RESULTS:** The prevalence of T2DM (FPG≥ 7mmol/L) was higher in HR than HG population with 13.2% (95%: CI, 9.9% – 16.8%) and 18.1% (95% CI:14.6% – 21.8%) among HG and HR, p=0.054, respectively. Among the whole population, the waist circumference and age were directly related to FPG level while physical activity has marginally an inverse relationship with the level of FPG. Obesity and ageing were risk factors for T2DM among both populations.

**CONCLUSIONS:** T2DM was more prevalent among HR than GH population. The main predictors were obesity and ageing among both populations. Therefore, these findings signal health promotion and disease prevention strategies and research are needed to curb new onset among HR.

Key words: non-genetic, Roma, Hungarian generals, prevalence, T2DM

#### Introduction

It is quite known that Diabetes mellitus (DM) has been a global pandemic, causing deaths and disability. T2DM predominates with 90–95% and is becoming an important public health problem worldwide among all types of diabetes. Nowadays, regardless of economic status and geographic locations, its burden has been escalating. Among noncommunicable disease (NCDs), it is the third leading cause of premature death and disability due to related complications and comorbidities (Dicker et al. 2017, GBD 2017). Both genetic and environmental risk factors trigger the prevalence of DM (Skyler et al. 2017).

Globally about 425 million people are living with DM. Among this figure, 58 million individuals are living with

known DM and averagely about 22 million adults are living with undiagnosed DM status in Europe. Also, people with prediabetes have been progressively developing T2DM. Thus, it is causing several morbidities, mortality and disability across the globe (IDF 2017).

More than half a million Roma are living in Hungary. Especially in the eastern counties, their proportion ranges from 11% to 16% among total population of HR. But their lower degree of seeking education and health care lead them to impoverished life (HGB 2002, Lukác 2017). Global findings also insist that less affordability of health-care services among the population would result in increased prevalence of diseases, predominantly NCDs (Metrics 2018). Moreover, migration and ethnic disparity were potential risk factors for T2DM and related CVDs

in Europe (Butler 2017, Bhopal 2012, Naseribafrouei et al. 2018, Morkos et al. 2018, Van Den Muijsenbergh et al. 2016, Eder et al. 2018, Jager et al. 2018, Parekh & Rose 2011).

Genetic, environmental and non-modifiable risk factors like age, ethnicity, family history and gender have been escalating both the prevalence and incidence of T2DM. Among nongenetic factors; urbanization, stress, unhealthy diet, obesity, air pollution, physically inactive and smoking tobacco were mentioned as the risk for T2DM (Shah et al. 2015, WHO 2016, Chen et al. 2011, Ardisson Korat et al. 2014).

Earlier literature reviews systematically analyzed and concluded that the higher magnitude of T2DM among Roma across Europe with their potential methodological limitations. For this reason, further studies need to be conducted to determine more information about the effect of non-genetic components on the development of T2DM between Roma and indigenous Europeans (Kučerová et al. 2018, Dobranici et al. 2012).

Therefore, our study investigated the T2DM magnitude and non-genetic correlates between HG and HR population.

#### Methods

#### Study setting, design and participants

Community based cross-sectional study was conducted in two counties namely Hajdú-Bihar and Szabolcs-Szatmár-Bereg, Hungary in 2018. Household members who were 18 years and above were our study participants.

#### Sample size, sampling procedure and inclusion criteria

An eligible sample of 417 HG and 404 HR were selected and included in our study made a total of 1029 participants. Multistage stratified sampling was done for selecting study participants. Total of two counties were selected using a cluster sampling technique. All eligible households were included for study. From selected households' members 18 years and above males and females were randomly selected and interviewed. Permanent residents with age greater than or equal to 18 years were included, while pregnant women, seriously ill participants who couldn't provide information during the interview were excluded from the study.

Definitions, measurement or procedure and physical examination

WHO STEPwise questionnaire validated to the context was used for data collection (WHO 2005). Trained health professionals collected the data using pretested, (structured and semi structured questionnaires).

Capillary blood sample was taken from each participant by finger pricking method. In this study, T2DM was defined according to IDF 2012 (Colagiuri 2012) and WHO 2006 definitions (WHO 2006). Again, ADA criteria (ADA 2019) for T2DM that individuals with FPG  $\geq$ 7 mmol/L and/or previously diagnosed diabetes and/or using antidiabetic drugs were considered as having T2DM. Secondly, glycosylated hemoglobin (HbA1c) was measured and those with HbA1c  $\geq$  48mmol/mol (6.5%) were considered as T2DM patients (WHO 2011). Physical activity was defined according to Global Physical Activity Questionnaire (GPAQ) analysis guideline (WHO 2012).

#### Statistical analysis

Data was entered into IBM SPSS software (version 21) for further analysis. Logistic regression were conducted to assess the relationship between predictor and dependent variables. Adjusted odds ratio were used in logistic regression. Finally, stratified multivariable logistic regression was done to control confounding variables. Those variables with p-value <0.05 were considered as statistically significant. Then the model fitness for data was checked by using Hosmer-Lemeshow test.

#### Ethical clearance

This study was approved by the Ethical Committee of the University of Debrecen, Medical Health Sciences Centre (reference No. 2462-2006) and by the Ethical Committee of the Hungarian Scientific Council on Health (reference Nos. NKFP/1/0003/2005; 8907-O/2011-EKU). This article does not contain any studies with animals performed by any of the authors.

#### **Results**

#### Population characteristics

Among total of 1029 (509 HG and 521 HR) participants, 821 (79.8%) (417 (82%) HG and 404 (77.6%) HR) were responded to our study. The detail population characteristics were depicted in Table 1.

 Table 1
 Sociodemographic and economic characteristics of Hungarian General and Roma population

Characteristics	Category	Hungarian General n=416	Hungarian Roma n=403	p-value
Mean age in years		43.9 ± 12.6	43 ± 12.9	0.332
Sex	Male	184(55.8)	107(26.6)	<0.001
	Female	232(44.2)	296(73.4)	
Family size	Below 4	339(81.5)	193(48.5)	<0.001
	4 and above	77(18.5)	205(51.5)	
Marital status	Unmarried	100(24)	75(8.6)	0.004
	Married and living together	246(59.1)	247(61.3)	
	Married but live separately	8(1.9)	16(4)	
	Widow	20(4.8)	36(8.9)	
	Divorced	40(9.6)	23(5.7)	
Economic category	Full-time employer	249(59.9)	146(36.2)	<0.001
	Part-time job	21(5)	13(3.2)	
	Causal job	9(2.2)	71(17.6)	
	Unemployed group	14(3.4)	58(14.4)	
	Other (housewife, pensioner, student, etc.)	123(29.6)	115(28.5)	
<b>Educational status</b>	Primary or less than grade 8	89(21.4)	341(84.6)	<0.001
	Vocational	87(20.9)	32(2.2)	
	High School	116(27.9)	20(5)	
	Tertiary	56(13.5)	3(0.7)	

#### Prevalence of T2DM among HG and HR population

The status of T2DM was clarified on FPG  $\geq$ 7 mmol/L including those who have been on treatment and have previous history of diabetes, the total prevalence of T2DM was 15.6%, 95% CI (13.2%-18.3%). Likewise, there is no significant difference in the prevalence among two populations (HG: 55 (13.2%), 95% CI (9.9% - 16.8%) vs HR: 73 (18.1%), 95% CI (14.6% - 21.8%), p-value =0.054).

Based on HbA1c test  $\geq$ 6.5% (48mmol/L), the prevalence of T2DM was 10.4% (95% CI: 7.5% - 13.3%) in HG and 15.7% (95% CI: 12.2% - 19.5%) in HR, p-value =0.024. The 91.7% HG and 85.9% HR of T2DM patient have not been identified before the survey. Also, prediabetics (whose FPG  $\geq$ 5.6–6.9 mmol/L) were 55 (13.2%) HG and 38(9.4%) in HR population with no significant difference between two groups, p-value=0.222. Regarding physical activity majority of participants were physical active among both HG and HR population.

Factors associated with prevalence of T2DM among Hungarian generals and Roma population

First, we carried out univariate analysis to assess the eligible variables which had association with dependent variable for an aggregate population (HG and HR together),

HG and HR separately. Secondly, we conducted stratified multivariable logistic regression (by ethnicity) to control cofounding factors in the same way.

In univariate analysis among aggregate population having increased age, being female sex, DBP hypertensive, SBP prehypertensive and hypertensive, being widow, being Roma, and having obesity were significantly associated with the T2DM. While for HG; having obesity, age ≥60 years old, being SBP prehypertensive and hypertensive, DBP hypertensive, and being widow were positively associated with risk of having T2DM. Finally, for HR; DBP hypertension, SBP hypertensive, having obesity, family number less than four, being widowed, were positively associated with risk of T2DM.

Lastly, multivariable logistic regression was carried out to assess the interaction effect and control confounding variables. Thus, increase WC, having obesity and ageing were independently associated significant factors with T2DM among aggregate population. Those who have obesity were two times more likely to have risk of T2DM than their counterparts (adjusted OR= 1.945, 95% CI 1.107, 3.418, p=0.021). Again, as the waist circumference increases, the odds of having T2DM increased by 3.4% (adjusted OR=1.034, 95% CI 1.014, 1.054).

Meanwhile, stratified multivariable analysis by ethnicity was carried. Thus, among HG two variables namely; ageing and WC were independently associated with T2DM. Those HGs who were more than 60 years and above were ten times more likely to have the risk of T2DM (adjusted OR= 0.61, 95% CI 1.942, 57.99, p=0.006). As the waist circumference increases, the odds of having T2DM increased by 5% (adjusted OR=1.05, 95% CI 1.019, 1.082, p=0.001).

In case of HR two variables namely, obesity and increased age were independently associated with T2DM. Obese individuals were four times more likely to have T2DM than non-obese ones (adjusted OR=3.841, 95% CI 1.644, 8.974, p=0.002).

Being old age particularly 30 years and above were more likely to have T2DM than below 30 years old individuals with different degree of exposure rates among HR population.

#### **Discussion**

Different environmental and behavioral factors have been escalating the prevalence of T2DM. This is the first study to investigate prevalence of T2DM with simultaneous application of FPG and HbA1c tests among then Hungarian general and Roma population. The study has revealed that the prevalence of T2DM was 15.6% based on FPG level (≥7mmol/L) and 13% based on HbA1c (≥6.5%) among the general population. This is due to scientifically proven fact that HbA1c is the most accurate test used to detect the level of blood glucose among chronic T2DM patients with in past three months (Kilpatrick 2008, Makris & Spanou 2011). Thus, further analysis was made by FPG test. However, the detection ability of HbA1c is higher than FPG test among diabetic patients (Gmbh 1978). This is in line with previous studies that HbA1c is more sensitive and accurate standard test than FPG (Takahashi et al. 2000, Brennan et al. 2007, IEC 2009).

Based on FPG the prevalence of T2DM (18.1%) among HR population in this study is relatively lower than the previous studies particularly among Roma population in Hungary and other European countries (Kučerová et al. 2018, Wong et al. 2005, Szabó et al. 2014, Nazari et al. 2015). Meanwhile it was higher than previous findings conducted in Serbia (11.1%) (Bethel et al. 2013) and Romania (11.7%) (Enache et al. 2016). All previous studies from Hungary (Nazari et al. 2015), Serbia (Beljić Živković et al. 2010), Slovakia (Tataranni et al. 2003) and Romania (Enache et al. 2016) used FPG>7mmol/L as a

cut off point for defining T2DM. A possible explanation for the increment might be study setting as well as the sample size differences. For instance, study from Romania (Enache et al. 2016) and Hungary (Nazari et al. 2015) have lower power with sample size of 344 and 77 study participants, respectively.

On the other hand, the current prevalence among HR showed considerable or about 9% reduction from earlier studies conducted in Hungary (27.09%) (Szabó et al. 2014) and 40% reduction from Slovakia (30%) (Beljić Živković et al. 2010, Tataranni et al. 2003). This reduction might be due to the diagnostic tests difference among the studies, interventions and EU political attentions given to Roma population health (EU 2014, EPHA 2014). Not only this but also earlier published studies and reports showed also Roma population has an unhealthy lifestyle in Europe (EPHA 2014, Balvin et al. 2011, Országh et al. 2007).

The risk factors associated with T2DM were separately investigated for both populations. Obesity, increased waist circumference and ageing were the risk factors for T2DM among aggregate population. But odds of obesity and contracting T2DM among HR was higher than total population. This is in line with findings from studies conducted in other European countries and elsewhere those obese individuals have higher risk of acquiring T2DM (Vazquez et al. 2007, Lee et al. 2011, Abbasi et al. 2012, Colditz et al. 1995, Chan et al. 1994). Waist circumference was one of the predictors along BMI in our study. This finding insisted that increased waist circumference and obesity is a primary risk factor for T2DM (Firouzi et al. 2018).

Strength of our study were; community based and HbA1c test showed higher specificity of 89.8 % (95% CI 85.9% to 93.7%). The current screening tests ability were at their best compared to the previous recommendations that concurrent tests of FPG and HbA1c for undiagnosed T2DM with sensitivity of 40-80% and specificity of 83%-99%, would medically predict the existence of T2DM with their standard cut-off points (Englelgau & Narayan 2000, WHO 2003).

However, there are some limitations in our study. These were during survey process study participants self-reported educational status and their ethnicity to whom they belonged. This could conceal or exaggerate the real effect of ethnicity on T2DM. Unfortunately, family history information was not included in this study since it is one of the main risks of T2DM. Moreover, there is dissonant between FPG and HbA1c in assessing unknown and/or patients on medication for T2DM.

#### **Conclusions**

The prevalence of T2DM relatively higher among HR than HG. Having obesity and aging were risk factors for T2DM among both populations. Overall, further emphasis should be given for ageing population to reduce the magnitude and risk level regardless of ethnicity.

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#### **Authors contribution**

BBB analyzed statistically, interpreted data and drafted the manuscript. BBB, PP, SF, SK, JS and AR took part in the study conception, design, interpretation of the results, revision and approval of the manuscript. SF and AR supervised the study.

#### Conflict of interest

The authors declare that there is no competing interest.

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## GENDER DIFFERENCES IN MORTALITY DUE TO CIRCULATORY DISEASES IN THE SLOVAK REPUBLIC 2000 - 2017

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**BACKGROUND:** Circulatory diseases are one of the leading causes of death worldwide. Male mortality due to circulatory diseases is higher in productive age, but it is increasing in women around the age of 60. The aim of this work was to evaluate gender differences in mortality due to circulatory diseases, myocardial infarction, and cerebrovascular diseases in the Slovak Republic (SR) in the period from 2000 to 2017.

**METHODS:** Data were obtained from the National Center of Health Information and the Statistical Office of the SR; and were processed as a mid-year population and as of December 31 every reference year and entered per 100 000 men and women. Statistical analyses of raw data were performed in IBM SPSS 22 and MS Excel.

**RESULTS:** Overall, time trends show a decreasing number of deaths among both genders in SR. The decrease in mortality can be explained by declining trends of risk factors such as smoking, cholesterol, and hypertension. We found that there is a higher mortality rate due to circulatory system diseases among women compared to men in Slovakia. It could be possibly linked to diabetes, which shows higher time trends among women.

**CONCLUSIONS:** Although circulatory disease mortality is declining, changes to improve health are still needed. Particularly, behavioural interventions changing the lifestyle such as healthy diet, regular physical activity, and smoking cessation are key factors that can lead to a decrease of cardiovascular diseases.

Key words: cardiovascular diseases, circulatory diseases, gender differences, time trends

#### Introduction

Cardiovascular disease is the most common cause of death in the world. It is estimated that 23.6 million people will die by 2030 (WHO 2017). Cardiovascular diseases are disorders where the heart and blood vessels are affected (WHO 2020) and their cause is atherosclerosis (WHO 2018). Myocardial infarction is an ischemic heart disease manifestation and demonstrates myocardial cell necrosis. Blood flow is restricted or stopped due to plaques in the coronary arteries but also may occur due to other obstructions in the bloodstream (Mendis et al. 2011). Cerebrovascular diseases are a diverse disorders group caused by haemorrhage or cerebral ischemia and a neurological deficit occurs (Billett 1990).

Male mortality due to circulatory diseases is higher in productive age, but it is increasing in women around the age of 60. Diabetes, obesity, and hypertension bring a higher risk in the post-menopausal period. As such, it is necessary to consider gender differences in cardiovascular disease prevention, diagnosis, treatment, and management.

The cardiovascular disease gender differences are mostly caused by environmental influences and innate genes and probable causes include age, hypertension, total cholesterol, and LDL cholesterol more in men and smoking, diabetes, triglyceride, HDL cholesterol more in women. There are also women-specific factors like reproductive endocrine disorders and pregnancy complications (Gao et al. 2019). There is a necessity to prevent and identify CVD risk factors at least 10-20 years sooner because unhealthy lifestyle consequences do not show immediately after risk factors appear (Mikkola et al. 2013).

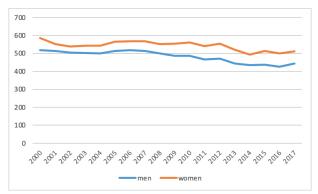
The aim of this work was to evaluate gender differences in mortality due to circulatory diseases, myocardial infarction, and cerebrovascular diseases in the Slovak Republic in the period from 2000 to 2017, which is latest available year for the SR.

#### Methods

Data were obtained from the National Center of Health Information and the Statistical Office of the Slovak Republic from the year 2000 to 2017 (Health Statistics Yearbooks of the Slovak Republic 1996 - 2017). Data were processed as a mid-year population and as of December 31 every reference year and entered per 100 000 men and women. Statistical analyses were performed in IBM SPSS 22 and MS Excel.

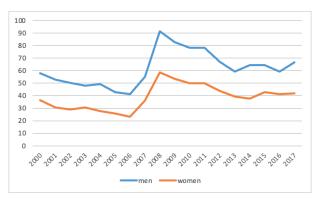
#### **Results**

Overall, time trends show a decreasing number of deaths among both genders (Figure 1). Mortality rates in 2000 were 518.1 and 585.8 deaths per 100,000 males and females, respectively. In 2017 the mortality rates were 443.5 and 512.7 deaths per 100,000 males and females, respectively.



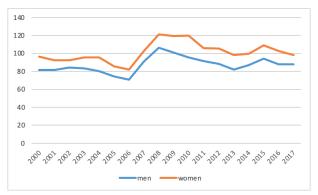
**Figure 1** Mortality rates of death caused by diseases of the circulatory system in 2000 – 2017 (per 100 000)

Deaths due to myocardial infarction are more common in men than in women (Figure 2). Over the whole period, there is approximately a difference of 20 deaths per 100,000. In 2000, 57.9 men per 100,000 and 36.3 women per 100,000 died, and in 2017, 66.8 men per 100,000 and 42 women died. It is also possible to observe a sharp increase in mortality in 2008. Overall, there was an increase in the incidence of death due to myocardial infarction in both genders.



**Figure 2** Mortality rates of death caused by acute and subsequent myocardial infarction in 2000 – 2017 (per 100 000)

Mortality caused by cerebrovascular diseases was higher in women than in men in the period 2000 – 2017. In 2000, the mortality rate was 81.5 per 100,000 for men and 96.6 per 100,000 for women. In 2017, the mortality was 88.1 per 100,000 for men and 98.2 per 100,000 for women. Overall, there was a slight increase in the death incidence from these diseases in this period (Figure 3).



**Figure 3** Mortality rates of death caused by cerebrovascular diseases in 2000 – 2017 (per 100 000)

#### Discussion

Time trends show a decreasing number of deaths among both genders. Mortality trends in Slovakia are decreasing similarly to the whole world mortality trends (Bots et al. 2017). The decrease can be explained by declining trends of risk factors such as smoking, cholesterol, and hypertension (SAFCD 2015). We found that there is a higher mortality rate due to circulatory system diseases among women compared to men in Slovakia. These findings are consistent with the study by Di Giosa et al. (2017). Higher cardiovascular disease mortality in women could be possibly linked to diabetes, which shows higher time trends among women in Slovakia (NCZI 2018). Also, cardiovascular disease awareness is still not entirely sufficient among women especially for atypical symptoms of cardiovascular disease (Mosca et al. 2013).

Compared to Finland (Mikkola et al. 2013), where is higher mortality among men than women, this difference could be mainly caused by different lifestyles in the Nordic populations. In general, there is a higher probability to develop coronary heart disease in men, while women usually have heart failure or cerebrovascular disease as the first cardiovascular disease, although they appear usually at higher age (Leening et al. 2014). So various cardiovascular diseases have different associations with both genders (George et al. 2015).

Mortality rates of death caused by myocardial infarction were higher in men than women in Slovakia in

2000 – 2017, and similar findings are also reported by Romania from this period (Ioacara et al. 2020). World time trends in stroke deaths have decreased (Johnson et al. 2019) while in Slovakia they slightly increased. Women had higher mortality due to cerebrovascular diseases in Slovakia. However, women who had cardiovascular disease and received similar care and information as men had better long-term outcomes compared to men (Meer et al. 2014).

Although circulatory disease mortality is declining, changes to improve health are still needed. Particularly, changing the lifestyle such as healthy diet, regular physical activity, and smoking cessation are key behavioural factors that can lead to a decrease of cardiovascular diseases. There is a necessity to create behavioural interventions focused on change cardiovascular risk factors to prevent the initiation of CVD and to reduce CVD mortality. It is also important to take into account gender differences during designing intervention programs, in particular by focusing on differences in risk factors among men and women.

#### **Conclusions**

Cardiovascular disease is the main cause of death among women and it is still often not adequately treated and underestimated, it is often due to the misinterpretation that cardiovascular diseases are not women's diseases (Maas & Appelman 2010). A deeper recognizing of the cardiovascular disease gender differences can bring better specific treatment for both genders (Gao et al. 2019) and also can contribute to the development of tailored public health intervention programmes.

#### **Acknowledgements**

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## ŽIVOTNÁ SPOKOJNOSŤ AKO DÔLEŽITÝ FAKTOR SEBAHODNOTENÉHO ZDRAVIA U DIABETIKOV 2 TYPU S DLHOTRVAJÚCIM OCHORENÍM

## LIFE SATISFACTION AS AN IMPORTANT FACTOR OF SELF-RATED HEALTH IN TYPE 2 DIABETES WITH LONG-TERM DISEASE

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**Úvop:** Identifikácia faktorov, ktoré ovplyvňujú sebahodnotenie vlastného zdravia (SRH – Self Rated Health) u diabetikov 2. typu (T2DM) je kľúčová na zmiernenie rastúcej záťaže dlhotrvajúceho ochorenia. Cieľom našej štúdie bolo skúmať vplyv psychologických a behaviorálnych faktorov na SRH u diabetikov T2DM.

**METÓDY:** Štúdie sa zúčastnilo 145 dospelých osôb s diagnózou T2DM (62,1% mužov, vek 59,2±6,3 rokov, trvanie ochorenia 11,7±8,0 rokov). Za závislú premennú bol vybratý indikátor SRH, miera sebaúcty bola meraná dotazníkom Rosenberg Self-Esteem Scale (RSES) a celková spokojnosť zo životom pomocou škály Cantrill's Ladder - Life satisfaction. Výsledky boli analyzované štatistickým balíkom pre spoločenské vedy 16.0 (IBM SPSS Inc. Chicago, IL, USA).

**VÝSLEDKY:** V korelačnej analýze vyššie skóre SRH pozitívne korelovalo so spokojnosťou s liečbou (r=0,17, p<0,05) a vysoko signifikantne s vyšším skóre RSES (r=0,44, p<0,001) ako aj celkovou spokojnosťou so životom v Cantrill's ladder (r=0,46 p<0,001). Následne regresné analýzy potvrdili mieru sebaúcty spolu s celkovou spokojnosťou so životom ako najsilnejšie psychologické faktory, ktoré vysvetľovali 14% celkovej variancie SRH.

**ZÁVER:** Na subjektívnom hodnotení vlastného zdravia u diabetikov T2DM sa výraznou mierou podieľa celková spokojnosť so životom a sebaúcta. Pre dosiahnutie dobrej glykemickej kompenzácie, musí lekár pristupovať k pacientovi s rešpektovaním a s vnímavosťou na jeho individuálne preferencie a hodnoty.

Kľúčové slová: diabetes mellitus 2 typu, sebahodnotenie zdravia, celková spokojnosť zo životom, miera sebaúcty

**INTRODUCTION:** Identifying factors that influence Self Rated Health (SRH) in patients with type 2 diabetes mellitus (T2DM) is key to alleviating the growing burden of chronic disease. The aim of our research was to study the influence of psychological and behavioural factors on SRH in patients T2DM.

**METHODS:** The study included 145 adults diagnosed with T2DM (62.1% of men, age 59.2±6.3 years, disease duration 11.7±8.0 years). SRH was chosen as the dependent variable, self-esteem was measured using the Rosenberg Self-Esteem Scale (RSES), and overall life satisfaction was measured by the Cantrill's Life Satisfaction Scale. The results were analyzed using the Social Science Statistical Package 16.0 (IBM SPSS Inc. Chicago, IL, USA).

**RESULTS:** In the correlation analysis, a higher SRH score was positively correlated with treatment satisfaction (r=0.17, p<0.05) and very significantly with a higher RSES score (r=0.44, p<0.001) as well as overall life satisfaction (r=0.46 p<0.001). The following regression analyses confirmed that self-esteem and overall life satisfaction are the strongest psychological factors explaining 14% of the SRH total variance.

**CONCLUSIONS:** Overall life satisfaction and self-esteem play an important role in the subjective assessment of their own health in patients with type 2 diabetes. To achieve good glycemic compensation, the physician must approach to the patient with respect and sensitivity to their individual preferences and values.

Key words: type 2 diabetes mellitus, self rated health, overall life satisfaction, self-esteem.

#### Úvod

Diabetes mellitus (DM) je chronické ochorenie, ktoré zahŕňa narušenú produkciu inzulínu alebo neúčinnosť inzulínu. Za posledných niekoľko desaťročí sa celosvetová prevalencia DM neustále zvyšuje. Podľa International Diabetes Federation (IDF) v roku 2019 celosvetovo trpelo ochorením diabetes mellitus 463 miliónov ľudí, z nich malo takmer 90% diabetes mellitus 2 typu (T2DM) (IDF atlas 2019). Zle kontrolovaný diabetes a progresia ochorenia môže viesť u mnohých pacientov k závažným a život ohrozujúcim zdravotným komplikáciám (Pantalone et al. 2018). Dobrá glykemická kompenzácia u ľudí s T2DM výrazne znižuje riziko cievnych komplikácií a má za následok menej makrovaskulárnych príhod.

Self Rated Health (SRH) - sebahodnotené zdravie je nástrojom, ktorý umožňuje u diabetických pacientov poskytnúť dôležité informácie o zdravotnom riziku ochorenia (McEwen et al. 2009). Je dobrým prediktorom pre množstvo dôležitých zdravotných indikátorov ako je úmrtnosť, chorobnosť alebo využívanie služieb zdravotnej starostlivosti (Moller et al. 1996, Idler & Benyamini 1997). Tento nástroj má dobré psychometrické vlastnosti, odráža celkový pocit zdravia ľudí a je možné ho ľahko použiť (Eriksson et al. 2001). Jedna z významných desaťročných štúdií v USA, realizovaná Centrom pre kontrolu chorôb (Centres for Disease Control and Prevention, CDC) zistila výrazne nižšiu úroveň sebahodnoteného zdravia u diabetikov v porovnaní s nediabetickou populáciou (CDC 2006). Na vnímanie sebahodnoteného zdravia u pacientov T2DM vplýva celá škála rôznych sociodemografických, klinických, behaviorálnych a psychologických faktorov.

Cieľom našej štúdie bola identifikácia faktorov, ktoré sa výraznou mierou podieľajú na sebahodnotení vlastného zdravia pacientov s T2DM. V aktuálnom príspevku prezentujeme parciálne výsledky štúdie zamerané na behaviorálne a psychologické determinanty SRH.

#### Metódy

Súbor pacientov a postup prác

Našej štúdie sa zúčastnilo 145 pacientov s ochorením T2DM. Zber dát prebiehal u ambulantne liečených pacientov z diabetologických ambulancií na východnom Slovensku. Jediným vstupným kritériom pre účastníkov bol diagnostikovaný T2DM a mentálna schopnosť odpovedať na otázky dotazníka. Pacienti vyplňovali dotazník zameraný na sebahodnotené zdravie, ako aj sociodemografické charakteristiky, klinické charakteristiky týkajúce sa ochorenia T2DM, behaviorálne a psychologické faktory. Pri vypĺňaní dotazníka asistoval vyškolený personál. Informovaný súhlas bol získaný od každého pacienta

#### Meracie nástroje

Rosenberg Self-Esteem Scale (RSES). Rosenbergov dotazník sebaúcty (Rosenberg, 1965), je škála určená na meranie základného pocitu sebahodnoty. RSES je hodnotiacou mierkou, v ktorej respondenti vyjadrujú postoj k vlastnej osobe. Samotný dotazník sebaúcty pozostáva z 10 otázok. Päť otázok je formulovaných ako pozitívne tvrdenia, resp. pozitívne postoje k vlastnej osobe a druhá pätica otázok je formulovaná vo forme negatívnych tvrdení. Pre účely analýzy bolo využité jednosmerné kódovanie odpovedí t. j. respondent, ktorý sa stotožňoval s takýmto tvrdením a "úplne súhlasil" získal 1 bod a respondent ktorý "vôbec nesúhlasil" získal 4 body. Maximálne skóre bolo 40 bodov. Cronbachova alfa dotazníka bola 0,72, čo poukazuje na dobrú vnútornú konzistenciu mierky.

Cantrill's ladder - Life satisfaction (Cantrill, 1965), sme použili na meranie celkovej spokojnosti so životom. Táto mierka hodnotí kvalitu života vo forme rebríka s jednou všeobecnou otázkou, v ktorej respondenti vyjadrujú spokojnosť so životom ako celkom, bez ohľadu na jeho jednotlivé komponenty. Mierka sa pohybuje od 0 bodov (v spodnej časti rebríka, čo naznačuje najhoršie predstaviteľnú kvalitu života) do 10 bodov (v hornej časti rebríka, s uvedením najvyššie predstaviteľnej kvality života). Pokyny pre respondentov boli nasledovné: "Na obrázku vidíte rebrík, ktorý predstavuje Váš rebrík života. Na ktorej priečke rebríka máte pocit, že stojíte v súčasnej dobe?

Spokojnosť s liečbou. Ako ďalší psychologický parameter sme zaradili hodnotenie spokojnosti s liečbou, ktorú respondenti momentálne podstupujú. Respondenti odpovedali na otázku: "Ako ste spokojný s Vašou súčasnou liečbou?" Odpovede sa zaznamenávali vo forme skóre od 5-veľmi spokojný až po 1- veľmi nespokojný.

Behaviorálne charakteristiky súboru. Vzhľadom k tomu, že úspešná liečba a prevencia diabetických komplikácií závisí vo veľkej miere na individuálnom správaní, tzv. "compliance" pacienta, do štúdie sme zaradili otázky týkajúce sa seba-monitoringu pacientov. Otázky sa tykali domácej kontroly hladiny glukózy, kontroly hmotnosti a dodržiavania stravovacích odporúčaní. Napr. Robíte domácu kontrolu krvného cukru pravidelne a systematicky? Kontrolujete svoju hmotnosť pravidelne (aspoň raz týždenne)? Stravujete sa podľa odporúčaní Vášho lekára? Respondenti mali možnosť na tieto otázky odpovedať vo forme skóre 1-nie, 2-väčšinou nie, 3-častejšie áno ako nie 4-väčšinou áno, 5-vždy.

#### Štatistické analýzy

Aby sme mohli preskúmať, ako je naša závislá premenná-SRH-sebahodnotené zdravie závislá od jednotlivých faktorov (sociodemografických, klinických, psychologických a behaviorálnych) boli realizované nasledovné štatistické analýzy. Po prvé, opis súboru sa hodnotil deskriptívnou štatistikou. Priemerné skóre a smerodajné odchýlky boli vypočítané pre všetky premenné. Po druhé, asociácie medzi premennými boli testované pomocou Pearsonových korelácii. Ako tretí krok bola zvolená multivariačná lineárna regresia, ktorú sme realizovali s cieľom určiť, akú časť variancie závislej premennej možno vysvetliť jednotlivými faktormi. Dáta boli analyzované pomocou štatistického programu SPSS (the Statistical Package for the Social Sciences) pre Windows verzia 16.0 (IBM SPSS Inc., Chicago, IL, USA).

#### Výsledky

#### Sociodemografické a klinické charakteristiky súboru

Našej štúdie sa zúčastnilo 145 pacientov s T2DM. Priemerný vek respondentov bol 59,2±6,3 rokov. Vzorku tvorilo 37,9% žien a 62,1% mužov. Priemerná dĺžka trvania ochorenia u respondentov bola 11,7±8,0 rokov. Liečbu inzulínom v sledovanom období podstupovalo 51,7% respondentov, 44,1% respondentov bolo liečených orálnymi antidiabetikami a 4,1 % respondentov podstupovalo liečbu zameranú na režimové opatrenia a diétu. Index telesnej hmotnosti BMI u respondentov bol 30,7 ± 4,9. Častá prítomnosť sprievodných ochorení pri ochorení T2DM sa potvrdila aj v našom súbore, viac ako polovica pacientov T2DM (67.6%) malo diagnostikovanú hypertenziu ako komorbiditný faktor a približne 30% respondentov malo diagnostikovanú ischemickú chorobu srdca (ICHS). Z psychologických faktorov respondenti hodnotili pomocou Cantrill's ladder svoju celkovú spokojnosť so životom v priemerných hodnotách 7,1±1,8 (Graf 1).

#### Výsledky korelačných analýz

SRH v našom súbore pozitívne korelovalo v oblasti behaviorálnych faktorov súvisiacich s pravidelnou kontrolou hmotnosti. Respondenti ktorí nesledovali pravidelne svoju hmotnosť (aspoň raz týždenne) hodnotili svoje zdravie ako horšie (r=0,17, p<0,05).

SRH najvýznamnejšie korelovalo s psychologickými faktormi. Vyššie skóre Rosenberg Self-Esteem Scale (RSES) pozitívne korelovalo s vyšším skóre SRH (r=0,44, p<0,001), rovnako ako spokojnosť s liečbou (r=017, p<0,05), a tiež celková spokojnosť zo životom (Cantrill's ladder) vysoko signifikantne korelovala s SRH (r=0,46 p<0,001) (Tabuľka 1). Respondenti, ktorí dosahovali v SRH vyššie skóre, udávali vyššiu úroveň sebaúcty, hodnotili lepšie svoju spokojnosť s liečbou a lepšie aj celkovú spokojnosť so životom.



Vysvetlivky: 1 - absolútna nespokojnosť so životom, 10- úplná spokojnosť

Graf 1 Charakteristika súboru - životná spokojnosť (Cantrill's ladder)

**Tabulka 1** Pearsonove korelačné koeficienty medzi behaviorálnymi a psychologickými premennými súboru a SRH

Behaviorálne a psychologické premenné	SRH
Self-monitoring glukózy	0,01
Kontrola hmotnosti	0,17*
Stravovanie	0,12
RSES	0,44***
Spokojnosť s liečbou	0,17*
Cantril's Ladder	0,46***

Vysvetlivky: SRH-Self Rated Health, RSES-Rosenberg's Self-Esteem Scale; \*p<0,05; \*\*\*p<0,001

#### Výsledky viacnásobnej regresnej analýzy

V modeli regresnej analýzy, ktorý zahŕňal psychologické faktory bolo vysvetlených 14% variancie SRH (p<0.001). Vyššie skóre sbaúcty (RSES-Rosenberg Self-Esteem Scale) a celkovej spokojnosti so životom (Cantrill's ladder) bolo

signifikantne asociované s lepším sebahodnoteným zdravím pacientov T2DM.

Vo finálnom modeli regresnej analýzy zostali ako signifikantné faktory: počet chronických diabetických komplikácii ( $\beta$ =-0.23, p<0.01), RSES ( $\beta$ =0.22, p<0.05) a Cantrill's ladder ( $\beta$ =0.26, p<0.05). Miera sebaúcty spolu s celkovou spokojnosťou so životom a klinickými faktormi vysvetľovali spoločne 31% variancie sebahodnoteného zdravia u pacientov T2DM.

#### Diskusia

Hlavným cieľom našej štúdie bolo identifikovať faktory asociované so sebahodnoteným zdravím u diabetikov T2DM so zameraním na psychologické a behaviorálne prediktory.

#### Behaviorálne determinanty SRH

Zaujímavým poznatkom v našej štúdii bol nízky podiel behaviorálnych faktorov ako prediktorov SRH. Selfmonitoring glukózy, kontrola telesnej hmotnosti a stravovanie sa ukázali ako faktory s nízkym podielom asociačných vzťahov k sebahodnotenému zdraviu pacientov T2DM. Podobne výsledky uvádza v štúdii Grubich (2003), ktorý hodnotí frekvenciu self-blood glucose monitoringu v súvislosti s kvalitou života. Pacienti, u ktorých je vyššia frekvencia dennej kontroly hladiny glukózy v krvi pri intenzifikovanej liečbe udávajú dokonca vyššiu kvalitu života.

#### Psychologické determinanty SRH

Skutočnosť, že na subjektívne vnímanie zdravotného stavu u diabetikov majú silný vplyv psychologické faktory sa potvrdila aj v našej štúdii. Silným prediktorom SRH bola miera sebaúcty pacienta k vlastnej osobe, v našom prípade meraná pomocou nástroja RSES Rosenbergovej škály sebaúcty. Spôsob, akým chorí o sebe zmýšľajú, aký majú postoj k vlastnej osobe, nakoľko si sami seba vážia, sa odráža aj na hodnotení vlastného zdravia. Ide teda o úzky vzťah obidvoch premenných.

Rovnako silným prediktorom SRH bola v našej štúdii aj celková spokojnosť zo životom. Spokojnosť zo životom všeobecne, je podobne ako sebaúcta multidimenzionálny konštrukt, kde príčinné vzťahy je ťažko špecifikovať, sú zložité a často recipročné. Podobné výsledky uvádza štúdia autorov Undén et al. (2008), kde celková spokojnosť zo životom signifikantne koreluje so sebahodnoteným zdravím u pacientov s diabetom.

Záverom možno konštatovať, v súlade z mnohými štúdiami, že práve vďaka intenzívnemu záujmu ktorý sa posledné dve desaťročia venuje výskumu kvality života u diabetikov, bolo možné odhaliť úzku súvislosť medzi diabetom a psychickými ochoreniami, najmä zvýšeným rizikom depresie u týchto pacientov (Jannoo et al. 2017, Jing et al 2018, Hussain et al., 2018).

#### Záver

Na subjektívnom hodnotení vlastného zdravia u diabetikov T2DM sa výraznou mierou podieľajú psychologické faktory ako spokojnosť s liečbou, miera sebaúcty a celková spokojnosť so životom. Pre adekvátnu compliance diabetika, s cieľom dosiahnuť dobrú glykemickú kompenzáciu, je potrebné rešpektovať jeho individuálne preferencie a hodnoty. Faktor spokojnosti s liečbou diabetu poukazuje na potrebu prispôsobiť terapiu diabetu čo možno najviac potrebám a požiadavkám pacienta.

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# HAEMOGLOBIN A<sub>1C</sub> AS THE GOLD STANDARD IN MONITORING OF GLYCAEMIC COMPENSATION IN PATIENTS WITH DIABETES MELLITUS: HOW TO INTERPRET AND USE OF THE RESULTS IN A CREATIVE WAY?

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A comprehensive review of the proper interpretation of  $HbA_{1c}$  in general diabetological practice. The interpretation is based on the biokinetic model of haemoglobin glycation. The recommendations take into account the recent developments in  $HbA_{1c}$  assay methods as well as the newly introduced markers of glycaemic compensation assessed by continuous blood glucose measurement methods. The creative and integrated evaluation of continuous blood glucose (or self monitoring) measurements, frequency and severity of hypoglycaemic events and results of regularly  $HbA_{1c}$  measurements by certified methods should constitute one multidimensional picture helping to achieve the best level of glycaemic compensation in each patients with diabetes mellitus.

**Key words:** diabetes mellitus, glycaemic compensation, HbA<sub>1</sub>, biokinetic model

#### Issue: The glycation of haemoglobin

HbA<sub>1c</sub> is considered as the gold standard of the assessment of glycaemic compensation in patients with diabetes mellitus and is also recommended to include it into the diagnostic algorithm of diabetes mellitus (ADS in press 2021a, ADS in press 2021b). The rationale of its widespread use is based on the assumption that HbA<sub>1c</sub> arises through slow and irreversible nonenzymatic addition of glucose to beta chain of human haemoglobin A during the 120-day lifespan of red cells and therefore it is an integrated retrospective marker of blood glucose concentration in the past months (Little 2009). Short-term fluctuations of blood glucose do not affect its concentration. A timetable of the most important discoveries associated with haemoglobin glycation are summarized in Table 1.

HbA<sub>16</sub> does not reflect changes of blood glucose in a linear way. This nonlinearity is caused by combination of two processes, namely the concentration-dependent binding of glucose to Hb and the constant rate of the replacement of old red cells with new ones. It was described in the biokinetic mathematical model of glycation (Beach 1979, Ladyzynsky et al. 2008). The model makes possible calculation of HbA<sub>16</sub> for different episodes of hyperglycaemia before the actually measured HbA<sub>1c</sub>. A simplified explanation of the situation is depicted in Figure 1, from which is possible to understand why recent changes in blood glucose have a greater impact on the value of actual HbA, as compared with those occurring in the past. However the model did not reach clinical acceptance because of its complicated mathematical formula and the lack of patient data about hyperglycaemic episodes occurring in the previous period before HbA<sub>1c</sub> measurement.

**Table 1** Milestones in the discovery of haemoglobin glycation and the establishment of  $HbA_{1c}$  as the gold standard of glycaemic compensation assessment

1912, Maillard	Description of nonenzymatic reaction of amino acids with sugars (Maillard 1912)
1969, Rahbar, Iran	Discovery of an abnormal haemoglobin in diabetics (Rahbar 1968)
1969, Rahbar et al., USA	Identification of the unusual haemoglobin with the minor Hb fraction, HbA <sub>1c</sub> (Rahbar et al.1969)
1971, Trivelli	Development of a cation exchange chromatograhic method suitable for measurement of HbA <sub>1c</sub> in laboratories of clinical chemistry (Trivelli 1971). Followed by numerous assays including micromethods, electrophoresis, affinity chromatography, etc. in the late 70's and in the 80's.
1975, Bunn (and many others in the 70's)	HbA <sub>1c</sub> is the product of nonezymatic glycation of Hb. This is the explanation of its elevated concentration in diabetics (Bunn et al. 1975)
1975 - 1989	Widespread use of glycated haemoglobin measurements in everyday diabetological practice (Rácz et al. 1989)
1982 – 1993, Diabetes Control and Complications Trial	Unambiguous proof of the association of glycaemic compensation assessed by HbA <sub>1c</sub> and the development of complications (DCCRC 1993, Nathan et al. 2014)
1993, Santiago	Criticism of the lack of HbA <sub>1c</sub> assay standardization (Santiago 1993)
1995 - 2002	Development of the unified reference system of HbA <sub>1c</sub> assays based on a defined primary analyte. Introduction of new units of HbA <sub>1c</sub> concentration (Weykamp et al. 2008)
2018, EurA1c	Investigation of the performance of HbA <sub>1c</sub> assays in 2166 laboratories across 17 countries and 24 manufacturers (ETC 2018)

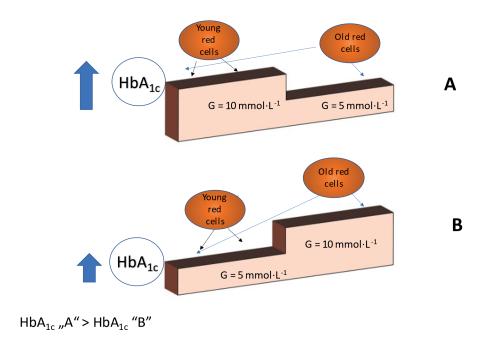


Figure 1 The effect of recent and past hyperglycaemia on the concentration of  $HbA_{1c}$ 

Recently occurring hyperglycaemia has a greater effect on the  $HbA_{1c}$  as compared with past hyperglycaemia. The models A and B have the same average blood glucose (7,5 mmol·L<sup>-1</sup>), but the calculated Hb  $A_{1c}$  according the biokinetic model in "A" is 77,0 mmol·mol<sup>-1</sup>, whereas in "B" only 49,0 mmol·mol<sup>-1</sup>.

### Description of the problem - from the point of view of practical diabetology

The development of recent HbA $_{\rm lc}$  assays from old cumbersome and not standardized ones was a long way (Little & Rohlfing 2013). Today all methods used in laboratories of clinical chemistry and most methods POCT type are fully tied to the primary standard and certified, what means that all of them should provide the same results (Table 2). In the same time there was a significant development of blood glucose monitoring including self-monitoring with glucometers and continuous glucose monitoring systems (CGMS) providing a detailed picture about the glycaemic compensation of diabetic patients. The newly introduced markers calculated from CGMS (time in, above and below the desired range (TIR, TAR and TBR (Advani 2020) should be in agreement of recommended values of HbA $_{\rm lc}$  for good compensation (Tables 3, 4).

Table 2 Current assays for HbA<sub>1</sub>, measurement

#### SEPARATION OF MINOR FRACTIONS OF HAEMOGLOBIN

#### HPLC AND CAPILLARY ELECTROPHORESIS

Based on different charge of the main and minor fractions of haemoglobin.

#### **BORONATE AFFINITY CHROMATOGRAPHY**

Binding of cis-diol groups of sugars to the carrier and the elution of the different (glycated and non-glycated) haemoglobin fractions separately.

The advantage of methods based on separation is that they "see" the HbA.

#### **IMMUNOCHEMICAL METHODS**

Antibodies against the terminal glycated peptide bind HbA<sub>1c</sub>. The concentration of HbA<sub>1c</sub> is measured by turbidimetry or other forms of immunoassay.

These methods are indirect ("blind") but they are suitable for serial measurement on automatic analysers.

#### **ENZYMATIC METHOD**

A specific proteinase splits fructosyldipeptide from the glycated haemoglobin beta chain and a second enzyme releases hydrogen peroxide from this peptide. Hydrogen peroxide is quantified with a routine spectroscopic method and HbA<sub>1c</sub> is calculated from the hydrogen peroxide concentration.

Note: An overview of currently available methods and the perspectives of future methodological solutions is in Gupta et al. 2017

**Table 3** Desired values of good glycaemic compensation according to continuous glucose measurement systems (CGMS)

Marker	Blood glucose mmol·L¹	Time % in one day and hours/minutes of a day
Time in range (TIR) In gravidity	3,9 - 10,0 3,5 - 7,8	At least 70 % 16 hours, 45 min- utes
Time above range	>10,0	Less than 20%
(TAR)	>13,9	4 hours, 45 minutes Less than 12% 2 hours, 53 minutes
Time below range	<3,9	Less than 5 %
(TBR) (hypoglycaemia)	<3,0	1 hour, 12 minutes Less than 3 % 53 minutes

According to Advani 2020

**Table 4** Different level of glycaemic compensation according to  $HbA_{1c}$  concentration

Compensation	IFCC units mmol·mol <sup>-1</sup>	DCCT units Hb %		
Good	< 43	< 6,0		
Satisfactory	44 - 60	6,0 - 7,5		
Unsatisfactory	61 - 75	7,6 - 9,0		
Bad	> 75	> 9,0		

Conversion of DCCT to IFCC units is possible with the:  $HbA_{1d,mmol-mol-1]} = HbA_{1c,(%)} *10,93 - 23,5$ 

From the point of practical diabetology, the expectation that between markers of actual blood glucose and results of HbA<sub>16</sub> should be an agreement is fully reasonable. In contrary, discordance between blood glucose and HbA, in diabetic patients is a common situation. Recently several studies were devoted this problem to explain the discordance. In such case the first step is the elimination of well-known confounding events as decreased red cell survival, haemoglobinopathies, etc. (Table 5). If these are not present, the discordance can be calculated and expressed as a difference between blood glucose-predicted and measured HbA<sub>1c</sub> (glycation gap) or their proportion (haemoglobin glycation index) (Campbell et al. 2019, Rodriguez-Segade et al. 2012, Van Steen et al. 2017, Hempe et al. 2018, Oriot & Hermans 2020). These parameters are however only a description of the discordance and not its explanation.

### Lessons learned: Possible solution of the problem through the application of biokinetic model

According to our view the differences revealed by the application of biokinetic model of glycation could be an important factor behind the glycation gap different from zero and haemoglobin glycation index different from one. In Figure 2 there are 5 models with the same average blood glucose and 24 day long hyperglycaemic episodes occurring in different period before the actual HbA $_{\rm lc}$  measurement, In table 6 there are results calculated according to the biokinetic model of haemoglobin glycation and there is obvious that the timing of hyperglycaemic episodes has a profound effect of HbA $_{\rm lc}$  values and according to these differences patients could be enrolled to incorrect group of compensation

**Table 5** Factors leading to false results of HbA<sub>1</sub>, measurements

#### Certain and assured

Decreased life span of red cells (haemolytic anaemia). False low results

Haemoglobins deferent from HbA. Hb F has no beta chain and no  $HbA_{1c}$ . Abnormal haemoglobins can have different beta chains and in homozygotes cause haemolytic anaemia. False results also in healthy heterozygotes. HPLC can reveal the problem but the results are not feasible.

#### Not quite certain and partly assured

Iron deficiency anaemia

Deglycation of glycated haemoglobin by enzyme fructosamine-3-kinase. False low results?

Vesiculation of mold red cells with loss of HbA1c. False low results?

Decreased capacity or activity of GLUT1 transporter in red cell membrane. False low results?

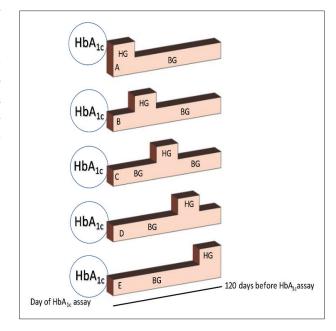
#### Uncertain, not assured

Ethnicity

Old age

Nutrition and alcohol

Note: For a comprehensive review see Soros et al. 2010



BG = basic blood glucose before or after the hyperglycaemic episode, (5 mmol·L<sup>-1</sup>);

 $HG = hyperglycaemic episode (15 mmol\cdot L^1)$ . The average blood glucose of all models with different timing of hyperglycaemia is the same (7 mmol·L<sup>1</sup>).

Duration of hyperglycaemic episodes: 24 days.

**Figure 2** Models of identical hyperglycaemic episodes occurring in different time before HbA<sub>1c</sub> assay

**Table 6** Differences of  $HbA_{1c}$  values and glycation index calculated according to the biokinetic model for identical hyperglycaemic episodes occurring in different period before  $HbA_{1c}$  measurement (Figure 2)

		Model				
Parameter	A	В	С	D	E	
Basic blood glucose mmol·L <sup>-1</sup>			5,0			
Increased blood glucose mmol·L·1			15,0			
Average 120 day blood glucose mmol·L¹			7,00			
Expected HbA <sub>1c</sub> according to average blood glucose, mmol·mol· <sup>1</sup>			57,6			
Time of hyperglycaemic period before HbA <sub>1c</sub> measurement, days	0-24	25-48	48-72	73-96	97-120	
HbA <sub>1c</sub> according to the biokinetic model, mmol·mol·1	72,7	63,6	54,8	46,1	37,7	
Glycation index Ratio of measured and from average blood glucose expected HbA <sub>1c</sub>	1,19	1,07	0,96	0,86	0,75	

#### Conclusions and recommendations for practice

According to (Lippi 2019) HbA<sub>1c</sub> is one of four laboratory tests which revolutionized clinical practice but its proper interpretation is not simple. HbA<sub>1c</sub> reflects past blood glucose concentration in a nonlinear way which can be described as "retrospective distortion". Current hyperglycaemic episodes have a greater impact on HbA1c as compared with those occurred in the past weeks. In general practice therefore it is not possible to asses the level of glycaemic compensation from HbA<sub>1c</sub> alone nor the blood glucose levels alone. In case of disagreement between the blood sugar values and the HbA<sub>1</sub>, the first step is the elimination of possible confounding factors distorting the result of HbA<sub>16</sub> by the given method and consult it with an expert of clinical chemistry. If the disagreement is a systematic one, the possible explanation can be the nonlinear association between blood glucose levels and haemoglobin glycation. Our final recommendation is a new variant of the famous "Joslin troyka" (Joslin 1953).

- "Time in range", according to CGMS or FLASH monitoring.
   (In T2DM results of carefully pursued self-monitoring are also sufficient).
- 2. Frequency and severity of hypoglycaemic episodes.
- 3. HbA<sub>1c</sub> results measured by certified methods in regular intervals.
   (2 4 times in a year and more often after change of therapy).
   (Use of certified POCT methods are also a possibility)

The integrated evaluation of continuous blood glucose monitoring) measurements, frequency and severity of hypoglycaemic events and results of HbA<sub>1c</sub> measurements should constitute one multidimensional picture helping to achieve the best level of glycaemic compensation in each patients with diabetes mellitus.

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# SCALING-UP STRATEGIES FOR EVIDENCE-BASED PREVENTION AND MANAGEMENT OF DIABETES AND HYPERTENSION IN SOUTH-EAST ASIA

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**Issue:** "Scaling-Up Noncommunicable Diseases Interventions in Southeast Asia" is a project funded by the EU Horizon 2020, coordinated by the University of Groningen and implemented in Indonesia, Myanmar and Vietnam from 2019 to 2022. Its overall aim is to validate scaling up strategies of evidence-based diabetes (DM) and hypertension (HT) prevention and management.

**DESCRIPTION:** One of the Work Packages (WP) is coordinated by the Trnava University team. Work of the group focuses on assessing, adapting and implementing DM and HT guidelines to scale up the chain of care from community to primary care facilities. Along with this the team develops materials required for capacity building for primary health care staff. This article aims to recapitulate the first results from this endeavour.

**Lessons:** The process was initiated with a systematic review of evidence on community prevention and its effects in targeted countries. Peer-reviewed papers from national and international sources were assessed along with documents from grey literature. Schemas comparing recommendations from local and international documents were used to discuss specifics for each target country. Education packages are being developed to facilitate the community mobilisation, behavioural change communication and health promotion. They were proposed and developed in close partnership with local partners and now are ready for online piloting.

**CONCLUSIONS:** It is expected that the WP will foster integrated capacity building to professionals in primary health services and community institutions. The results of an ambitious international project so far have confirmed the need for a careful analysis of the situation and respect for local specifics.

Key words: prevention upscaling, diabetes, hypertension, evidence, guidelines, capacity building, South-East Asia

#### Issue

The vision of modern public health is healthy people in healthy communities (Gostin et al 2004). Effective prevention of non-communicable diseases (NCDs) with the support of integrated health services are important components. Three quarters of all NCDs deaths occur in low- and middle-income countries. While countries in Europe struggle with ever-increasing costs of NCDs, Southeast Asian (SEA) countries have developed innovative communities-oriented strategies to curb the epidemic of NCDs in an early phase.

The project Scaling-Up Noncommunicable Diseases Interventions in Southeast Asia (SUNI-SEA) is funded from the EU Horizon 2020. Activities are coordinated from the University of Groningen, the Netherlands and focused on Indonesia, Myanmar and Vietnam from the year 2019 to 2022. Overall aim of the project is to implement scaling-up strategies of evidence-based prevention

and management programmes for diabetes (DM) and hypertension (HT) in underprivileged communities. It also targets validating efficiency and cost-effectiveness of interventions to be used for developing new policies.

The Work Package (WP) on evidence-based interventions is coordinated by the Trnava University team. It is directed to improving and testing evidence-based procedures as well as instruments for prevention and management of HT and DM. Disseminating experiences represents the second main component of the WP portfolio. It is based on good quality of education provided by international teams.

This article aims to recapitulate the first results from this endeavour.

#### Description

Scaling up health promoting interventions designed to reduce the incidence of NCDs in whole communities is

basic approach implemented. Beneficial outcomes are expected to be observed in the form of reduced risky behaviours of community members, namely tobacco, diet, and physical inactivity. Three attitudes to expansion of prevention activities are considered: selection of geographical area, defining the package of service and facilitating access to services (SUNI-SEA project overview 2019).

An innovative project design based on the concept of Dissemination and Implementation Research was implemented. There is dramatic shift from an era in which processes of dissemination and implementation were considered to be beyond science. The process in which diverse scientists, practitioners, and policymakers are actively pursuing knowledge on how to accrue the most public health benefit from their scientific discoveries is fostering. (Brownson et al. 2012).

One can consider implementation and scaling-up of interventions as complex processes that are not unique to the health sector. In international cooperation and development organisations, more and more attention is given to complex change processes that take place when projects are being executed. The project makes use of the Theory of Change. This outcomes-based approach applies critical thinking to the design, implementation and evaluation of initiatives and programmes for the purpose of supporting change in broader contexts. Theory of Change offers more comprehensive approach than the logical framework approach and facilitates thorough and effective implementation (SUNI-SEA project overview 2019, Vogel 2012)

Subsequently, approaches projected for the WP activities were setup as: Reviewing the critical success factors concerning sustainability of scaling-up the comprehensive community-based and primary health facility-based programmes (micro-level); Sharing lessons learned from Indonesia, Myanmar and Vietnam for wider implementation of NCDs interventions with an optimal synergy between management and prevention programmes worldwide; and Reviewing and updating global scaling-up and assessment tools, which will be available via international agencies.

To support capacities of health professionals, to educate and build cooperation with existing community initiatives, implementing principles of adult education in combination with specifics of education in health environment, including inclusive leadership as well as relying on the competence model defined for health care professionals should be respected (Frank et al. 2015).

#### Lessons

#### Preliminary results

Situation analysis - epidemiological patterns of hypertension and type 2 diabetes mellitus in targeted SEA countries were documented in the form of three articles ready to be published (Sivco et al., Grendova et al., Pekarcikova, in press). The content comprises a description of existing epidemiologic data on hypertension and diabetes and reported health service capacities including availability of public health specialists. Authors of those papers attempted to point out indicators of trends within the countries. Webinars depicting the findings were provided for an academic audience in Slovakia.

Current evidence and recommendations from guidelines in partner countries were collected and appraised. This was followed with seeking evidence of how guidelines for hypertension and diabetes are implemented and respected in everyday practice. Comparisons to current international standards and recommendations were based on identifying compliances and differences among them. Particularly, at this stage, the research team relies on a sufficient degree of assistance and cooperation with local partners.

The WP project team was involved in capacity building for professionals in primary health care services and community institutions, too. Originally, the intention was to transform evaluated research outputs from the clinical guidelines study to training activities and training modules development. However, in seeking consensus for suitable education activities which reflect the actual needs and structure of basic health staff (BHS) (Saw YM et al. 2019) a modification was needed, because of specifics of the environment in Myanmar.

Information was exchanged with partners – lecturers from the University of Public Health in Yangon (UPH) and representatives of Help Age and Inclusive Self-Help Groups (ISHG) in Myanmar. While the UPH is responsible for education of BHS, HelpAge is involved in strengthening social protection and building communities through ISHG (HAIM - HelpAge International Myanmar 2020.). Finally, the managerial soft skills training was proved to be a priority. Training modules were developed in close cooperation with local partners. Three specific areas - Community mobilisation, Behavioural change communication and Health promotion were agreed to address through elaborating suitable training tools. Attention was paid to the monitoring and evaluation tools to measure outcomes of educational activities.

It was agreed that the training is delivered in the form of webinar series for trainers. BHS will be trained in the field. The decision was influenced also by existing pandemic situation. The ZOOM platform in combination with the MOODLE platform are used as repositories of educational materials. Educational materials in the form of PowerPoint presentations and a user manual with a broad list of recommended literature are accessible for both - trainers and participants. It is assumed that the educational approaches and materials already developed could be used in other SEA project countries and for education purposes at our university as well. The reader will be edited and peer reviewed and will be offered to all partners in electronic format.

#### Discussion

During the progression of the project, which has not been without unexpected changes, several interesting observations can be shared so far. Based on an initial literature review, inspirational findings were in approach to NCDs prevention. The cooperation with pharmacies and pharmacists turned out to be an effective tool. The significant role and commitment of nursing and public health students have been mentioned in several publications from the SEA region. Also, it was found out that NCDs are becoming a problem not only for urban but also for remote communities e.g. tribes in northern Thailand (Duangtep et al. 2010). Attention to monitor economically deprived groups and their participation in diseases prevention was observed in Singapore (En et al. 2011).

The WP team was also not surprised by the information about developed community activities in the SEA project countries aimed at promoting physical activity, healthy eating and basic screening for NCDs. However, closer cooperation among community centres and healthcare providers is proving to be an important area for intervention. Education and training supported integrated care is necessary and further steps are expected in this direction.

Management of the SUNI-SEA project provided the Trnava University team with a challenging experience in familiarisation with principles of Implementation research and Change management within multicultural project environment. Mechanisms for coherence and cooperation among all stakeholders and individual work packages were embedded in the project management from the beginning.

The need for such an approach was confirmed in WP activities, when it was necessary to react to turbulent

changes inclusive reaction to the stressful political development. We understand, that change processes are not linear, often iterative, and difficult to predict.

It is also important to patiently seek consensus in defining common goals for planned project activities. We had such experience in planning of common educational activities, too. Establishing and supporting smooth interindividual communication and cooperation was proved as a successful strategy. Transfer the formal declaration of cooperation to joint performance of tasks is vital. This applies to international teams, but involvement of PhD as well as Master' program students into project activities proved to be useful, too.

Finally, experiences gained from activities and project management in geographically distant countries dependent on online contacts exclusively, is undoubtedly specific experience. Information and communication technology help in the progress of project activities during COVID-19 pandemic without discussion, but there are significant obstacles, too. Replacing face-to-face contacts in cooperating in foreign languages and cultures makes the project more difficult. A similar situation is in providing interactive training of skills.

#### **Conclusions**

The vision of the SUNI-SEA project is to develop a set of evidence-based guidelines and instruments that can be used in South-East Asia and worldwide to scale-up hypertension and diabetes prevention and management programmes.

The project team faces not only advantages but also limitations of work in a broad international environment. Barriers were envisaged; however, pandemic and even political instability need to be overcome.

The results so far have confirmed the need for a careful analysis of the situation and respect for local specifics. This is particularly evident in efforts to introduce evidence-based practice approaches. Progress is not possible without obtaining the consensus of numerous stakeholders.

Fewer barriers and better acceptance of potential cooperation are for education and training, especially in the development of soft managerial skills. But even here, it is necessary to build on the existing capacities structure and roles of health professionals. Constant challenge is to harmonize community activities and existing primary care services. Also, online education proved to be promising.

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# INTEGRATED MANAGEMENT OF TYPE 2 DIABETES MELLITUS (T2DM): RECOMMENDATIONS FOR ESTABLISHING NATIONAL DIABETES REGISTRY AT HEALTH AND WELLNESS CENTERS IN INDIA

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**Issue**: Diabetes is a rising burden in India. The aim of this paper is to advocate establishing a National Diabetes Registry to capture disease data for better population management of diabetes. It also deals with using recently established Health & Wellness Centres (HWCs) in India as ideal platforms for this, as well as to integrate traditional health practices for better management of Type 2 Diabetes Mellitus (T2DM) at primary levels of healthcare.

**DESCRIPTION**: This paper is based on available secondary literature. The authors thoroughly reviewed Diabetes Registries in two Indian states of Goa and Puducherry; policies pertaining to Ayushman Bharat, and peer reviewed research papers focusing on importance of Yoga in preventing T2DM.

**Lessons:** A phased roll out of National Diabetes Register is envisioned at HWCs. By using HWCs for data collection, and a single MIS linking HWCs at multiple levels, disease data can be captured, analysed and used for policy generation. Counselling at HWCs regarding incorporation of Yoga and traditional eating patterns by beneficiaries can contribute to better clinical outcomes in T2DM patients.

**CONCLUSIONS:** NDR is envisioned to promote data-driven policies regarding T2DM by analysing epidemiological data for better clinical outcomes. Additionally, HWCs can act as integrating centres by focusing on long ignored components of health promotion and disease prevention to provide better management of T2DM at primary levels.

Key words: diabetes, health & wellness centres, ayushman bharat, diabetes register

#### Issue

It is well-established that diabetes is a global burden and diabetes prevalence has been rising in low and middle income countries (Tabish 2007). According to the American Diabetes Association, >75% of people with diabetes will reside in developing countries by the year 2025, as compared with 62% in 1995 (King et al. 1998). According to the WHO, India will rank first among the top 10 countries of the world, with 79.4 million people suffering from diabetes, by 2030.

According to a study conducted by Tripathy JP in 2016, the total deaths in India attributed to diabetes increased from 0.98% in 1990 to 3.1% in 2016. There is also great inter-state variation in the prevalence of T2DM-it being higher in the Southern states of Tamil Nadu, Kerala, Goa, Andhra Pradesh & Telangana (Tandon et al. 2018). Northern states of Punjab, Uttarakhand, Jammu &

Kashmir, Haryana, Sikkim and the Andaman & Nicobar Islands have the highest prevalence of DM in the country (Tandon et al. 2018).

There are multiple challenges faced by Indian diabetics. While population management of the disease is still nascent due to unavailability of data-driven policies targeting better clinical outcomes, there is also a very low sense of importance of screening for the disease at the primary level. Additionally, the disease is rarely managed at the primary level, resulting in patients presenting at secondary and tertiary centres with complications, leading to worse clinical outcomes. Due to the overwhelmed state of Indian public healthcare institutions, patients often seek private healthcare which drives up their out-of-pocket expenditure. More importantly, maintenance of basic healthcare statistics and data related to non-communicable diseases (NCD) at the primary healthcare level is very limited. Even at secondary and tertiary levels, there are no

organized health records of patients, other than fragmented documentation from a handful of tertiary care institutes of India. Even if hospital records are available, they are centre-specific, and are not integrated enough to drive public health policy generation related to T2DM.

#### **Description**

Disease registries are special databases that contain information about people diagnosed with a specific type of disease (Glicklich et al. 2014). Population based diabetes registries are available in countries such as Sweden, initiated in 1996 and one of the largest NDRs in the world (Hallgren Elfgren et al. 2016), Denmark (Jørgensen et al. 2016), Saudi Arabia (Al-Rubeaan et al. 2013), Singapore (Heng et al. 2010), and Malaysia (Tai 2018). It is the authors' logical conclusion that these registries have been instrumental in collecting, analysing and interpreting diabetes data, and using it to develop policies that have yielded better clinical outcomes for diabetic patients in their respective nations.

Presently in India, there are only 2 regional population based diabetes registries available in the states of Goa and Puducherry. The Goan Registry was developed by Novo Nordisk Education Foundation under the "Changing Diabetes Barometer Project" for the Govt. of Goa where 19,021 diabetes patients were registered who were undergoing treatment in Govt. hospitals. According to the report published by National Health Mission of Goa, the data collected and analysed from the register enabled the

Govt. of Goa to develop stronger policies for diabetes management. They developed newer strategies for early diagnosis, developed a dedicated cadre of health professionals called "Diabetes Surveyors" at health centres for disease management and enrolment of patients into the registry, and designed creative IEC campaigns for awareness generation among the masses.

According to the research published by Lakshminarayan et al (2017), a diabetes registry was developed in six primary healthcare centres in accordance with the Directorate of Health Services (DHS) in Puducherry. 2,177 patients with diabetes were registered out of 2,948 patients attending public chronic disease clinics in the state. The available literature spoke about the process of establishing this registry in Puducherry, and how it provided the DHS with a unique scope of scaling it into a State-wide registry, performing a house-to-house enumeration for data collection and advocating for developing a dedicated MIS for diabetes management.

Ayushman Bharat, which literally translates to "Longevity to India", is India's vision to achieve Universal Health Coverage (UHC), and has 2 components: the first is the ambitious Prime Minister's National Health Protection Mission, which assures 100 million poor and vulnerable Indian families an insurance cover of INR 500,000 (roughly 6000 euro), per family per year for secondary and tertiary care hospitalization and treatment. The scheme is technology driven, with a single large database created for all transactions. The scheme has connected 18,000 empanelled healthcare providers within the country to



#### Sweden:

Initiated in 1996

One of the largest NDRs in the world 40% of all diabetes patients were registered by 2005



#### Denmark

The Danish Adult Diabetes Registry
In 2014, DADR included data from a total of 70,826



#### Saudi Arabia:

Saudi National Diabetes Registry Operational since 2001

84,942 patients registered till date



#### Singapore:

Singapore National Healthcare Group Diabetes Registry

Established in 2007 170,513 patients until 2008



#### Malaysia

National Diabetes Registry (NDR) of Malaysia Established in 2008

22,055 patients are covered

Figure 1 Population based Diabetes Registries in the world

a single transaction management system which provides hospitals and the (Federal and State) Governments access to patient information, and treatment details (including referrals, deaths or any other change in patient status).

The second component is the development of 150,000 Ayushman Bharat Health & Wellness Centres (HWC) across the country to provide comprehensive primary and secondary care, focusing specifically on NCD, amongst other services. In February 2018, the Government of India decided to upgrade its two lowest levels of public health centres-the Sub-Health Centres and Primary Health Centres by transforming them into HCWs. The delivery of universal comprehensive primary health care, through HWCs is envisioned to bring services closer to the communities and address the needs of the most marginalized populations of the country.

#### Lessons

After studying the systems of Goa & Puducherry, with a basic knowledge of other systems of the world, the authors conclude that for effective management of diabetes, developing a National Diabetes Register (NDR) is the need of the hour for India. Political will has been established in the form of the National Health Policy 2017 which aims to "Reduce premature mortality from cardiovascular diseases, cancer, diabetes and chronic respiratory diseases by 25% by 2025". A phased establishment of the NDR is envisaged by the authors where process and outcome indicators may be selected from literature available on other registries of the world. The NDR, like the registry of Singapore (Toh et al. 2009), is envisioned to provide data on population

demographics, epidemiological disease variations, current treatment practices, and compliance to existing treatment guidelines. Publicizing the registry and establishing necessary channels for access to data would also be an essential step in implementation (Lakminarayan et al. 2017). Electronic health records and hospital based registers of stakeholders such as Medical Colleges and large private sector hospitals would be essential building blocks for this exercise. Questions about data security and privacy would need to be raised and addressed on priority.

Currently, the expenditure on health by India is 1.5% of GDP (Matthew 2018). However, the National Health Policy of 2017 states that the government would be increasing the percentage of health expenditure of GDP to 2.5% by 2025 (NHP 2017). With strong political commitment and enhanced health budget allocations, it is evident that tackling the increasing burden of NCDs in the country is becoming a priority for Indian policy makers. Hence the authors suggest that HWCs, with their newly upgraded infrastructure and dedicated human resources, act as ambassadors for a phased roll out of the proposed National Diabetes Registry. As NHPM has already proven, it is possible to link more than 18,000 health facilities (both public and private) with a central server as a central database. A similar MIS can be created to generate a National Diabetes Registry, with a dedicated Diabetes Dashboard for visualization of disease characteristics, epidemiological trends, and data regarding quality indicators of diabetes care.

The phased roll-out for the proposed NDR in HWCs is illustrated below:

### Phase 1 Data Collection

- Diabetes registration counter at HWCs
- Registration diabetes patients with unique ID
- Data collected under following heads:
- Demographics
- Risk factors
- Disease and treatment details glycemic control
- •End-organ disease data.
- •Referral details

## Phase 2 Integrating MIS

- Developing frameworks for reporting to district and state NCD cells
- Details of patient, glycemic control, referrals and compliance to treatment
- •Diabetes Dashboard:
- Number of patients achieving glycemic control
- Number of patients screened
- Number of patients who developed complications
- Patient compliance
- Number of referrals

### Phase 3 Achieving Universality

- Designing strategies for better clinical outcomes upon data analysis
- Envisaging patients lost to follow up and/or treatment defaulters
- Developing strategies to involve patients seeking treatment in the private sector
- Addressing questions of cyber security and data privacy

Figure 2 Phased roll-out of the proposed National Diabetes Registry

Building upon the concepts created by Lakshminarayan et al. (2017), Phase 1 can entail getting patients registered. These may be newly diagnosed patients and those coming for regular follow-up at HWCs. Data from government-run NCD clinics may also be integrated. Patients can also be registered by house-to-house enumeration by frontline workers stationed at HWCs (Lakminarayan et al, 2017). Each patient can be given a unique ID (already proposed to be given to each family registered with their local HWCs), and data can be collected under various heads. Phase 2 can focus on developing internal frameworks for monitoring this data and creating reporting pathways to District and State NCD cells under the onus of National Program for the Prevention and Control of Diabetes Cancer and Stroke, where this data can be analysed and collated to be forwarded to the Central NCD Cell. A Diabetes Dashboard can be developed to display epidemiological and patient-wise data of disease progression and glycaemic control which can be visualized by service providers to evaluate trends in disease management, in both their patient as well as the population, to make informed decisions for better clinical outcomes. The 1st and 2nd phases of rollout are also expected to give policy makers the opportunity to develop strategies for better population control of diabetes. An important aspect would be the engagement of private healthcare providers who would be major stakeholders in this initiative.

Other than providing primary healthcare to its beneficiaries, HWCs are also envisaged to focus on long ignored components of health promotion and disease prevention (Operational Guidelines-HWCs 2018). Promoting lifestyle modifications by incorporating established Indian practices such as Yoga, and advocating for traditional dietary patterns are supposed to be one of the key performance indicators of HWCs. It is well-established that some ancient Indian practices are still as relevant as they were thousands of years ago. Extensive research has been conducted which concludes that various psycho-neuro-endocrine and immune mechanisms are involved in the beneficial effects of yoga on diabetes (Raveendran et al. 2018). Studies conducted in various social settings have proven that Indians consuming regional, locally grown, traditionally prepared meals have a reduced risk of developing chronic lifestyle diseases (Green et al. 2016). A Systematic Review of Dietary Pattern in India published in the British Journal of Nutrition suggests that a diet high in fruits, vegetables, pulses and nuts was associated with lower cholesterol, indicating that more traditional diets may have a healthier profile (Green et al. 2016). Promoting physical activity by providing licensed yoga instructors at all 150,000 HWCs will be an essential building block in primary prevention of this disease. Education about traditional eating patterns by service providers and frontline workers will be an important landmark in diabetes care for their patients. Hence HWCs can serve as a two-fold integration centre for T2DM management-being an integral data collection point for NDR as well as promoting traditional lifestyle practices that would aid in achieving glycaemic control by weight regulation, physical exercise, and hormonal balance, thus resulting in better management of T2DM at the primary level.



**Figure 3** Contribution of HWCs towards integrated management of T2DM

#### **Conclusions**

Diabetes can only be managed if its management is seen as parts of a whole, instead of the fragmented approach that is currently being undertaken. Diabetes cannot be effectively managed only with allopathic medication nor can it be managed solely with physical activity and dietary modifications. Federal commitment for establishing an NDR for data-driven T2DM policy generation would be a cornerstone achievement in diabetes care. Central agreement for data driven policy generation for T2DM obtained from national and state level real-time patient data, targeted approach by balancing disease management with counselling pertaining to lifestyle modifications and advocacy for inter-departmental coordination and coalition between the various ministries that will be important stakeholders in this exercise comprise the three pillars of the integrated management of T2DM. Combining modern medicine with traditional health practices would be

beneficial for patients who can then effectively manage and control T2DM by gaining the impetus to modify their lifestyle. Clinicians and policy makers of the country must realize that holistic health is the ultimate goal that has to be achieved for any country to be truly "Ayushman". By combining the powers of modern medicine with traditional health practices, and using the available infrastructure for undertaking logical documentation like developing nationalized disease registries, service providers and patients are envisioned to effectively manage and control T2DM.

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## SECTION 3

Improving health outcomes and quality of care in chronic conditions

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# ZDROJE INFORMÁCII PACIENTOV SO SRDCOVO-CIEVNYMI CHOROBAMI V KLINICKEJ PRAXI

## SOURCES OF INFORMATION FOR PATIENTS WITH CARDIOVASCULAR DISEASE IN CLINICAL PRACTICE

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**Úvop:** Vysoký nárast mortality u pacientov so srdcovo-cievnymi ochoreniami a klinická prax poukazujú na nedostačenú informovanosť o túto skupinu ľudí a s tým súvisiacu non-compliance s predpísanou liečbou. Cieľom príspevku je poukázať na zdroje získavania informácii u pacientov so srdcovo-cievnymi chorobami v súčasnej klinickej praxi.

**Metódy:** Súbor tvorilo 878 pacientov so srdcovo-cievnymi chorobami. Zber dát prebiehal dotazníkovou metódou. Na vyhodnotenie dát boli použité metódy deskriptívnej štatistiky.

**VÝSLEDKY:** V nami sledovanom súbore uviedli pacienti, že najčastejším zdrojom poskytnutých informácii súvisiacich s ich ochorením bol lekár špecialista – kardiológ 67.5% (n=523). Sestry pracujúce v nemocničných zariadeniach sa na poskytovaní informácii z pohľadu pacienta podieľali len v 4.2% (n=24) zastúpení. 72.3%(n=390) respondentov nezískalo žiadne informácie z letákov, brožúr a časopisov pričom sú tieto zdroje považované za významný edukačný materiál. **ZÁVER:** Zvyšovanie informovanosti pacientov o prevencii a liečbe srdcovo-cievnych chorôb je jedným z kľúčových zámerov štátnej politiky zdravia. Výsledky poukazujú na potrebu zlepšenia kooperácie a efektivity poskytovania informácii týmto pacientom aj stimulovaním aktívneho prístupu v oblasti edukácie zo strany sestier.

Kľúčové slová: pacient, srdcovo cievne ochorenia, zdroje informácii, lekár, sestra

**INTRODUCTION:** The high increase in mortality in patients with cardiovascular disease and clinical practice point out the lack of information for those patients which is associated with non-compliance of prescribed treatment. The aim of the paper is to point out the sources of obtaining information in patients with cardiovascular diseases in current clinical practice.

**METHODS:** The sample consisted of 878 patients with cardiovascular diseases. Data collection was performed by the questionnaire method. Descriptive statistics methods were used to evaluate the data.

**RESULTS:** In our sample, patients reported that the most common source of information provided related to their disease was a specialist physician - cardiologist 67.5% (n = 523). Nurses working in hospital facilities participated in the provision of information from the patient's point of view in only 4.2% (n = 24) representations. 72.3% (n = 390) of the respondents did not obtain any information from leaflets, brochures and magazines, although these sources are considered as the important educational material.

**CONCLUSIONS**: Raising patients' information about the prevention and treatment of cardiovascular disease is one of the key objectives of public health policy. The results point out to the need to improve the cooperation and effectiveness of providing information to these patients also by stimulating an active approach to patients' education by nurses.

Key words: patient, cardiovascular diseases, sources of information, doctor, nurse

#### Úvod

Štatistické údaje z európskych krajín vrátane Slovenskej republiky naznačujú, že preventívna starostlivosť nielen sekundárna, ale aj primárna, v oblasti kardiovaskulárnych ochorení je nepriaznivo nízka. Mnohí pacienti po hospitalizácii na tieto ochorenia nedodržiavajú odporúčane zmeny životného štýlu, nepoznajú rizikové faktory a nedodržiavajú predpísané farmakologické i nefarmakologické liečebné intervencie.

Podľa súčasných medicínskych poznatkov na vzniku a rozvoji kardiovaskulárnych ochorení sa podieľa veľké množstvo rizikových faktorov, pričom platí, že čím je ich viac, tým skôr ochorenie vzniká a rýchlejšie sa rozvíja. Je možné ich rozdeliť z rôznych hľadísk. Najviac v popredí je rozdelenie na tie, ktoré nie je možné ovplyvniť životným štýlom a zmenou správania a na tie, ktoré sa dajú ovplyvniť rôznymi preventívnymi opatreniami (Studenčan 2014, Piepoli et al. 2016). K prevencii na národnej úrovni prispieva aj vládou schválený Národný program podpory zdravia, ktorého súčasťou je "Strategický rámec starostlivosti o zdravie pre roky 2014 – 2030", a v neposlednom rade Národné akčné plány, ktorých súčasťou sú programy podporujúce zdravie, ako napr. Národný program prevencie srdca a ciev, Národný akčný plán v prevencii obezity, CINDI program SR (ÚVZ SR 2016). Súčasťou všetkých menovaných dokumentov je edukácia obyvateľstva SR, najmä vyvolanie záujmu obyvateľstva o vlastné zdravie a zmenu postoja k životnému štýlu, zvýšenie zdravotnej gramotnosti, využívanie nových nástrojov informačno-komunikačných technológii. Súčasný súhrn odporúčaní Európskej kardiologickej spoločnosti (ECS) zahŕňa činnosti zamerané na preventívne opatrenia, ktoré zamedzujú rozvoju kardiovaskulárnych ochorení spojených so zvýšenou chorobnosťou a predčasnou úmrtnosťou (Piepoli et al. 2016). ECS podporuje stratégie, projekty a implementáciu preventívnych edukačných programov, ktoré sa zameriavajú na zvyšovanie povedomia obyvateľstva o svojom zdravotnom stave, šírenie informácií a rozširovanie osvedčených postupov a odporúčaní, ktoré môže realizovať tím zdravotníckych pracovníkov. Zdroje získavania informácii pre pacientov sú rôzne. Primárnym zdrojom by mal byť človek s odbornou spôsobilosťou ako je lekár, sestra, fyzioterapeut, asistent výživy. Ďalšími médiami šírenia informácií sú informačno-komunikačné technológie, elektronické informačné zdroje, letáky, brožúry, internetové stránky zdravotníckych zariadení či pacientske portály.

Cieľom príspevku je analyzovať zdroje získavania informácii u pacientov so srdcovo-cievnymi chorobami v súčasnej klinickej praxi.

#### Metódy

Súbor tvorilo 878 pacientov so srdcovo-cievnymi chorobami hospitalizovaných vo Východoslovenskom ústave srdcových chorôb v Košiciach. Na zber údajov sme použili dotazník vlastnej konštrukcie. Vyhodnotenie dát sme realizovali prostredníctvom metód deskriptívnej štatistiky v štatistickom programe IBM SPPS 23.0.

#### Výsledky

Z celkového počtu respondentov (N=878) bol priemerný vek  $57,81\pm 7,58$  rokov. Vekové rozpätie výskumného súboru bolo od 24 do 75 rokov. Súbor tvorilo 60% mužov (n= 527) a 40% žien (n= 351).

V Tabuľke 1 je uvedené zastúpenie respondentov podľa toho, z akého zdroja získali informácie o svojej chorobe, jej liečbe a rizikových faktoroch. V najfrekventovanejšej odpovedi bol uvedení lekár špecialista - kardiológ 67.5% (n=523). Najmenej informácií majú od sestry (4.2%) (n=24), čo považujeme za dôležité zistenie nakoľko sestra je z pravidla osoba, ktorá trávi s pacientom najviac času. V položke "letáky, brožúry, časopisy" sme očakávali vyššiu frekvenciu pretože sú bežne súčasťou čakární a často odporúčaním zdrojom informácií.

Tabulka 1 Zdroje získavania informácií

Zdroje informácií	Frekvencia odpovedí n (%)
kardiológ	523 (67.5%)
internista	311 (31.7%)
obvodný, všeobecný lekár	163 (27.8%)
letáky, brožúry, časopisy	149 (27.6%)
iní pacienti so srdcovo-cievnymi chorobami	33 (6.2%)
sestra	24 (4.2%)

Pre detailnejšie analýzy sme zisťovali, či pacienti v nami sledovanom súbore majú záujem o viac informácií súvisiacich z ich ochorením. V tabuľke 2 uvádzame odpovede respondentov.

Tabulka 2 Záujem o rozšírenie informácii

Možnosti	Frekvencia odpovedí n (%)
mám veľký záujem o ďalšie informácie	29 (2.9%)
mám záujem o ďalšie informácie	102 (11.4%)
mám trochu záujem o ďalšie informácie	178 (20.3%)
nemám záujem o ďalšie informácie	570 (65.4%)

#### Diskusia

O význame poskytovania informácií ako účinnej prevencie kardiovaskulárnych ochorení niet pochýb. V súbore sa ako významným zdrojom javí komunikácia medzi lekárom a pacientom, čo sa zakladá na vzájomnom rešpekte a dôvere. Na túto skutočnosť poukazuje aj Kristová (2020). K podobným zisteniam dospeli aj autori Ankuda et al. (2014), ktorí uvádzajú, že najčastejším zdrojom informácií sú lekári špecialisti a všeobecný lekári.

Súčasným trendom je vzrastajúci záujem pacientov o informácie z prostredia mimo zdravotníckej starostlivosti v podobe internetových stránok alebo pacientskych organizácií. Používanie internetu ako zdroja informácií o zdraví a ochoreniach rastie (Koch-Weser et al. 2010). Podľa štúdie Wong et al. (2014) z 2944 účastníkov čerpalo informácie 28.1% z internetových zdrojov. V našom oslovenom súbore pacientov sme tento trend nezaznamenali. Atlas et al. (2019) uvádza myšlienku smerovanú k lekárom, že internet je pacientmi vnímaní ako rovnako dôležitý zdroj, a že môže pomôcť v ich vzájomnej komunikácii. Je potrebné však myslieť na to, že predpokladmi zlepšenia poskytovania informácií pacientom prostredníctvom internetu je počítačová gramotnosť personálu aj pacientov, adekvátne materiálno-technické vybavenie zdravotníckych zariadení, prístup na internet, kritická analýza zverejňovaných informácií, jazyková korektúra a grafická úprava (Mergečiaková 2020). Písomné zdroje v podobe brožúr a letákov často obsahujú informácie o zdraví v jednoduchom a ľahko zrozumiteľnom jazyku. Tento zdroj informácii v našom súbore označilo len 27.6% pacientov na rozdiel od štúdie Atlas et al. (2019).

Prekvapením pre nás bolo zistenie, že pacienti uviedli sestru ako zdroj informácií vo veľmi nízkej miere. Keďže edukácia je jednou z významných kompetencií sestry je potrebné na tento fakt poukázať a zlepšiť edukačnú činnosť v klinickej praxi. O skutočnosti, že pacienti nemajú dostatočné informácie, vedomosti či presvedčenie o podpore svojho zdravia svedčia aj viaceré zdroje ako napr. Kotseva et al. (2016), ktorí uskutočnili prierezovú štúdiu s názvom EUROASPIRE IV (intervencie v oblasti sekundárnej a primárnej prevencie). Negatívne výsledky tejto štúdie naznačujú, že po infarkte myokardu väčšina pacientov nedokázala prestať fajčiť, nejesť nezdravé potraviny, nemala dostatočnú fyzickú aktivitu a preto viacerí pacienti trpeli nadmernou hmotnosťou alebo obezitou a vysokou prevalenciou diabetes mellitus. Podobné výsledky priniesla aj ďalšia randomizovaná štúdia od O'Brien et al. (2014), s počtom respondentov 585 v intervenčnej a 551 v kontrolnej skupine, kde pacienti po edukácii sestrou v zdravotníckom zariadení počas ich hospitalizácie preukázali lepšie vedomosti ako pacienti bez edukácie.

Medzi iniciatívy medzinárodných organizácií v presadzovaní preventívnych opatrení na populačnej úrovni patrí Rámcová konvencia na kontrolu tabaku, Iniciatíva EU pre obezitu, Globálna stratégia WHO pre výživu, telesnú aktivitu a zdravie a Deklarácia o zdraví srdca z Osaky (Piepoli et al. 2016). V roku 2019 prebiehala pilotná kampaň Občianskeho združenia Hlas nášho srdca s výraznou podporou Slovenskej kardiologickej spoločnosti a masmédií s názvom "Červené ponožky v liečebných kúpeľoch 2019", ktorej cieľom bolo zvýšiť povedomie o srdcovom zlyhávaní, skríningu prvých príznakoch a dôležitosti včasnej diagnostiky. Aktivity tohto druhu je možné taktiež vnímať ako informačný kanál pre pacientov so srdcovo-cievnymi ochoreniami.

#### Záver

Problematike zdravia a zdravotnej výchovy o srdcovo-cievnych ochoreniach je treba venovať neustálu pozornosť, preto informovanosť zohráva v zlepšovaní zdravia dôležitú úlohu, ktorá vedie ľudí k tomu, aby žili zdravším životným štýlom a predchádzali návratu do nemocníc. V kontexte sekundárnej prevencie kardiovaskulárnych ochorení, treba pripomenúť, že hospitalizácie na choroby obehovej sústavy sú najčastejším dôvodom prijatia do ústavnej zdravotnej starostlivosti, predovšetkým na oddeleniach vnútorného lekárstva alebo do špecializovaných nemocníc pre pacientov s kardiovaskulárnymi ochoreniami do tzn. Kardiocentier. Medzi najčastejšie diagnózy v roku 2018, kvôli ktorým boli pacienti hospitalizovaní boli srdcové zlyhanie, mozgový infarkt, chronická ischemická choroba srdca. Z toho najviac úmrtí bolo zaznamenaných na diagnózu srdcové zlyhanie, ktorá je už chronickou formou ochorenia srdca (NCZI 2019). Z týchto skutočností vyplýva, že problematike zdravia a zdravotnej výchovy pacientov s kardiovaskulárnymi ochoreniami treba venovať neustálu pozornosť.

#### **Poďakovanie**

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#### COLITIS -

#### NEW POSSIBILITIES OF PREVENTION AND TREATMENT

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**BACKGROUND:** In this study was investigate the effect of the probiotic strain *Lactobacillus plantarum* LS/07 and prebiotic inulin on the activity of  $\beta$ -glucuronidase, transcription nuclear factor kappa B (NF $\kappa$ B), myeloperoxidase (MPO), cytokine levels (IL-6, IL-8, IL-13), and counts of coliforms and lactobacilli in rats with dextran sulphate sodium (DSS) induced acute colitis.

**METHODS:** Sprague-Dawley rats were divided into groups: control (CG), acute colitis (AC), prebiotic (AC+PRE), and probiotic (AC+PRO).

**RESULTS:** Dextran sulphate sodium induced inflammatory process in the colonic tissue, increased the activity of  $\beta$ -glucuronidase (p<0.05), increased counts of coliforms, decreased lactobacilli counts (p<0.05), and activated production of the measured indicators NFkB, MPO, IL-6, IL-8, except of IL-13. Diet supplemented with *L. plantarum* and inulin alleviated DSS induced inflammatory process by inhibiting production of IL-6, IL-8, activities of NFkB and MPO, and by stimulation of IL-13.

**CONCLUSIONS:** These results indicate that the dietary intake of *Lactobacillus plantarum* LS/07 and inulin suppressed the expression of markers playing an important role in the inflammatory process, which predisposes their use in prevention or treatment of acute colitis.

Key words: colitis, probiotics, prebiotics, gut microbiota, prevention

#### Introduction

Ulcerative colitis (UC) a subtype of inflammatory bowel disease (IBD) is a chronic, idiopathic inflammatory disease that affects the colon and is characterized by relapsing and remitting mucosal inflammation (Ungaro 2017). UC patients mostly present blood in the stool and diarrhea. The multifactorial pathophysiology of UC includes genetic predisposition, epithelial barrier defects, dysregulated immune responses, microbial dysbiosis, and environmental factors (Ramos 2019).

High morbidity, serious early and late complications with potential disability, shortening of life and a significant reduction in the quality of life of patients with chronic diseases including colitis are the reasons for the search for new options for prevention, rational diagnosis and treatment. Disruption of the bacterial microbiota of the digestive tract and long-term action of negative factors causing the inflammatory process which stimulates the development of the tumour process play an important role. In the long run, alternative or supportive treatment aimed

at improving the overall health of the patient plays a key role. Modulation of the digestive tract microbiota by natural food ingredients / products represents a benefit that prevents the digestive tract from being colonized by bacteria that promote inflammatory changes, which contributes to preventing the development or in the treatment of colitis. In general, the first approach with UC usually involves dietary modification of bacterial flora, the use of probiotics and prebiotics may attenuate the inflammatory process and prevent relapses and maintenance of remission in ulcerative colitis.

The aim of the presented study was to obtain information regarding the effects of the probiotic *Lactobacillus plantarum* LS/07 and prebiotic inulin on the activity of  $\beta$ -glucuronidase and counts of coliform and lactobacilli in fresh caecal digesta, cytokine levels (IL-6, IL-8, IL-13), transcription nuclear factor kappa B (NFkB) and myeloperoxidase (MPO) activities in the colon tissue and blood samples of rats with dextran sulphate sodium (DSS) induced acute colitis.

#### Methods

Animals: Male Sprague-Dawley rats (n = 32) 7 weeks old were used in experiment conducted in accordance with the principles of the Slovak Republic for the Care and Use of Laboratory Animals and approved by the Ethical Committee of the Faculty of Medicine of PJ Safarik University in Kosice (Ro-1136/14-221). The rats were randomly assigned to groups: control group (CG) received the conventional MP-OŠ-06 feed (Snina, Slovak Republic) at an interval of 14 days; the acute colitis group (AC) received the conventional feed without DSS at an interval of 7 days followed by 7 days of feed with DSS; the prebiotic group (AC+PRE) received the conventional feed supplemented with prebiotic inulin (BeneoSynergy 1, ORAFTI, Tienen, Belgium) at a dose of 80 g/kg feed without DSS at an interval of 7 days, followed by 7 days of the same feed with DSS; and the probiotic group (AC+PRO) received the conventional feed with the probiotic Lactobacillus plantarum LS/07 given in pasteurized milk containing 0.5% fat at a daily dose 1.5×109 CFU/1 ml, without DSS at an interval of 7 days, and then for 7 days with DSS.

Colitis was induced using DSS (molecular weight 40 000, TdB Consulting AB, Uppsala, Sweden) added to drinking water at a final concentration of 5% (wt/vol) for 7 days. Controls were all time-matched and consisted of rats receiving normal drinking water only. The DSS solution was replenished daily and mean DSS consumption was noted per cage at the end of the 7-day treatment.

All animals had free access to water and feed. Animal weights and clinical monitoring of the health status were recorded daily. After 14 days of consuming the experimental diets, the animals were euthanized under anaesthesia Zoletil (Virbac S.A., France) administered at a dose of 50 mg/kg body weight with xylazine (Riemser, Germany) at a dose of 15 mg/kg bodyweight, intramuscularly). Blood samples were drawn by cardiac puncture to measure selected indices. Caecal and tissue samples from the colon were recovered for biochemical and immunological analyses.

Disease Activity index: The disease activity index (DAI) is the combined score of animal weight loss, stool consistency and bleeding in stool. Stool probes were tested to evaluate rectal bleeding using HemoFEC test (Roche Diagnostics, Slovak Republic). All indices were assessed on a scale from 0 to 3 or 4, the maximum score was 10.

These indices were each assigned a score and utilized to calculate an average daily disease activity index score for each rat as previously described (Vasina 2010).

Biochemical, microbial a immunological methods: The probiotic strain of Lactobacillus plantarum LS/07 was isolated from rectal human swabs (Strojný 2011). The activity of β-glucuronidase (β-GLUCUR) enzyme was measured in fresh caecal digesta (Juskiewicz 2002). Samples of blood were centrifugation for 15 min at 1 000  $\times$  g, removed serum samples were stored at -20 °C. Tissue samples from the entire colon were rinsed in ice-cold PBS and stored at -20 °C. All endpoints were measured by ELISA method as follows: NFκB in tissue by USCN Life Science, Inc., USA; IL-6 in blood and tissue by eBioscience, IL-8 and IL-13 in tissue by Cusabio (Biotech Co., China), and MPO in tissue and blood by BlueGene (Biotech Co., China). The final values of each indicator were measured on the Synergy H4 multiplate reader (BioTek Instruments, Inc. USA). The data were expressed as mean ± standard deviation (S.D.). One-way analysis of variance and Tukey test (MINITAB for Windows 11.21) was used to evaluate significance of differences between the control and experimental groups. Differences were considered significant at p < 0.05.

#### Results

The maximum DAI score = 6.50 was in the AC group, in group AC+PRE was decrease = 4.13 and AC+PRO = 3.50. Changes in the monitored indices correspond to the changes in weight as well as the results of the DAI score. Within a short experimental period, preventive dietary supplementation with prebiotic inulin and Lactobacillus plantarum LS/07 positively decreased the activity of  $\beta$ -glucuronidase which is believed to be a biomarker of increased risk of neoplasm. The activity of  $\beta$ -glucuronidase was significantly increased (p<0.05) in group AC. Lactobacillus plantarum LS/07 and inulin positively reduced its activity (p<0.05), (Table 1). Acute colitis elevated (non-significantly) the number of coliforms and significantly (p<0.05) decreased the number of lactobacilli in group AC compared to the control group (Table 1). Table 2 shows changes in NFκB and MPO activities in serum (s) and colon tissue (t). Serum and tissue cytokine levels of IL-6, IL-8 and IL-13 in CG, AC, AC+PRE and AC+PRO groups are shown in Table 3.

**Table 1** Activity of  $\beta$ -glucuronidase and total counts of lactobacilli and coliform

Parameters	CG	AC	AC+PRE	AC+PRO
β-GLUCUR µmol/min/g	$0.14 \pm 0.02^{b}$	$0.54 \pm 0.05^{a}$	$0.49 \pm 0.18^{a}$	$0.39 \pm 0.18^{a}$
Lactobacilli log <sub>10</sub> CFU/g	7.78 ± 0.17 <sup>a</sup>	$7.15 \pm 0.90^{b}$	$7.31 \pm 0.45^{\circ}$	7.40 ± 0.44 °
Coliforms log <sub>10</sub> CFU/g	$5.18 \pm 0.56$	$5.74 \pm 1.03$	5.51 ± 0.77	$5.19 \pm 0.57$

The data are presented as mean ± standard deviation (S.D.), a.b.c – values in a row sharing different letters are statistically different (p<0.05)

Table 2 NFkB and MPO activities in serum (s) and tissue (t)

Parameters	CG	AC	AC+PRE	AC+PRO
NFkB(t) ng/mL MPO (s)	41.73 ± 7.41 <sup>b</sup>	60.21 ± 10.31 <sup>a</sup>	$11.65 \pm 1.32^{\circ}$	$50.52 \pm 17.56^{a,b}$
pg/mL MPO (t)	$53.38 \pm 30.53^{b}$	98.78 ± 18.26 <sup>a</sup>	88.35 ± 10.49 <sup>a</sup>	$69.94 \pm 32.95^{a,b}$
pg/mL	362.53±71.55a,b	$424.12 \pm 73.46^{a}$	296.96 ± 63.78b	$346.04 \pm 92.13^{a,b}$

The data are presented as mean  $\pm$  standard deviation (S.D.), a.b.c – values in a row sharing different letters are statistically different (p<0.05)

Table 3 Cytokine levels of IL-6, IL-8 and IL-13 in serum (s) and tissue (t)

,	<u>,                                      </u>			
Parameters	CG	AC	AC+PRE	AC+PRO
IL-6 s pg/mL	49.31 ± 15.83 <sup>a,b</sup>	61.89 ± 15.33°	$45.83 \pm 9.99^{a,b}$	$43.00 \pm 6.09^{b}$
IL-6 t pg/mL	47.00 ± 8.53 <sup>b</sup>	62.65 ± 12.19 <sup>a</sup>	48.77 ± 5.31 <sup>a,b</sup>	41.27 ± 14.88 <sup>b</sup>
IL-8 t pg/mL	$37.78 \pm 7.42^{\circ}$	50.12 ± 7.32 °	$47.67 \pm 8.49^{a,b}$	$39.34 \pm 5.39$ b,c
IL-13 t pg/mL	62.81 ± 5.99°	47.87 ± 6.91 <sup>b</sup>	57.93 ± 11.26 <sup>a,b</sup>	$53.20 \pm 14.52^{a,b}$

The data are presented as mean  $\pm$  standard deviation (S.D.), a,b,c - values in a row sharing different letters are statistically different (p<0.05)

#### **Discussion**

Epidemiological and experimental studies have suggested that diet is one of the environmental factors that contributes to the onset and pathophysiology of ulcerative colitis (Aggeletopoulou 2019, Keshteli 2019, Mack 2011). For UC, interactions are expected between genetic, immunologic, microbial and environmental factors, while the exact aetiology and pathogenesis are still unclear. Chronic inflammation is known to lead to derangement in the signalling processes and to a local microenvironment described as lying somewhere between pre-cancerous stromal cells and cancer cells, even as the details of the steps in the transformation to a cancer cell are not completely understood (Nathan and Ding 2011). Signalling pathways triggered by NFκB play a key role in the colonic inflammation development. The NFκB regulates the expression

of various cytokines and modulates the inflammatory processes characteristic of IBD (Atreya 2008).

In our study, the activity of NF $\kappa$ B in colon tissue samples was markedly increased in group AC (p<0.05) which may provide a sensitive means of assessing the state of activation of the mucosal immune response. Inulin treatment suppressed the activity of critical transcription factor in mucosa cells (p<0.05). The application of *Lactobacillus plantarum* LS/07 decreased colon tissue NF $\kappa$ B slightly. Activated NF $\kappa$ B in the acute colitis group significantly activated serum and colon tissue levels of pro-inflammatory cytokine ((IL-6 and IL-8) compared to the control group. Inulin diet intervention in group Pre significantly downregulated the synthesis of proinflammatory cytokines IL-6 (p<0.05) in serum and colon tissue and IL-8 (p<0.05) in tissue compared to group AC. *Lactobacillus plantarum* 

LS/07 significantly downregulated the synthesis of IL-6 and IL-8 (p<0.05) compared to group AC. Inulin and Lactobacillus plantarum LS/07 stimulated IL-13 production thus demonstrating their anti-inflammatory activity and immune enhancing effect. The determination of MPO can be used as one of the non-invasive markers of disease and prediction of relapse, and is also considered as an inflammatory damage marker (Pulli 2013). Increased activities of MPO were found in serum and colon tissue homogenate of rats. Its activity was significantly suppressed by administration of prebiotics and probiotics. The release of MPO correlated with an enhanced local release of the neutrophil activating interleukine-8 (Massodi 2011). Within the short experimental period, the preventive dietary supplementation with inulin and probiotic positively modified the values of observed microorganisms and activity of  $\beta$ -glucuronidase.

#### **Conclusions**

The results of our research show the ability of prebiotic inulin and probiotic strain *Lactobacillus plantarum* LS / 07 to influence the pathophysiological process of acute colitis by suppressing the expression of markers that play an important role in the inflammatory process accompanying colitis and can be use as suitable form of preventing colitis.

#### Acknowledgements

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### INDIKAČNÉ KRITÉRIA REHABILITAČNEJ LIEČBY U PREŽIVŠIEHO ONKOLOGICKÉHO PACIENTA

### INDICATIVE CRITERIA OF REHABILITATION TREATMENT IN CANCER-SURVIVING PATIENTS

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Rehabilitačná liečba je prirodzenou súčasťou následnej starostlivosti o onkologického pacienta v stabilizovanom stave. Tento prehľadový článok je pokusom o náčrt základných symptómov, s ktorými pacient prichádza v súvislosti s narušením štrukturálnej a funkčnej integrity organizmu. Pokúša sa definovať najviac frekventované dysfunkcie a problémy pacienta, pomenovať a klasifikovať subjektívne a objektívne príznaky a stanoviť indikačné kritéria pre použitie širokej škály rehabilitačných postupov a techník.

Kľúčové slova: dysfunkcia, disabilita, onkologický pacient, rehabilitácia

Rehabilitation therapy is a common part of subsequent treatment of a cancer patient in a stabilized phase. This review article is an attempt to outline the underlying symptoms that a patient experiences in relation with structural and functional integrity impairment. We will try to define the most frequent dysfunctions and disabilities of the patient, to name and classify subjective and objective symptoms and to set up indicative criteria for using a wide range of rehabilitation procedures and techniques.

Key words: dysfunction, disability, oncological patient, rehabilitation

#### Úvod

Onkologické ochorenie zasahuje a narúša rôzne dimenzie osobnosti a vedomia pacienta. V súčasnosti je starostlivosť o chronické onkologické ochorenie postavená na komprehenzívnom prístupe a multidisciplinárnej spolupráci. Fyzioterapia a liečebná rehabilitácia v procese znovuobnovenia porušenej funkcie hrá významnú úlohu. Ako 'cancer survivors' (ďalej len preživší) sa označujú všetci pacienti s diagnostikovaným onkologickým ochorením už od momentu stanovenia diagnózy. V užšom ponímaní sa ako preživší častokrát označujú onkologickí pacienti po adekvátnej liečbe, ktorí nemajú aktuálne žiadne známky aktívneho onkologického ochorenia.

#### Popis problému: rehabilitačná liečba u preživšieho onkologického pacienta

Rehabilitácia môže byť indikovaná v rôznych etapách života onkologického pacienta, čo zohľadňuje klasifikácia podľa Dietza (1969) a môžeme hovoriť o preventívnej rehabilitácii - tá predstavuje veľmi včasnú intervenciu s cieľom prevencie rozvoja neskorších následkov spojených s komplexnou onkologickou liečbou (chirurgickou, rádioterapiou a chemoterapiou). Ďalšou možnosťou je obnovujúca (restoratívna) rehabilitácia. Ide o rehabilitáciu v prípade, kedy očakávame plné uzdravenie, účelom rehabilitácie je dosiahnutie plného zaradenia sa do spoločnosti, komunity, školy alebo práce. Treťou oblasťou je suportívna rehabilitácia aplikovaná pacientom, u ktorých základná diagnóza alebo jej liečba viedla

k permanentnému deficitu, a naším cieľom je znovuzískanie funkčnej nezávislosti v maximálnej možnej miere. V neposlednom rade netreba zabúdať ani na paliatívnu rehabilitáciu - ide o pomoc pacientom v pokročilom štádiu ochorenia, kedy intenzívna rehabilitácia nie je možná a účelom rehabilitácie je maximalizovať komfort pacienta. V našich podmienkach však chýbajú jasné indikačné a hodnotiace kritéria rehabilitačnej liečby. V klinickej praxi často vzniká situácia, kedy onkológ nedoceňuje vplyv prebiehajúcich dysfunkcií na kvalitu života preživšieho pacienta. Na druhej strane nedostatočná medziodborová komunikácia vedie k situácii, kedy fyzioterapia neponúkne svoje "služby" príslušnému špecialistovi a takisto pacient nevytvára tlak zdola a nedožaduje sa úplnej úpravy narušenej funkcie.

#### Získané poznatky a odporúčania pre klinickú prax

#### Pozitívne účinky pohybu a imobilizačné zmeny

Pozitívne účinky pohybu na ľudský organizmus sú v dnešnej dobe nesporne dokázané mnohými odbornými štúdiami a metaanalýzami. Pohybová aktivita vytvára celkový tonizačný efekt s vplyvom na všetky systémy tela: obehový, dýchací, imunitný, metabolický, vylučovací, nervovo-svalový, vegetatívny s ovplyvnením celkového psychického stavu. Imobilizačnými zmenami narušené funkčné vzťahy v organizme sú častou príčinou ďalšej symptomatizácie pacienta a nastávajú situácie, keď narušenie funkcie je pre jeho každodenný život viac obmedzujúce ako primárne onkologické ochorenie. V súčasnosti sa komplexicita týchto zmien označuje termínom imobilizačný syndróm. Rozvíja sa už vo včasnej fáze (3-10 dni) po akomkoľvek invazívnom operačnom zákroku. Zvlášť ohrozenou skupinu sú seniori Wawruch et al. 2004. Podcenenie a nezvládnutie tejto fázy môže viesť k prechodu týchto zmien do chronicity a tie vyznamným spôsobom narušia život pacienta a nesporne prispievajú k zhoršeniu kvality života pacienta.

#### Funkčné zmeny a základné prejavy dysfunkcie

Funkčné prejavy sú označované predponou dis-, dys-(dis- lat. roz-, ne-, dys- gr. oslabený, chybný, porušený) (Králik 2015). Vplyv distresu sa prejavuje zvýšenou sympatikovou aktivitou a vedie k dystenzii. Zmena tonusu (napätia) predstavuje základný mechanizmus reflexných obranných dejov, prostredníctvom ktorých sa ľudský organizmus vysporiadava s narušením poriadku a dezorganizáciou v organizme. U pacientov po rakovine prsníka dochádza k zmenám napätia hrudnej apertúry a dystrofii hornej končatiny, ktorá vedie k zníženiu perfúzie krvného axoplazmatického a lymfatického obehu.

Urogynekologické ochorenia sú sprevádzané dysuriou, dysmenoreou a pretrvávajúcou sexuálnou dysfunkciou. Onkologické ochorenia v hrudnej a brušnej dutine vedú k poruchám mobility a motility vnútorných orgánov s prejavmi dysfagie (poruchy prehĺtania), dyspepsie (poruchy trávenia) a dysmotility (poruchy črevnej pasáže). Rakovina pľúc vedie primárne k zníženiu ventilačnej kapacity a vzniku dýchavičnosť (dyspnoe). Expanzívne nádorové procesy v hlavovej dutine alebo spinálnom kanáli vedú k narušeniu citlivosti (dyzestézia) a motoriky (dyskinéza), s prejavmi narušenia riadenia svalového napätia (dystonia). Podľa lokalizácie postihu nervových štruktúr môžeme pozorovať prejavy poruchy rovnováhy (dysbalancia) alebo poruchy reči (dysartria) a ďalšie funkčné prejavy. U týchto prejavov fyzioterapia ponúka širokú škálu overených hodnotiacich a terapeutických techník, ktorými upravuje uvedené poruchy.

#### Symptomatizácia dysfunkcie

Prebiehajúca dysfunkcia často rozhoduje o rozsahu a charaktere symptómov. Narušením pôvodnej symetrie systémom pozitívnych alebo negatívnych spätných väzieb dochádza k stimulácii alebo inhibícii reakcie. V diagnostike sú tieto zmeny označované predponou hyper- alebo hypo-. Základné hodnotiace parametre vo funkčnej medicíne sú tonus (hypertonus-hypotonus), mobilita (hypermobilita hypomobilita), perfúzia, citlivosť, trofika atď. Primárnym symptómom narušenej funkcie je inabilita (neschopnosť). Od inability sa odvíjajú ďalšie symptómy. Najčastejšie u pacientov udávaný a najviac obmedzujúci symptóm je bolesť. Ďalšími symptómami sú parestézie, slabosť, necitlivosť, závrat, poruchy rovnováhy, únava a ďalšie. Pri pretrvávaní symptómov (spinálna úroveň riadenia motoriky) dochádza k rozvoju adaptačných a kompenzačných mechanizmov s vytváraním náhradných pohybových vzorov (podkôrová úroveň) alebo k zmene návykov a uhýbového správania (kôrová úroveň riadenia motoriky).

#### Zmena stereotypov

Pretrvávanie a fixáciu symptómov nachádzame spravidla so zmenami a narušením stereotypov. Základné stereotypy sú dýchanie, stoj a chôdza.

Dýchanie. Dysfunkčný pacient pôsobením bolesti a stresových faktorov vykazuje zvýšenie sympatikovej aktivity. Sympatikotonus zvyšuje úsilie automatizmov a vytvára tenziu v organizme. Narušuje sa nádychovo-výdychová rovnováha. Vzniká inspiračná hyperinflácia, ktorá vedie k zvýšeniu krvného tlaku, zvýšenej reaktivite, únave a vyčerpaniu organizmu. Pridružujú sa poruchy spánku, ktoré prehlbujú vznik-

- nutú dysreguláciu. Poloha počas spánku a odpočinku je ovplyvňovaná vynútenou antalgickou polohou.
- Ďalšou opakujúcou sa činnosťou je transfer (zmena polohy). Otáčanie, posadzovanie a postavovanie sú nevyhnutné pre vykonávanie bežných denných činností a uspokojenie základných potrieb človeka. Pohyb vo vertikále je podmienený kvalitou stoja. Stoj je vyjadrením váhonosnej funkcie. Vekom a ochorením dochádza k poklesu ťažiska a zhoršeniu gravicepcie, propriocepcie (polohocitu a pohybocitu) a balančnej funkcie s vyhasínaním posturálnych reflexov (Jendrichovský 2019).
- Kľúčovým stereotypom, ktorý tvorí základ rehabilitačných programov je chôdza. (Jendrichovský 2019). Dysfunkčný jedinec nemusí zákonite cvičiť, musí sa však hýbať. Chôdzová aeróbna aktivita rôznej intenzity, frekvencie a trvania je nevyhnutná pre kardiopulmonálnu výkonnosť organizmu. Účinky chôdze sú popísané v odstavci imobilizačné zmeny. V súvislosti so špecifickými onkologickými ochoreniami pozorujeme narušenie ďalších vitálnych pohybových stereotypov: prehĺtanie, žuvanie, príjem potravy, komunikácia, úchop, močenie alebo defekácia.

#### Subjektívne a objektívne hodnotenie

Funkčný prístup je charakteristický orientáciou na problém pacienta. Diagnostika a terapia je orientovaná na detekciu problému a kvantifikáciu symptómov dominujúcich v základnom klinickom obraze. V subjektívnom hodnotení získavame základné informácie o prejavoch dysfunkcie. Pre lepšiu orientáciu používame rôzne schematické vyjadrenia lokalizácie symptómov (body chart). Z hľadiska stratifikácie pacientov vzniká potreba kategorizácie symptómov a dysfunkcií. Hodnotiace škály sú aplikované hlavne v súvislosti s bezpečným výkonom praxe. Jedná sa hlavne o údaje subjektívneho vnímania pohybovej záťaže pacienta (Borgova škála, NYHA klasifikácia, mMRC škála a rôzne vizuálno- analógové škály a iné) (Borg G 1998, Gurin a Frankova 2014).

Bezprostredná reakcia na záťaž je hodnotená základnými fyziologickými ukazovateľmi (TK- tlak krvi, TF-tepová frekvencia, SpO2-saturácia kyslíka). Základné funkcie pohybového systému objektivizujeme klinickým, fyzikálnym vyšetrením: inšpekcia, palpácia, auskultácia, vyšetrenie aktívneho, pasívneho pohybu, pruženia kĺbov, špecifické a provokačné testy v zmysle napínacích, distrakčných a kompresných testov. Klinicky je cieľom diagnostiky určiť typ dis-

- funkcie, ktorá dominuje v klinickom obraze. Každá disfunkcia vykazuje špecifické prejavy. Základnými typmi dysfunkcie sú synoviálna, neurálna, mofasciálna, kapsulárna, viscerálna alebo kostná.
- Celková reakcia na pohybové programy je hodnotená rôznymi funkčnými testami. Základným funkčným testom je 6-minútovy chôdzový test (6MWT). Jeho výhodou je hodnotenie integrovanej pohybovej, obehovej a ventilačnej funkcie vo vzťahu k funkčným zmenám a prejavom dysfunkcie. Z hľadiska prežívania pacienta má vysokú výpovednú hodnotu (2002).

Orientácia na problém pacienta je v onkológii vyjadrená záujmom o pocit zdravia a kvalitu života preživšieho pacienta. Dôraz kladieme na sociálno-behaviorálne parametre a hodnotiace škály: mobilita (HHS), únava (MFI-20), spánok (PQSI), adaptácia (GARA), anxieta a depresia (GHQ-28), práca a zdravie (WL), očakávania od liečby (FEX A), fyzickej funkcie (UCLA) a kvality života (SF 36, EQ5D) (Nagyova et al. 2009).

#### Spolupráca onkológa a fyzioterapeuta

Ide o multiodborovú spoluprácu. Pre optimálne fungujúcu spoluprácu v rámci interdisciplinárnej starostlivosti je potrebné vytvoriť bezpečný rámec používaných intervencií a záťaže. Prvou otázkou je samotná indikácia fyzioterapie. Vykazuje pacient kontraindikácie pohybovej a mobilizačnej liečby? Rozhodnutie prináleží onkológovi zodpovednému za celkový manažment liečby ochorenia. Fyzioterapia je stále vnímaná odbornou obcou pod prizmou osteopatie, hraničiaca s alternatívnou liečbou s použitím násilných, mechanických manipulačných techník. V posledných rokoch dochádza v našom odbore k prechodu z mechanického (myoskeletálneho) ku neuromuskulárnemu prístupu. Táto revolúcia vo fyzioterapii priniesla možnosť aplikovať poznatky neurofyziológie bolesti, riadenia pohybu a senzomotorických aplikácií. Výsledkom je určitá elegancia terapie, ktorá je postavená u "hands on" a "hand off" konceptov postavených na metódach taktilnej facilitácie a inhibicie a senzomotorickej integrácie (vid nižšie). Vo vzťahu k spolupráci so špecialistami v onkológii vzniká potreba zavedenia pravidiel indikácie rehabilitačných postupov a stratifikácie rizika. Onkológ stanovuje stupeň rizika, klinicky je potrebné stratifikovať pacientov vo vzťahu k pohybovému, obehovému a respiračnému riziku. Spýtaj sa svojho onkológa na stupeň rizika a svojho fyzioterapeuta na spôsob záťaže resp. pohybu. Pri tomto je potrebné sa zmieniť, že sa stále v praxi uplatňuje pasívny a statický prístup k liečbe, ktorý je často z hľadiska imobilizačných zmien

kontraproduktívny až škodlivý pre pacienta a vedie k terapeutickému nihilizmu. "Aby sme niečo nepoškodili, radšej nerobme nič."

Postupy rehabilitácie a terapeutické možnosti

Na spinálnej úrovni dochádza k designalizácii postihnutého tkaniva resp. oblasti v dôsledku operačnej intervencie, rádioterapie alebo chemoterapie. Mechanicky dochádza k procesom adaptívnej fibrózy tkaniva s narušením visko-elastických vlastností, perfúzie, signalizácie (nocicepcie) a senzomotoriky. Vo včasnej fáze primárne používame senzibilizačné (scitlivovacie) techniky s navodením normalizácie napätia, pohyblivosti a perfúzie tkaniva. Metódou je taktilná facilitácia alebo inhibícia. Prostriedky sú driftovacie techniky a metódy na zlepšenie krvnej perfúzie, lymfatickej cirkulácie alebo axoplazmatického prietoku pri prezentácii neuropatickej bolesti.

Základným princípom fyzioterapie v liečbe je mobilizácia a pohybová liečba. Podľa stanoveného typu disfunkcie aplikujeme špecifický druh mobilizačnej terapie (neurálna, svalová, fasciálna, viscerálna a iné).

Na podkôrovej úrovni, pracujeme s metódami reedukácie základných stereotypov technikami na zlepšenie neuromuskulárnej a antigravitačnej kontroly, metódou reedukácie, dýchania, stoja, chôdze, transferu a pohybových zručnosti. Prioritu ma úprava vitálnych funkcií (obeh, dýchanie, hltanie, vylučovanie, komunikačne a sexuálne funkcie). Úprava senzoriky a signalizácie navodzuje stav normálnej pocitovosti, ktorú integrujeme do somatosenzorickej (telesnej) schémy pohybu.

Na kôrovej úrovni pracujeme s termínom ideomotorika, kde pracujeme s "pocitovosťou" a pohybovým vedomím pacienta. Východiskom sú kognitívne procesy (uvedomenie si dysfunkcie), emočne spracovanie (emócia ako neurofyzický proces) a navodenie behaviorálnych zmien pacienta. Výsledok je preladenie s motiváciou k pohybu a prepojenie uzdravovacích procesov s voľnočasovými aktivitami. Terapia je orientovaná na prijatie zmeny podporu pri prekonávaní bariér ochorenia a prostredia.

#### Záver

Tento článok je pokusom o predstavenie funkčného a holistického prístupu v starostlivosti o pacienta s onkologickým ochorením. Rehabilitácia je prirodzenou súčasťou následnej liečby onkologického pacienta a v procese znovuobnovenia porušenej funkcie hrá významnú úlohu. Jednotlivé metódy fyzioterapie predstavujú pre onkológa v praxi veľmi prínosnú možnosť skvalitnenia života

preživšieho. Kľúčové je včasné rozpoznanie jednotlivých dysfunkcií pacienta a správne indikovanie a následná aplikácia rehabilitačnej liečby predstavuje pre pacienta významný benefit, ktorý znižuje dopad primárneho ochorenia a zlepšuje kvalitu jeho života.

#### **Poďakovanie**

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### PERCEIVED SOCIAL SUPPORT IN PSYCHOTIC PATIENTS AND THE NUMBER OF HOSPITALIZATIONS

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**BACKGROUND:** Social support is an important factor that can have an impact on one's mental health. The role of social support and sustained supportive relationships can help in coping with severe mental illness where patients are more likely to experience social isolation and stigmatization. The aim of our study was to examine the associations between perceived social support and number of hospitalizations in psychotic and non-psychotic patients.

**METHODS:** The sample consisted of 65 patients diagnosed with psychiatric disorders F00-F60, of which 35 were psychotic and 30 non-psychotic patients. The mean age of the group was 41.7±14.0 years (range 20-78), 54% were females. Perceived social support was measured using the Berlin Social Support Scale and Zimet's Multidimensional Perceived Social Support Questionnaire. Statistical analyses included t-tests for two independent samples, Pearson's correlations and Pearson's chi-square tests.

**RESULTS:** We found no statistically significant differences in the level of perceived social support between psychotic and non-psychotic patients (t=1.935; p>0.05). Similarly, perceived social support was not found to be significantly associated with the number of hospitalizations in any group (r=-0.180; p>0.05). Among patients with affective disorders, intimate partner was the most frequent source of social support; whereas among patients suffering from schizophrenic circuit disorder, in the majority of the cases, the closest person was one of the parents (chi-squared = 17.928; p<0.05). **Discussion:** The role of social support and sustained supportive relationships can help in managing severe mental disorders, often associated with social isolation and stigmatization of patient.

Key words: social support, mental disorders, psychosis, hospitalization

#### Introduction

Social support reflects the perception of social resources provided by other people, whether in primary social groups that are small, intimate, informal or in secondary groups, larger ones, where the interaction is regulated by certain rules and hierarchies (Cohen et al. 2001). There is strong evidence linking social support to improving and enhancing mental health (Kawachi et al. 2001, Lakey et al. 2011, Cohen et al. 1985). In this case, social support acts as a positive factor in managing the disease and improves the quality of life of the patient. It has also been shown that social support can in a way act as a "buffer" that protects an individual from experiencing mental health problems in times of life stress and stress (Lakey et al. 2011, Milner et al. 2016, Olstad et al. 2001).

We consider it important to emphasize that in most cases we may also encounter associated somatic disabilities in mental disorders, which may be congenital or acquired

during life, for example due to the side effects of pharmacological therapy. People with long-term, chronic severe mental disorder live with severe and exhausting symptoms that can adversely affect their somatic health, quality of life, and can lead to consequences such as premature mortality, morbidity, and obesity (Quirk et al. 2017). Such consequences of mental illness also contribute negatively to the overall deterioration of the patient's mental state. It is important to emphasize the protective factor of social support for the development of mental disorder, but also the effect of social support in the diagnosis of serious mental illness, which could not be prevented and the subsequent lengthy process of comprehensive health care - adjustment for pharmacological or biological treatment, bridging relapses and subsequent psychotherapeutic and social care. Thus, the role of social support in sustained supportive relationships can help manage a severe mental disorder in which patients tend to experience social isolation and stigmatization (Soundy et al. 2012, Gorczynski et al. 2010, Carless et al. 2009).

The effect of social isolation has consequences in various areas, from the quality of life of patients, through the worsened course of the disease with multiple psychotic symptoms, to more frequent hospitalizations. Their empirical longitudinal study showed that most patients had social support from their immediate family and friends (often fellow patients), with only a small proportion of patients having partners and children. During hospitalization, patients reported as parents social support and close friends as continuous social support in managing the disease (Müller et al. 2007).

This study aimed to focus on description of psychotic and non-psychotic patients in terms of perceived social support (PSS) and their comparison, finding out whether there is a association between the number of hospitalizations and PSS and detection of differences in perception of closest persons of psychotic and non-psychotic patients at the level of individual diagnoses and also in women and men.

#### Methods

#### Study design and settings

This was a cross-sectional design. The research sample consisted of patients of the 1<sup>st</sup> Psychiatric Clinic of the Louis Pasteur University Hospital in Kosice, Slovakia, the Psychiatric Outpatient Clinic in Vranov nad Toplou, and clients of the Rehabilitation Center for People with Mental Disorders ZPP Radost in Kosice. Each patient completed and signed an informed consent form prior to their participation in the study. The study was fully voluntary and included no incentives for participation.

#### Sample, procedure, and measures

Study was performed on a sample of 65 patients aged between 20 and 78 years. The sample included patients with various diagnoses of mental disorders. According to the appropriate distribution of psychotic symptoms, we divided the patients into two groups, with 35 psychotic

and 30 non-psychotic. Data were collected within the basic anamnestic interview with the patient and sociode-mographic information. From the medical records, we retrieved information on the established diagnosis, positive or negative psychotic symptoms and the number of hospitalizations. The patients filled in three questionnaires of perceived social support – the Berlin Social Support Scale (BSSS), Zimet's multidimensional questionnaire (MSPSS) and the Social Support Questionnaire (SSQ) focused on the received social support and from whom the recipient perceives/receives it. Cronbach's alfa for BSSS was 0.90, for MSPSS was 0.94, and for SSQ 0.92.

#### Statistical analyses

We processed the results in IBM SPSS v21 and JASP 0.8.6.0. For comparison, we used a t-test for two independent samples, where the conditions were not met, we used a non-parametric Mann-Whitney U test. We also used Pearson's chi-square to test the independence of the distribution. Finally, we used Pearson's and Spearman's correlation coefficients to determine the associations between variables under study.

#### Results

A baseline description of the study population is given in Table 1 (N=65). The study sample consisted of 65 patients, of which 46% were male. The mean age of patients was 41.7 years (SD=14.05). As to diagnoses, 53.8% of patients were diagnosed with psychotic symptoms and was 46.4% without. The largest part of the sample consisted of patients with diseases of the schizophrenic spectrum (43.1%), the second most frequent diagnosis was affective disorders, which accounted for 30.8%. In the sample, 43.1% of patients were single, 32.3% were married and 13.8% were in a relationship. Secondary education was the most dominant (66.1%). Almost half of the respondents were on a disability pension (44.6%).

**Table 1** Baseline characteristics of the study population (N=65)

		Means ± SD / N (%)
Age in years		41.7± 14.05
Gender	Male	30 (46.4%)
	Female	35 (53.8%)
Psychotic symptoms	Psychotic	35 (53.8%)
	Non-psychotic	30 (46.4%)
Diagnosis	F00 F00	3 (4.6%)
	F10	4 (6.2%)
	F20	28 (43.1%)
	F30	20 (30.8%)
	F40	8 (12.3%)
	F60	2 (3.1%)
Relationship status	Single	28 (43.1%)
	Married	21 (32.3%)
	In relationship	9 (13.8%)
	Divorced	4 (6.2%)
	Widowed	3 (4.6%)
Education	Elementary	10 (15.4%)
	Secondary	43 (66.1%)
	University	12 (18.5%)
Employment	Disability pension	29 (44.6%)
	Employed full-time	12 (18.5%)
	Unemployed	11 (16.9%)
	Retired	6 (9.2%)
	Student	4 (6.2%)
	Employed part-time	2 (3.1%)
	Self-employed	1 (1.5%)

In Table 2 using frequency tables, the results show us that the most frequently reported closest person was their mother, in 32.3%. The second was husband and wife in 20% of cases. In 12.3% of patients, the closest person was their partner (boyfriend/ girlfriend). 1.5% stated that they have no such person.

 Table 2
 The closest person as a source of perceived social support

Source of social Support	N (%)
Mother	21 (32.3%)
Husband/Wife	13 (20%)
Partner	8 (12.3%)
Father	5 (7.7%)
Friend	5 (7.7%)
Sibling	4 (6.2%)
Family member	3 (4.6%)
Children	3 (4.6%)
Colleague/ Ex-partner/ Other	2 (3 %)
No support	1 (1.5%)

 Table 3
 Comparison of perceived social support between psychotic and non-psychotic patients

Questionnaire	Group	N	Mean	SD	t	df	р
DOCC	Non-psychotic	30	54.1	8.5	1.02	63	p>0.05
BSSS	Psychotic	35	49.4	10.7	1.93		
MCDCC	Non-psychotic	30	64.5	15.5	1.72	63	p>0.05
MSPSS	Psychotic	35	56.9	19.5			
	Non-psychotic	30	49.3	11.2	1 70	/2	~> 0.0F
SSQ	Psychotic	35	44.6	10.1	1.78	63	p>0.05

There were not statistically significant differences in the perceived social support between psychotic and non-psychotic patients in either one of the questionnaires measuring social support (Table 3). However, scores in each of the questionnaires were higher in non-psychotic patients.

We identified no statistically significant differences in the perceived social support between men and women in either one of the questionnaires (Table 4). In this comparison, there is a positive trend in higher perceived social support score in females.

**Table 4** Comparison of perceived social support between male and female patients

Questionnaire	Group	N	Mean	SD	t	df	р
DCCC	Male	30	51.4	8.8	0.10	63	p>0.05
BSSS	Female	35	51.7	10.9	-0.10		
MCDCC	Male	30	60.1	15.9	-0.12	63	p>0.05
MSPSS	Female	35	60.7	19.9			
CCO	Male	30	45.1	11.9	1 17	/2	p>0.05
SSQ	Female	35	48.3	9.7	-1.17	63	

 Table 5
 Correlation between perceived social support and the number of hospitalizations

Questionnaire	r	р
BSSS	18	<i>p</i> >0.05
MSPSS	09	<i>p</i> >0.05
SSQ	09	<i>p</i> >0.05

Correlation analysis (Table 5) illustrates that there were no statistically

significant relation between the perceived social support and the number of hospitalizations (p>0.05).

The chi-square analysis (Table 6) showed statistically significant difference ( $x^2 = 17.928$ ; df = 2; p <0.05) between the frequencies found in the sample and the expected frequencies. The results showed the difference in patients diagnosed within the category F20 and F30. In patients with F20 diagnosis, the closest person were parents (F20 = 94.7%, F30 = 5.3%) and in F30 patients, it was their partner (F20 = 26.7%, F30 = 73.3%).

**Table 6** Comparison of the source of perceived social support in F20 and F30

Diagnosis		Parents	Parents Partner Other			
F20+	N	18	4	6		
F20*	%	37.5%	8.3%	12.5%		
<b>-</b> 00+	N	1	11	8		
F30*	%	2.1%	22.9%	16.7		
Decree Chi Course	17.020	df		p		
Pearson Chi-Square	17.928	2		<0.05*		

<sup>\*</sup>F20 - Schizophrenia, schizotypal, delusional and other non-mood psychotic disorders, F30 - Affective disorders

#### **Discussion**

Patients suffering from psychotic symptoms are included to be the most serious stage of the disease in psychiatric diagnoses, which significantly affects all areas of life and possibly lead to social isolation and stigma (Soundy et al. 2012, Gorczynski et al. 2010, Carless et al. 2009). Based on the findings that the social networks of schizophrenic patients are smaller and thinner structured than in neurotic (non-psychotic) patients (Hultman et al. 1997), we decided to examine these two groups. Our results showed that psychotic patients reported a lower level of support in the "partner" subscale than non-psychotic patients. In other cases, however, the difference in perceived social support between psychotic and non-psychotic patients was not statistically significant.

The association between perceived social support and the number of hospitalizations did not prove to be statistically significant in our research. We can consider whether, after repeated hospitalizations, patients do not feel an increase or decrease in perceived social support due to its initial absence or deficit, or actually perceive sufficient social support from their surroundings. In the case of patients who have been hospitalized for the first or second time, we can assume that their illness has not yet affected interpersonal relationships to such an extent that they can perceive a decline in their social support (Müller et al. 2007).

Comparing the closest persons as a source of perceived social support showed that there are differences between individual psychiatric disorders, most visible in schizophrenic spectrum and affective disorders in which social support is most often perceived by a partner, unlike patients suffering from schizophrenic circuit disorder, for whom the closest person is usually one of the parents (Awad & Voruganti 2008). With these results, we can see the negative impact of disorders on the social support of patients who experience psychotic symptoms. Patients suffering from the most serious form of mental illness, especially diagnoses of category F20 - schizophrenia, schizotypal, delusional, and other non-mood psychotic disorders, are often limited to the care of the immediate family (mother, father), which is also their source of social support. The consequences of the disease may limit the patient in the social field at the level of interpersonal relationships to such an extent that his health condition does not allow him to establish a full-fledged partnership (Hooker & Park 2002). In non-psychotic patients (mood disorders, neurotic disorders or personality disorders), the symptoms of the particular disease may not limit the patient's functioning to such proportions.

We consider the benefits of our work to be the study of the social support of psychiatric patients, which is not given enough attention in Slovakia. Research on the clinical population and the specificity of the sample allowed us to form an overview of the degree of perceived social support of patients suffering from mental disorders. We advise a wider range of diagnoses as positive. Therefore, we were able to observe diversity not only in specific diagnoses, but also in the severity of the disease, the current mental state and the emotional state of the patient and the differences in the number of hospitalizations. This does not necessarily indicate the state of health of a patient suffering from a serious mental disorder. The influence of stigmatization enters the process. Schizophrenia is one of

the most stigmatized mental illness, which is reflected in the quality of life and social adaptation of these patients. The painful experience of patients leads to the avoidance of potentially threatening social contact and further to social isolation.

#### **Conclusions**

Social support may have a protective role against the development of mental disorders, but also the effect of social support in the process of diagnosing severe mental illness, which formation could not be prevented. The role of social support and sustained supportive relationships can thus help in managing severe mental disorders, often associated with social isolation and stigmatization of patient. Building on this recognition, healthcare professionals may encourage and empower the patient and her/his significant other(s) to build supportive relationships.

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### SECTION 4

Strengthening public health and healthcare capacities and services

Index of authors

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## COALITION OF PARTNERS ON STRENGTHENING THE PUBLIC HEALTH WORKFORCE THROUGH PROFESSIONALIZATION OF PUBLIC HEALTH PROFESSION IN SLOVAKIA

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**Issue/Problem:** In 2017-2018 Slovakia has joined the WHO activities aimed to accelerate a progress to strengthen public health services and capacities in Europe and in individual Member States. A lack of experts and unbalanced infrastructure was recognized as one of the main problem of the Slovak public health system.

**DESCRIPTION:** The current critical decline of public health workforce in Slovakia is a result of increasing retirement of physicians, decreasing interest of young physicians and public health professionals, and limited opportunities for other professionals to enter to practice. Therefore, the key stakeholders agreed to deal with strengthening the public health workforce and took the responsibility for mobilizing the resources needed to implement the agenda for action.

**Lessons Learned:** In September 2019, the online evaluation of the public health workforce professionalization was carried out. In October-December 2019, three national round tables were organized. In February 2020, the core team and three experts' teams were formed to continue on prioritising the future recommendations in the fields of: education and training, research and development, and system and financing.

**CONCLUSIONS:** From long-term perspective, the initiative supporting professionalization has a potential to form a national coalition of partners on strengthening public health capacities and services in Slovakia.

Key words: public health professionalization, coalition of partners, rapid assessment tool

#### Introduction

In 2012, Member States of the WHO/Europe endorsed the European Action Plan (EAP) for Strengthening Public Health Capacities and Services with aim to develop, implement, monitor and evaluate actions to strengthen public health capacity and services (WHO 2012). In response, the WHO Regional Office for Europe launched the Coalition of Partners (CoP) to bring together experts and practitioners from national public health services, international organizations, civil society and academia and invited them to co-create the agenda for action and form solutions to strengthen public health capacities and services in countries and to take joint responsibility for their implementation.

In 2017-2018 Slovakia has joined the WHO/Europe activities aimed to accelerate a progress in the field of implementation of the EAP for Strengthening Public Health Capacities and Services. As in other countries, one of the

main problems in Slovakia is the quantitative and qualitative shortage of experts in public health.

#### Description

In Slovakia, the 1<sup>st</sup> evaluation of the public health system in all 10 areas (essential public health operations) according to the EAP for Strengthening Public Health Capacities and Services was carried out within the BCA 2012-2013 (Priority 2: Strengthening the health system and public health). The National Working Group appointed by the State Secretary of the Ministry of Health of the SR (MoH), was responsible for the performance of the task. The evaluation was done by the pilot EPHO Tool (WHO 2015, final version), including Module 7 - Ensuring a qualified workforce in public health (Table 1).

The persistent critical shortage of public health workforce in Slovakia is a result of increasing retirement of physicians, decreasing interest of young physicians and public health professionals, and limited opportunities for other professionals to enter to public health practice. Therefore, the Ministry of Health of the SR and the Public Health Authority of the SR, the relevant academic institutions and non-governmental organisations agreed to deal with strengthening the public health workforce and took the responsibility for mobilizing the resources needed to implement the agenda for action.

The following activities were carried out:

- In September 2019, the relevant experts were invited to evaluate the public health workforce professionalization using an online rapid assessment tool (Czabanowska & Slock 2019), which was translated into Slovak language.
- 2. Three national round tables were held with aim to formulate the areas for cooperation. In October 2019 (21 participants, Kosice), the results on rapid evaluation together with the findings on qualified forces provision from the 1<sup>st</sup> Slovak public health system assessment done in 2012-2013 (Table 1) were used as a starting point for mutual discussion. In November 2019 (42 participants, Trnava), the problems, needs and priorities to be solved were further discussed. In December 2019 (28 participants, Banska Bystrica), further cooperation (implementation phase) was agreed.

#### Lessons learned

In September 2019, all 36 regional public health authorities, universities providing education in the field of public health, professional associations, and other relevant experts were addressed to provide online their feedback on the status of professionalization of public health workforce in Slovakia. The most common answers were that the assessed professionalization measures are "created, but need less adjustment" (Table 2). Therefore, areas discussed in the preparatory phase were oriented on: the current structure of the workforce; identified problems and needs of the current state of the workforce; and possibilities for changes in education and practise in public health.

With regard to the current state of the workforce in the public health system in Slovakia the following <u>problems</u> were identified:

 Even though 1627 people completed their first degree in bachelor study program in public health and 1186 people completed their second degree in magister

- study program in public health within 2010-2018, several universities record **declining interest on public health study** in recent years;
- Lack of workforce in the public health system, because of retirement of doctors, the problematic application (enforcement), lack of interest of doctors and public health professionals to enter to practice, and absence of possibility for other professionals to work in public health (e.g. veterinarians, engineers);
- Ambiguous definition of competencies for individual professions in the public health system in legislation (scope of practice of health professions);
- Insufficient financial remuneration and possibilities of continuous education, as well as insufficient support for scientific research and participation in scientific teams, especially international teams.

The following <u>needs</u> were recognized in the field of public health workforce:

- To put more emphasis on linking the undergraduate education to the needs of current reality and practice and to enable students to complete not only 'formal', but standard, high quality and reasonably long professional practice
- Multidisciplinarity motivating different professionals to work in the public health system by pointing out other benefits (non-financial) such as e.g. work without services (on weekends or at night), possibility to combine with other work activity;
- Modification of legislation for different types of workers in public health and exhaustive definition of competences in individual professions in public health system and their transfer to job description (individual activities);
- Reconciliation of financial evaluation of workers with other fields of state administration;
- Adjustment of classification of workers in the public health system (in state administration and in public interest) and in individual professional organizations.

<u>Possibilities for changes</u> in education and practice in public health in Slovakia were uncovered as follows:

Strengthening the link between undergraduate education with public health practice and the cooperation between educational institutions, NGOs and

- the private sector with the main state public health authorities at national and regional level;
- Improvement of cooperation between Health counselling centres at public health authorities and primary health care providers the GP's recommendation of a healthy person with risk factors for a health counselling centre and/or counselling services provided by the regional public health authorities to a citizen with risk factors refunded through health insurance companies;
- Differentiation of the regional public health authorities' network as the number and geographical distribution is appropriate, but it is necessary to adapt its structure and activities to the needs of the region;
- Expanding the structure beyond the regional public health authorities network re-establishing or establishing new organizations in the current system in Slovakia, there is a lack of, for example, the national research "authority" (in the past The Institute of Preventive and Clinical Medicine), the coordination centre for health promotion (in the past The National Centre for Health Promotion), the coordination centre for disease prevention and control (analogous to ECDC), coordination centre for all existing and newly established NRCs in Slovakia;

- Expanding the employment of experts in public health e.g. at the level of the self-governing regions, NGOs, within integrated health and social care, crisis management;
- Support in the enforcement of needs (legislation, media coverage, introduction to professional practice and real life), which will be identified by the National Public Health Authority in the framework of currently running national projects within the Operational program on Effective public administration.

#### **Conclusions**

In February 2020, the planning of implementation phase started. The core team and three experts' teams were nominated by the State secretary of the Ministry of Health of the SR to continue on prioritising the future recommendations in the fields of: education and training, research and development, system and financing. Despite the fact, that the process was suspended due to the ongoing COVID-19 pandemic, from long-term perspective, the launched initiative supporting public health professionalization has a potential to form a national coalition of partners on strengthening public health capacities and services. Its long-term vision is focused on effectively and efficiently governed public health system in Slovakia.

Table 1 EPHO - Module 7: Ensuring a qualified workforce in public health (PH), 2012-2013

Module 7 Ensuring a qualified workforce in public h	ealth
Strengths	Weaknesses
<ul> <li>Existence of partial planning of human resources in PH on national level</li> <li>Existence of a legislative framework for the obtaining of pro- fessional qualification (university education, specialization and</li> </ul>	<ul> <li>Strategic planning of human resources in PH on national level is realized by the method of setting the limits of the number of employees; it does not take into account population needs and regional conditions</li> </ul>
<ul> <li>continuing education) an employment of professionals in PH</li> <li>Existence of institutions providing university education and further education in PH</li> <li>Processes of accreditation and evaluation of the quality of educa-</li> </ul>	<ul> <li>Qualified workforce in PH is gradually decreasing (overall decrease in the number of professional employees due to lack of finance, lack of doctors), while the number of university graduates prepared for PH is increasing in the same time (demand-supply</li> </ul>
tion (AC MoE SR) and further education in PH (AC MoH SR, SACC-ME) are in place  Implementation of the project within Education OP "Creation and"	<ul> <li>imbalance)</li> <li>There is no offer of further education, especially in the teamwork of communication skills, partly in the field of management of PH</li> </ul>
implementation of the education system for staff of RHAs in the SR"	<ul> <li>The sustainability of further education is limited by the decrease in financial resources allocated in PH system</li> <li>There is no continuous quality control at all levels of education in PH</li> </ul>

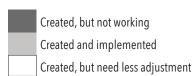
#### **Proposed measures**

- In cooperation with the MoH SR to consider introducing strategic and decentralized planning of human resources in PH with regards to the needs of the population and regional conditions
- In cooperation with the MoH SR and other departments/ministries to consider the possibilities of wider employment of graduates of PH
  in the labour market
- In cooperation with AC MoE SR, AC MoH SR and SACCME to review the current offer of educational programs for the preparation a qualified workforce in PH, including the content framework (EPHO), educational methods and legislative modifications (eg. possibility of accreditations of new study programs, innovation of clinical subjects in the framework of doctoral study)
- In cooperation with AC MoE SR, AC MoH SR and SACCME to consider introducing a system of continuous evaluation of the quality of education in PH at all levels.

Abbreviations: AC MoE SR - Accreditation Commission of The Ministry of Education, Science, Research and Sport of the Slovak Republic; AC MoH SR Accreditation Commission of The Ministry of Health of the Slovak Republic; SACCME - Slovak Accreditation Council for Continuing Medical Education

**Table 2** Status of professionalization of public health workforce in Slovakia, 2019 – the share of two most common answers for evaluated areas

- 1 . (1 1 1 ( 1 1 1 2	The most	The most common answers (%)				
Evaluation of the level of professionalization measures	1 <sup>st</sup>	2 <sup>nd</sup>	n			
Workforce taxonomy	60,6	24,2	33			
Key competences of the workforce	56,8	21,6	37			
Job description	56,4	38,5	39			
Financing the workforce	56,4	20,5	39			
Continuous professional development	47,2	16,7	36			
Personnel capacities – data, numbers, planning, forecasting	35,9	20,5	39			
Granting professional licences and authorizations	35,1	24,3	37			
Recruitment and retention strategies	28,9	23,7	38			



Not created, but with urgency to create

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### BURNOUT AND WORK-RELATED STRESS IN HIGH RISK PROFESSIONS

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**BACKGROUND:** The meaning of work-related stress and its consequences for health is underlined by the increasing prevalence of absence from work due to burnout. The aim of this study was to explore the factors of work-related stress associated with burnout in high-risk professions.

**METHODS:** The study sample consisted of 276 police officers, prison guards, customs officers and physicians (72.1% men, average age 36.6 years). They filled out questionnaires focused on sociodemographic variables (age, gender, working time), Occupational Stress Inventory–Revised (OSI-R), and Maslach Burnout Inventory (MBI-HSS). Multiple regression analysis was performed to analyse data.

**RESULTS:** The model consisting of night work, responsibility, physical strain and rational/cognitive coping in OSI-R explained 40.2% of the variance in burnout – emotional exhaustion. The second model comprising gender, role insufficiency, responsibility, interpersonal strain, physical strain and recreation in OSI-R explained 30.4% of the variance in burnout – depersonalization. In the last model, gender, role insufficiency, role ambiguity and recreation in OSI-R explained 37% of variance in personal accomplishment in the total sample.

**CONCLUSIONS:** Employees of high-risk professions should apply an active approach to manage perceived work stress and reduce the risk of developing an occupational syndrome, including through recreation and rational/cognitive coping.

Key words: burn-out, mental health, personal resources, work-related stress

#### Introduction

A noteworthy exposure to work-related stress was associated with an increased risk of developing of burnout syndrome and some mental disorders. Psychosocial risks and stress resulting from work are currently the most studied issues in the field of health and safety at work (EU-OSHA 2020). Despite the negative effects on work performance, burnout syndrome has not yet been classified as an occupational disease. Consideration on the diagnostic classification of burnout as an occupational disease is important in the view of the need to recognize working incapacity of employees with more severe acute symptoms.

Burnout syndrome is a psychological construct, state of fatigue, exhaustion, loss of interest, disappointment and demotivation related to the profession. This state is affected by chronic stress, resignation and the belief that although a considerable effort had been put into the activity being carried out, the expected result did not occur and cannot be achieved at all (Kebza & Šolcová 1998, Carta et al. 2017, Ráczová & Köverová 2017).

Some external risk factors of burnout include exposure to chronic stress, emotional demands on work, overloading, stereotype, job insecurity, overtime, time pressure, high control over work performance, conflicts of personal and professional life, insufficient evaluation (financial and verbal), interpersonal conflicts, mobbing, and many more. Internal risk factors may include excessive engagement, high enthusiasm, high expectations, unrealistic goals, personal sensitivity, failure in meeting goals perceived as personal loss, low assertiveness, perfectionism, anxious traits, etc. (Křivohlavý 2003, Berryová 2009, Kebza 2009). On the other hand, some protective factors can be useful, such as ability to relax, social support, appropriate time-management and effort not getting under time pressure (Rowe 1998).

Personal resources of employees contribute to their occupational adjustment. Recreation, self-care, social support or rational/cognitive coping resources play a key role as protective factors in mental health. Recreation, as an important personal resource in high-risk professions, may involve a variety of actions that employees find relaxing and satisfying. High levels in self-care domains reveals those who regularly exercise, sleep well and enough, who are careful about their diet, practice relaxation approaches and avoid harmful substances. Social support reflects that there is at least one person employees can count on, one who values or loves them. They may report having a person with whom may talk about their work problems. Rational/cognitive coping resources mean a systematic approach to solving problems, through the consequences of the decisions, and ability to identify important issues of the faced problems (Osipow 2010, Lovaš et al. 2014).

The main objective of this cross-sectional study was to find out how work-related stress predicts burnout in high risk professions. It was expected that variables of work-related stress predict higher rates of burnout, while higher levels of personal resources predict less burnout in the study sample. The dependent variables were burnout syndrome - emotional exhaustion, depersonalization, and personal accomplishment, the independent ones included gender, work time, work-related stress and personal resources.

#### Methods

#### Sample and procedure

The sample consisted of 276 responders from the field of government and health care in Slovakia, including police officers (n=69), customs officers (n=65), prison guards (n=77), and physicians working in state hospitals (n=65). Firstly, a written informed-consent form was presented, then questionnaires on a voluntary and anonymous basis were explained in a group of employees by a psychologist. Each responder provided a signed informed-consent form before participating in this study. The data were collected from December 2018 to April 2019.

#### Measures

The study consisted of a questionnaire focused on sociodemographic variables, self-reported questionnaire on work-related stress and burnout dimensions. Firstly, responders filled out a questionnaire focused on sociodemographic variables including age, gender, marital status, education level, employment status and working time, such as work at night, in shifts, overtime and in emergency.

Work-related stress and personal resources were measured by the Occupational Stress Inventory Revised (OSI-R), including Occupational Role Questionnaire (ORQ, 60 items), Personal Strain Questionnaire (PSQ, 40 items), and Personal Resources Questionnaire (PRQ, 40 items). Responders answered on a 5-degree scale (from Never to Most).

ORQ contains six dimensions: role overload (RO), role insufficiency (RI), role ambiguity (RA), role boundary (RB), responsibility (R) and physical environment (PE). PSQ estimates four dimensions: vocational strain (VS), psychological strain (PSY), interpersonal strain (IS) and physical strain (PHS). High score in ORQ and PSQ suggest a significant level of work-related stress in the measured work domains. PRQ reports on four dimensions: recreation (RE), self-care (SC), social support (SS) and rational/cognitive coping (RC). High scores indicate highly developed coping resources (Osipow 2010).

Burnout was detected by Maslach's Burnout Inventory (MBI-HSS). It comprises the following dimensions: emotional exhaustion (EE), depersonalization (DP), personal accomplishment including work performance and competences (PA). EE reflects personal exhaustion, energy loss, fatigue. DP measures cynicism, non-sensitivity to clients, patients. PA shows how employees are satisfied with their competences and work performance. The responders assessed 22 items on a 7-degree Likert scale from Never to Daily (Ráczová & Köverová 2020).

#### Statistical analysis

Firstly, the sociodemographic variables, variables of work-related stress (OSI-R) and burnout (MBI-HSS) were studied. Pearson's correlations, according to the normal distribution of the data, were used for testing the associations between the examined variables. Hierarchical multiple regression analysis, the stepwise method, was performed to determine significant predictors of burnout in this study. The variables explaining the variances of burnout in the following steps were added in the models: 1. gender, 2.ork time, and 3.imension in OSI-R (ORQ, PSQ, PRQ). The statistical software IBM SPSS Statistics v.23 was used to analyse the data.

#### Results

The tables show the sociodemographic data and the total score for burnout dimensions for high-risk professions used in this study. The average age of all the responders was 36.6 years, with range 18-77 years (N=276). They consisted of more men than women (72.1% males). As regards work time, 51.4% of them worked in shifts, 75.7% worked at night, 62.3% worked overtime, and 48.2% worked in the emergency services.

**Table 1** Basic descriptive statistics of samples prison guards (N=77) and custom officers (N=65)

	Prison guards			Custom officers		
	M	SD	%	M	SD	%
Age in years	36.5	8.2		36.8	7.2	
Gender						
Men			93			66.2
Women			7			33.8
Marital status						
Single			28.6			18.5
Married			63.6			55.4
Education						
High school			59.8			21.5
College			39.0			64.6
Work time						
Shifts			39.0			29.2
Night			41.6			92.3
Overtime			40.3			89.2
Emergency			24.7			50.8
<b>Burnout MBI-HSS</b>						
EE	15.4	10.7		16.5	9.3	
DP	10.4	6.9		6.5	6.2	
PA	23.7	8.8		21.9	8.4	

Note: gender 1=man, 2=woman

Table 2 Descriptive statistics of samples physicians (N=65) and police officers (N=69)

		Physicia	ns		Police offi	icers
	М	SD	%	М	SD	%
Age in years	38.2	11.9		35.1	8.4	
Gender						
Men			49.2			75.4
Women			50.8			24.6
Marital status						
Single			29.7			26.1
Married			57.8			42.0
Education						
High school			0.0			45.9
College			100			50.7
Work time						
Shifts			52.4			87.0
Night			90.8			84.1
Overtime			75.8			52.2
Emergency			89.2			33.3
<b>Burnout MBI-HSS</b>						
EE	19.2	11.6		17.7	10.9	
DP	7.5	6.7		7.3	6.2	
PA	12.1	7.7		17.9	8.7	

Note: gender 1=man, 2=woman

Table 3 Work-related stress and personal resources in OSI-R (N=276)

OSI-R	Mean T-score	Range		
ORQ				
role overload RO	22.1±5.9	10-41		
role insufficiency RI	24.2±7.4	11-46		
role ambiguity RA	21.2±6.4	10-42		
role boundary RB	16.2±4.7	8-33		
responsibility R	17.4±5.3	8-31		
physical environment PE	18.2±6.0	9-41		
PSQ				
vocational strain VS	15.9±4.5	10-36		
psychological strain PSY	18.5±5.5	10-40		
interpersonal strain IS	16.5±4.9	9-31		
physical strain PHS	20.0±6.2	10-43		
PRQ				
recreation RE	31.5±6.8	11-50		
self-care SC	21.0±5.4	9-35		
social support SS	40.9±8.7	11-96		
rational/cognitive coping RC	32.7±6.1	15-45		

Notes: OSI-R=Occupational Stress Inventory, ORQ=Occupational Role Questionnaire,

PSQ=Personal Strain Questionnaire, PRQ=Personal Resources Questionnaire

The models explaining EE, DP and PA in burnout consisted of gender, work time variables, work-related stress and personal resources in OSI-R. R² was 44.9% in the final model explaining variance of emotional exhaustion, R² was 35.9% in the final model explaining variance of depersonalization, and 42% in the final model explaining variance of personal accomplishment in MBI-HSS. Significant predictors are presented in Tables 4, 5, and 6.

**Table 4** Linear regression analyses: significant predictors of emotional exhaustion EE in study sample (N=276)

Step	EE predictors	В	Sig.	
1.	gender	0.06	0.27	
2.	night work	0.23	0.004	
3.	responsibility R	0.26	0.000	
	physical strain PHS	0.22	0.009	
	rational/cognitive coping RC	-0.15	0.02	
R <sup>2</sup>	44.9%			

Table 5 Linear regression analyses: significant predictors of depersonalization DP (N=276)

Step	DP predictors	В	Sig.
1.	gender	0.16	0.01
2.	shift work	-0.05	0.15
3.	role insufficiency RI	0.16	0.03
	responsibility R	0.15	0.02
	interpersonal strain IS	0.17	0.05
	physical strain PHS	0.21	0.02
	recreation RE	0.20	0.003
R²	35.9%		

Table 6 Linear regression analyses: significant predictors of personal accomplishment PA (N=276)

Step	PA predictors	В	Sig.
1.	gender	0.12	0.04
2.	shift work	-0.08	0.28
3.	role insufficiency RI	0.27	0.001
	role ambiguity RA	0.16	0.03
	recreation RE	-0.19	0.03
R <sup>2</sup>	42.0%		

#### Discussion

In the presented research, the relationships between burnout and work-related stress in high-risk professions before the pandemic situation were studied. Although the employees arose from the professions that are considered as stressful, their statements in the burnout dimensions did not ascertained pathological scores at the time of testing, except for personal accomplishment where they perceived significant dissatisfaction as regards their performance at work.

The findings revealed that night work, high responsibility (R), high physical strain (PHS) and good rational/ cognitive coping (RC) were significantly associated with emotional exhaustion in the total sample. High score in responsibility for work performance of employee or subordinates may reflect responsibility for other people's problems, report stress when they have to work with angry and unsatisfied colleagues, and if it takes a long time, it can lead to exhaustion. High score in physical strain means a frequent concern about their health, having physical symptoms. The employees may refer about sudden weight loss, alcohol abuse, sleep disturbances, lethargy or apathy. Good rational/cognitive coping reveals a systematic approach to problem solving, the employees can make appropriate decisions, prioritize and follow them. They know how to reorganize a schedule, displace the work out of the mind (Osipow 2010, Hicks et al. 2015).

The outcomes of the second analysed model showed that female gender and dimensions RI, R, IS, PHS and RE were the risk factors for possible developing of depersonalization. Regarding the role insufficiency (RI), the insufficient employees match skills and work, they are uncertain about future, their need for appreciation and success is not fulfilled. High score in interpersonal strain (IS) may reflect conflicts, dependence on family, partner, not having time for friends. As regards recreational activities in relation to depersonalization (RE), the employees might avoid the work and spend more time away from work, might express disinterest, or may only want

to keep distance from clients, patients, preferring to do activities that are relaxing and satisfactory, not unpleasant work tasks. Interpersonal strains and work-life balance were studied in the sample of physicians and health care workers (Higgins et al. 2014, Carta et al. 2017, depression, and a low mental quality of life (QOLRajani et al. 2016, Lederer et al. 2018which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited. Currently, healthcare management fosters a maximization of performance despite a relative shortage of specialists. We evaluated anaesthesiologists' workload, physical health, emotional well-being, job satisfaction and working conditions under increased pressure from consolidated working hours. A nationwide cross-sectional survey was performed in Austrian anaesthesiologists (overall response rate 41.0%).

As regards personal accomplishment, its significant risk factors were female gender, RI, RA, and RE. The female employees in the studied sample perceived dissatisfaction with their work. Except higher insufficiency (RI), role ambiguity (RA) means uncertainty what is expected from employees, what they should do exactly, how they should be evaluated, etc. Recreation (RE) points to the adequate use of free time by the employees, leisure activities are relaxing and satisfactory for them. Personal resources have been described in uniformed professions, especially in association with their preventive effect of development of post-traumatic stress disorder, or with general health (Sutker et al. 1995, Oginska-Bulik 2005, Klimley et al. 2018).

The responders involved in this study worked in the emergency services, and they belonged to risk professions due to their job-related risks that may weaken their general health. The stressors responsible for poor mental health in customs officers, prison guards, policemen or physicians are spending long hours at work, conflicting demands, poor social support, badly-designed organizational structure and unclear management, reward system, dangerous clients, role of human factors in accidents, and many others (Kahn 2003, Zhao et al. 2019).

Practical points for discussion include differential-diagnosis of burnout syndrome, it is necessary to distinguish it from related, such as neurotic disorders, manager diseases, depressive syndrome, chronic fatigue syndrome (Kahn 2003, Kebza 2009). As regards absences from work due to burnout, they may result in long-term absence from work. Work-related stress has been the main reason not only for absenteeism, but also for long-term incapacity to work and for early retirement (Adams 1998, van Vilsteren et al. 2015)when compared to usual care or clinical interventions. SEARCH METHODS We searched the Cochrane Work Trials Register, the Cochrane Central Register of Controlled Trials (CENTRAL.

These results underline the need for aiming interventions for high-risk professions that can be on the overall risk of development of stress-related disorders and burnout syndrome than in the previous years. These interventions should focus on protection of women's work (Bird & Rieker, 2011), reducing insufficiency and ambiguity in their work, enhance recreation and rational/cognitive coping strategies to avoid worsened psychological well-being (Schliebener 2010, Patterson et al. 2014, Tsirigotis et al. 2015).

#### **Conclusions**

The results of this cross-sectional study indicate practical solutions for protection against burnout in the study sample. For good mental health it is necessary to properly manage work time, delegate responsibility among employees, take care of one's own overall health, effectively solve problems at the workplace, not isolate from friends, develop social relationships. What is important is the feeling of usefulness of work, obviously defined roles, clear expectations from employees, and also a support in recreational activities.

On the other hand, the employers' interventions should be focused on increasing employees' understanding of their work roles and responsibilities. It is important not to overload them and to create space for some rest. Another way out could be intervention programs to manage work-related stress, including development of effective communication within the work team, and effective resolution of employees' mental health complications.

We should always keep in mind that despite the concerns about work-related stress referred to so far, work is beneficial for our mental and physical health.

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### SECTION 5

#### **Transition towards integrated patient-centered care systems**

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### RETHINKING SUSTAINABLE DEVELOPMENT GOALS TO ADDRESS DISABILITY

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**Issue:** Disability is a prior concern of public health as it affects almost one in seven people globally. Today there are almost one billion disabled persons in the world. Disabled people are facing with various difficulties due to discrimination, labelling, stigmatization, and the negative influences of other determinants of health. A global perspective can be helpful to eliminate such obstacles. United Nations (UN) Sustainable Development Goals (SDGs) can play crucial role to lead the international science and social platforms to improve the situation.

**DESCRIPTION:** In this paper, we presented our research results on 17 SDGs of the UN with disability perspective to understand both the strong and the lacking points which can potentially influence practice.

**Lessons:** Although all SDGs are expected to have connection with disability, only "some" of the Goals tackle the issue with a stronger emphasis. Goals number 4, 8, 9, 11, and 17 have specified targets about disability.

**CONCLUSIONS:** Disability can be a separate title/concern within SDGs, when the frequency and the sensitivity of the subject is considered. Horizontal and vertical links among the Goals and their targets should strongly be established which will facilitate to follow the developments in an easier manner.

**Key words:** Disability, Sustainable Development Goals, Integrated system(s)

#### Issue

Disability is among prior topics of public health (WHOa, 2021). Almost one billion people in the world have disability which is about 15% of the total population and many of them live in developing countries (WHOb, 2021). Disabled people are facing with various difficulties like discrimination, labelling, stigmatization, and the negative influences linked with the major determinants of health. The vicious cycle between the disability and social determinants may have the potential to worsen the health conditions of the disabled people. Difficulty to access to health and other services may be among prior issues to be solved. Solutions need a broad and an integrative global perspective. In this regard, United Nations organizations take the lead. Convention on the Rights of Persons with Disabilities (CRPD) of UN was adopted in 2006 and since then, it is used as a guide to advocate the human rights of the disabled people in the global community (UNa, 2021). Another international document, the UN Disability Inclusion Strategy, provides the inclusion of the disabled people as well (UNb, 2021). Besides all these documents, we could not have solved the existing problems related with disability. The Novel Coronavirus Disease (COVID-19) pandemic complicated the burden and questioned the inclusiveness of the disabled persons once more (Armitage and Nellums, 2020).

To cover all the missing issues, a more comprehensive step can be taken in this regard and the United Nations (UN) Sustainable Development Goals (SDGs) may be a good address. Currently, there are 17 SDGs and 169 specific targets to be achieved in 2030 (UNc, 2021). United Nations has crucial role to lead and activate the international science and social platforms. In this manner, the burden of disability may somehow be lessened with the collaborative work of the partner countries of the UN.

The aim of this paper is to analyze 17 SDGs of the UN to understand how disability issue has been placed in the Goals and targets, to understand both the strong and the lacking points which can potentially influence the practical implementations/life and to propose solutions to overcome the burden at the global level.

#### **Description**

UN SDGs constitute a wide range of global problems. Disability is one of the reaffirmed points in the Universal Declaration of Human Rights (UNd, 2021), Although there is not a specific UN SDG which tackles on disability, UN SDGs include the concern within the details. Table 1 shows the content analysis of the UN SDGs documents with the progress reports.

 Table 1
 Disability content of the UN SDGs (UNe, 2021)

	UN SDG number and title	Specific emphasize on disability in the content
1	End poverty in all its forms everywhere	No specific emphasize
2	End hunger, achieve food security and improved nutrition and promote sustainable agriculture	No specific emphasize
3	Ensure healthy lives and promote well-being for all at all ages	No specific emphasize
4	Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all	The original definition is below and there is a specific emphasize "4.5. By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities,  4.a Build and upgrade education facilities that are child, disability and gender sensitive and provide safe, non-violent, inclusive and effective learning environments for all"
5	Achieve gender equality and empower all women and girls	No specific emphasize
6	Ensure availability and sustainable management of water and sanitation for all	No specific emphasize
7	Ensure access to affordable, reliable, sustainable and modern energy	No specific emphasize
8	Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all	The original definition is below and there is a specific emphasize "8.5 By 2030, achieve full and productive employment and decent work for all women and men, including for young people and persons with disabilities, and equal pay for work of equal value"
9	Build resilient infrastructure, promote sustainable industrialization and foster innovation	The original definition is below and there is a specific emphasize "10.2 By 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status"
10	Reduce inequality within and among countries	No specific emphasize
11	Make cities inclusive, safe, resilient and sustainable	The original definition is below and there is a specific emphasize "11.2 By 2030, provide access to safe, affordable, accessible and sustainable transport systems for all, improving road safety, notably by expanding public transport, with special attention to the needs of those in vulnerable situations, women, children, persons with disabilities and older persons  11.7 By 2030, provide universal access to safe, inclusive and accessible, green and public spaces, in particular for women and children, older persons and persons with disabilities"
12	Ensure responsible consumption and production	No specific emphasize
13	Take urgent action to combat climate change and its impacts	No specific emphasize
14	Conserve and sustainably use the oceans, seas and marine resources	No specific emphasize
15	Protect, restore and promote sustainable use of terrestrial ecosystems, sustainably manage forests, combat desertification, and halt and reverse land degradation and halt biodiversity loss	No specific emphasize
16	Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels	No specific emphasize
17	Strengthen the means of implementation and revitalize the global partnership for sustainable development	The original definition is below and there is a specific emphasize "17.18 By 2020, enhance capacity-building support to developing countries, including for least developed countries and small island developing States, to increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts"

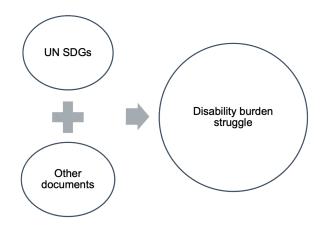
#### Lessons

Goals number 4, 8, 9, 11, and 17 have specific targets covering disability (Table 1). In fact, all SDGs can be linked with disability burden. Inclusion of the theme into all SDGs may help to overcome the negative influences of disability as it has a preventive feature and needs a multi-disciplinary approach. The solution may become more complicated if the issue has not been clearly specified.

There are many UN documents produced on disability, however, there should be a stronger mechanism which also will help to monitor and follow up the situation and improvements.

Novel Coronavirus Disease (COVID-19) has made weak points of life more visible. Science is also discussing the dilemmas including ethical, legal, medical aspects of disability (Sabatello M, et al., 2020). Since the beginning of the pandemic, a "recent" discussion has started on the need of the revision of the SDGs. Human well-being, economy, food and nutrition, energy, urban development, environment was proposed to be redistributed (Nature, 2021). As all are the major challenges of the world, we can understand the rationale of the proposed recommendation. However, monitorization and follow up may be more difficult and complicated when the goals and targets are generalized rather than specified.

The current paper focused on the search of UN SDGs to raise awareness on the inclusion need of the disabled people. The fact that the results emphasize only the frame can be defined as the major limitation of this work. A more integrative search accessing all other international documents is thought to be helpful to overcome this limitation (Figure 1).



**Figure 1** Integrative approach proposal to strengthen to cover the disability needs.

#### **Conclusions**

Disability is recommended to be a separate title/concern within SDGs, when the frequency and the sensitivity of the subject is considered. Horizontal and vertical links among the Goals and their targets should strongly be established which will facilitate to follow the developments in an easier manner. To improve health and well-being of the disabled people, mission of public health should be drawn to the theme (Lollar and Crews, 2001) and all global documents should support the mechanism. In brief, we can conclude that there is a strong rationale to rethink on the SDGs to address disability in a more specified topic.

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#### TELEOŠETROVATEĽSTVO AKO SÚČASŤ ZDRAVOTNEJ STAROSTLIVOSTI O PACIENTOV S CHRONICKÝMI CHOROBAMI

### TELENURSING AS A COMPONENT OF HEALTH CARE FOR PATIENTS WITH CHRONIC DISEASES

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**Úvop:** Súčasný technologický rozvoj prináša nové možnosti v poskytovaní zdravotníckych služieb. Teleošetrovateľstvo ako moderný ošetrovateľský prístup je súčasťou informatizovaného a elektronizovaného zdravotníctva. Cieľom príspevku je priblížiť problematiku teleošetrovateľstva na Slovensku a v zahraničí.

**Popis problému:** Osobný kontakt medzi sestrou a pacientom je v rámci teleošetrovateľstva nahradený technológiami. K preferovaným zariadeniam patria telefóny (pevné linky, mobily, smartphony), faxovacie prístroje, tablety, počítače, internet, videohovory, teleroboti. Cestou teleprenosu je riešený monitoring vitálnych funkcií, sledovanie stavu zdravia, sebaopatery, stavu chronickej rany a iné. Teleošetrovateľstvo sa premieta aj do edukácie a poradenstva.

**ZÍSKANÉ POZNATKY:** Na Slovensku je teleošetrovateľstvo v začiatkoch. Publikované sú lokálne výstupy zamerané na oblasť domácej ošetrovateľskej starostlivosti. V zahraničí má teleošetrovateľstvo najdlhšiu históriu vo Švédsku, USA, Veľkej Británii a Brazílii. V klinickej praxi sa teleošetrovateľstvo aplikuje najmä pri podpore a ochrane verejného zdravia, pri poskytovaní domácej ošetrovateľskej starostlivosti, u pacientov s chronickými chorobami a zníženou pohyblivosťou. Benefitom teleošetrovateľských zdravotníckych služieb môže byť zníženie nákladov na zdravotnú starostlivosť, šetrenie ľudských zdrojov, možnosť zotrvania pacienta v jeho prirodzenom prostredí a zabezpečenie lepšej kvality života vo vzťahu k zdraviu.

**ZÁVER:** Prostredníctvom teleošetrovateľstva zapojené strany zvyšujú zdravotnú gramotnosť, získavajú potrebné zručnosti na zabezpečenie optimálnych postupov v rámci ošetrovateľskej starostlivosti ako aj pri dodržiavaní liečebných a režimových opatrení. Sestry implementáciou tohto nového prístupu v praxi môžu rozšíriť tradičnú starostlivosť a podporiť zdravie populácie. Teleošetrovateľstvo môže nájsť uplatnenie aj v rámci integrovanej zdravotnej starostlivosti.

Kľúčové slová: teleošetrovateľstvo, sestra, pacient s chronickou chorobou

**Issue/Problem:** Current technological developments bring new opportunities in the provision of health services. Telenursing as a modern nursing approach is a part of computerized and electronic healthcare. The aim of the paper is to elucidate the issue of telenursing in Slovakia and abroad.

**DESCRIPTION:** Personal contact between the nurse and the patient is replaced by technology within the telenursing. Preferred devices include telephones (landlines, mobile phones, and smartphones), fax machines, tablets, computers, internet, video calls, telerobots. Monitoring of vital functions, monitoring of the state of health, self-care, state of chronic wound and others is solved by means of teletransmission. Telenursing is also reflected in education and counseling. **Lessons Learned:** In Slovakia, telenursing is in its infancy. Local outputs focused on the area of nursing home care are published. Abroad, telenursing has the longest history in Sweden, the USA, Great Britain and Brazil. In clinical practice, telenursing is applied mainly in the support and protection of public health, in the provision of home nursing care, in patients with chronic diseases and reduced mobility. The benefits of telenursing health services can be a reduction in health care costs, saving human resources, the possibility of the patient remaining in his or her natural environment and ensuring a better quality of life in relation to health.

**CONCLUSIONS:** Through telenursing, the involved persons increase their health literacy, acquire the necessary skills to ensure optimal procedures in nursing care, as well as in adhering to treatment and regimen measures. By implementing this new approach in practice, nurses can expand traditional care and support the health of the population. Telenursing can also be used in integrated healthcare.

Key words: telenursing, nurse, patient with chronic disease

#### Úvod/Popis problému

Zavádzanie informačných a komunikačných technológií v rámci zdravotníctva patrí medzi najvýznamnejšie aktuálne trendy. Súčasťou elektronického zdravotníctva (e-Health) je aj telemedicína a teleošetrovateľstvo. Podľa WHO je telemedicína poskytovanie zdravotníckych služieb tam, kde vzdialenosť je kritický faktor, pričom všetci zdravotnícki profesionáli používajú informačné a komunikačné technológie na výmenu platnej informácie o diagnóze, liečbe a prevencii chorôb a úrazov, na výskum a celoživotné vzdelávanie zdravotníckych poskytovateľov v záujme zlepšenia zdravia jednotlivcov a spoločnosti (Kukurová & Vlčák, 2009). Využívanie telemedicíny nadobúda v súčasnosti nový rozmer presahujúci pôvodný zámer poskytovania zdravotníckych služieb v geograficky odľahlých lokalitách. V krajinách Európskej únie, kde na trvalú udržateľnosť systémov zdravotníctva negatívne vplýva starnutie populácie, je práve telemedicína prostriedkom, ako znížiť náklady na poskytovanie zdravotnej starostlivosti. Zároveň umožňuje čiastočne riešiť aj problém nedostatočného počtu lekárov a iných kvalifikovaných zdravotníckych pracovníkov, s ktorým sa tiež mnoho európskych krajín stretáva (Danilák et al. 2010).

#### Získané poznatky a odporúčania pre klinickú prax

Teleošetrovateľstvo (telenursing) je jednou z inovatívnych a vylepšených metód poskytovania ošetrovateľskej starostlivosti. Podľa Medzinárodnej rady sestier (ICN) je definované ako využívanie telemedicínskej technológie na poskytovanie ošetrovateľskej starostlivosti a vykonávanie ošetrovateľskej praxe. Teleošetrovateľstvo je účinné pri znižovaní počtu ambulantných a pohotovostných návštev, skracovaní pobytu v nemocniciach, zlepšovaní kvality života súvisiacej so zdravím a znižovaním nákladov na zdravotnú starostlivosť. Americká asociácia sestier (ANA) definovala teleošetrovateľstvo ako podmnožinu telezdravia (telehealth), v ktorej sa pozornosť zameriava na prax konkrétneho povolania (t. j. ošetrovateľstvo). Poskytuje prístup k zdravotnej starostlivosti pre chudobných a pre ľudí žijúcich vo vidieckych oblastiach, ktorí potrebujú pomoc v otázkach ako je diabetologické poradenstvo, strava, zdravý životný štýl, pooperačný monitoring a akákoľvek iná oblasť starostlivosti, ktorá spadá pod túto profesiu (Kamei 2013).

Okrem základných prínosov, ktoré spočívajú v skvalitnení a zefektívnení niektorých druhov vyšetrení a liečby, telemedicína a teleošetrovateľstvo zároveň priaznivo zasahujú aj sociálnu sféru. Najmä v prípade starších ľudí a ľudí s obmedzenou pohybovou schopnosťou, ktorým je možné výrazným spôsobom prispieť k zlepšeniu kvality života.

Telemedicínske a teleošetrovateľské služby poskytujú:

- Tele-konzílium službu, ktorá umožní realizovať konzílium, aj keď niektorí členovia konzília sú fyzicky vzdialení, aj vrátane odborníkov zo zahraničia. Využíva sa k tomu videokonferenčný resp. tele-prezenčný systém s vysokým rozlíšením.
- Tele-konzultácie službu, ktorá umožní sprostredkovať konzultáciu so vzdialeným špecialistom prostredníctvom videokonferenčných technológií (napr. mladý lekár v rámci lekárskej služby prvej pomoci (LSPP) so skúseným odborníkom).
- Tele-monitoring službu, ktorá umožní monitorovanie vitálnych funkcií a iných parametrov (hmotnosť, hladina glukózy) pacienta. Informácie kontroluje poskytovateľ zdravotnej starostlivosti v prostredí oddelenom od toho, kde sa pacient nachádza. To je možné vykonávať synchrónne alebo asynchrónne. Dáta zachytávané prostredníctvom zdravotníckych prístrojov doma sú následne prenesené do systému poskytovateľa cez internet.
- Tele-starostlivosť službu, ktorá umožní poskytovanie časti zdravotnej alebo sociálnej starostlivosti a podporných služieb pre starých občanov v domácom prostredí na diaľku (vhodné napr. pre ADOS).
- Tele-návštevy službu, ktorá umožní komunikáciu izolovaných a dlhodobo hospitalizovaných pacientov s ich sociálnym okolím prostredníctvom videokonferenčných technológií.
- Mobilné zdravie (mHealth) znamená použitie internetu a bezdrôtových zariadení na prístup k infor-

máciám o zdraví s možnosťou zúčastňovať sa aj na online diskusiách (Burdeaux et al. 2019, Danilák et al. 2010).

Podľa klasifikácie ošetrovateľských intervencií (NIC), ktoré popisuje Kuriakose (2011) rozlišujeme štyri telefonické ošetrovateľské intervencie:

- a) telefonická konzultácia (telephone consultaion),
- b) telefonické sledovanie (telephone follow-up),
- c) telefonické triedenie (telephone triage),
- d) telefonický dohľad (telephone surveillance).

**Technológie**, ktoré sú používané v teleošetrovateľstve môžu zahŕňať tieto zariadenia: telefóny (pevné linky, mobily a smartphony), faxovacie prístroje (faxy), tablety, počítače, internet, video a audio konferencia, teleroboti a iné (Kristová, 2018 podľa College of Nurses of Ontario, 2009).

Benefity a nevýhody teleošetrovateľstva:

- Benefity pre pacienta, vyplývajúce zo služieb teleošetrovateľstva konkretizuje Rawat (2018) nasledovne: vysoko kvalitná starostlivosť, spokojnosť pacienta, menej cestovania, pohodlné a jednoduché služby, žiadne čakanie v radoch a ekonomické výhody. Popisované benefity pre sestru sú najmä flexibilný pracovný čas, nákladová efektívnosť, príležitosť na rozvoj zručností, výhodné platové ohodnotenie, spokojnosť s prácou a menej cestovania.
- K nevýhodám vo všeobecnosti môžeme priradiť to, že pacienta nie je možné osobne vidieť, pridružené technologické ťažkosti, určité obavy o súkromie, bezpečnosť a dôvernosť, oneskorené alebo chýbajúce informácie a nepochopené rady. Z právnych a etických otázok sa naskytá opäť otázka súkromia, autonómie a dôvernosti pacienta, nemožnosť zabrániť poškodeniu, problémy s úhradou za službu.

#### Základné kompetencie:

Ak sa sestry chcú stať telesestrami (telenurse) musia mať pozitívny prístup, otvorenú myseľ, vedomosti a schopnosť orientovať sa v technológiách a porozumieť ich obmedzeniam (Mohamed & Hasan El-Sol, 2020). Holistický model požadovaných kompetencií telesestry zahŕňa širokospektrálne sociálne, osobnostné, profesionálne a metodologické kompetencie. Samostatne priblížime, čo k jednotlivým kompetenciám patrí. Sociálne kompetencie predstavujú schopnosť motivovať iných, komunikačné

zručnosti, sociálnu citlivosť, empatiu, priateľskosť, asertivitu a schopnosť počúvať. Z osobnostných kompetencií sa uvádza afinita k technológiám, profesionálna vzdialenosť, ochota učiť sa, odolnosť proti stresu, spoľahlivosť, psychická odolnosť a sebapoznanie. K profesionálnym kompetenciám patria predovšetkým právne znalosti, prax pri používaní informačných technológií, praktické skúsenosti v rámci odboru, základy ošetrovateľstva/medicíny, vedomosti o poskytovanej zdravotnej starostlivosti a manažment kvality. Z potrebných tzv. metodologických kompetencií sú dôležité pre sestru anamnestické, verbálne a analytické zručnosti, schopnosť reagovať a autonómia pri práci (Carius et al. 2016).

#### Aplikácia teleošetrovateľstva v praxi

Využitie telemedicínskych a teleošetrovateľských služieb bolo preukázané v mnohých zahraničných štúdiách, menej na Slovensku. Medzi krajiny s etablovaným teleošetrovateľstvom patria Austrália a Nový Zéland, Švédsko, Nórsko, USA, Kanada, Nemecko, Švajčiarsko, Veľká Británia, Brazília a India (Souza-Junior et al. 2016).

Na národnej úrovni Poledníková et al. (2014) vychádzajúc z vlastných zistení potvrdzujú, že jedným z najčastejších ošetrovateľských prostredí pre uplatnenie teleošetrovateľstva je starostlivosť v prirodzenom sociálnom prostredí, akým je byt pacienta (telehomecare). Ako vysoko prínosná starostlivosť "na diaľku" je najmä pre pacientov s chronickými ochoreniami (Astma bronchiale, Diabetes mellitus, onkologické ochorenia, duševné a neurodegenetatívne ochorenia - Alzheimerova choroba, Parkinsonova choroba, pacienti s chronickými ranami, stómiami, imobilní pacienti…).

O teleošetrovateľstve v intenzívnej starostlivosti sa zmieňujú Williams et al. (2012) a prízvukujú, že nič síce nenahradí úlohu sestier pri lôžku, no je možné tieto služby rozšíriť, vylepšiť alebo uľahčiť aj praktizovaním tzv. "Tele-ICU Nursing" v rámci kritickej starostlivosti o pacientov. Gynekologicko-pôrodnícky odbor má tiež zaujímavé výsledky z uplatnenia teleošetrovateľstva najmä v problematike dojčenia (Miller & Kinahan, 2012) ako aj starostlivosť o matky po predčasnom pôrode (Jafarzadeh et al. 2019). V austrálskej štúdii, ktorá porovnávala sestry pracujúce v call centre pre zdravie so sestrami, ktoré pracovali v rámci komunitnej sféry v domácnosti pacienta sa zistilo, že sestry v call cente poskytovali služby dostatočne bezpečne, boli produktívnejšie a celkovo prejavovali vysokú mieru spokojnosti. Nepotvrdili sa žiadne nevýhody tejto práce zo strany sestier (George, 2009).

#### Záver

Teleošetrovateľstvo, ktoré možno definovať ako ošetrovateľské postupy zahŕňajúce telefonické triedenie, poradenstvo sestier a starostlivosť, je rastúcou a komplexnou súčasťou zdravotnej starostlivosti na celom svete (Eriksson et al. 2020). Informačno-komunikačné technológie ponúkajú široké možnosti využitia ďalších technológií, ktorých použitie musí byť založené na empirických poznatkoch pre podporu ošetrovateľskej praxe, aby sestra mohla vykonávať holistickú starostlivosť vo virtuálnom prostredí (Poledníková et al. 2017). Na Slovensku je podľa nášho názoru ako aj podľa dostupných literárnych prameňov teleošetrovateľstvo v začiatkoch, považujeme ho za málo rozvinuté a preskúmané. Sestry zavádzaním tohto nového prístupu môžu rozšíriť hranice tradičnej starostlivosti a podporiť v značnej miere zdravie populácie. Teleošetrovateľstvo môže nájsť uplatnenie aj v rámci integrovanej zdravotnej starostlivosti s cieľom pozitívne ovplyvniť jej efektivitu a kvalitu. Vzhľadom na tento rozvíjajúci sa trend chceme poukázať na potrebu zaradenia predmetnej problematiky do pregraduálnej a postkvalifikačnej prípravy sestier v každej modernej a kvalitnej vzdelávacej inštitúcii.

#### **Poďakovanie**

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# BARRIERS TO INTEGRATED CARE AMONG MULTIPLE STAKEHOLDERS: FROM ASSESSMENT TO INTERVENTION. THE EXPERIENCE OF PUGLIA REGION WITH THE SCIROCCO EXCHANGE ONLINE TOOL

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**BACKGROUND**: Health and welfare are complex systems undergoing major changes which will eventually lead to an integrated system. Many barriers are slowing down these changes, despite large efforts at different levels. This paper presents the experience of the six Local Health Authorities in Puglia Region.

**METHODS:** Self-assessment of the integrated care maturity level through the SCIROCCO Exchange online Tool.

**RESULTS:** The results highlight the gap of "Removal of Inhibitors" in all the six Local Health Authorities (LHAs), as perceived by all the stakeholders who took part to the project. On average, the level of maturity of each LHA health and social care system varied from medium to high.

**CONCLUSIONS:** The research conducted with the SE online Tool has provided a qualitative multi-dimensional and multi-professional representation of the IC maturity level of the Puglia LHAs from the stakeholders' point of view in relation to the Tool's 12 dimensions. The outcomes suggest the need for a Knowledge Transfer Program that will provide an Improvement Plan.

Key words: integrated care, removal of inhibitors, stakeholders, online tool, SCIROCCO

#### Introduction

Puglia Region, by means of its Strategic Regional Agency for Health and Social Care (AReSS), aims at improving social welfare and health care through innovation policies targeting value based care systems and patient's needs. The aforementioned policies included the experimentation of the Integrated Care (IC) Model "Puglia Care" to improve the disease and care management of chronic patients (Robusto et al. 2018).

The Model is now at its 3.0 revision and it is based both on the vertical integration among different care settings (i.e. specialised care and primary care), and on the horizontal integration among professionals within the same care setting, which shall start in the GPs practices. This implies the definition of new specific healthcare pathways based on pathology; promotion of patient empowerment; co-creation of digital systems to support the delivery of care to citizens and facilitate communications among professionals and a better control of resources and more appropriate setting for care delivery. This Model revolves around the patients who are engaged in decisions about their personal care plans. The plan is tailored to patient needs as a result of a team work between the GP, the Specialist, the specialised nurse (care manager), and the care giver.



Figure 1 Integrated care model in Puglia Region

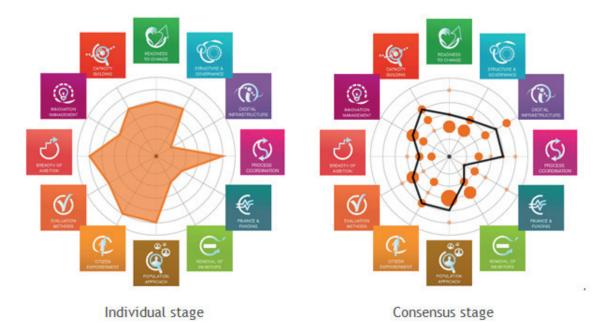
In order to acquire data on the stakeholders' perception on the organisational governance of IC in the Region, AReSS assessed the IC maturity level of the Local Health Authorities (LHAs) using the EU Health Programme funded SCIROCCO Exchange (SE) online Tool (Anderson et al. 2019)

#### Methods

The SE project provides a 12-dimensions online tool for European regions to assess their maturity in the provision of IC, including identification of strengths, gaps and areas for improvement (Grooten et al. 2019). It is intended to stimulate discussion, to encourage regions to share their experience, and to provide inputs for knowledge transfer

and capacity-building activities with an objective to address the emerged maturity gaps.

The methodology provides the following steps: 1) selection of key role stakeholders participating in the assessment process at macro, meso and micro level; 5-7 stakeholders for each LHA were selected to provide a multi-perspective assessment: General/Clinical Director; Integrated Health and Social care Community Centre Director; Care Manager; IT specialist; Patients' Representative; 2) Conducting the individual assessments; 3) Building the consensus among the involved stakeholders (the bigger the bubbles, the greater the agreement on the specific score). The outcomes of the assessment were captured in the form of spider diagrams, highlighting Puglia' LHAs strengths and weaknesses in IC (Figure 2).



Self-assessment tool visualisation

Figure 2 Examples of the SCIROCCO assessment

#### Results

SE Project has provided a multi-dimensional representation of the IC maturity level of the Puglia LHAs including the "Removal of Inhibitors" dimension addressed in this paper. Below we describe the results of how the dimension Q6 "Removal of Inhibitors" in the SE online Tool was rated by the selected stakeholders on a scale 0 to 5, within each of the six LHAs.

- 1. In Bari (BA LHA), four out of seven stakeholders agree on a rating towards the lowest end of the scale (i.e. "0" and "1"), also due to the individual resistance that some professional categories are posing (e.g. GPs and nursing staff). One point of agreement among the stakeholders is the need to integrate across professional categories (vertical integration) and to overcome the individual resistance. Despite the amount of available training courses, there is sometimes opposition in undertaking them. This is acknowledged at nurse and GP level.
- 2. In Brindisi (BR LHA), three out of five stakeholders agree on assessing this dimension with the medium-hight score 3 *Implementation Plan and process for removing inhibitors have started being implemented locally.* The Nurse Coordinator agrees with all the fellow stakeholders the existence of an active training plan, despite being unsuccessful. The President of Voluntary Association suggests a better organisational model as a useful tool to support the removal of inhibitors. The Chief Medical Officer (CMO) confirms the strong desire and effort towards innovation that is bringing results even if on a longer term. The action is in progress. Although existing, implementation processes are not yet evenly distributed.
- 3. In Barletta (BT LHA), almost all stakeholders (i.e. four out of five) agree on assessing this dimension 1 Awareness of inhibitors but no systematic approach to their management is in place, as inhibitors are perceived and identified. Nevertheless, there is not a systematic plan in place for removal, nor reduction. The assessment is due to the lack of perception of inhibitors by some of the stakeholders, but not all of them.
- 4. In Foggia (FG LHA), the stakeholders have split views. Two out of three have negative perception, while three have a more positive opinion, even if not fully positive. In particular, they all acknowledge different levels of literacy and cultural inhibitors. There are currently no strategies in place.

- 5. In Lecce (LE LHA), three out of six stakeholders rate 1 Awareness of inhibitors but no systematic approach to their management is in place. The Chief Executive Officer (CEO) confirms that at the managerial level there is clear knowledge and understanding of the inhibitors and that action needs to be taken. Nevertheless, as already stated at the very beginning of the consensus building process, there are those who are enthusiast of the change and those who are resistant to the change, hence to taking action towards removing inhibitors. There is a strategy to remove inhibitors shared at the management level. Nevertheless there is a limited response from the bottom, which has started to be implemented.
- 6. In Taranto (TA LHA), three out of five stakeholders rate this dimension 2 Strategy for removing inhibitors agreed at a high level. Nevertheless, the other two stakeholders rate it 1 Awareness of inhibitors but no systematic approach to their management is in place. During the discussion it is brought to evidence that inhibitors may well be in the process to be removed, but this situation is mostly limited to healthcare pathways, and not integrated care delivery pathways.

#### Discussion

Stakeholders with different roles and experience perceive the dimension Q6 "Removal of Inhibitors" in different ways. The presence of inhibitors is perceived more by stakeholders at managerial (i.e. CMO and CEO) and technical levels (i.e. IT services Director, IT services Manager), while stakeholders with clinical roles (i.e. H&SC District Director, Nurse Coordinator) and patients' representatives provided a higher rating. Stakeholders who have been within the organisation for a longer period of time appear to have a more detailed and analytical perception of which the major inhibitors are and which actions shall be put in place to enable their removal.

A common factor among this specific dimension and its low rating amongst several Puglia Region LHAs is its relationship to management and governance. Overall, three LHAs (i.e. BA LHA, BT LHA, and TA LHA) rated it extremely low on the 0 to 5 scale.

The available training opportunities are not always enough to remove the long-term eradicated resistance in undertaking courses. Among some LHAs (i.e. FG LHA), there were no strategies in place at the time of the research. However, in order to put in place an organisational strategy, being mindful of the exact background

situation is crucial. For instance, the low assessment is sometimes (i.e. BT LHA) due to the lack of perception of inhibitors by some of the stakeholders, while others have precise knowledge about them. Finally, there is sometimes (i.e. LE LHA) a strategy to remove inhibitors shared at the management level; nevertheless there is a limited response from the bottom, which has recently started to be implemented.

Puglia's self-assessment outcomes and local context for IC are coherent with the peer-assessment conducted by the European Commission which awarded Puglia in 2019 as a 4-star Reference Site in the European Innovation Partnership on Active and Healthy Ageing.

The outcomes of the six consensus workshops have brought to evidence space for improvement in the delivery of IC services to the citizens in Puglia Region, especially on a systematic basis, and particularly in the three dimensions where scores were lower: Finance & Funding; Removal of Inhibitors; Evaluation Methods.

Focusing on Inhibitors to a full IC deployment, they are still present and require systematic and organised action to be removed. All six LHAs share similar perceptions of this dimension, as variations are reported in the approach depending upon the recognition of inhibitors (e.g. perception and identification) within the organisations (i.e. LHAs) and outside (e.g. citizens). Besides, both within and outside the LHAs, there are those who are "enthusiastic" and those who are "resistant", adding a further element to the overall picture. During the six workshops the stakeholders demonstrated their willingness to bring this process to a further level, with full awareness that knowledge sharing and information transfer to all participant stakeholders is among the key enablers of a fully IC pathway.

Focus groups conducted as part of the SE methodology, revealed a very satisfactory experience of the stakeholders participating in SE Project, highlighting as the most significant element of the process lies in the promotion of multi-stakeholder tables. This process, facilitated by a powerful instrument as the SE Tool, was able to:

- Facilitate the reflection on IC, supporting both creative and critical thinking about it.
- Facilitate discussion among different levels of stakeholder groups. These discussions help to align theoretical IC implementation process with current practice.
- Facilitate interdisciplinary discussion and to enable different visions together.

#### Lessons learnt and future recommendations

The lesson learnt shows how an intervention to remove inhibitors to the implementation of IC has to be based on a systemic approach applied to the co-creation of health and socials care services; this approach does not consider stakeholders working at different levels as separate elements of the IC system and it is based on the capability to identify and valorize different roles. The necessary navigability between the cure and care is only possible if all the key actors share the same values, the same mission, and the same piece of information. Only that way can they reach the objective to share plans and perspectives and to remove inhibitors. This is important in the long term but also in the short run to guarantee connectivity, alignment and collaboration. Finally, a strong leadership is needed to guide this process with a clear vision.

To pursue this objective, after the self-assessment process, comprising the 33 on-line individual assessment surveys, the six LHAs workshops, and the data analysis, AReSS Puglia is launching a Knowledge Transfer Program in collaboration with the SE Consortium, at local and regional scale (i.e. Puglia Region). As the most important element of this improvement plan, AReSS is promoting a training course under the National CME - Continuing Medical Education that will be addressed to all the different categories of involved stakeholders to favor a multi-stakeholder approach to remove the still existing barriers to IC and to facilitate a systemic approach to the removal of inhibitors.

The course aims at being a think tank for regional IC and to boost a permanent dialog between the health system's actors; it will use the SCIROCCO Exchange Knowledge Management Hub as an integrator and facilitator for accessing personalised learning and capacity-building support.

The activated process has in itself great potential for the improvement of IC in Puglia and, once completed, it will require a second phase of evaluation with the online tool to verify the concrete results.

#### **Conclusions**

The research conducted with the SE online Tool has provided a qualitative multi-dimensional and multi-professional representation of the IC maturity level of the Puglia LHAs from the stakeholders' point of view in relation to the Tool's 12 dimensions. On average, the level of maturity of each LHA health and social care system varies from medium to high. The outcomes suggest the need for a Knowledge Transfer Program that will provide an Improvement Plan.

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# NON-PHARMACOLOGICAL INTERVENTIONS (NPIS) IN CHRONIC DISEASE MANAGEMENT WITHIN THE CONTEXT OF REORGANIZATION OF HEALTHCARE SYSTEMS AND INTEGRATED CARE

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For hundreds of years, case reports have mentioned the benefits of Non-pharmacological interventions (NPIs) for health and well-being, especially in patients with chronic disease. For the last few decades, observational studies have indicated their role in longer lifespans and better quality of life. In recent years, clinical trials have shown specific benefits with respect to biological, psychological and socio-economic markers. However, authorities and academic societies remain skeptical. Some healthcare corporations protest against these practices. The article details scientifically-based proposals to overcome these resistances.

Key words: non-pharmacological interventions, assessment framework, effectiveness

#### Introduction

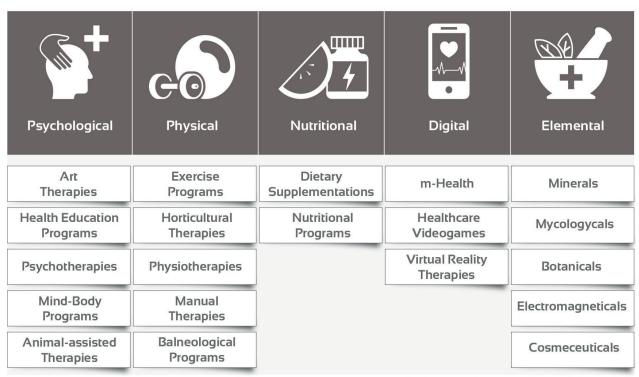
Non-pharmacological interventions (NPIs) divide opinion. There are pros and cons, as much in the ranks of clinicians as among researchers, patients and decision-makers. The skeptics want to understand everything before using them and recall the many falsifications that have undermined confidence in NPIs throughout the history of medicine. At best they are no more effective than placebo solutions or general public health messages coming from healthy lifestyle cohort studies (Behrens et al. 2013). Those who are convinced of the merits of NPIs stress the fact that they work with people around them and that they have observed benefits for themselves, a close person or their patients. The article presents the scientific challenges that are being overcome in the course of the last 10 years.

#### 1. Demand for effectiveness

In a world dominated by rationality and single-causality, explaining that a mechanism of action is at work in a "complementary medicine empirically tinkered with" is no longer enough (Ninot 2020). The patient who becomes a client demands a guaranteed benefit with minimum risk and expense. He or she wants to avoid the mistakes of the past where decisions were taken blindly or intuitively. Authorities and health funders, and most importantly

patients, are requiring evidence of effectiveness and safety of NPIs, specifications for implementation, and trained and responsible professionals. Demand for the evaluation of the effectiveness of NPIs (Figure 1) is accelerating under the pressure of six categories of actors:

- patients who have become organized and informed consumers demanding to know the real effects of NPIs, the risks incurred for health and the constraints of use,
- health professionals wishing to offer their patients practices based on scientific evidence to differentiate themselves from charlatans,
- researchers, convinced today by mechanistic studies and observational cohorts,
- academic societies encouraging the construction of consensual prescription decision trees and good practices,
- health insurance companies and provident organizations wishing to clarify the responsibilities of each, estimate the risks in the event of a problem and reimburse the NPI at the best value for money,
- decision-makers faced with an epidemiological transition unprecedented in human history (exponential increase in the number of elderly and people with chronic disease) who are waiting to know which are the best NPIs before taking action.



Version 3.0, Plateforme CEPS, Universities of Montpellier, France, 2020

Figure 1 Classification of non-pharmacological interventions (Ninot 2020)

### 2. Medical and institutional caution contrast with evolving practices

Numerous published pilot studies have been reporting benefits of NPIs in improving health, autonomy and quality of life in participants with disease or frailty (Ninot 2020). These studies can sometimes signal a reduction in direct and indirect health costs. Unfortunately, these observations do not prove it irrefutably. Collective expertise published by authorities remain reserved due to methodological shortcomings. Without recommendations from the authorities, NPIs will remain the subject of endless contradictory debate, provocatively illustrated by a simplistic position evident in an editorial titled by Ernst (2018) "alternative practitioners amuse the patient, while medics cure the disease". They will continue to attract individuals fond of paranormal explanations such as crab to heal cancer (Atshan et al. 2020), questionable testimonies, improbable amalgams, manipulations of all kinds. Their chances of systematic integration into the care pathways and reimbursement by insurance authorities will be compromised in a sector subject to strong economic, political and corporate lobbies.

#### 3. Drugs framework

It was not that long ago, only around 50 years, that drugs were at the same level of uncertainty as NPIs today (Bouvenot & Vray 2006). "Until the 1960s, many therapeutic interventions [drugs] had as their only justification, so to speak, the force of routine, the credulous attachment to traditions, or a generalization from a few occasional and anecdotal examples improperly called professional experience" (Bouvenot & Vray 2006, p. 13). Everything changed with the adoption of a single, standardized model for drug validation and monitoring. It was clinical and experimental research that helped remove doubts and wipe out dangerous practices. Demonstrating the effectiveness of an NPI on health means providing irrefutable evidence via a clinical trial, of its effect on one or more endpoints, based on a sufficient number of representative participants and a finding of significant statistical difference between the group testing the NPI and the control group. In other words, demonstrating significant differences, and not just observing appearances. An NPI will be demonstrated to be effective if its administration to people in an experimental group shows a greater benefit than that evident in a control group taking a placebo or following routine care.

#### 3. Before market research

Increase of pragmatic trials

The non-pharmacological scientific and medical literature shows evidence of an increase in pragmatic trials

(Schwartz & Lellouch 2009). These intervention studies demonstrate the effectiveness of NPIs, alone, in combination with, or in addition to, biological treatments. The rigor of the NPIs protocols has been improving (Boutron et al. 2008, 2012; Ninot 2020). The science of solutions complements the science of problems working on the mechanisms involved (basic research) (Hawe & Potvin 2009). Specialists speak of intervention research as that aiming to show the effectiveness (real life effect) and not efficacy (effect on ultra-selected participants in an artificial laboratory context) of an innovative health solution.

#### Improvements in the methodological quality of studies

Since 2010, the number of controlled trials verifying the efficacy of NPIs has increased despite the financial, human and material resources required by these protocols. They are gaining statistical power, increasing the number of subjects included, as well as improving outcome measure instruments (Ioannidis 2014). They are gaining in methodological rigor (internal validity) and in transferability to real life (external validity). Systematic reviews of intervention studies are a key for motivation, especially in areas that are less easy than testing health products (e.g., plants, food supplements, cosmetic products) such as education programs. The evaluation criteria are broader: benefits (effectiveness on health determinants and health-related quality of life), risks (side effects and risks of interaction with other therapies), utility (cost-effectiveness), constraints (additional burden, non-adherence).

The description of the NPIs evaluated is more precise and more exhaustive, although there is still room for improvement when compared to that for drugs (Glasziou et al. 2008). Comparison groups are more credible.

A collaborative study conducted within an academic structure is a guarantee of rigor, transparency, ethics and a limitation of conflicts of interest. Randomization is also an important methodological aspect to scrutinize. For example, the standard of a double-blind trial required for testing drugs is often impossible in the NPI context. How can you hide from the patient and the healthcare provider that the healthcare provider is pricking the patient with acupuncture needles?

International standardization recommendations are emerging for the design of protocols for evaluating NPIs (Boutron *et al.* 2008, Chan *et al.* 2013, Hoffmann *et al.* 2014) with some essential specificities when compared to drugs or medical devices (Falissard 2015):

- systematic registration of the protocol before its implementation,
- ethics,

- transparency of interest links,
- description of the NPI (e.g., addendum available online),
- implementation techniques by professionals (Michie *et al.*, 2013),
- potential accessibility of data and protocol notebooks (e.g., Open Science),
- systematic publication and follow-up of citations (Boutron *et al.*, 2008).

The WHO Plan 2014-2023 for traditional and complementary medicines encourages innovation in evaluation methods and outcome criteria for NPIs given their specificity, in particular because of their human mediation (WHO 2013). The WHO points in particular to the need for medico-economic studies likely to convince decision-makers to recognize these practices and better reimburse them. The WHO also encourages the implementation of real-world experiments combining several methods and several scientific disciplines to consolidate the available knowledge and evidence-based practices.

Many experts encourage research to go further in this direction (Boutron *et al.* 2012, Ninot 2020). They invite researchers to use mixed methods combining, qualitative and quantitative techniques. The challenge is just as much to verify the statistical superiorities of groups testing an NPI, as to understand the participants' experience (Ninot 2020). Last but not least, studies need to assess possible side effects, because any therapy involves risks.

#### 4. Post-market research and surveillance

#### Users

The evaluation of NPIs is not just a matter of researchers, manufacturers and creators. Users are now invited to report benefits, interactions, side effects and abuses. Platforms are created for the good of the community. Consumers can score their experience, register appreciation of what worked and indicate what didn't work, and testify to drug interactions, usage constraints, experiences and failures. They must become alter launchers if necessary directly to health authorities or indirectly via social networks.

#### **Practitioners**

The data collected on NPIs comes from practitioners. They can rate the best and worst NPIs to resolve a health condition. Moreover, healthcare professionals can also assess NPI practitioners on specific digital platforms.

#### **Authorities**

The market surveillance system for safety of herbal medicines is relatively close to that for drugs, and in many countries benefits from drug monitoring procedures (WHO 2019). Some countries have created specific entities for following the safety and benefits of NPIs such as National Center for Complementary and Integrative Health in the US or the University College of Integrative and Complementary Medicine in France. However, most countries currently use conventional health surveillance systems to carry out the after-market evaluation of NPIs, unfortunately without making NPIs a priority as they are presumed to be less potentially dangerous than biomedical treatments.

#### 5. A need for a consensual validation and surveillance framework

Minimal methodological requirements in a unique validation and surveillance framework should be required and known to all, in order to serve meta-analyses and better justify the usefulness of new clinical trials. This standard has been the case for drug development for 50 years. Researchers and manufacturers share a consensual framework which guides them from the laboratory to authorization and implementation post-marketing. According to the guidance of the US Food and Drug Administration, the framework characterizes the collection and evaluation of data, from the process design stage through commercial production, in which scientific evidence of efficacy,

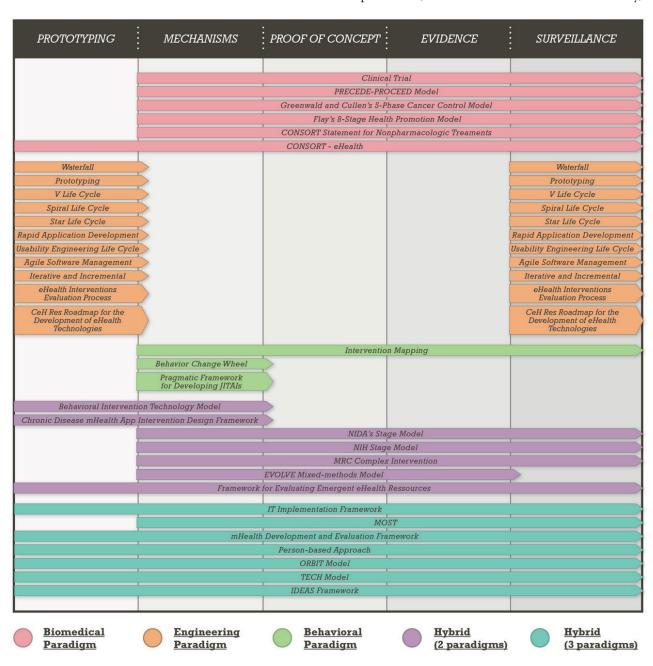


Figure 2 Validation and surveillance frameworks for NPIs published in the scientific and medical literature

safety and quality of product are consistently established. The principles and methods are similar across Western countries. The framework is organized in five phases: phase 0 (preclinical) to identify mechanisms, phase 1 to determine tolerance in healthy humans, phase 2 to identify the optimal dose for a small number of patients (pilot trial), phase 3 to demonstrate evidence of efficacy and safety (randomized controlled trial) and phase 4 to ensure long-term safety. A narrative review that sorted and categorized validation and surveillance frameworks on NPIs has been published in the scientific and medical literature (Carbonnel & Ninot 2019). The results showed the absence of a unique and consensual model (Figure 2). In April 2019, 46 frameworks coexist, without one of them being predominant or even showing a convergence emerging towards one of them. Their numbers have increased exponentially over time since the 70s.

In the same way for drugs 50 years ago, it is urgent to adopt a consensual framework for validation and monitoring of NPIs (Carbonnel & Ninot 2019). If, naturally, there will always remain an element of singularity due to the contribution of the relationship between the practitioner and the patient, it becomes urgent to adopt on a supranational, even international scale a consensual approach of verification of the safety and effectiveness of NPIs through rigorous intervention studies, optimization of practices through implementation studies, and usage monitoring analyses using big data and artificial intelligence. Such an approach would undoubtedly help to remove the barriers, skepticism and stubborn false beliefs regarding NPIs. Big data analyses and patient opinions will count in this process.

#### **Conclusions**

Science is advancing slowly, counterintuitively, but surely. With about 2 million publications of intervention studies evaluating NPIs, their number has increased exponentially since 2000 (Ninot 2020). Study after study, trial after trial, the results converge to show the benefits and limits of each NPI for human health. Unnecessary and dangerous alternative medicines are isolated and excluded from practice. Relevant NPIs are described with precise specifications and are progressively improved by new studies. A consensual validation and surveillance framework is necessary, as was the case for drugs 50 years ago.

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# INTEGRATED CARE IN SLOVAKIA: RESULTS OF A SCIROCCO SELF-ASSESSMENT PROCESS IN THE KOSICE REGION

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**BACKGROUND:** The traditional disease-oriented healthcare systems are no longer sufficient to meet the increasing disease burden and the complexity of needs arising from them. There is a demand to rethink the delivery systems and transform fragmented health and social care services towards people-centred integrated care. This study aimed to assess the maturity of the Slovak healthcare system for integrated care.

**METHODS:** A mixed-method study design was used. Representatives of relevant stakeholder organizations in the Kosice Self-Governing Region were invited to participate in a self-assessment process and a follow-up consensus-building workshop. Data were collected using a SCIROCCO tool that evaluates 12 dimensions relevant to integrated care on a scale ranging from 0 (lowest maturity) to 5 (highest maturity).

**RESULTS:** Overall, the maturity of the Slovak healthcare system for integrated care was evaluated as low. Out of 12 dimensions, four were assigned a score '0', seven a score '1', and one dimension reached a score '2'. The highest mean score was achieved on dimension 4-Process Coordination  $(2.00\pm0.82)$ , while the lowest on dimension 9-Evaluation Methods  $(0.43\pm0.79)$ . Compared to other SCIROCCO Exchange countries, the maturity of the Slovak healthcare system for integrated care falls behind these countries in almost all dimensions.

**CONCLUSIONS:** The outcomes of the self-assessment process helped to identify the areas that need to be developed further in order to successfully deploy integrated care in Slovakia.

Key words: integrated care, disease burden, healthcare reform, people-centred care, SCIROCCO

#### Introduction

European countries are dealing with a marked increase in the proportion of people with chronic conditions and related societal, economic, and individual burdens (EC 2015). Care is often too fragmented and has apparent deficiencies in quality, low responsiveness, and low satisfaction with health services. Health and social care systems are under tremendous pressure to undergo significant transformations to meet the evolving needs of their populations. Integrated care has emerged as a way to overcome these health challenges, having the potential to improve population health, quality of care, and optimize costs (Nolte & McKee 2008).

According to the WHO, integrated care is defined as "bringing together inputs, delivery, management and organization of services related to diagnosis, treatment, care, rehabilitation, and health promotion, wherein integration is regarded as a mean to improve the services in relation to access, quality, user satisfaction and efficiency"

(WHO 2001, Gröne & Garcia-Barbero 2001, p.7-8,). Over the years, there has been a considerable evolution in the definition of integrated care. A shift can be recognised from a definition focused on services towards a focus on people-centred care, including a comprehensive perspective of people's needs and a sensitivity to the context-specific nature of health systems. In 2015, WHO highlighted a people-centred and integrated health services approach as a global strategy, offering a way forward for comprehensive health system design (WHO 2015).

In Slovakia, the integration of health and social care services, including the transformation of long-term care and hospital care, have been discussed over the past 20 years. Integrated care is recognised as an approach that could help address current national healthcare challenges, such as chronic disease burden and suboptimal population health outcomes, weak gatekeeping at the primary level, the concentration of service delivery in higher levels, fragmentation, overspecialisation, discontinuity of care, and limited availability of health promotion or disease

prevention services (Mesaros 2016). In 2013 the Slovak government made a commitment to a thorough health system reform to move away from the hospital-centric paradigm and strengthening the role of primary care. Formalising this aim through the Strategic Framework of Healthcare 2014-2030; this strategy proposed plans for developing a network of primary-level integrated healthcare centres (MoH SR 2013, Mesaros 2016). This was followed by a series of additional strategic documents dealing with long-term care, implementation strategy for integrated care, the transformation of hospitals, and evidence-based guidelines (MoH SR 2014, MoH SR 2020a, MoH SR 2020b); aiming to achieve system-level transformations, including the performance-based financing mechanisms. Yet, the concept of integrated care is still not well understood in Slovakia, nor there is an agreement about how to put it into practise. Numerous attempts to create a legal framework for the integration of health and social care services have been abandoned due to a lack of political will and inter-stakeholder collaboration. Also, several integrated care initiatives, such as in Trencin or Banska Bystrica self-governing regions (Mesaros 2016) remained at the pilot stage.

The European Commission dedicated a programme - the European Innovation Partnership on Active and Healthy Ageing (EIPonAHA), B3 action on integrated care - to support countries and regions in their endeavours towards effective implementation of integrated patient-centred care services (Bousquet et al. 2017). Within this programme, a conceptual Maturity Model was developed that evaluates 12 dimensions relevant to integrated care. The Maturity Model was later on transformed into an online self-assessment tool, tested and validated within two EUfunded projects, SCIROCCO (Scaling Integrated Care in Context, 2020) and SCIROCCO Exchange (2020a). Slovakia has been a project partner in the latter project. The aim of this study was to assess the maturity of the progress to implement integrated care delivery in Slovakia, and specifically in the Kosice Self-Governing Region, using the 12 dimensional SCIROCCO tool.

#### Methods

#### Sample and procedure

The sample comprised stakeholders from the Kosice Self-Governing Region that were identified on the basis of their potential knowledge, experience, and competence in the field of integrated care with regard to the main dimensions of the SCIROCCO Maturity Model. In total, 23 stakeholders were invited to participate in the self-assessment process. They were representatives of the state

administration, self-government (regional and local level), academia, professional healthcare associations, primary health care providers, health and social care providers, and patients' non-governmental organisations. Individual self-assessment surveys were conducted in February and March 2020. After that, the follow-up consensus-building workshop was held on the 26 March 2020. Due to COVID-19 restrictions, the meeting was held on-line.

#### Measures

The data were collected using the Slovak version of the SCIROCCO self-assessment tool (Appendix 1) (Nagyova & Katreniakova 2019, SCIROCCO Exchange 2020a). The tool measures the maturity of the health and care systems for integrated care in 12 dimensions that are deemed key to deliver integrated patient-centred care: 1-Readiness to Change, 2-Structure and Governance, 3-eHealth Services, 4-Process Coordination, 5-Funding, 6-Removal 7-Population Approach, 8-Citizen of Inhibitors, Empowerment, 9-Evaluation Methods, 10-Breadth of Ambition, 11-Innovation Management, and 12-Capacity Building. Each of the 12 dimensions is described in terms of its objectives (brief description of the dimension), followed by an assessment scale reflecting the potential level of maturity with a score ranging from 0 (lowest maturity) to 5 (highest maturity) (SCIROCCO Exchange 2020a).

#### Statistical analyses

Data were analysed using descriptive statistics (frequencies, means, standard deviations) and presented visually in spider diagrams/radar plots. The differences in stakeholders' perceptions on the level of maturity for integrated care in the Kosice Self-Governing Region were delineated in the composite spider diagram, while the local stakeholders' consensus reached across the 12 dimensions was depicted in the consensus spider diagram.

#### Results

Out of 23 invited stakeholders, the Regional Public Health Authority in Kosice and Kosice Self-Governing Region nominated only one person per institution (i.e. 2 respondents instead of the 9 invited), 7 stakeholders did not respond and 2 stakeholders sent an apology that they could not participate. A total of 7 stakeholders took part in the self-assessment process and filled out the paper version of the tool, yielding a response rate of 30%. In the follow-up stakeholder's consensus-building workshop, 3 professionals took part and 4 stakeholders sent their apology in advance. All attendees were representatives of different settings at regional or local levels, including self-governing region, health and social services, and clinical care. One

of the presumed reasons for lower participation in the self-assessment process and the follow-up workshop was the fact that the data collection occurred during the first wave of the COVID-19 outbreak in Slovakia.

#### Individual assessments

Overall, on the 12 dimensions, the stakeholder's evaluations ranged from 0-3 (Table 1). The highest mean rating was achieved on dimension 4-Process Coordination  $(2.00\pm0.82)$  and the lowest on dimension 9-Evaluation

Methods (0.43±0.79). The highest discrepancy in the stakeholders view was observed in dimension 7-Population Approach (SD=1.11), while the stakeholder's view was most in accord in dimension 1-Readiness to Change (SD=0.38). The differences in stakeholders' perceptions on the level of maturity for integrated care in the Kosice Self-Governing Region illustrates the composite spider diagram (Figure 1-A).

Table 1 Means and standard deviations (SD) of the stakeholders' individual responses on all SCIROCCO dimensions

SCIROCCO dimension	Mean ± SD	Range*
1 Readiness to Change	$1.14 \pm 0.38$	1-2
2 Structure and Governance	$1.43 \pm 0.98$	0-2
3 eHealth Services	1.14 ± 1.07	0-3
4 Process Coordination	$2.00 \pm 0.82$	1-3
5 Funding	$1.14 \pm 0.82$	0-2
6 Removal of Inhibitors	$0.71 \pm 0.49$	0-1
7 Population Approach	1.29 ± 1.11	0-3
8 Citizen Empowerment	$1.00 \pm 0.82$	0-2
9 Evaluation Methods	$0.43 \pm 0.79$	0-2
10 Breadth of Ambition	0.71 ± 1.11	0-3
11 Innovation Management	$1.43 \pm 0.79$	0-2
12 Capacity Building	0.86 ± 1.07	0-3

<sup>\*</sup> Note: theoretical range is 0-5

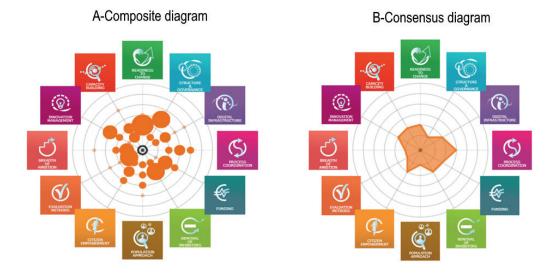


Figure 1 Results of self-assessments in Kosice Self-Governing Region

#### Final stakeholder's consensus

The consensus-building process was based on a moderated discussion in a duration of 2.5 hours. The outcomes of the group discussions illustrates the consensus spider diagram (Figure 1-B). The final consensus showed that no single dimension was identified as having reached an appropriate maturity level. The overall dimension scores were very poor and the maturity levels in the final consensus varied mostly between 0 (in 4 dimensions) and 1 (in 7 dimensions). Only one dimension (4-Process Coordination) was able to reach a higher, but still not satisfactory level of maturity (score 2).

#### Slovakia compared to SCIROCCO Exchange countries

Compared to other SCIROCCO Exchange project partners, the Slovak healthcare system's maturity for integrated care falls behind these countries in almost all dimensions (Figure 2). Slovakia is especially lagging behind such countries/regions as the United Kingdom (Scotland, Midlothian), Spain (Basque country), and Italy (Puglia region), which have a long tradition of integrated care service provision; but it also falls behind countries with a shorter tradition of integrated care (e.g. Germany), including new EU member states, such as Lithuania.



Figure 2 Slovakia compared to SCIROCCO Exchange countries

#### **Discussion**

The results of the evaluation of the maturity of the Kosice Self-Governing Region for integrated care, as assessed using the SCIROCCO tool, were overall on the lower side. These self-assessment outcomes were, however, not surprising, taking into account previous failed attempts to implement integrated care on a national level. The stakeholders agreed that the main reason for the insufficient maturity level of health and social care integration in Slovakia at regional, as well as at national level, is the lack of effective communication and co-ordination between the Ministry of Health (MoH) and the Ministry of Labour, Social Affairs and Family (MLSAaF) of the Slovak Republic. Governmental authorities are aware of insufficient integration between health and social care systems, or under-developed long-term care. Nevertheless, no efficient policy or systematic actions have been taken so far.

During the self-evaluation process, only one dimension (4-Process Coordination) was able to reach a higher, but still not satisfactory, level of maturity (score 2). This positive evaluation was due to some basic norms adopted and standard procedures developed by the Slovak Ministry of Health; in particular the Standard Preventive, Diagnostic, and Therapeutic Procedures (MoH SR 2020b). Since September 2017, the MoH SR has been intensively working on standard procedures for individual medical and non-medical fields as well as interdisciplinary areas. This process involves the adoption and adaptation of clinical procedures and guidelines, legislative changes as well as securing technical equipment and human resources, including capacity building and training of specialists and other follow-up procedural changes. The standard procedures aspire to eliminate outdated methods in prevention, diagnosis, and treatment and outbalance physicians accustomed to using obsolete procedures in their practice, and thus to improve health care quality.

The lowest valued maturity level (score 0) was found in four dimensions: 2-Structure and Governance, 7-Population Approach, 9-Evaluation Methods, and 10-Breadth of Ambition. Of those, dimension 2-Structure and Governance appears to be the most important starting point that might help to facilitate the process of adoption of all inevitable changes and transformations. Common factors connecting all the lowest dimensions are the absence of clear, uniform, and effective state governance and coordination, at the governmental level – primarily, the Ministry of Health; the Ministry of Labour, Social Affairs and Family; and the Ministry of Investments, Regional Development and Informatization. Also, the absence of

community-based services, the lack of a person-centred care approach in care provision, and changes usually driven by bottom-up initiatives and from non-governmental organisations, can be considered other important weaknesses of integrated care implementation process in Slovakia at both national and regional levels.

The SCIROCCO tool, as a standardized measuring instrument, provides an opportunity to assess and compare the implementation of the integrated care services across countries and regions. It also allows triangulating data and enhances in-depth insight into implementation processes and phases. The outcomes of the SCIROCCO Exchange project revealed that the maturity of the Slovak health and social care systems for integrated care falls behind all the countries involved in the project (SCIROCCO Exchange 2020b). Slovakia is especially lagging behind such countries/regions that have a longer tradition of integrated care service provision (Scotland, Italy, Spain) but is also falling behind countries with a shorter tradition of integrated care, including new EU member states (Lithuania, Poland, Slovenia).

The insights and knowledge transfer obtained in the project helped to understand what to consider when interested to ultimately scale up integrated care initiatives in Slovakia (SCIROCCO Exchange 2020a). Furthermore, informed by the outcomes of the maturity assessment on strengths and weaknesses, the identified priority for further action was to conduct a needs assessment to understand better the stakeholders' gaps in knowledge and obstacles in cross-system collaboration and effective communication. It is expected that focusing on capacity building (including dissemination of knowledge through trainings, educational material, and digital tools) the stakeholders' awareness of integrated care will increase, inter-professional collaboration pathways will be developed, and a person-centred integrated model of care to improve patient's experiences and outcomes will eventually be established in Slovakia.

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#### APPENDIX 1. Slovak version of the SCIROCCO tool

**Citing the sources:** In case of using the Slovak version of the SCIROCCO tool, please cite the original source as follows: Nagyova I, Katreniakova Z. SCIROCCO tool: Maturity Model for Integrated Care - Slovak version. SCIROCCO Exchange: EU project 2019.

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## SCIROCCO Exchange Maturity Model for Integrated Care - Slovak version

Model pripravenosti pre integrovanú starostlivosť



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#### 1. Pripravenost' na zmenu

#### Ciele

Pokiaľ je potrebné zmeniť existujúce systémy starostlivosti pre poskytovanie lepšie integrovanej sady služieb, bude si to vyžadovať zmenu naprieč mnohými úrovňami systému, vytvorenie nových rolí, procesov a pracovných postupov a nových systémov pre podporu zdieľania informácií a spoluprácu medzi tímami poskytujúcimi starostlivosť. Toto bude pôsobiť rušivo v zabehnutých systémoch a môže byť vnímané negatívne zo strany pracovníkov, médií a verejnosti, a preto je nutné jasné vysvetlenie potreby týchto zmien, vrátane odôvodnenia, strategického plánu a vízie lepšej starostlivosti.

- Vytvorenie presvedčivej vízie zdôrazňujúcej naliehavosť a získanie podpory zainteresovaných aktérov (stakeholderov) vrátane politického vedenia, riadiacich pracovníkov, odborníkov v oblasti starostlivosti, verejnosti a médií.
- Akceptovanie skutočnosti, že systémy starostlivosti sú naďalej neudržateľné a potrebujú zmenu.
- Zohľadnenie potreby riešenia rizika zdravotných a sociálnych nerovností.
- Zverejnenie jasného popisu problémov, rozhodnutí, ktoré bude potrebné urobiť, a zadefinovanie želaného stavu systémov starostlivosti s vysvetlením, ako bude táto starostlivosť v budúcnosti vyzerať.
- Vytvorenie vedomia urgencie ohľadom potreby dlhodobého sústredenia sa na danú tému a budovanie "vodcovskej koalície" pre dosiahnutie zmien.

#### Stupnica hodnotenia

- 0 Žiadna akceptácia naliehavosti pre potrebu zmeny
- 1 Naliehavosť potreby zmeny je akceptovaná, ale chýba jasná vízia alebo strategický plán
- 2 Prebieha dialóg a hľadanie konsenzu, je rozvíjaný plán
- 3 Vízia alebo plán je súčasťou politiky, objavujú sa vodcovské osobnosti a zástancovia zmeny
- 4 Vodcovstvo, vízia a plán sú širokej verejnosti jasné, je vyvíjaný tlak na zmenu
- 5 Politický konsenzus, verejná podpora, viditeľné angažovanie sa zainteresovaných strán

#### 2. Štruktúra a systémové riadenie

#### Ciele

Široký rozsah zmien potrebných k poskytovaniu integrovanej starostlivosti na regionálnej alebo národnej úrovni predstavuje veľkú výzvu. To si vyžaduje viacročné programy s efektívnym riadením zmien, financovaním a komunikáciou a schopnosťou ovplyvňovať a (niekedy aj) nariaďovať nové pracovné postupy. To znamená zosúladenie zámeru naprieč rôznymi organizáciami a profesiami a ochotu spolupracovať a postaviť záujem o celkový systém starostlivosti nad individuálne záujmy. Znamená to tiež zavádzanie technológiami podporovaných služieb starostlivosti tak, aby boli ľahko použiteľné, spoľahlivé, bezpečné a prijateľné ako pre profesionálnych poskytovateľov starostlivosti tak aj pre občanov.

 Umožnenie riadne financovaných programov so silným obsahom, manažovaním projektov a riadením zmien; zriadenie digitálnych centier kompetentnosti pre podporu zavádzania služieb; rozloženie vodcovstva za účelom zníženia závislosti na jedinom lídrovi; vynikajúca komunikácia cieľov, progresu a úspechu.



- Manažovanie úspešných digitálnych inovácii v rámci riadne financovaného viacročného transformačného programu.
- Zohľadnenie potreby riešenia rizika zdravotných a sociálnych nerovností.
- Zriadenie organizácií poverených výberom, vývojom a poskytovaním digitálnych služieb.

#### Stupnica hodnotenia

- 0 Existujúca štruktúra a systémové riadenie je fragmentované
- 1 Akceptovanie potreby štrukturálnej zmeny a zmeny riadenia
- 2 Vytvorenie pracovných skupín, spojenectiev alebo iných neformálnych spôsobov spolupráce
- 3 Systémové riadenie je ustanovené na regionálnej alebo národnej úrovni
- 4 Plán programu zmeny je definovaný a prijatý zainteresovanými stranami
- 5 Zavedený je kompletný, integrovaný program s financovaním a jasným mandátom

#### 3. Digitálna infraštruktúra

#### Ciele

Integrovaná starostlivosť si vyžaduje zdieľanie dát naprieč rôznymi tímami starostlivosti. To postupne vedie k vytvoreniu systémov umožňujúcich sústavnú spoluprácu, meranie a manažovanie výstupov. Znamená to budovať na už existujúcich digitálnych infraštruktúrach poskytovania starostlivosti, prepájať ich novými spôsobmi podporujúcimi integráciu a rozširovať ich o nové funkcie, ako napríklad zvýšená bezpečnosť a mobilita. Zjednodušenie digitálnej infraštruktúry poskytovania starostlivosti je možné dosiahnuť znížením počtu rôznych systémov a typu formátov ukladania a zdieľania dát. Dôležité prvky digitálnej infraštruktúry sú:

- Zásada "digitálna forma má prednosť/digital first" (t.j. presmerovať osobnú komunikáciu na digitálne služby s cieľom znížiť závislosť na personáli a podporovať samoobslužné činnosti).
- Dostupnosť základných zložiek (IKT infraštruktúra) umožňujúcich zdieľanie dát.
- Konsolidácia a štandardizácia infraštruktúry a riešení IKT; menej bodov technickej integrácie, ktoré je potrebné riadiť; interoperabilita a obstarávanie.
- Požiadavky na bezpečnosť a ochranu dát sú integrované do pacientskych záznamov, registrov a on-line služieb.
- Umožnenie nových kanálov pre poskytovanie zdravotnej starostlivosti a nových služieb založených na pokročilých komunikačných technológiách a technológiách pre spracovanie dát.

- 0 Neexistuje digitálna infraštruktúra na podporu integrovanej zdravotnej a sociálnej starostlivosti
- 1 Potreba je akceptovaná, ale neexistuje žiadna stratégia a/alebo plán zavedenia a štandardizácie digitálnej infraštruktúry na podporu integrovanej starostlivosti
- 2 Existuje mandát a plán(y) na zavedenie regionálnej/národnej digitálnej infraštruktúry vrátane schválených technických štandardov v rámci systému zdravotnej a sociálnej starostlivosti, ktoré však ešte nie sú implementované
- 3 Digitálna infraštruktúra na podporu integrovanej starostlivosti je pilotne zavedená, ale zatiaľ nedošlo k pokrytiu celého regiónu. Existuje súbor schválených technických



štandardov umožňujúci zdieľané obstarávanie nových systémov; prebiehajú rozsiahle konsolidácie niektorých IKT systémov

- 4 Digitálna infraštruktúra na podporu integrovanej starostlivosti je zavedená vo veľkom rozsahu, ale nevyužívajú ju všetky zainteresované strany. Je zverejnený jednotný súbor schválených štandardov, mnoho spoločných verejných obstarávaní nových systémov sa už uskutočnilo; zdieľané služby sú široko zavedené
- 5 Existuje univerzálna, rozsiahla regionálna/národná digitálna infraštruktúra používaná všetkými zúčastnenými stranami (stakeholdermi). Jednotný a záväzný súbor schválených štandardov je plne zavedený do obstarávacích procesov; systémy sú plne interoperabilné; a využívanie zdieľaných služieb (vrátane cloudu) je bežnou praxou

#### 4. Koordinácia procesu

#### Ciele

Poskytovanie zdravotnej a sociálnej starostlivosti predstavuje komplexnú sériu vzájomne prepojených procesov, ktoré sa podieľajú na dosiahnutí stanovených výsledkov. Koordinácia týchto procesov poskytovania starostlivosti si vyžaduje nové trasy (pathways) a služby na dosiahnutie zlepšenia kvality a efektívnosti starostlivosti a vyhnutie sa zbytočným odlišnostiam. Potreba koordinácie narastá, keď si starostlivosť o pacienta vyžaduje zásah zo strany rôznych profesionálov. Trasy starostlivosti sa široko používajú pre štruktúrované a detailné plánovanie procesu starostlivosti, vrátane štandardov starostlivosti. Nastavenie a použitie štandardov variuje medzi jednotlivými zložkami procesu. Odborníci a organizácie môžu tieto štandardy dodržiavať dobrovoľne alebo na základe právnych predpisov. Koordinácia procesov umožňuje efektívnu implementáciu a zlepšovanie integrovanej starostlivosti prostredníctvom:

- Vývoja nových procesov a trás starostlivosti, ktoré sú replikovateľné, financované a/alebo refundované a dohodnuté príslušnými zainteresovanými aktérmi (stakeholdermi).
- Vrátane explicitného stanovania cieľov a kľúčových zložiek starostlivosti.
- Definovania na dôkazoch založených štandardných postupov a dohodu na plánoch pre formálne zavedenie a rozšírenie nových služieb do praxe.
- Rokovania so širokou škálou odborníkov a autorít ohľadom predstavenia a zavedenia merateľných štandardov starostlivosti.
- Zabezpečenia udržateľnosti nových služieb a trás starostlivosti.

- 0 Neexistujú ani sa nevyvíjajú žiadne formálne usmernenia, popisy, dohody alebo štandardy týkajúce sa inovatívnych procesov koordinovanej starostlivosti v rámci služieb integrovanej starostlivosti
- 1 Zainteresované strany vypracúvajú určité usmernenia a uznávajú potrebu pre štandardizáciu procesov koordinovanej starostlivosti, ale neexistujú formálne plány na ich vytvorenie
- 2 Niektoré štandardizované procesy koordinovanej starostlivosti prebiehajú. Usmernenia sa používajú, niektoré iniciatívy a postupy sú formálne opísané, ale neplánuje sa systematický prístup



- 3 Služby, trasy a procesy starostlivosti sú formálne popísané štandardizovaným spôsobom zainteresovanými stranami (stakeholdermi). Systematický prístup k ich štandardizácii je plánovaný, ale nie zavedený
- 4 Systematický prístup je uplatňovaný vo väčšine procesov koordinovanej starostlivosti, vrátane trás starostlivosti; procesy sú štandardizované a zavedené v rámci celého regiónu/krajiny.
- 5 V regióne/krajine existuje systematický prístup k štandardizácii procesov koordinovanej starostlivosti. Procesy sa rozširujú, udržiavajú a redizajnujú podľa štandardov

#### 5. Financovanie

#### Ciele

Zmena systémov starostlivosti, aby mohli ponúknuť vyššiu mieru integrácie, si vyžaduje počiatočné investície a financovanie. Potrebný je tiež určitý stupeň financovania prevádzkových nákladov počas prechodu na nové modely starostlivosti a následná finančná podpora, až kým nové služby nebudú plne funkčné a staršie služby budú zrušené. Zabezpečenie toho, aby počiatočné a priebežné náklady mohli byť financované, je základnou aktivitou, ktorá využíva celý rad mechanizmov od regionálnych/národných rozpočtov po stimulačné fondy, investičné fondy Európskej únie, verejno-súkromné partnerstvá (PPP - public - private partnerships) a mechanizmy zdieľania rizika.

#### Stupnica hodnotenia

- 0 Nie sú k dispozícii žiadne ďalšie finančné prostriedky na podporu prechodu na integrovanú starostlivosť
- 1 Finančné prostriedky sú k dispozícii, ale najmä na pilotné projekty a testovanie
- 2 Konsolidované financovanie inovácií dostupné prostredníctvom súťaží/grantov pre jednotlivých poskytovateľov starostlivosti a implementáciu v malom rozsahu
- 3 Dostupné je regionálne/národné (alebo európske) financovanie alebo PPP širšiu implementáciu
- 4 Dostupné sú regionálne/národné schémy financovania a/alebo refundovania pre rozširovanie implementácie služieb integrovanej starostlivosti a ich dlhodobú prevádzku
- 5 Je zabezpečený niekoľkoročný rozpočet a/alebo refundačné schémy, dostupné pre všetkých zainteresovaných aktérov (stakeholderov) umožňujúce ďalší rozvoj integrovaných služieb

#### 6. Odstránenie inhibítorov

#### Ciele

Aj v prípade politickej podpory, financovaných programov a dobrej eHealth infraštruktúry, poskytovanie integrovanej starostlivosti môže skomplikovať mnoho faktorov a to, odďaľovaním zmeny alebo obmedzením jej rozsahu. Patria sem právne otázky týkajúce sa spravovania dát (data governance), odpor voči zmene zo strany jednotlivcov alebo profesijných orgánov, kultúrne prekážky voči používaniu technológií, neadekvátne finančné stimuly a nedostatok zručností. Tieto faktory je potrebné včas rozpoznať a vypracovať plán na ich odstránenie, aby sa minimalizoval ich dopad.



- Opatrenia na odstránenie prekážok: právne, organizačné, finančné a zručnosti týkajúce sa potreby riešiť riziko zdravotných a sociálnych nerovností.
- Zmeny v legislatíve týkajúce sa napr. zdravotníckych výkonov, riadenia toku informácií, zdieľania dát faktory, ktoré môžu brzdiť inováciu.
- Vytváranie nových organizácií alebo spolupráce k podpore práce naprieč rôznymi sektormi (normative integration).
- Zmeny v refinancovaní, ktoré budú podporovať zmenu správania a procesné zmeny.
- Vzdelávanie a tréning na zvýšenie porozumenia inováciám a technológiami podporovaným službám starostlivosti s cieľom urýchliť poskytnutie riešení.

#### Stupnica hodnotenia

- 0 Žiadne povedomie o účinkoch inhibítorov na integrovanú starostlivosť
- 1 Povedomie o inhibítoroch existuje, ale nie je zavedený žiaden systematický prístup k ich manažovaniu
- 2 Stratégia pre odstránenie inhibítorov je dohodnutá na vysokej úrovni
- 3 Implementačný plán a proces odstraňovania inhibítorov sa začal zavádzať na lokálnej úrovni
- 4 Riešenia pre odstránenie inhibítorov sú vyvinuté a bežne používané
- 5 Vysoká miera dokončenia projektov a programov; inhibítory už nie sú problémom pre rozvoj integrovaných služieb

#### 7. Populačný prístup

#### Ciele

Integrovanú starostlivosť je možné rozvinúť v prospech tých občanov, ktorí neprosperujú v existujúcich systémoch starostlivosti, a pomôcť im tak lepšie manažovať ich potreby v oblasti zdravia a starostlivosti, vyhnúť sa volaniu záchrannej služby a prijatiu do nemocnice a tiež skrátiť dĺžku pobytov v nemocnici. Toto je praktické riešenie pre naplnenie potrieb dnešnej doby. Populačný prístup tento rámec presahuje a používa metódy na porozumenie tomu, odkiaľ budú prichádzať budúce zdravotné riziká (a teda aj dopyt). Ponúka spôsoby, ako konať vopred, predvídať a očakávať, aby si občania mohli dlhšie udržať svoje zdravie a boli s postupujúcim vekom menej závislí na službách starostlivosti.

- Pochopenie a predvídanie dopytu; lepšie uspokojovanie potrieb a riešenie zdravotných a sociálnych nerovností.
- Zlepšenie odolnosti systémov starostlivosti použitím existujúcich údajov o verejnom zdraví, zdravotných rizikách a využívaní služieb.
- Podniknutie krokov k nasmerovaniu občanov k vhodnejším a pohodlnejším trasám starostlivosti (care pathways) založeným na preferenciách užívateľov.
- Predpovedanie budúceho dopytu a podniknutie krokov k zníženiu zdravotných rizík prostredníctvom technológiami podporovaných verejno-zdravotníckych intervencií.

- 0 Populačný prístup nie je aplikovaný v rámci poskytovania služieb integrovanej starostlivosti
- 1 Stratifikácia rizík na populačnej úrovni je uznávaná, ale jej realizácia nezačala
- 2 Prístup stratifikácie rizík sa experimentálne používa v niektorých projektoch



- 3 Stratifikácia rizík sa používa pre konkrétne skupiny, tj. u tých, u ktorých existuje riziko, že sa stanú častými užívateľmi služieb
- 4 Prístup hodnotenia populačného rizika sa uplatňuje v službách integrovanej starostlivosti, ale ešte nie systematicky alebo nie v rámci celej populácie
- 5 Stratifikácia rizík na populačnej úrovni je rozvinutá a plne implementovaná

#### 8. Posilnenie postavenia občanov

#### Ciele

Systémy zdravotnej a sociálnej starostlivosti sú pod narastajúcim tlakom reagovať na požiadavky, ktoré by inak mohli byť riešené samotnými občanmi a poskytovateľmi starostlivosti. Dôkazy naznačujú, že mnohí jednotlivci by boli ochotní viac sa podieľať na ich vlastnej starostlivosti, pokiaľ by mali k dispozícii ľahko použiteľné služby, ako sú napríklad - rezervovanie si termínu návštevy u poskytovateľa starostlivosti (lekára, sociálneho pracovníka, ...), monitorovanie vlastného zdravotného stavu a iné možnosti lekárskeho vyšetrenia. To znamená poskytovanie služieb a nástrojov, ktoré sú pohodlné, ponúkajú možnosť výberu a podporujú samoobsluhu a zapojenie sa do manažmentu vlastného zdravia, pričom sa berie do úvahy potreba riešiť riziko zdravotných a sociálnych nerovností.

#### Stupnica hodnotenia

- 0 Posilnenie postavenia občanov sa nepovažuje za súčasť poskytovania integrovanej starostlivosti
- 1 Posilnenie postavenia občanov sa považuje za dôležitú súčasť poskytovania integrovanej starostlivosti, ale efektívne politiky na jeho podporu sú vo vývoji
- 2 Posilnenie postavenia občana sa považuje za dôležitú súčasť poskytovania integrovanej starostlivosti, efektívne politiky na jeho podporu existujú, ale občania nemajú prístup k informáciám a dátam o zdraví
- 3 S občanmi sú služby integrovanej starostlivosti konzultované a občania majú prístup k informáciám a dátam o zdraví
- 4 Existujú stimuly a nástroje na motiváciu a podporu občanov pre spoluvytváranie zdravotníckych služieb a využívaní týchto služieb pre účasť občanov na procesoch rozhodovania o ich zdraví
- 5 Občania sa plne zapojení do procesov rozhodovania o ich zdraví a sú zahrnutí do rozhodovania ohľadom poskytovania služieb a tvorby politík

#### 9. Metódy hodnotenia

#### Ciele

Spolu so zavádzaním nových trás starostlivosti (care pathways) a služieb na podporu integrovanej starostlivosti, vzniká jasná potreba zabezpečiť, aby tieto zmeny mali požadovaný účinok na kvalitu starostlivosti, náklady na starostlivosť, dostupnosť a skúsenosť občanov. To podporuje koncepciu investícií založených na dôkazoch, pri ktorých sa hodnotí dopad každej zmeny, napr. zdravotníckymi ekonómami pracujúcimi na univerzitách alebo v špecializovaných agentúrach. Dôležitou metódou v tomto kontexte je Hodnotenie zdravotníckych technológií (HTA), ktorú je možné využiť pri odôvodnení nákladov na rozširovanie integrovanej starostlivosti na regionálnu alebo národnú úroveň.



- Stanovenie základnej úrovne (v oblasti nákladov, kvality, dostupnosti atď.) pred zavedením nových služieb.
- Systematické meranie dopadu nových služieb a postupov pomocou vhodných metód (napr. observačné štúdie, prírastkové zlepšenie, klinické štúdie).
- Vytváranie dôkazov, ktoré vedú k rýchlejšiemu prijatiu osvedčených postupov.

#### Stupnica hodnotenia

- 0 Nie je zavedené ani vyvíjané žiadne hodnotenie služieb integrovanej starostlivosti
- 1 Plánuje sa uskutočniť hodnotenie služieb integrovanej starostlivosti ako súčasť systematického prístupu
- 2 Hodnotenie služieb integrovanej starostlivosti existuje, ale nie ako súčasť systematického prístupu
- 3 Niektoré iniciatívy a služby integrovanej starostlivosti sú hodnotené ako súčasť systematického prístupu
- 4 Väčšina iniciatív integrovanej starostlivosti je hodnotená systematicky; výsledky sú publikované
- 5 Systematický prístup k hodnoteniu služieb integrovanej starostlivosti, schopnosť reagovať na výsledky hodnotenia a hodnotenie želaného dopadu na redizajn služieb (t.j. proces "uzavretej slučky")

#### 10. Rozsah ambícií

#### Ciele

Integrovaná starostlivosť zahŕňa mnoho úrovní integrácie, napríklad integráciu medzi primárnou a sekundárnou starostlivosťou, všetkých zainteresovaných strán zapojených do procesu starostlivosti alebo naprieč mnohými organizáciami. Integrovaná starostlivosť môže byť vyvíjaná jednoducho pre potreby zdravotnej starostlivosti (t.j. vertikálna integrácia) alebo môže zahŕňať sociálnych pracovníkov, dobrovoľnícky sektor a neformálnu starostlivosť (t.j. horizontálna integrácia). Čím sú ambície väčšie, tým početnejší a rozmanitejší sú aktéri (stakeholderi), ktorých je potrebné zapojiť. Podobne integrácia môže zahŕňať všetky úrovne systému alebo môže byť obmedzená len na zdieľanie klinických informácií. Dlhodobým cieľom by mali byť plne integrované služby starostlivosti, ktoré občanom poskytujú kompletný súbor bezproblémových interakcií a vedú k lepšej starostlivosti a zlepšeným výsledkom.

- Integrácia podporovaná na všetkých úrovniach zdravotníckeho systému na úrovni makro (politická, štrukturálna), mezo (organizačná, profesijná) a mikro (klinická).
- Integrácia medzi systémom zdravotnej starostlivosti a ostatnými službami starostlivosti (vrátane sociálnych, dobrovoľníckych, neformálnych, rodinných služieb).
- Bezproblémový pohyb pacienta medzi službami starostlivosti a v rámci nich.

- 0 Koordinačné činnosti vznikajú, ale nie ako výsledok plánovania alebo implementácie stratégie
- 1 Občan alebo jeho rodina môžu potrebovať konať ako integrátor služieb, a to nepredvídateľným spôsobom
- 2 Integrácia v rámci rovnakej úrovne starostlivosti (napr. primárnej starostlivosti) je dosiahnutá



- 3 Integrácia medzi rôznymi úrovňami starostlivosti (napr. medzi primárnou a sekundárnou starostlivosťou) je dosiahnutá
- 4 Zavedená je zlepšená koordinácia potrieb služieb sociálnej starostlivosti a služieb zdravotnej starostlivosti
- 5 Plne integrované zdravotnícke a sociálne služby sú zavedené a funkčné

#### 11. Riadenie inovácií

#### Ciele

Mnohé z najlepších nápadov pravdepodobne prídu od lekárov, zdravotných sestier a sociálnych pracovníkov, ktorí chápu, kde je možné zlepšiť existujúce procesy. Tieto inovácie je potrebné uznať, vyhodnotiť a podľa možnosti rozšíriť, aby boli prínosom pre celý systém. Univerzity a spoločnosti zo súkromného sektora sú zároveň stále viac ochotné zapojiť sa do otvorených inovácií a inovatívneho obstarávania s cieľom vyvíjať nové technológie, testovať zlepšenia procesov a poskytovať nové služby, ktoré zodpovedajú potrebám občanov. Tiež je prínosné pozerať sa mimo systému do iných regiónov a krajín, ktoré čelia rovnakým výzvam a učiť sa z ich skúseností. Celkovo to znamená riadenie inovačného procesu, aby sa dosiahli najlepšie výsledky pre systémy starostlivosti a zabezpečilo sa povzbudenie a odmeňovanie dobrých nápadov.

- Rýchlejšie prijímanie osvedčených nápadov.
- Vytvorenie atmosféry pre inovácie zhora nadol, so zhromažďovaním a šírením najlepších postupov.
- Učenie sa z vnútra systému, ako aj z iných regiónov, na rozšírenie myslenia a urýchlenie zmien.
- Zapojenie regionálnych orgánov zdravotnej a sociálnej starostlivosti, univerzít a spoločností zo súkromného sektora a ďalších sektorov do inovačného procesu (t.j. "otvorené inovácie").
- Využívanie inovatívnych prístupov k obstarávaniu (obstarávanie vo fáze pred komerčným využitím, verejné obstarávanie inovácií, verejno-súkromné partnerstvá, zdieľané riziko, platba na základe výsledku).
- Využívanie európskych projektov a partnerstiev (napr. Horizont 2020, Európske fondy regionálneho rozvoja, Európske sociálne investičné fondy a iné).

- 0 Nie je zavedené žiadne riadenie inovácií
- 1 Inovácia sa podporuje, ale neexistuje celkový plán
- 2 Inovácie sú zachytené a existujú určité mechanizmy, ktoré podporujú transfer poznatkov
- 3 Formalizovaný proces riadenia inovácií je plánovaný a čiastočne implementovaný
- 4 Formalizovaný proces riadenia inovácií je zavedený a široko implementovaný
- 5 Existuje rozsiahla otvorená inovácia v kombinácii s podporou obstarávania a šírením osvedčených postupov



#### 12. Budovanie kapacít

#### Ciele

Budovanie kapacít je proces, ktorým jednotlivci a organizácie získavajú, zlepšujú a udržiavajú zručnosti a vedomosti potrebné na kvalifikované vykonávanie svojej práce. Spolu s transformáciou systémov starostlivosti bude potrebné vytvoriť mnoho nových rolí a rozvíjať nové zručnosti. Tieto budú siahať od technologickej odbornosti a manažovania projektov až po úspešné riadenie zmien. Systémy starostlivosti sa musia stať "učiacimi sa systémami", ktoré sa neustále usilujú o zlepšovanie kvality, nákladovosti a dostupnosti. Musia budovať svoje kapacity tak, aby sa stali prispôsobivejšími a odolnejšími. Spolu s neustálou zmenou požiadaviek je nutné zachovať zručnosti, nadanie a skúsenosti. To znamená zabezpečiť, aby znalosti boli uchované a využívané na zlepšenie budúcich projektov, čo povedie k lepšej produktivite a väčším úspechom.

- Zvyšovanie zručností; neustále zlepšovanie.
- Vybudovanie základne zručností, ktorá môže vyplniť medzeru a zabezpečiť, aby potreby kapacít boli pochopené a riešené digitálnymi technológiami tam, kde je to možné.
- Poskytovanie nástrojov, procesov a platforiem, ktoré organizáciám umožnia posúdiť samých seba a vybudovať si vlastné kapacity na dosiahnutie úspešnej zmeny.
- Vytvorenie prostredia, kde sú vylepšenia služieb neustále vyhodnocované a poskytované v prospech celého systému starostlivosti.

- 0 Služby integrovanej starostlivosti nie sú brané do úvahy pri budovaní kapacít
- 1 Niektoré prístupy k budovaniu kapacít pre služby integrovanej starostlivosti existujú
- 2 Spolupráca v oblasti budovania kapacít pre integrovanú starostlivosť rastie v rámci regiónu
- 3 Vzdelávanie o integrovanej starostlivosti a manažovaní zmien existuje, ale nie je široko implementované
- 4 Systematické vzdelávanie o integrovanej starostlivosti a manažovaní zmien je široko implementované; poznatky sú zdieľané, zručnosti sú zachované a je nižšia fluktuácia skúseného personálu
- 5 "Na jednotlivca zameraný učiaci sa zdravotnícky systém" zahŕňajúci reflexiu a neustále zlepšovanie, je zavedený

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#### Conference

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"Chronic Diseases and Integrated Care: Rethinking Health and Welfare Systems"

24-25 October 2019 in Kosice, Slovakia

#### Hosted by

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