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ADDRESSING THE PARADOX OF REST WITH INNOVATIVE TECHNOLOGIES

PREMAGOVANJE PARADOKSA POČITKA Z INOVATIVNIMI TEHNOLOGIJAMI

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ABSTRACT

The paradox of rest lies in its dual nature: essential for recovery yet potentially harmful when prolonged. Prolonged physical inactivity (PI) significantly contributes to non-communicable diseases (NCDs). Studies show nearly a third of adults worldwide were insufficiently active in 2022, with the economic costs of PI projected to reach INT\$ 520 billion by 2030.

Keywords:

Physical inactivity
Functional and cognitive decline
Rehabilitation
Extended reality
Multimodal interventions

Bedrest models have illuminated the rapid onset of insulin resistance, general functional decline and muscle atrophy associated with PI, particularly in hospitalised older adults. Innovative technologies, such as extended reality (XR), offer promising solutions for mitigating the effects of PI and can enhance non-physical rehabilitation techniques such as motor imagery and action observation. These technologies provide immersive, personalised therapeutic experiences that engage multiple senses, transforming passive recovery into an active process and addressing both the physical and cognitive consequences of inactivity.

Results of bedrest study showed significant preservation of muscle mass, improved strength and enhanced insulin sensitivity in the intervention group compared to controls. These findings highlight the potential of XR-based strategies in addressing structural and functional declines during inactivity. As part of the Interreg VI-A Italia-Slovenija project X-BRAIN.net, advanced XR-equipped active rooms were developed to aid post-stroke rehabilitation in acute care settings. XR technologies, particularly VR, have shown promise in providing dynamic and adaptable therapeutic environments that facilitate early and targeted interventions. Future advancements focus on integrating XR with brain-computer interfaces (BCIs) and synchronised visual-haptic neurofeedback, enhancing sensorimotor cortical activation and improving rehabilitation outcomes. Comprehensive multimodal approaches, including nutritional, physical and non-physical interventions, are emerging as effective strategies to personalise and optimise patient recovery.

IZVLEČEK

Paradoks počitka leži v njegovem dvojnem značaju: nujen je za okrevanje, vendar lahko postane škodljiv, če traja predolgo. Dolgotrajna gibalna neaktivnost (GN) pomembno prispeva k nastanku kroničnih nenalezljivih bolezni (KNB). Študije kažejo, da je bilo leta 2022 skoraj tretjina odraslih na svetu premalo telesno aktivnih, ekonomski stroški KNB pa naj bi do leta 2030 dosegli 520 milijard ameriških dolarjev.

Ključne besede:

gibalna neaktivnost
funkcionalni in kognitivni upad
rehabilitacija
razširjena resničnost
multimodalne intervencije

Modeli raziskovanja GN z dolgotrajnim ležanjem v postelji so osvetlili hitro pojavljanje inzulinske rezistence, splošnega funkcionalnega upada ter mišične atrofije, povezane s GN, zlasti pri starejših bolnikih v bolnišnicah. Inovativne tehnologije, kot je razširjena resničnost (XR), ponujajo obetavne rešitve za omilitev učinkov GN in lahko izboljšajo ne-fizične rehabilitacijske tehnike, kot sta lastna predstavnost gibanja in opazovanje gibanja. Te tehnologije omogočajo poglobljeno, personalizirano terapevtsko izkušnjo, ki vključuje več čutov, ter spreminjajo pasivno okrevanje v aktiven proces, ki naslovi tako fizične kot kognitivne posledice neaktivnosti.

Rezultati študije dolgotrajnega ležanja v postelji so pokazali znatno ohranitev mišične mase, izboljšanje moči in občutljivosti na inzulin v intervencijski skupini v primerjavi s kontrolno skupino. Ti rezultati poudarjajo potencial strategij, temelječih na XR, za reševanje strukturnih in funkcionalnih upadov med neaktivnostjo. V okviru projekta Interreg VI-A Italia-Slovenija X-BRAIN.net so bile razvite napredne aktivne sobe, opremljene z XR tehnologijami, za pomoč pri rehabilitaciji po možganski kapi v akutni fazi zdravljenja. XR tehnologije, zlasti VR, so obetavne pri zagotavljanju dinamičnih in prilagodljivih terapevtskih okolij, ki omogočajo zgodnje in ciljno usmerjene intervencije. Prihodnji napredek se osredotoča na integracijo XR z možgansko-računalniškimi vmesniki (BCI) in usklajenim vidno-haptičnim nevrofeedbackom, ki izboljšujeta aktivacijo senzor motorične skorje in izboljšujeta rezultate rehabilitacije. Celostni multimodalni pristopi, ki vključujejo prehranske, fizične in ne-fizične intervencije, postajajo učinkovite strategije za personalizacijo in optimizacijo okrevanja pacientov.

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1 INTRODUCTION TO THE PARADOX OF REST

The paradox of rest lies in its dual nature: while rest is essential for recovery and healing, particularly for patients, prolonged physical inactivity (PI) can be detrimental. Extended periods of rest can negatively impact various systems of the body, especially the musculoskeletal system, leading to muscle atrophy, weakened bones and decreased overall function (1-4). In the *Art of Medicine* (5) Galen warns: when, for example, the body is in need of motion, exercise is healthy and rest morbid; when it is in need of a break, rest is healthy and exercise morbid. Balancing rest and activity are crucial to ensure recovery without causing harm.

PI has emerged as a critical global health challenge, significantly contributing to the rise of non-communicable diseases (NCDs) such as cardiovascular disease, stroke, type 2 diabetes, and certain cancers (6). The World Health Organization (WHO) highlights that physical inactivity is a primary, modifiable risk factor for NCDs and mortality. According to the WHO, physical inactivity is responsible for approximately 6% of deaths worldwide, making it one of the top four risk factors for mortality. People who are insufficiently active have a 20% to 30% increased risk of death compared to people who are sufficiently active (7). There is an estimate that nearly a third of adults globally (31.3%; 1.8 billion) were insufficiently physically active in 2022, an increase from 23.4% (900 million) in 2000 (8). A recent analysis (9) estimated that the global economic cost of physical inactivity could amount to approximately INT\$520 billion between 2020 and 2030 if current physical activity levels remain unchanged. The study further identified the European region as bearing the highest economic burden attributable to physical inactivity during this period.

It has long been understood that rest is vital for healing. It facilitates regeneration and affects every system, from cognitive function to immune health. However, research into the effects of physical inactivity on the human body highlights numerous consequences, including the deterioration of various subsystems—ranging from the musculoskeletal and cardiovascular systems to respiratory function, motor control, perception and overall well-being. These processes are especially pronounced in older individuals, where recovery is often slower (1). Such catabolic phases can significantly impact not only the return to normal life but also the recurrence of injuries and illnesses, along with increased mortality rates. These insights underscore our responsibility to thoroughly study the mechanisms behind these changes and, most importantly, to develop effective interventions that can slow down deterioration and promote the maintenance and swift recovery of patients' functional abilities.

The physiological consequences of PI have been extensively studied through controlled models such as bedrest campaigns. Bedrest protocols vary in duration, ranging from short-term campaigns of a few days to long-term studies lasting several weeks or even months. These protocols follow strict guidelines to ensure consistency across studies, such as maintaining a horizontal position with only minimal movements permitted and controlled dietary intake. These conditions help researchers isolate the effects of inactivity from other variables, providing valuable insights into its physiological consequences. Studies have highlighted critical changes in neuromuscular function, including the remodeling of motor units and the underlying mechanisms driving muscle deterioration (10-12). Acute exposure to inactivity has been strongly linked to a rapid onset of insulin resistance in muscle tissue, reduced glucose uptake and utilisation, and accelerated muscle protein degradation, ultimately leading to muscle atrophy (13, 14). These findings underscore the metabolic and structural vulnerability of skeletal muscle to even short-term reductions in PI. This challenge is particularly acute in hospital settings, where prolonged bedrest is often unavoidable. Research indicates that hospitalised older adults may spend as much as 86% of their time inactive (15). Such extended periods of inactivity significantly threaten both physical and mental health, accelerating muscle atrophy, impairing functional independence and substantially increasing the risk of chronic disability (16). Our research team recognises the urgent need to make more meaningful use of the time patients spend confined to their beds. One promising solution lies in leveraging innovative technologies, such as extended reality (XR), to immerse patients in synthetically produced enriched environments that support rehabilitation efforts (17). In short, XR encompasses immersive technologies such as Virtual Reality (VR), Augmented Reality (AR) and Mixed Reality (MR), which blend physical and virtual environments to enhance user experiences (18). These technologies offer an opportunity to enhance non-physical rehabilitation techniques, including motor imagery (MI) and action observation (AO). MI involves the mental rehearsal of movements through kinesthetic experiences or visual representations, while AO involves observing the execution of movements. Both MI and AO have been shown to alleviate the detrimental effects of prolonged immobilisation (19-21). By integrating these approaches, we can transform passive recovery into an active process, addressing both the physical and cognitive consequences of inactivity in hospitalised patients while fostering their active participation in the rehabilitation process.

2 HARNESSING XR FOR ACTIVE REHABILITATION

While MI and AO have proven effective in reducing physiological decline and promoting motor recovery in bedridden patients, their application is significantly constrained by the patient's ability to generate vivid mental imagery and maintain focused attention in rehabilitation settings that are often sensory-deprived or filled with distractions, such as clinical environments. These traditional settings fail to replicate the dynamic and unpredictable challenges of real-life scenarios, limiting the practical applicability of these approaches beyond the controlled clinical context. In contrast, XR systems provide a unique advantage in rehabilitation by allowing precise control over treatment parameters, including the ability to adjust stimuli and distractors. This flexibility enables highly personalised therapy sessions tailored to individual needs. By immersing patients in a fully synthetic environment, XR systems deliver a multisensory experience that extends beyond visual stimuli, effectively engaging kinesthetic, visual and auditory senses for a more immersive and impactful therapeutic experience (17).

2.1 Innovative technologies in practice

In Šlosar et al. (17), we hypothesised that combining XR interventions with MI and AO could effectively mitigate muscle strength decline. This hypothesis was confirmed by findings from our 2023 bedrest campaign, where older adults engaged in a multimodal intervention approach. This included exercise prehabilitation prior to bedrest, a leucine-rich, high-protein diet and a daily VR-based brain training programme. Compared to the control group, participants demonstrated significant benefits, including the preservation of muscle mass and strength and significant improvements in insulin resistance (22). These findings underscore the promise of XR-based strategies, especially when integrated with complementary practices, in mitigating both structural and functional declines during periods of physical inactivity, as illustrated in Figure 1.

As part of the EU project Interreg VI-A Italia-Slovenija: X-BRAIN.net, our team played a key role in the development of active rooms, state-of-the-art spaces equipped with advanced XR technologies designed to support the rehabilitation of post-stroke patients in the acute stage in the General Hospital of Izola and ASUGI - Azienda sanitaria universitaria Giuliano Isontina, Trieste, Italy (22). Healthcare professionals involved in the project highlighted the potential of XR systems, particularly VR, to facilitate earlier and more targeted interventions. By immersing patients in a controlled yet engaging therapeutic environment, XR technologies align with modern rehabilitation practices, offering a more dynamic and

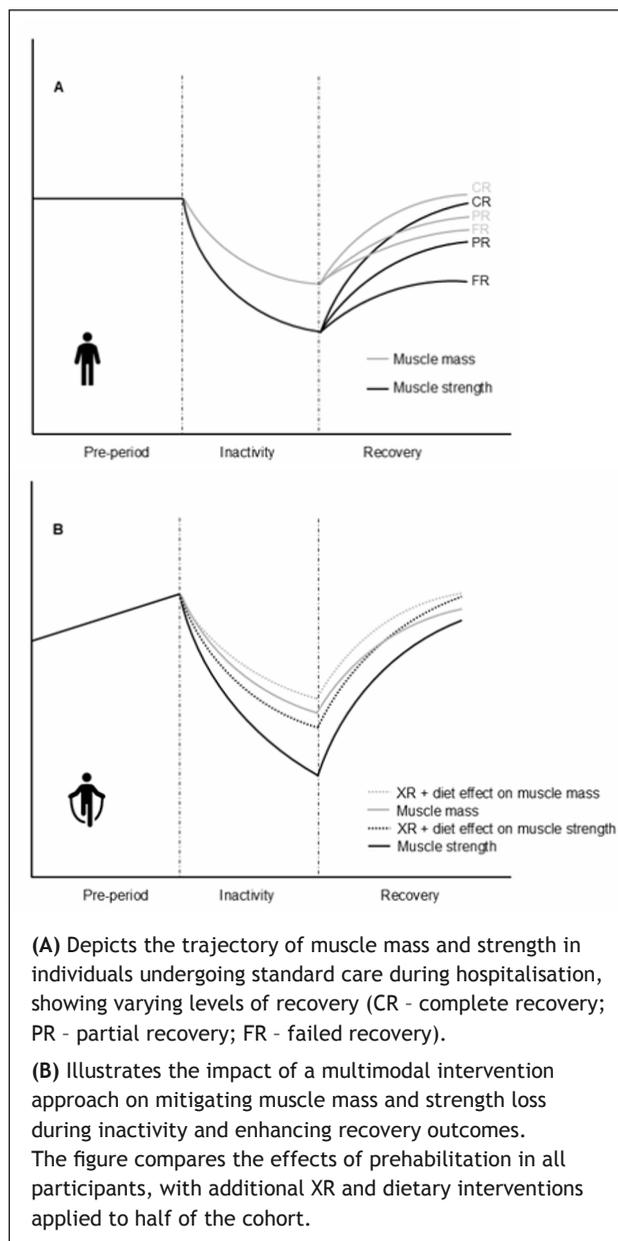


Figure 1. Comparative effects of standard care and multimodal intervention approach on muscle mass and strength during periods of inactivity and recovery. Adapted from Soendenbroe et al. (23).

adaptable approach to recovery. This initiative represents a pioneering step in post-stroke care, integrating advanced technologies to complement traditional rehabilitation techniques while addressing the unique needs of each patient. Such anticipatory approaches have shown promise in promoting neurological function improvement and potentially accelerating recovery timelines, particularly for neurological patients (24).

3 SHAPING THE FUTURE OF REHABILITATION

Future directions in this field emphasise the potential of synchronised visual-haptic neurofeedback during MI, a technique that combines visual and tactile feedback to enhance mental rehearsal of movements. For example, a typical setup might involve a participant wearing a VR headset to visualise a limb movement while receiving corresponding tactile feedback through a haptic glove or device. Studies have demonstrated that this approach can improve outcomes compared to traditional neurofeedback training by providing more immersive and realistic sensory input (25). Additionally, the integration of XR solutions with brain-computer interfaces (BCIs) (26-28), particularly in stimulating sensorimotor cortical activation, represents a significant milestone in refining rehabilitation processes. Multimodal and comprehensive interventions, incorporating both traditional physical treatments and non-physical strategies, are emerging as optimal approaches for rehabilitation in hospital settings. These include non-physical interventions such as multisensory stimulation, nutrition-focused programmes and prehabilitative processes designed to prepare patients for physical recovery. For instance, multisensory stimulation delivered through XR or virtual environments can promote neural plasticity and improve patient engagement. Proper nutritional interventions further support the body's recovery by addressing metabolic needs during inactivity or recovery phases. Prehabilitative exercise programmes, which aim to maintain neuromuscular integrity and prepare patients for post-disuse recovery, complement these innovative approaches (23).

However, while these advancements hold great promise, several limitations must be acknowledged. Challenges such as cybersickness—a form of motion sickness induced by VR—can hinder patient adherence and comfort. Additionally, the high cost of advanced technologies like BCIs and VR systems, as well as the technical expertise required to implement and maintain them, may limit accessibility and scalability in clinical settings. These barriers highlight the need for developing more cost-efficient, user-friendly and widely accessible methods to ensure equitable adoption across healthcare systems.

Despite these challenges, the integration of advanced technologies with traditional rehabilitation methods offers precise control over therapeutic structures and functions, paving the way for more personalised, effective and sustainable interventions. By addressing current limitations and fostering further research in this promising field, the future of rehabilitation can evolve to be both patient-centered and holistically impactful, ensuring that innovative solutions are not only effective but also practical and inclusive.

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THE EFFECTIVENESS OF INTERVENTION TO REDUCE BLOOD-BORNE PATHOGEN EXPOSURE INCIDENTS IN HEALTHCARE WORKERS IN THE LARGEST CLINICAL SETTING IN SLOVENIA

UČINKOVITOST INTERVENCIJ ZA ZMANJŠEVANJE IZPOSTAVLJENOSTI S KRVJO PRENOSLJIVH PATOGENOV PRI ZDRAVSTVENIH DELAVCIH V NAJVEČJI KLINIČNI USTANOVI V SLOVENIJI

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ABSTRACT

Aim: Aimed at evaluating the effectiveness of intensified organised training programmes introduced in 2016 and 2017 for raising awareness of the problem of blood-borne incidents (BBIs), the objective was to analyse the incidence of reported BBIs (RBBI) over a 15-year period in different groups of healthcare workers (HCWs) employed at the University Medical Centre in Ljubljana (UMCL).

Keywords:

Occupational incidents
Sharps
Large clinical setting

Methods: All UMCL incidents that occurred and were reported from 1 January 2008 to 31 December 2022 were included in the study. The entire period was divided into two observation periods, 2008-2017 and 2017-2022. For testing a linear trend, whenever applicable a piecewise/segmented linear regression was applied, with the year 2017 as a break-point.

Results: In the 2008-2017 period, the trend of annual incidence risk was mostly on the increase. The increase was statistically significant in medical doctors (MDs) and dental medicine doctors (DMDs) ($p < 0.001$) as well as in other occupational groups ($p = 0.015$). In the 2017-2022 period, the decrease was statistically significant in females ($p = 0.011$), in MDs and DMDs ($p = 0.007$), in nurses ($p = 0.021$) and in HCWs in the Surgery Division ($p = 0.023$).

Conclusion: The results of the present study suggest that measures introduced in the UMCL were partially effective. The findings could serve as a basis for the development of improved programmes for better prevention, reporting and reducing the consequences of blood-borne pathogen exposure incidents among HCWs not only in Slovenia, but also worldwide.

IZVLEČEK

Ključne besede:

nezgode pri delu
ostri predmeti
velike zdravstvene
ustanove

Namen: Z namenom ovrednotenja učinkovitosti programov organiziranega usposabljanja za ozaveščanje o problemu incidentov s krvjo prenosljivimi patogeni, izvedenih v letih 2016 in 2017, je bil cilj analizirati pojavnost prijavljenih incidentov v 15-letnem obdobju pri različnih skupinah zdravstvenih delavcev (ZD), zaposlenih v Univerzitetnem kliničnem centru Ljubljana (UKCL).

Metode: V študijo so bili vključeni vsi incidenti v UKCL, ki so se zgodili in bili prijavljeni od 1. januarja 2008 do 31. decembra 2022. Celotno obdobje je bilo razdeljeno na dve opazovani obdobji, in sicer 2008-2017 in 2017-2022. Za testiranje linearnega trenda je bila, kjer je to bilo možno, uporabljena segmentirana linearna regresija z letom 2017 kot mejno točko.

Rezultati: V obdobju 2008-2017 je trend letnega pojavnega tveganja incidentov večinoma naraščal. Povečevanje tveganja je bilo statistično značilno v skupini zdravnikov in zobozdravnikov ($p < 0,001$) in v mešani skupini zdravstvenih delavcev ($p = 0,015$). V obdobju 2017-2022 je bilo zmanjševanje trenda statistično značilno pri ženskah ($p = 0,011$), v skupini zdravnikov in zobozdravnikov ($p = 0,007$), v skupini medicinskih sester ($p = 0,021$) in pri ZD na kirurškem oddelku ($p = 0,023$).

Zaključek: Rezultati te študije kažejo, da so bili ukrepi, uvedeni v UKCL, v nekaterih skupinah ZD učinkoviti. Ugotovitve bi lahko služile kot osnova za razvoj izboljšanih programov za boljše preprečevanje, poročanje in zmanjševanje posledic izpostavljenosti s krvjo prenosljivim patogenom med ZD tako v UKCL kot tudi v drugih podobnih ustanovah v Sloveniji in izven nje.

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1 INTRODUCTION

Healthcare workers (HCWs) are at high risk of developing infections caused by blood-borne pathogens, due to injuries with sharp medical devices (sharps), and skin and mucous membrane contacts with blood or other potentially infectious materials (1-6). Accidental occupational exposure to blood-borne pathogens, particularly to blood-borne viruses such as hepatitis B, hepatitis C and HIV, can affect an HCW's health and lead to debilitating or even fatal consequences (1, 2, 4). Additionally, the HCWs may experience significant emotional distress, fear and anxiety that may sometimes result in behavioural and occupational changes (3, 5, 7, 8). The infection is not only health damaging, but could also destroy the HCW's career and impact the hospital costs (3, 8).

Therefore, early reporting of blood-borne pathogen exposure incidents (BBIs) is crucial for immediate medical evaluation and follow-up. The beginning of immediate intervention is very important to address possible infection of the HCW and it can also help to avoid spreading blood-borne infection to others (9). Unfortunately, numerous studies show that underreporting of BBIs is considerable (10-12).

BBIs may occur in various health occupations (6, 7) as many medical procedures require the use of sharps that may penetrate the skin and cause an injury (1, 2, 6, 13). The responsible services at the University Medical Centre Ljubljana (UMCL), the largest medical centre in Slovenia, have recognized the problem and already faced it - since 1998, HCWs have been monitored and treated for incidents. However, the period 2016-2017 represents a major milestone, when intensified organised intervention - health promotion and administrative measures for reducing BBIs - was introduced.

Aimed at evaluating the effectiveness of this intervention, the objective was to analyse the incidence of reported BBIs (RBBIs) over a 15-year period in different HCW groups.

2 METHODS

2.1 Study design, time frame, observed population

A time-trend study with one year as a unit of observation was performed.

The subjects included were HCWs employed at the UMCL who reported BBIs and were treated according to the guidelines for BBIs between 1 January 2008 and 31 December 2022. This period was divided into two periods: 2008-2017 and 2017-2022. The observed HCW groups were medical doctors (MDs) and dental medicine doctors (DMDs), nurses, nurse assistants (NUAs) and others (such as laboratory workers and researchers, radiological engineers, physiotherapists and so forth).

2.2 Intervention to reduce BBIs in 2016 and 2017

Intensified educational and promotional activities included:

- information on the most common causes of BBIs;
- the importance of incident reporting;
- information on the risk of infection when exposed to infected blood;
- the protocol for the organisation and treatment of incidents in UMCL;
- preventive measures from a technical, medical and educational point of view;
- the use of safe devices;
- legislation on this issue;
- the presentation of an annual BBIs report;
- implementation of a new information system and introduction of safety discussions for deviation reporting.

The activities were first performed among health coordinators, hygienists, teaching nurses and nurses who are in charge of quality at the UMCL. They transferred the content of the trainings to other HCWs.

2.3 Data collection

The basic data were collected as extracts from the medical exposure reports, each comprising the date and time of the RBBI, date and time when the HCW reported the incident, details of the procedures being performed, including where and how the exposure occurred, and whether the exposure involved sharps or skin/mucous membrane contacts with blood or other potentially infectious materials. Following this, the incidents were first aggregated at the annual level as the annual incident number (AIN). Then the incidence risk was expressed as the incidence number in relation to the number of HCWs in each group of HCWs as a percentage - annual incidence risk (per 100 staff) (AIR). The denominator in the groups of HCWs by sex, occupation and department/division was the number of HCWs in each group, while the denominator in the types of incidents was the total number of UMCL staff. In addition, the percentage of incidents due to the individual cause (per 100 incidents) was expressed.

2.4 Statistical analysis

The distribution of AIR was statistically described by non-parametric typical values: minimum-maximum (min-max), median and interquartile range (Q1-Q3). The differences between HCW groups were tested using non-parametric tests (Mann-Whitney and Kruskal-Wallis tests).

The temporal patterns of AIR are presented as sequence plots (trend line is added where applicable). For testing the linear trend, whenever applicable, a piecewise/segmented linear regression was applied, with the year 2017 as a break-point. P-values <0.050 were considered

statistically significant. Data were analysed by SPSS for Windows (Version 27.0. SPSS Inc. Chicago, IL, USA).

2.5 Ethical aspects

The basic data were collected from the UMCL medical exposure reports. As the reports contain personal data, access to them is strictly limited and the data is anonymised before any analysis. For the purpose of this study, individual data were further aggregated, and as such did not allow the disclosure of any identity of HCWs. The study was also approved by the Republic of Slovenia National Medical Ethics Committee (No. 0120-153/2018/7).

3 RESULTS

3.1 Basic description of the study population

In the period 2008-2022, the average annual number of HCWs employed at the UMCL was 5,644. Their structure by gender, occupation and division/department is presented in Table 1.

3.2 AIN of RBBI

The average AIN of RBBI was 115.2, with the minimum in 2022 and the maximum in 2017 (Table 2). The AIN of RBBI by gender, occupation and by division/department is presented in Table 2.

Table 1. Healthcare workers employed at University Medical Centre Ljubljana, Slovenia, 2008-2022, by gender, occupation and division/department.

Group	Year														
	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
All	5198	5279	5257	5513	5520	5496	5596	5696	5871	5807	5921	5861	5870	5934	5837
GENDER															
Males	1092	1109	1104	1157	1159	1154	1175	1216	1274	1149	1185	1340	1163	1202	1204
Females	4106	4170	4153	4356	4361	4342	4421	4480	4597	4658	4736	4521	4707	4732	4633
OCCUPATION															
MDs/DMDs	1308	1256	1191	1211	1184	1160	1171	1206	1240	1264	1331	1482	1520	1547	1537
Nurses	3198	3232	3272	3454	3491	3509	3589	3651	3777	3793	3818	3680	3622	3642	3547
Nurse assistants	105	199	208	216	215	211	216	219	225	227	231	219	209	210	204
Other occupations	587	592	586	632	630	616	620	620	629	523	541	480	519	535	549
DIVISION/DEPARTMENT															
Internal Medicine	1014	1035	1003	1052	1074	1084	1106	1133	1178	1205	1235	1189	1076	1170	1181
Surgery	1563	1570	1588	1645	1641	1658	1674	1727	1782	1785	1781	1763	1584	1696	1693
Neurology	239	267	266	268	294	288	296	308	319	331	334	344	310	325	331
Stomatology	78	69	72	73	71	68	66	67	69	68	76	75	69	69	74
Infectology	213	217	209	245	245	253	257	266	280	270	277	268	774	298	279
Dermatovenerology	69	67	66	71	69	60	66	66	67	67	69	75	62	73	73
Otorhinolaryngology	123	118	116	128	128	127	132	137	137	141	144	151	137	132	128
Gynaecology/Obstetrics	504	492	495	498	486	459	480	477	466	481	496	482	438	472	467
Ophthalmology	149	146	147	155	152	151	152	149	154	162	171	170	156	171	173
Paediatrics	445	451	444	439	446	429	436	430	431	423	432	428	404	494	499
Other	801	847	851	939	914	919	931	936	988	874	906	916	860	1034	939

Legend: MDs=medical doctors, DMDs=dental medicine doctors

Table 2. The number of reported blood-borne pathogen exposure incidents in healthcare workers at the University Medical Centre Ljubljana, Slovenia, 2008-2022, by gender, occupation and division/department.

Group	Year														
	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
All	86	106	115	103	132	135	131	134	109	159	131	116	100	99	72
GENDER															
Males	10	28	19	24	26	27	27	27	26	49	39	33	13	18	20
Females	76	78	96	79	106	108	104	107	83	110	92	83	87	81	52
OCCUPATION															
MDs/DMDs	20	25	17	21	28	29	34	32	33	41	35	32	24	28	23
Nurses	40	57	57	51	65	72	51	62	45	72	61	66	59	47	29
Nurse assistants	15	10	12	11	17	13	10	7	5	17	10	6	11	10	3
Other occupations	11	14	29	20	22	21	36	33	26	29	25	12	6	14	17
DIVISION/DEPARTMENT															
Internal Medicine	22	18	28	30	27	34	17	21	21	29	44	27	37	16	19
Surgery	21	50	45	33	55	53	61	56	42	69	38	48	36	31	18
Neurology	1	3	7	3	4	7	2	13	6	10	8	7	3	6	5
Stomatology	6	4	4	9	8	7	5	11	9	6	7	7	1	4	5
Infectology	1	0	9	8	10	4	7	1	0	6	2	1	0	3	7
Dermatovenereology	0	0	0	2	0	2	2	0	0	2	1	0	1	1	0
Otorhinolaryngology	3	6	2	5	1	4	2	2	3	1	2	2	1	3	0
Gynaecology/Obstetrics	6	9	7	3	8	6	5	8	7	9	5	9	9	7	3
Ophthalmology	4	0	2	1	4	5	7	4	6	4	5	4	3	4	3
Paediatrics	1	2	0	1	6	4	1	3	5	3	3	3	0	6	2
Other	21	14	11	8	9	9	22	15	10	20	16	8	9	18	10

Legend: MDs=medical doctors, DMDs=dental medicine doctors

3.3 AIR of RBBI in the entire group of HCWs

The median value of AIR of RBBI in the entire group was 2.01 (min-max: 1.23-2.74; Q1-Q3: 1.70-2.35). It was possible to assess the linear trend in both observed periods. In the 2008-2017 period, it increased statistically marginally significantly ($b=0.067$; $p=0.062$), while in the 2017-2022 period it significantly decreased ($b=-0.270$; $p=0.001$) (Figure 1).

3.4 AIR of RBBI in HCW groups

A statistical description of AIR of RBBI in HCW groups is given in Table 3. There were no significant differences between genders (Figure 2), while significant differences were detected between occupations and divisions/departments (Figures 3-4).

Among occupations, the lowest values were detected among nurses and the highest among NUAs. The pairwise comparison showed some significant differences: nurses vs. NUAs ($p<0.001$), nurses vs. other occupations ($p<0.001$), and MDs/DMDs vs. NUAs ($p<0.001$) (Figure 3).

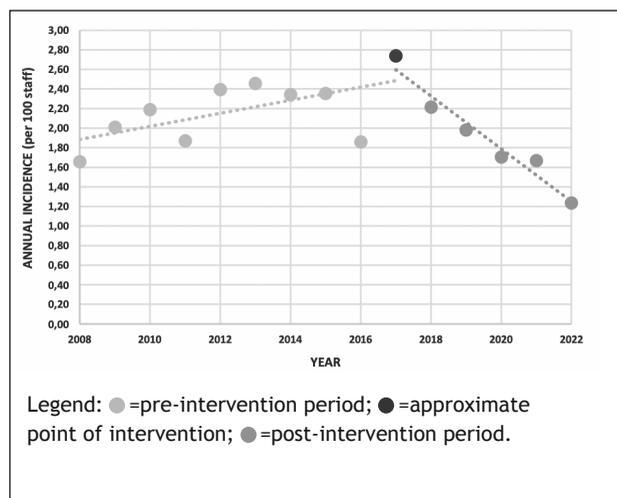


Figure 1. Annual incidence risk (per 100 staff) of reported blood-borne pathogen exposure incidents in healthcare workers at the University Medical Centre Ljubljana, Slovenia, 2008-2022.

Table 3. Statistical description of annual incidence risk of reported blood-borne pathogen exposure incidents in healthcare workers at the University Medical Centre Ljubljana, Slovenia, 2008-2022.

Group	MEDIAN	MIN-MAX	Q1-Q3	p
GENDER				
Males	2.22	0.92-4.26	1.66-2.46	0.803
Females	1.87	1.12-2.49	1.81-2.36	
OCCUPATION				
MDs/DMDs	2.16	1.43-3.24	1.58-2.65	<0.001
Nurses	1.63	0.82-2.05	1.29-1.79	
Nurse assistants	5.03	1.47-14.29	3.20-6.16	
Other occupations	3.41	1.16-5.81	2.50-4.95	
DIVISION/DEPARTMENT				
Internal Medicine	2.27	1.37-3.56	1.74-2.85	<0.001
Surgery	2.72	1.06-3.87	2.01-3.24	
Neurology	1.85	0.42-4.22	1.12-2.43	
Stomatology	8.82	1.45-16.42	5.80-11.27	
Infectology	1.01	0.00-4.31	0.37-2.72	
Dermatovenerology	0.00	0.00-3.33	0.00-2.82	
Otorhinolaryngology	1.52	0.00-5.08	0.78-2.44	
Gynaecology/Obstetrics	1.48	0.60-2.05	1.04-1.83	
Ophthalmology	2.47	0.00-4.61	1.73-2.92	
Paediatrics	0.69	0.00-1.35	0.23-0.93	

Legend: Q1-Q3=interquartile range, MDs=medical doctors, DMDs=dental medicine doctors.

Among divisions/departments, the lowest values were detected in the Paediatrics and the highest in the Stomatology Divisions. The pairwise comparison showed a significant difference between the Stomatology Division and the Paediatrics Division ($p<0.001$), the Dermatovenerology Department ($p<0.001$), the Gynaecology/Obstetrics Division ($p<0.001$), the Infectious Diseases Department ($p<0.001$), the Otorhinolaryngology Department ($p=0.001$) and the Neurology Division ($p=0.001$), as well as between the Paediatrics Division and the Ophthalmology Department ($p=0.004$), the Internal Medicine Division ($p=0.002$) and the Surgery Division ($p<0.001$) (Figure 4).

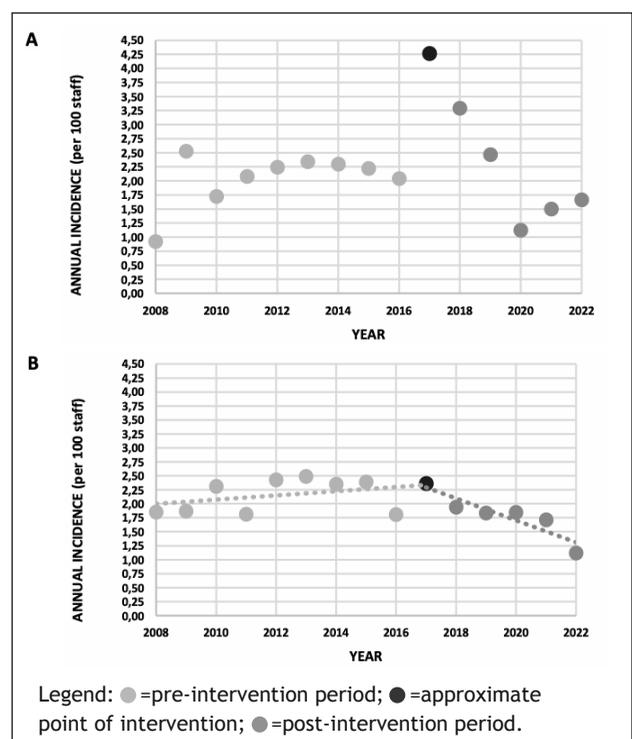


Figure 2. Annual incidence risk (per 100 staff) of reported blood-borne pathogen exposure incidents in healthcare workers at the University Medical Centre Ljubljana, Slovenia, 2008-2022, in A) males, and B) females.

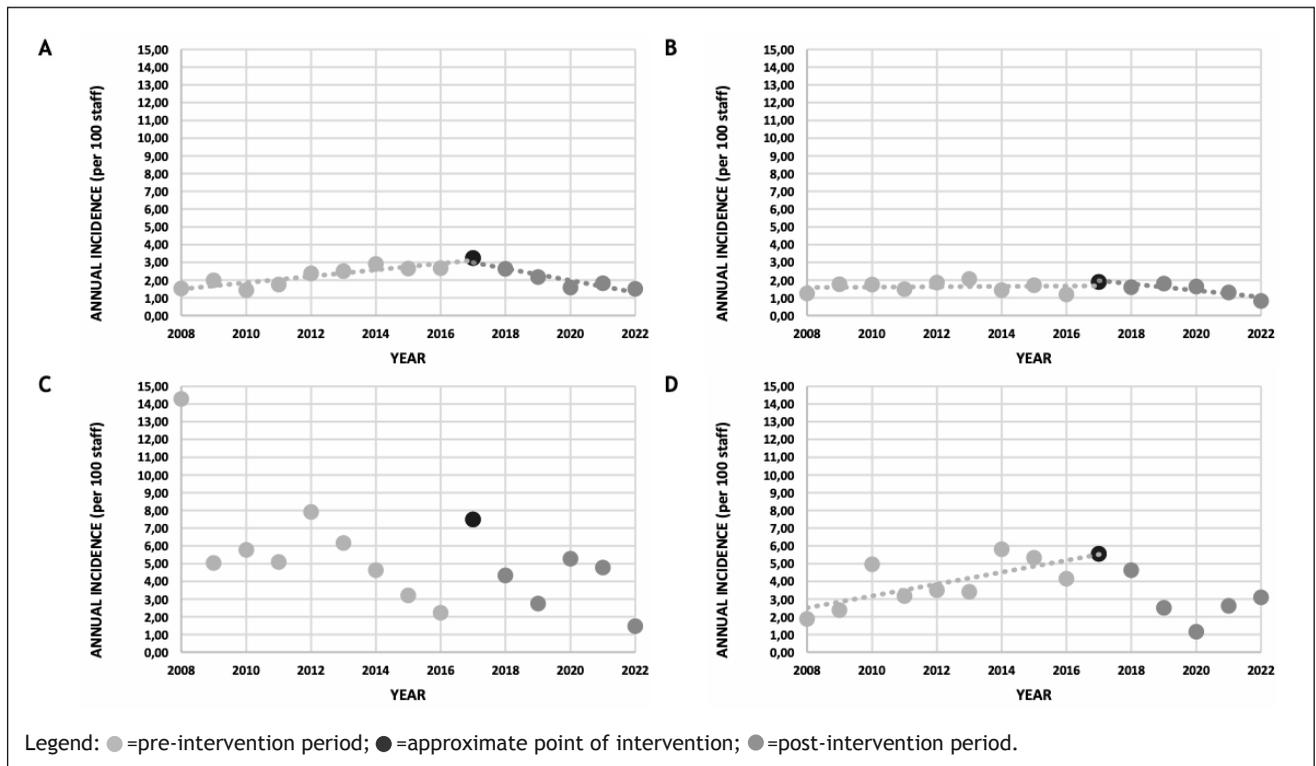


Figure 3. Annual incidence risk (per 100 staff) of reported blood-borne pathogen exposure incidents in healthcare workers at the University Medical Centre Ljubljana, Slovenia, 2008-2022, in A) medical doctors/dental medicine doctors, B) nurses, C) nurse assistants, and D) other healthcare workers.

The linear trend in both observed periods was possible to assess in the majority of HCW groups (Table 4). It mostly increased in the 2008-2017 period (it was significant in MDs/DMDs, and in other HCWs (Table 4), while in the 2017-2022 period it was mostly decreasing in all HCW groups (it was significant in females, MDs/DMDs, nurses, and in the Surgery Division (Table 4).

The decrease in incidence in the 2017-2022 period was also close to being significant in the Neurology Division and in the Ophthalmology Department (Table 4). However, it is clearly visible in Figures 4C and 4I that these two organizational units already showed the beginning of a decline in incidence before 2017. In the Neurology Division, a statistically significant downward trend started in 2015 ($b=-0.305$; $p=0.033$) and in the Ophthalmology Department in 2014 ($b=-0.277$; $p=0.008$).

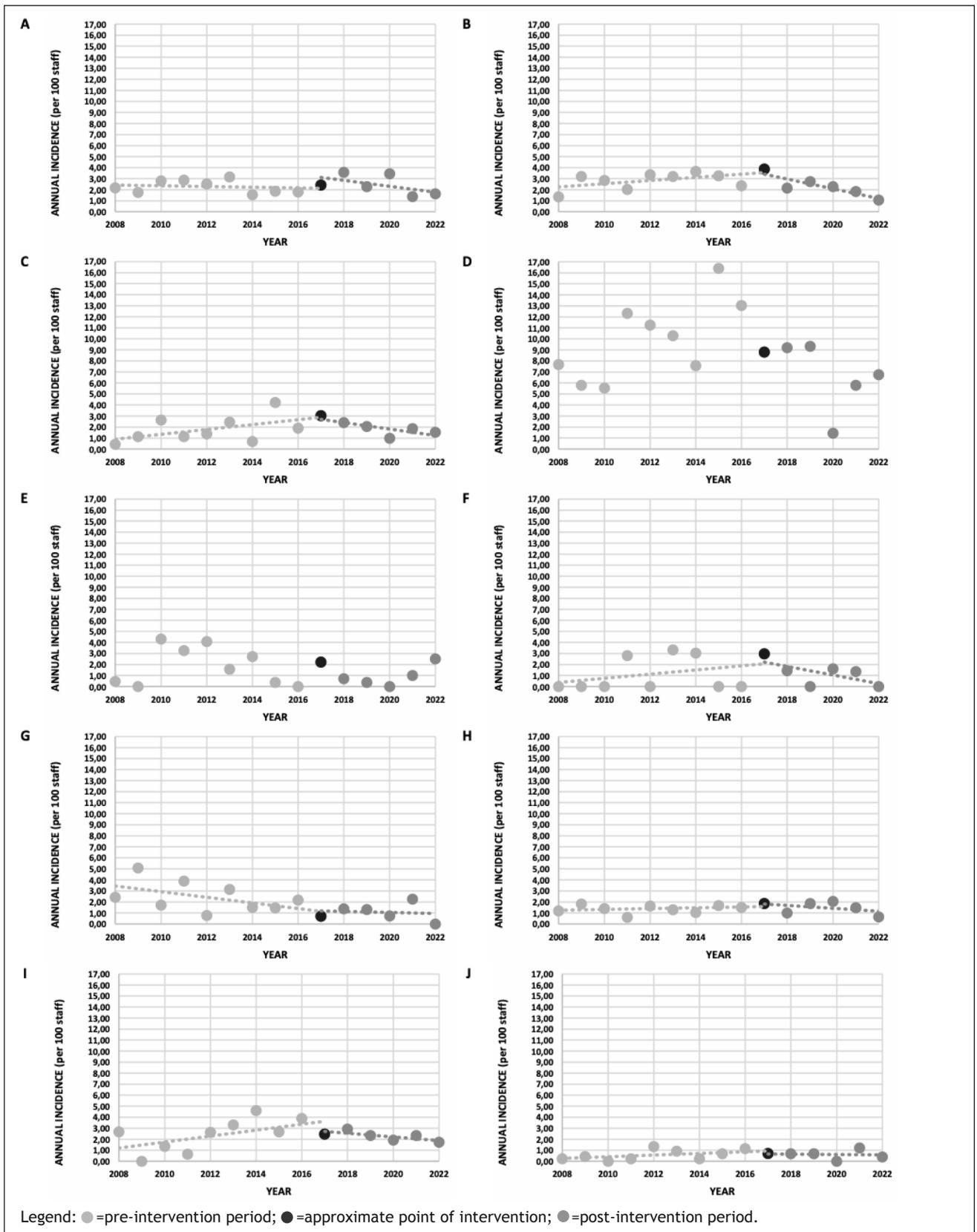


Figure 4. Annual incidence risk (per 100 staff) of reported blood-borne pathogen exposure incidents in healthcare workers at the University Medical Centre Ljubljana, Slovenia, 2008-2022, in observed departments/divisions: A=Internal Medicine, B=Surgery, C=Neurology, D=Stomatology, E=Infectology, F=Dermatovenereology, G=Otorhinolaryngology, H=Gynaecology/Obstetrics, I=Ophthalmology, J=Paediatrics.

Table 4. Trend of annual incidence risk of reported blood-borne pathogen exposure incidents in healthcare workers at the University Medical Centre Ljubljana, Slovenia, by gender, occupation and division/department in two predefined periods.

HCW GROUP	2008-2017		2017-2022	
	b	p	b	p
GENDER				
Males	NA	NA	NA	NA
Females	0.038	0.258	-0.197	0.011
OCCUPATION				
MDs/DMDs	0.181	<0.001	-0.335	0.007
Nurses	0.010	0.769	-0.185	0.021
Nurse assistants	NA	NA	NA	NA
Other occupations	0.334	0.015	NA	NA
DIVISION/DEPARTMENT				
Internal Medicine	-0.034	0.605	-0.269	0.254
Surgery	0.144	0.093	-0.440	0.023
Neurology	0.221	0.089	-0.293	0.071
Stomatology	NA	NA	NA	NA
Infectology	NA	NA	NA	NA
Dermatovenerology	0.187	0.308	-0.388	0.167
Otorhinolaryngology	-0.254	0.099	-0.043	0.845
Gynaecology/Obstetrics	0.037	0.420	-0.130	0.386
Ophthalmology	0.270	0.081	-0.168	0.089
Paediatrics	0.076	0.130	-0.020	0.862

Legend: NA=not applicable, MDs=medical doctors, DMDs=dental medicine doctors.

3.5 AIR of RBBIs due to selected causes in the total group of HCWs

Table 5 shows that the majority of RBBIs were due to contact with sharps. The median value was 88.8% (min-max: 85.5-92.2%). Other causes were rare.

Table 5. Distribution of reported blood-borne pathogen exposure incidents due to selected causes in healthcare workers at the University Medical Centre Ljubljana, Slovenia, 2008-2022.

Cause	Year															
	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	
Sharp device	82	93	105	95	120	125	113	119	101	140	112	97	72	88	59	
Splash into eye	3	8	8	3	5	6	12	8	6	9	6	5	6	8	6	
Skin contact	0	3	2	4	2	3	2	1	2	3	7	3	1	0	0	
Other causes	1	2	0	1	5	1	4	6	0	7	6	11	21	3	7	

Also, the AIR of RBBIs due to contact with sharps was the highest (Figure 5). The median value of AIR of RBBIs due to contact with sharps over the observed period in the entire group of HCWs was 1.76 (min-max: 1.01-2.41; Q1-Q3: 1.58-2.09).

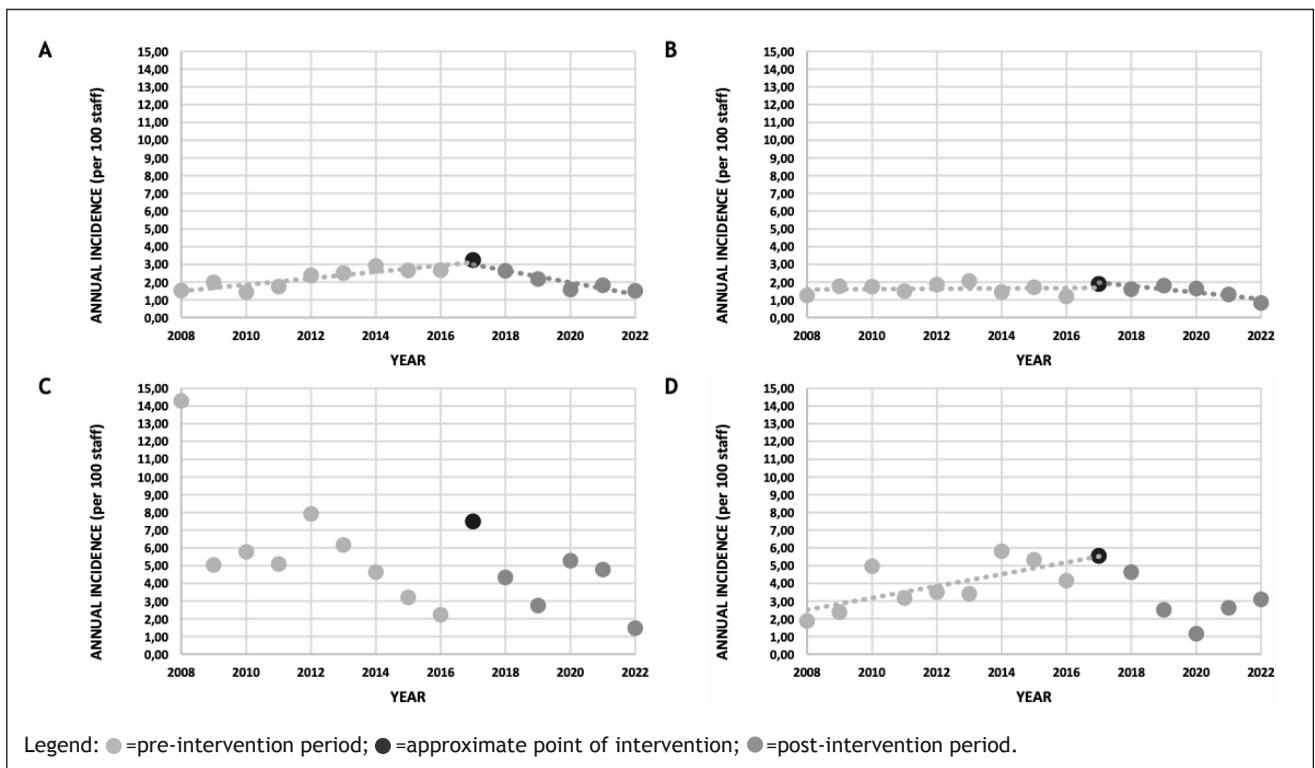


Figure 5. Annual incidence (per 100 incidents) of reported blood-borne pathogen exposure incidents in healthcare workers at the University Medical Centre Ljubljana, Slovenia, 2008-2022, due to A) sharps incidents, B) splashes into eyes, C) skin contact with potentially infectious materials, and D) other causes.

The linear trend of AIR of RBBIs due to selected causes was possible to assess in all causes in both observed periods (Table 5).

Table 6. Trend of annual incidence of reported blood-borne pathogen exposure incidents due to selected causes in healthcare workers at the University Medical Centre Ljubljana, Slovenia in two predefined periods.

Cause	2008-2017		2017-2022	
	b	p	b	p
Sharp device	0.052	0.076	-0.247	0.007
Splash into eye	0.006	0.329	-0.004	0.502
Contact of skin	0.000	0.880	-0.018	0.081
Other causes	0.008	0.133	NA	NA

The dynamics are most evident in RBBIs due to sharp devices, where the decrease in AIR in the 2017-2022 period is statistically significant (Table 6).

4 DISCUSSION

The study results showed that intervention was in general effective, as there was a statistically significant trend of decreasing AIR of RBBLs in the post-intervention period.

Unfortunately, the comparison of the results of our study with the results of similar studies was limited, since we have not found any very similar study in the literature. We were able to compare, for example, AIR of RBBLs, and the comparison showed that the incidence of RBBLs at UMCL was lower than in other studies (1, 14), which could mean underreporting, especially because even in studies with a higher incidence, underreporting is exposed as a problem (4, 11, 13, 15).

In terms of gender, the study showed that the intervention had a positive effect on female HCWs. Unfortunately, a linear trend could not be assessed in men. Interestingly, our study did not find a significant difference in BBIs between males and females, which is in contrast to some other studies, some of which reported a higher incidence in women (7, 16-18) and others in men (14).

Among the different occupational groups of HCWs, the effect of the intervention was greatest in the MD/DMD group, especially because this group recorded a significant increase of RBBLs before the intervention, and after it the strongest decline among all occupational groups. Despite the fact that the group of nurses in general has the lowest values, the intervention seems to have resulted in a further decrease of the problem. This may be due to the fact that the educational programmes on preventive measures were most intensively performed in this occupational group. On the other hand, RBBLs were most frequent in NUAs. This result is consistent with the findings of some other studies reporting a substantial risk of incidents among NUAs especially with sharps (1, 19). The reason was mostly sharps laid wrongly or placed in overfilled containers, inappropriate placing or emptying sharps containers. However, there is no evidence of effectiveness of intervention in this occupational group. It was similar in the other HCWs group.

The study also provided some important results related to divisions/departments. First, the most notable result was the high AIR of RBBLs in the Stomatology Division. However, this is consistent with some other studies which indicate that dental HCWs are at highest risk of BBIs (20, 21). On one hand percutaneous injuries prove to be a substantial risk (22), while on the other, exposure to blood and body fluids due to the nature of the occupation also represents a common problem (23). Unfortunately, the intervention did not achieve its goal in this division. Second, a significant decrease in AIR in the period 2017-2022 was recorded in the Surgery Division, where, due to the nature of the work, there is a lot of contact with sharps and, as a result, exposure to injuries is high (16, 24). This

result suggests that the intervention was successful in this division. Finally, a significant decrease in AIR of RBBLs was also recorded in the Ophthalmology Department and the Neurology Division. However, this decline began before the observed intervention (in 2014 and 2015 respectively), which could be explained by the intensive trainings that took place in both units at that time.

Regarding the causes of BBIs, the intervention resulted in a significant decrease in BBIs only in sharps. However, this is actually the most important result, since this cause is by far the most common, as reported also in many other studies (1, 4, 7, 8, 25-27). It is even more important because in the pre-intervention period there was an increasing trend of BBIs with sharps. It seems that HCWs generally started to follow precautions more strictly after the intervention.

The current study has some limitations. First, only reported incidents were included, which were certainly not all. However, we believe that this gap does not represent a significant problem. Second, one can argue that participants from only one health institution were included. However, this institution is one of the largest healthcare facilities in Central Europe (28). Next, the increase in BBIs in the pre-intervention period could also be influenced to some extent by UMCL's efforts to increase the reporting of incidents, which had been going on for several years before the observed intervention. However, we believe that these activities did not have a major impact on the presented results. Next, within the post-intervention period, the Covid-19 pandemic was included, which could represent a source of bias. However, we believe that the pandemic in fact resulted in greater awareness of the importance of reporting BBIs along with a much greater consideration of precautionary measures, so the effect of the decrease shown by the results can be attributed mainly to the intervention. Finally, one might argue that the study provides no comparison with data from other hospitals in the country. However, such a comparison was out of the scope of this study, as it was a UMCL project. On the other hand, this study has an important strength - according to the available literature, it is the first to systematically investigate the data on RBBLs in a large clinical setting over a longer period of time, which also included an intervention to reduce the problem.

Despite the limitations, the study provides important implications for occupational medicine. The findings could serve in development of improved programmes for better prevention, and earlier and more accurate reporting of BBIs.

Among the promotional activities in UMCL, the most effective measures were training of HCWs, activities that promoted BBIs reporting, and preventive procedures that included proper use of safety devices. On the other hand, the protocol for reporting and treatment of BBIs proved

to be less appropriate and needs to be further upgraded. Accordingly, the findings suggest that additional health promotion and/or supervisory work-related interventions are needed. At UMCL, it will definitely be necessary to pay more attention to the education of the male section of HCWs, those HCWs who are not MD/DMDs or nurses, especially to the education of NUAs, and among the departments/divisions to the Stomatology Division, which should be supported by regular periodic surveys, as is already the case with nosocomial infections (29).

Although the findings of the current study make a significant contribution, further research is needed to elucidate the situation. First, additional data on subjects who have experienced BBIs in the UMCL, will enable more extensive statistical analysis and provide more data necessary for the development of even more reliable programmes for the management of BBIs. Next, it would be very reasonable to extend the UMCL project to at least other hospitals in Slovenia, to highlight whether the trends at UMCL are consistent with broader patterns or unique to this institution, and it would be even better if it could be extended to similar hospitals in neighbouring countries.

5 CONCLUSIONS

The results of the study showed that intervention introduced at the UMCL was partially effective; however, at the same time the study showed in which HCW groups it was less effective. The findings could serve as a basis for development of improved prevention programmes and BBIs reporting among the HCWs, not only in Slovenia, but also more widely.

CONFLICTS OF INTEREST

The authors declare that no conflicts of interest exist.

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ETHICAL APPROVAL

The study was approved by the Republic of Slovenia National Medical Ethics Committee (No. 0120-153/2018/7) and was carried out according to the Helsinki Declaration.

AVAILABILITY OF DATA AND MATERIALS

The basic data were collected from the UMCL medical exposure reports, which include personal data, therefore the data and materials are not available unless approved by the data owner.

LLM STATEMENT

During the preparation of this work the authors used no AI and AI-assisted technologies.

PREPRINTS STATEMENT

No preprint has been deposited on any preprint server.

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THE RELATIONSHIP BETWEEN THE MENTAL HEALTH OF SLOVENIAN ADOLESCENTS AND THE SUPPORT OF THEIR VARIOUS PERSONAL SOCIAL NETWORKS

POVEZANOST MED DUŠEVNIM ZDRAVJEM SLOVENSКИH MLADOSTNIKOV IN PODPORA NJIHOVIH OSEBNIH SOCIALNIH MREŽ

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ABSTRACT

Aim: To analyse the relationships between individual social networks and selected indicators of mental health among Slovenian adolescents aged 15 and 17.

Keywords:
Adolescents
Mental health
Social support
School
Family
Friends

Methods: Data from the international Health Behaviour in School-aged Children (HBSC) survey in 2018 were used. Cronbach's alpha coefficient was used to calculate the reliability of the scales. Data were presented using descriptive statistics and frequency distributions. Differences between the two groups were determined using the chi-square or t-test. Pearson's correlation coefficient was used to test the associations. Multiple linear regression was also used to explain adolescents' mental health.

Results: The mental health of adolescents is statistically significantly related to the experience of support in their social networks ($p \leq 0.05$). Adolescents with better mental health differ from those with poorer mental health in the degree to which they experience support from their social networks. Support from a greater number of social networks is statistically significantly associated with lower perceived stress and the risk of depression. In explaining adolescents' good mental health, the support of the school environment, i.e. classmates and teachers, proved to be more important than the support of the family.

Conclusions: The support of personal social networks is essential for good mental health in young people. In practice, it would be reasonable to strengthen the support of teachers and classmates, as the school environment proved to be a very important source of support at that age.

IZVLEČEK

Namen: Analizirati povezave med posameznimi socialnimi mrežami in izbranimi pokazatelji duševnega zdravja pri 15- in 17-letnih vsolanih slovenskih mladostnikih.

Ključne besede:
mladostniki
duševno zdravje
socialna podpora
šola
družina
prijatelji

Metode: Analizirani so bili podatki raziskave Z zdravjem povezana vedenja v šolskem obdobju (HBSC), izvedene leta 2018. Za izračun zanesljivosti lestvic je bil uporabljen Cronbachov alfa koeficient. Podatki so bili prikazani z opisnimi statistikami in frekvenčnimi porazdelitvami. Razlike med dvema skupinama smo ugotavljali s testom χ^2 ali t testom. Za preverjanje povezanosti je bil uporabljen Pearsonov koeficient korelacije. Uporabljena je bila tudi multipla linearna regresija z namenom pojasnjevanja duševnega zdravja mladostnikov.

Rezultati: Duševno zdravje mladostnikov je statistično značilno povezano z doživljanjem podpore v njihovih socialnih mrežah ($p \leq 0,05$). Mladostniki z boljšim duševnim zdravjem se od tistih s slabšim duševnim zdravjem razlikujejo glede na stopnjo doživljanja podpore njihovih socialnih mrež. Tudi podpora večjega števila socialnih mrež je statistično značilno povezana z manjšim zaznanim stresom in tveganjem za depresijo. Pri pojasnjevanju dobrega duševnega zdravja mladostnikov se je za pomembnejšo od podpore družine izkazala podpora šolskega okolja, torej sošolcev in učiteljev.

Zaključki: Podpora osebnih socialnih mrež je ključna za dobro duševno zdravje mladostnikov. V praksi bi bilo smiselno okrepiti predvsem podporo učiteljev in sošolcev, saj se je šolsko okolje izkazalo za zelo pomemben vir podpore.

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1 INTRODUCTION

The Constitution of the World Health Organization (WHO) defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (1). Mental illness accounts for 16 percent of the global burden of disease in the 10-19 age group (2). Mental health problems developing in adolescence account for ten times the long-term healthcare costs of those developing in adulthood (3). According to epidemiological studies, 10-20 percent of children and adolescents under the age of eighteen suffer from mental disorders corresponding to international classifications (4). Data on the prevalence of mental illness become even more important in light of international research findings stating that 50-70 percent of adults with severe mental illness experienced disorders or recognizable traces thereof already in childhood or adolescence, meaning that with a different approach the disorders could have been limited or prevented much earlier (5).

Mental health (as defined by WHO) is influenced by individual factors as well as those at the socio-economic, environmental and societal levels. The existing categorisations of mental health factors differ (6), but those relating to children and adolescents predominantly include (a) individual, (b) family, (c) school environment and (d) wider environment factors (5).

In adolescence, relationships change both quantitatively and qualitatively. In the context of close interpersonal relationships, adolescent social development is primarily influenced by the relationships with parents, friends and peers (7). Family represents the fundamental social framework for learning and developing values and rules, and family life is gradually perceived as a key mechanism of well-being and health (8). During adolescence, peer relationships become more extensive and intense. The importance of peers increases as they encourage the development of identity, personality traits and social skills (9). A large part of our lives is spent at school, which has been proven to influence health and health behaviour: a stimulating school environment strengthens the development of healthy habits, health and life satisfaction, and vice versa (10). Support from teachers and peers and school satisfaction are often associated with protective factors of mental health (11).

The number of Slovenian children and adolescents with mental disorders has been increasing in the last decade, together with a growing number of visits to primary and secondary healthcare and of prescriptions issued for treating mental disorders (5). The aim of the study was to examine the role and importance of Slovenian adolescents' social networks for their mental health, in order to meaningfully strengthen social support where necessary and possible, with the desire for changes not only at the individual or local level, but in the direction of

the design and implementation of policies and intervention strategies at the national level. With this aim in mind the study objectives were to determine 1) whether adolescent mental health (perceived stress and risk of depression) is related to the support experienced in various personal social networks (family, friends and school environment, i.e. classmates and teachers), 2) whether experiencing support from a larger number of personal social networks has a cumulative effect on adolescent mental health, and 3) whether the importance of support from individual social networks is equivalent.

In our literature review, we did not find any research measuring the same indicators, i.e. the association of social network support with the Cohen Perceived Stress Scale and the WHO-5 Well-Being Index, but we did find research examining the association between different sources of social support and other variables as indicators of mental health. To the best of our knowledge, this topic has not been systematically explored on Slovenian or other data until now.

2 METHODS

2.1 Study design and time frame

The present study is a part of a larger research project - the international cross-sectional Health Behavior in School-aged Children (HBSC) survey that is carried out periodically every four years. The data originate from a survey conducted in Slovenia in 2018 (HBSC 2018) in the period from 5 to 16 February 2018.

2.2 Target population and sampling

The sampling unit was a school class. The 2017/2018 enrollment data were collected for the 6th and 8th grades (11- and 13-year-olds) of all primary schools (a total of 489 schools) and for the 1st and 3rd years (15- and 17-year-olds) of all secondary schools (a total of 152 schools). Only 18 schools refused to participate. The detailed description of this process is presented elsewhere (12-14).

The HBSC 2018 database, which was the base for the present study, included 7,449 adolescents. Our sample included 15- and 17-year-olds. The response rate in this group was 69 % (12).

2.3 Study instrument and data collection process

The international HBSC study uses a standardized international self-reported questionnaire (12). For the purpose of the present study targeted questions were used, which are described below.

Students completed the online questionnaire on school computers in computer classrooms or libraries of selected schools (12). An open-source online survey software was used for data collection.

2.4 Phenomena under study

2.4.1 Observed outcomes

HBSC questions on perceived stress and risk of depression were used for designing the observed outcomes.

To evaluate perceived stress, the HBSC questionnaire uses questions from the 5-point Cohen Perceived Stress Scale (15). The sum of individual items generates a global stress score (GSS) based on four general questions about a sense of control over life. This score represented the first observed outcome for the present study. The GSS items and the range of GSS values are described in detail in Table 1. The scale from 1 to 5 was changed to a scale from 0 to 4. The average perceived stress was recoded as “more perceived stress” up to a value of 2.5, and as “less perceived stress” from a value of 2.6 onwards.

To evaluate the risk of depression, the HBSC questionnaire uses questions from the 6-point WHO-5 Well-Being Index instrument (16). The sum of individual items generates a well-being index (WBI) based on five statements that can be used as a screening tool for depression. This index represented the second observed outcome for the present study. The WBI items and the range of WBI values are described in detail in Table 1. The scale from 1 to 6 was changed to a scale from 0 to 5. The average risk of depression was recoded as “higher risk of depression” up to a value of 2.5, and as “lower risk of depression” from a value of 2.6 onwards.

2.4.2 Explanatory factors

Perceived support from individual social networks (i.e. family, friends, classmates and teachers) served as explanatory variables for both observed outcomes.

The items in the HBSC questionnaire that measure the perceived availability of emotional support from family and friends form two of the three subscales which make up the Multidimensional Scale of Perceived Social Support (17). The items were expressed on a 7-point scale through the average of four statements in each set (Table 2). The average perceived support in both sets was recoded as “no support” up to a value of 4.5 and as “expressed support” from a value of 4.6 onwards.

The items in the HBSC questionnaire that measure classmate and teacher support were designed within the HBSC network to measure the perceived satisfaction with, and the helpfulness and availability of, support from classmates and teachers (18). The items were expressed on a 5-point scale through the average of three statements in each set (Table 2). The average perceived support in both sets was recoded as “no support” up to a value of 3.5 and as “expressed support” from a value of 3.6 onwards. The support scores of individual social networks were formed as the sum of the values of all items included in individual sets of the variables (Table 2).

Table 1. Description of observed outcomes in the study of the mental health of Slovenian adolescents and the support of their various personal social networks.

Observed outcome (score)/Item	Item values	Range of score values
Perceived stress (Perceived stress score - PSS)		
In the last month ...		
... how often have you felt that you were unable to control the important things in your life?	1 - Never to 5 - Very often	4-20
... how often have you felt confident about your ability to handle your personal problems?		
... how often have you felt that things were going your way?		
... how often have you felt difficulties were piling up so high that you could not overcome them?		
Risk of depression (Well-being index - WBI)		
Over the last two weeks ...		
... I have felt cheerful and in good spirits.	1 - At no time to 6 - All the time	5-30
... I have felt calm and relaxed.		
... I have felt active and vigorous.		
... I woke up feeling fresh and rested.		
... my daily life has been filled with things that interest me.		

2.4.3 Other factors

The set of other observed factors included gender (male, female), age (15 and 17 years old), socio-economic status (SES) (high, middle, low) and family type (single-parent family, two-parent family, reconstituted family) (19).

2.5 Methods of analysis

First, the internal consistency of observed outcome scores was assessed by using the Cronbach α coefficient.

For multivariate analysis of the association between OO and observed EF, multiple linear regression was used.

In all statistical procedures the value of less than $p < 0.05$ was used to assess the statistical significance of the results.

Data analysis was performed using SPSS Statistics for Windows (Version 25.0. SPSS Inc. Chicago, IL, USA). All analyses were performed on a refined and weighted basis.

Table 2. Description of explanatory factors in the study of the mental health of Slovenian adolescents and the support of their various personal social networks.

Explanatory factor (score)/Item	Item values	Range of score values
Family support (Family support score - FaSS)		
My family really tries to help me.	1 - Very strongly disagree to	4-28
I get the emotional help and support I need from my family.	7 - Very strongly agree	
I can talk about my problems with my family.		
My family is willing to help me make decisions.		
Friend support (Friend support score - FrSS)		
My friends really try to help me.	1 - Very strongly disagree to	4-28
I can count on my friends when things go wrong.	7 - Very strongly agree	
I have friends with whom I can share my joys and sorrows.		
I can talk about my problems with my friends.		
Classmate support (Classmate support score - CSS)		
The students in my class(es) enjoy being together.	1 - Strongly disagree to	3-15
Most of the students in my class(es) are kind and helpful.	5 - Strongly agree	
Other students accept me as I am.		
Teacher support (Teacher support score - TSS)		
I feel that my teachers accept me as I am.	1 - Strongly disagree to	3-15
I feel that my teachers care about me as a person.	5 - Strongly agree	
I feel a lot of trust in my teachers.		

3 RESULTS

3.1 Study group description

3.1.1 Basic characteristics of the sample

Our sample included 3,463 15- and 17-year-old adolescents, of which there were a few more males (51.6%) than females (48.4%). Almost half (n=1739, 49.9%) described their SES as high.

3.1.2 Explanatory factors description

Family support was assessed on average with 4.97 ± 2.08 and friend support with 5.26 ± 1.73 .

Classmate support was rated on average higher than teacher support, with a rating of 3.88 ± 0.84 . Teacher support was assessed with 3.48 ± 0.91 .

3.2 Results of relationship analysis between perceived stress score and explanatory factors

The internal consistency of Cohen PSS was acceptable ($\alpha=0.63$).

On average, participants scored 9.62 ± 2.98 points on a scale with a maximum value of 16 points. Males ($\bar{x}=10.33$; ± 2.74) statistically significantly ($p < 0.05$) perceived more stress on average than females ($\bar{x}=8.85$; ± 3.04).

The multivariate model as a whole was highly statistically significant ($p < 0.001$) and explained 10.7% of perceived stress. Other results of multiple linear regression are shown in Table 3.

3.3 Results of relationship analysis between well-being index and explanatory factors

The internal consistency of WBI was good ($\alpha=0.86$).

The average value of the risk of depression among participants on a scale of 0-25 was $13.16 (\pm 5.44)$.

The multivariate model as a whole was highly statistically significant ($p < 0.001$) and explained 12.2% of the risk of depression. Other results of multiple linear regression are shown in Table 4.

Table 3. Results of multivariate relationship analysis between perceived stress score and the support scores of various personal social networks of adolescents in the HBSC study, Slovenia 2018 (n=3463).

Support score	b	95% CI for b		p-value
		Lower limit	Upper limit	
FaSS	0.209	0.161	0.257	$p < 0.001$
FrSS	0.198	0.140	0.256	$p < 0.001$
CSS	0.352	0.229	0.476	$p < 0.001$
TSS	0.552	0.441	0.664	$p < 0.001$

Legend: b=regression coefficient; CI=confidence interval; FaSS=family support score; FrSS=friend support score; CSS=classmate support score; TSS=teacher support score

Table 4. Results of multivariate relationship analysis between well-being index and the support scores of various personal social networks of adolescents in the HBSC study, Slovenia 2018 (n=3463).

Support score	b	95% CI for b		p-value
		Lower limit	Upper limit	
FaSS	0.295	0.208	0.382	p<0.001
FrSS	0.356	0.251	0.461	p<0.001
CSS	1.140	0.916	1.364	p<0.001
TSS	0.933	0.730	1.135	p<0.001

Legend: b=regression coefficient; CI=confidence interval; FaSS=family support score; FrSS=friend support score; CSS=classmate support score; TSS=teacher support score

3.4 Comparative analyses between observed outcome (perceived stress and risk of depression) and explanatory factors (family, friend, classmate and teacher support)

There was a weak correlation between adolescent mental health ($p<0.001$) and the experience of support in various personal social networks.

Adolescents with higher perceived support from family [$r=0.156$, $r=0.199$, $r=0.180$], friends [$r=0.235$, $r=0.180$, $r=0.184$], classmates [$r=0.323$, $r=0.188$, $r=0.256$] and teachers [$r=0.283$, $r=0.226$, $r=0.234$], on average show lower perceived stress and lower risk of depression.

Statistically significant differences were found between adolescents who perceive stress more and less often regarding the average expressed support of family ($p<0.001$), friends ($p<0.001$), classmates ($p<0.001$) and teachers ($p<0.001$). Adolescents who perceive stress less often, more likely agree on support from friends ($\bar{x}=5.27$, ± 1.72), family ($\bar{x}=5.00$, ± 2.07), classmates ($\bar{x}=3.89$, ± 0.83) and teachers ($\bar{x}=3.50$, ± 0.90).

Similarly, statistically significant differences were found between adolescents with average higher and lower risk of depression regarding the average expressed support of family ($p<0.001$), friends ($p<0.001$), classmates ($p<0.001$) and teachers ($p<0.001$). Adolescents with a lower risk of depression more likely agree on support from friends ($\bar{x}=5.29$, ± 1.71), family ($\bar{x}=5.00$, ± 2.06), classmates ($\bar{x}=3.89$, ± 0.82) and teachers ($\bar{x}=3.50$, ± 0.90).

Based on the results, adolescents who on average perceive less stress or have a lower risk of depression, on average have higher expressed support from family, friends, classmates and teachers.

4 DISCUSSION

Our research has found that the perceived support from family, friends, classmates and teachers in adolescents is negatively related to perceived stress and the risk of depression, that adolescents with the support of a larger number of personal social networks have better mental health, and that in explaining adolescent mental health in terms of perceived stress and the risk of depression, family is not the most important source of support. Multiple linear regression results showed that support from classmates and/or teachers is more important than family support in explaining mental health in adolescents. Many other studies also show that parental, teacher, classmate and friend support are significantly associated with adolescent mental health (20-25). In adolescents, good social support is associated with reduced symptoms of stress, anxiety and depression (20, 21), better subjective well-being and positive emotions (22, 23), better self-image (24) and better academic achievements (25).

Our analyses confirm that the support of a greater number of personal social networks is significantly related to better mental health of adolescents. Other studies discuss the cumulative impact of protective and risk factors as well (20, 26), but their independent and combined impact on mental health should be considered for a complete understanding (20). For example, some studies show that family and peer support are more likely to have additive rather than compensatory effects (27, 28), meaning that if an adolescent does not receive adequate support at home, good peer support cannot fully compensate for this loss.

Our results show that teacher support is more important than family support in explaining good adolescent mental health in terms of perceived stress. In the risk of depression, classmate and teacher support are most important, while family support is equal to friend support. We did not find any research examining the experience of support in personal social networks in relation to the Cohen Perceived Stress Scale and the WHO-5 Well-Being Index, but we did find research that included other variables as indicators of mental health. Some support our findings (22,

29, 30), while others, on the contrary, state that parental or family support is the strongest predictor of mental health during this period (23, 31). The mutual influence of individual social support sources proved to be important here as well. One study found that school staff support was positively associated with good mental health among youth with less family support, suggesting that teacher support is most beneficial for youth with a less supportive family environment. It also showed that peer friendships can act as a protective or risk factor depending on the level of connectedness with school - connectedness with peers was associated with better mental health only for students with a higher level of connectedness with school staff (20). The same applies to how interaction between family and peers affects the occurrence of risky behaviors (32). Lower levels of family support may exacerbate the potentially negative effects of adolescent relationships on their health and well-being. Conversely, peer support can have a positive effect on young people's well-being if accompanied by family support (33).

Our research had some limitations. Different scales were used to measure perceived family and friend support and perceived teacher and classmate support, but the internal consistency of individual sets was good nevertheless. Also, the research shows the relationship between social support and perceived stress and the risk of depression, but not the causality. Another limitation is that our sample includes numerically fewer adolescents with more frequently expressed stress and the risk of depression. Despite the limitations, the research has some strengths in advancing the theoretical understanding of the complex relationship between social support from multiple sources and adolescent mental health, and may have practical implications.

This research primarily demonstrates the importance of perceived social support for adolescent mental health. The findings provide recommendations for a sensible and effective formulation of much-needed national mental health policies and strategies in contrast to existing fragmented and less effective individual mental health programmes. The school, together with teachers and classmates, proved to be a very important source of support compared to other sources, therefore it is reasonable and necessary to strengthen its role in the area of young people's mental health. Interventions focused on student-teacher relationships may be particularly important for adolescents with lower family support (20). Interventions based on peer support (e.g. organised school and extracurricular activities, workshops and gatherings) must take into account possible harmful effects for students with less family support and carefully monitor the dynamics and events within groups.

Regarding future research, an agreement on unified variables as indicators of mental health would facilitate the comparison of results. The advantage of the used instruments measuring perceived stress and the risk of depression is their international applicability and thus comparability. Also, while an increasing number of studies, including the present one, demonstrates the importance of individual microsystems, little progress has been made in considering various environmental levels and understanding the interactions between them that also influence adolescent mental health. Therefore, we suggest studies in this direction in the future. Furthermore, much of the existing evidence is based on cross-sectional studies (20, 25, 29-31, 34) that do not include prior mental health problems. There is an association of lower social support and smaller and poorer social networks with youth with a history of mental health problems, which may in turn result in an inflated effect size (21). Therefore, longitudinal studies are needed to establish causal relationships.

5 CONCLUSION

Taking into account the results of the research and the factors that prevent adolescents from accessing appropriate professional help (e.g., parental burden, shame from stigma, insufficient or inadequate resources, geographical distance, paid services), the school environment may be the one that can provide the most opportunities for strengthening the social support and mental health of adolescents through effective public health programmes and interventions. Systematic placement of psychosocial and public health content in the Slovenian educational system and everyday educational process can in the long run lead to the normalisation and destigmatisation of the mental health field. However, this requires effective mutual cooperation and connection between the health and education professions.

CONFLICTS OF INTEREST

The authors declare that no conflicts of interest exist.

FUNDING

The study received no funding.

ETHICAL APPROVAL

The study was conducted in accordance with the Declaration of Helsinki, and the protocol was approved by the Slovenian Medical Research Ethics Committee No. 0120-639/2017/8.

AVAILABILITY OF DATA AND MATERIALS

The data used for this study are available from the Health Behaviour in School-aged Children survey database, which is freely available from the National Institute of Public Health. The data set includes information on demographic characteristics, health behaviours, health outcomes and social environments of school-aged children. The data set is available in both SAS and SPSS formats.

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CULTURAL ADAPTATION OF PATIENT-REPORTED INDICATOR SURVEYS (PaRIS) PATIENT AND PRIMARY CARE PRACTICE QUESTIONNAIRES TO THE SLOVENIAN CONTEXT

KULTURNA PRILAGODITEV VPRAŠALNIKOV O KAZALNIKIH, O KATERIH POROČAJO PACIENTI (PATIENT-REPORTED INDICATOR SURVEYS - PaRIS), ZA PACIENTE IN AMBULANTE PRIMARNEGA ZDRAVSTVENEGA VARSTVA SLOVENSKIM RAZMERAM

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ABSTRACT

Keywords:

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Introduction: The objective of the study is to describe the adaptation process (with emphasis on cognitive testing) of the Slovenian version of the PaRIS international survey, including two questionnaires to assess patient-reported health outcomes and the experiences of adults living with one or more chronic conditions managed in primary care settings: (1) Patient questionnaire (targets patients aged 45 and older) and (2) Provider questionnaire (targets health care providers working in primary care).

Methods: The translation process of both PaRIS questionnaires followed a team-based double translation and reconciliation approach. Cognitive interviewing with 29 participants was performed. An analysis grid and debriefing were implemented, and the cognitive testing rating was assessed for each tested question. Cross-national error source typology (CNEST) was used.

Results: The results of cognitive interviewing revealed difficulties in 30 questions / segments (out of a total of 44 tested) in the Patient questionnaire and difficulties in 23 questions / segments (out of a total of 24 tested) in the Provider questionnaire. In both questionnaires most difficulties were identified as poor source question design.

Conclusions: Our study showed that cognitive interviewing is a crucial step in questionnaire adaptation, especially while transferring internationally developed questionnaires on Patient Reported Experience Measures and Patient Reported Outcome Measures into different national contexts. Through a rigorous process of translation and cognitive testing, we obtained better quality PREMs and PROMs measures in the Slovenian language. However, the measurement tools need to be piloted, and psychometrically evaluated in future to test reliability and validity.

IZVLEČEK

Gljučne besede:

osnovno zdravstvo
izidi zdravstvene oskrbe
kognitivno testiranje

Uvod: Cilj raziskave je opisati proces prilagoditve (s poudarkom na kognitivnem testiranju) slovenske različice mednarodne ankete PaRIS, ki vključuje dva vprašalnika za oceno pacientovih poročanih zdravstvenih izidov in izkušenj pacientov, ki živijo z enim ali več kroničnimi stanji, obravnavanimi v okviru osnovne zdravstvene oskrbe: (1) vprašalnik za paciente (cilja na paciente, stare 45 let in več) in (2) vprašalnik za zdravstvene delavce (osredotočen na zdravstvene delavce, ki delajo v osnovni zdravstveni oskrbi).

Metode: Postopek prevajanja obeh vprašalnikov PaRIS je sledil pristopu dvojnika in usklajevanja, ki temelji na timskem pristopu. Izvedeno je bilo kognitivno intervjuvanje z 29 udeleženci. Uporabljena sta bila analiza in povratni pregled, ter ocenjena ocena kognitivnega testiranja za vsako testirano vprašanje. Za zmanjšanje in izogibanje napakam pri merjenju ter zagotavljanje mednarodne primerljivosti je bila uporabljena tipologija virov napak v presečnih raziskavah (CNEST).

Rezultati: Rezultati kognitivnega intervjuvanja so razkrili težave v 30 vprašanjih/segmentih (od skupno 44 testiranih) v vprašalniku za paciente in težave v 23 vprašanjih/segmentih (od skupno 24 testiranih) v vprašalniku za zdravstvene delavce. Pri obeh vprašalnikih so bile večinoma težave povezane s slabim izhodiščnim oblikovanjem vprašanj.

Zaključki: Naša raziskava je pokazala, da je kognitivno testiranje ključni korak pri prilagajanju vprašalnikov, zlasti pri prenosu mednarodno razvitih vprašalnikov o pacientovih poročanih izkušnjah in zdravstvenih izidih v različne nacionalne kontekste. S strogim postopkom prevajanja in kognitivnega testiranja smo pridobili bolj kakovostna orodja za merjenje izidov zdravstvene oskrbe in izkušenj z zdravstveno oskrbo na osnovni zdravstveni ravni. Omenjena orodja pa je treba v prihodnosti pilotno preizkusiti in psihometrično ovrednotiti, da se preveri njihova zanesljivost in veljavnost.

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1 INTRODUCTION

Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) are crucial in evaluating healthcare quality from the patient's perspective, particularly in chronic care management within primary care settings. PROMs provide insights into the patient's health status, treatment outcomes and quality of life, while PREMs focus on patient experiences with healthcare services and healthcare professionals (1). Primary care has a significant place in the management of people with chronic conditions as it offers continuous, coordinated, people-centred and comprehensive care. Yet PROMs and PREMs data in primary care are scarce.

In large-scale international studies, ensuring international comparability is essential, through using the same survey design and instruments. However, adaptation of the survey and tools to the national context is important to address contextual issues (4). Structured and rigorous translation processes are key in international studies where the source instruments are developed in a foreign language, and ensure the validity and reliability of data collection. While using existing instruments has the advantage of established validity, a previously validated instrument may not be valid in a different time, culture, or context (2). Self-report scales can show variations due to culturally determined factors such as social desirability and response styles (3). Therefore, cultural adaptation, in addition to translation, becomes important to ensure content equivalence between source and target versions (3). There is no consensus on how to adapt instruments for different cultural settings, but simple translation is insufficient, as it can result in multiple, inconsistent translations, losing the original intent (4). Rigorous translation and cognitive testing are two important steps in ensuring that instruments such as PROMs and PREMs are appropriately adapted to different cultural contexts, preserving their original intent (7, 8).

The OECD's Patient-Reported Indicator Survey (PaRIS) (5) aims to measure the performance of health systems in delivering high quality safe primary care by collecting PROMs and PREMs. It assesses the outcomes and experiences of the healthcare of people living with chronic conditions aged 45 and above through a patient questionnaire (PaRIS-PQ) (2) and through a primary care practice questionnaire (PaRIS-PCPQ) (3) which collects information on the characteristics of care such as delivery design and type of practice (e.g., group practice). Based on the PaRIS conceptual framework, PaRIS-PQ and PaRIS-PCPQ were developed in English and French through a rigorous process of review of literature, modified Delphi process and stakeholder consultations from existing validated instruments (10-13).

The aim of this study was to adapt the PaRIS-PQ and PaRIS-PCPQ to the Slovenian setting and language. The study focused on cognitive testing to ensure the questionnaires' comprehensibility, relevance and effectiveness in the national context.

2 METHODS

2.1 Study type and settings

This was a qualitative study based on the translation and cultural adaptation of the PaRIS-PQ and PaRIS-PCPQ. It was performed among Slovenian family medicine providers and patients as part of the OECD's PaRIS survey (5, 6). The OECD led the development and implementation of the PaRIS survey, with support from the PaRIS-SUR consortium, an international team highly experienced in primary care research and survey development (5). The development of the PaRIS questionnaires was an iterative co-development process (3), including countries, academics, primary care professionals and patient organisations (10).

The study was approved by the National Ethical Committee of Slovenia (approval number 0120-260/2021/3).

2.2 Participants

We involved primary care providers and their patients; a purposive sampling technique was used. For providers, interested family physicians were contacted by the researchers, with the aim of including a range of providers (age, gender, area of work and work experiences).

In Slovenia, the family medicine practice team consists of a family physician, registered nurse and practice nurse (7). Therefore, the inclusion criterion for the providers' sample was that the participant needed to be a family physician, registered nurse, or practice nurse. We contacted 10 providers.

The inclusion criteria for patients were: 1) adults aged 45 years or older, 2) living in a private household in the community, and 3) have had one or more consultations with a primary/outpatient healthcare provider in the past six months.

To get the patient contact information, we asked the providers to find interested patients and obtain their consent to send their contact data to the research team. Through this process, 20 patients were contacted to participate in the study.

2.3 Measurement tools

The English version of the PaRIS-PQ (2) and PaRIS-PCPQ (3) source questionnaire were used as the measurement tools.

2.4 Procedures

The entire adaptation process followed the following phases: 1) translation of source questionnaires into Slovenian; 2) First round of cognitive testing; 3) Second round of cognitive testing; 4) Field trial of survey design and instruments and 5) Final questionnaires for the main survey implementation.

2.4.1 Translation of source questionnaires into Slovenian

The translation process followed a team-based double translation and reconciliation approach (TRAP-D - Translation, Review, Adjudication, Pretesting and Documentation) (5). The team approach to translating and adapting questionnaires is a well-established practice in international research and is recommended by the guidelines for intercultural research (8). Using a collaborative and iterative approach ensures that translated versions accurately reflect the local context while maintaining the integrity of the original source.

The process began with a translatability assessment to verify the suitability of the source version for translation. This assessment identified potential translation issues and offered alternative phrasings or translation/adaptation notes to clarify terms or expressions and guide the translators on necessary adaptations. The PaRIS-SUR consortium reviewed this translatability report to finalise the source version.

Following this, two translations were produced: a local translator appointed by the national research team, and an external translator, provided by cApStAn (a specialist linguistic quality control agency). An external adjudicator (also provided by cApStAn) then reconciled these translations into a single version. This merged translation was discussed in an adjudication meeting, involving both translators, the adjudicator, the Slovenian national project manager and a PaRIS-SUR member. The purpose of these meetings was to resolve any controversial or difficult translation choices to finalise the questionnaire wording. Once the translation had been finalised by adjudicators, a final proof check of each national version was carried out by a proof-reader.

Throughout the translation, adaptation and reconciliation/adjudication process, all steps were documented in an Excel monitoring tool called the Questionnaire Translation and Adaptation Workbook (QTAW). The entire translation, adaptation and proofreading process utilised the open-source software OmegaT (9). To support the translations, a glossary was created, which provided descriptions, translation notes and examples for unclear terms identified during the translatability assessment. This glossary aimed to enhance the comprehensibility of terms and ensure consistent translations.

2.4.2 Cognitive testing

Cognitive interviews were implemented in two rounds of semi-structured interviewing using the think aloud technique, verbal probing (pre-prepared probes and spontaneous probes) and observation (hesitation, confusion, request for clarification etc.). We used the four-stage model of cognitive interviewing (4), focusing on the process of understanding, recall, judgement and response while people are answering questionnaires. Researchers took detailed notes and completed a structured analysis grid to ensure evidence was available to support the need for any changes throughout the two rounds of testing. Each round led to recommendations for changes to the questionnaires. Changes that were considered were either source changes (changes or revisions to the source questionnaires to be implemented in all countries) or localisations (issues that were identified in the national context, allowing adaptation of the questions or response options to support comprehension, as well as to correct translation errors).

All participants received the following materials in advance (via regular mail or e-mail): 1) Information sheet (with all the information about the study and our contacts), 2) Consent form, and 3) Privacy notice. All participants received a small thank you for taking part (a small first aid kit package), which was not offered in advance. Due to COVID-related restrictions the interviews were conducted in two modes: 1) online (GoToMeeting (video)conference), and 2) by telephone.

2.4.2.1 First round of cognitive testing

The first round of cognitive interviewing took place between 8 and 19 July 2021. We aimed to include 15 participants (5 healthcare providers and 10 patients). Cognitive testing only included items that the PaRIS consortium had previously identified as necessary for testing (3). Researchers documented their observations and utilised a structured analysis grid to substantiate the need for any modifications during the second round of testing. These changes were categorised as either recommendations for source changes, which involved alterations or revisions to the original questionnaires to be implemented across all countries, or localisations, which addressed issues identified within the national context. This allowed the national research team to adapt questions or response options to enhance comprehension and correct translation errors.

2.4.2.2 Second round of cognitive testing

This took place between 25 October and 2 November 2021. Again, we aimed to include 15 participants (5 healthcare providers and 10 patients), all different to those included in the first round. We tested only the items that needed adaptation based on the results of the first round, and

an additional two questions (in which issues appeared spontaneously during the first round of testing).

2.4.3 Data analysis

According to the results of the cognitive testing (based on observed problems), the researchers (NR, EM) assessed each question independently, rating them as: Not problematic; Somewhat problematic; or Very problematic. The researchers (NR, EM) assigned a quantitative number to each descriptive assessment: Not problematic = 0 points; Somewhat problematic = 1 point; Very problematic = 2 points. For each question, total difficulty points (sum of all points over all tests) were calculated, separately for round 1 and round 2 of cognitive interviewing. Where there was disagreement between the researchers (NR, EM), a consensus meeting with ZKK took place.

For an easier assessment of the actual cognitive complexity, a ratio was also calculated of Total difficulty points / Number of tests for each question in each round of cognitive testing. A higher ratio indicated greater cognitive difficulty of the question, and a greater need to change or modify the question, response options or introductory text. A ratio of 0.5 or higher per question was decided as the cut-off point for further detailed consideration. Since this was an international project, including many countries each with different healthcare systems, the cross-national error source typology (CNEST) (10) was used with the intention to reduce and avoid measurement error, and to provide international comparability. CNEST error source typology focused on three types of errors: 1) poor source question design, 2) translation error, and 3) difficulties resulting from cultural portability (10).

2.4.4 Finalisation of the questionnaires

We analysed cognitive testing results using the Cross-National Error Source Typology (3) to identify and categorise errors related to source question design, translation and cultural adaptation (3). This analysis allowed researchers to pinpoint issues and recommend solutions for each question tested.

3 RESULTS

3.1 PaRIS-PQ

The patient sample comprised 20 participants: 11 females and nine males. All participants were aged 45 years or older at the time of sampling and lived in a private household in the community (i.e. not in a long-term care facility, healthcare or other residential institution). The age of participants varied between 47 years old and 95 years old (mean 67 years, standard deviation 12 years). Of the participants, 11 had a chronic condition.

The results of cognitive testing revealed difficulties in 30 questions or segments (out of a total of 44 tested, and out of total 120 items in the questionnaire), where changes would be beneficial.

The table below lists question codes, number of tests, total difficulty points, ratio and identified error types.

In addition to the CNEST error typology (poor source question design, translation error, cultural portability) we also added Poor introduction to a section or sequence of questions (Table 1).

Table 1. Error types revealed after cognitive testing of the PaRIS-PQ.

Question content	Round 1			Round 2			Error Type
	N of tests	Tot. diff. score	Ratio	N of tests	Tot. diff. score	Ratio	
Difficulties in breathing	9	4	0.4	10	5	0.5	Poor source question design.
Emotional problems (anxiety, depression, irritability)	7	4	0.6	9	3	0.3	Poor source question design.
Care for health and healthcare	7	4	0.6	10	5	0.5	Poor source question design.
Health professionals spoken about healthy eating	8	4	0.5	10	5	0.5	Poor source question design.
Information about health issues	8	11	1.4	/	/	/	Translation error.
Experience with healthcare	9	6	0.7	9	5	0.6	Cultural portability.
Consulted with a doctor	8	4	0.5	9	5	0.6	Poor source question design, Translation error.
Diagnosed with disease by a doctor	7	4	0.6	/	/	/	Poor source question design, Poor introduction / section design (text after diagnosed with disease by doctor).
Healthcare professional coordinating health services	9	11	1.2	10	7	0.7	Translation error / Cultural portability, Poor introduction / section design (Experience in family medicine practice, text after Diagnosed by doctor with disease).
Same health professional for most problems	7	7	1.0	/	/	/	Poor introduction / section design (Single healthcare professional for coordination, Experience with family medicine practice, text after Diagnosed with disease by doctor).
Who is this health worker?	7	10	1.4	9	5	0.6	Poor introduction / section design (Experience with care in family medicine practice, text after Diagnosed with disease by doctor, questions Is there a single professional responsible for coordinating care, Is it the same professional as for most health problems), Translation error (response option 3).
Health professional for most health problems	8	4	0.5	10	6	0.6	Cultural portability, Poor introduction / section design (Relationship with care in your family medicine practice, Diagnosed by doctor with any disease).
Setting health goals with health professionals	8	7	0.9	10	6	0.6	Poor section design, Poor source question design. * Firstly, question was without introduction.

Question content	Round 1			Round 2			Error Type
	N of tests	Tot. diff. score	Ratio	N of tests	Tot. diff. score	Ratio	
Questions relate to treatment plan/ Treatment plan for health needs	8	10	1.3	10	10	1.0	Poor introduction design, Poor source question design, Cultural portability.
Health care involves family, friends, caregivers	8	1	0.1	8	7	0.9	Poor source question design, Poor introduction / section design.
Reviewing all the medications	7	4	0.6	10	2	0.2	Poor source question design, Poor introduction / section design.
Last consultation/main purpose of consultation	9	11	1.2	9	11	1.2	Poor introduction design (Relate to last consultation in medical clinic), Poor source question design, Translation error, Cultural portability.
Most time spent with healthcare professionals	9	5	0.6	7	8	1.1	Poor introduction / section design, Cultural portability.
Employment of a health worker	9	13	1.4	5	3	0.6	Poor introduction /section design, Cultural portability.
Best describes the type of medical care	8	6	0.8	6	4	0.7	Poor introduction / section design, poor source question design.
How quickly you got the appointment for consultation	8	2	0.3	7	6	0.9	Poor introduction / section design, poor source question design.
Symptoms of COVID-19 in last two months	8	2	0.3	8	7	0.9	Translation error / Cultural portability.
Highest level of education	10	6	0.6	/	/	/	Translation error / Cultural portability.
Your sex	7	7	1.0	/	/	/	Cultural portability.
Your gender	9	8	0.9	/	/	/	Cultural portability.
Current employment status	4	5	1.3	/	/	/	Translation error / Cultural portability.
Enough money for healthy food	8	5	0.6	4	1	0.3	Poor source question design.
Need for emotional care	9	7	0.8	/	/	/	Poor source question design.
Agree or disagree that healthcare system can be trusted	8	1	0.1	8	5	0.6	Poor source question design.
Best describes the live in place	/	/	/	6	5	0.8	Poor source question design (difficult international comparability).

Legend: *= questions which were additionally tested only in Slovenia. N of test = Number of tests, Tot. diff. score = Total difficulty score, Ratio = Total difficulty score / Number of tests.

The terms “Ni ustrezno” (English: Not relevant) were not understood correctly by some participants, therefore these terms were substituted everywhere in the questionnaire with “Vprašanje ni ustrezno zame” (English: Question is not relevant to me). In the paper version of the Patient questionnaire some problems were detected with the routing markings (identifying which question people should answer next when skipping questions). Some problems were detected also due to the length of the questionnaire, especially long, complex introductory text (which was even longer in the Slovenian language due to usage of both grammatical genders). As a result, to reduce cognitive complexity, the wording in the Patient questionnaire was changed to use the male grammatical gender only. In the web version it was noticed that the information buttons (which included some additional description of terms) were often overlooked. To resolve this, it was suggested the important text be included directly in the wording of the main questions.

3.2 PaRIS-PCPQ

The sample included nine participants: five females and four males. Five worked as nurses in family medicine and four as family physicians. Seven worked in a solo practice (as part of a healthcare centre) and two in a group practice as part of a private clinic.

The results of cognitive testing revealed difficulties in 23 questions or segments (out of a total of 24 tested, and out of a total 34 in the questionnaire). The following error types were revealed after the cognitive testing of the PaRIS-PCPQ: Poor source question design, Translation error and Cultural portability (Table 2).

Cognitive testing revealed the need to clarify in the PaRIS-PCPQ that the survey refers to primary care, including model family medicine practices. This clarification was added because some participants were unsure whether model family medicine practices should be included. Similarly to the PaRIS-PQ, it was observed that in the web version, the information buttons (containing additional descriptions of certain terms) were frequently overlooked. Consequently, it was recommended that essential information be included directly in the main questions.

4 DISCUSSION

Cognitive testing of the PaRIS-PQ and PaRIS-PCPQ have significantly improved the clarity and user experience of the PaRIS questionnaires in the Slovenian context. The assessment identified beneficial changes for 30 out of 120 PaRIS-PQ items and for 23 out of 34 PaRIS-PCPQ items, improving comprehension of the questionnaires through changes including question design, translation accuracy, cultural relevance and sequence design. Clearer

terminology was introduced, replacing terms that were not well understood, and adjustments were made to simplify wording and reduce complexity in the questionnaire.

Cognitive testing identified “Poor source question design” as a significant issue. Despite using validated questions, cognitive testing highlighted issues with how these questions functioned in the context of the Slovenian survey. These problems suggest that even validated instruments can fail in new cultural or linguistic contexts. This finding is very important since cognitive practice often focused more on checking specific question understanding, rather than how a question plays out in the context of an entire questionnaire. This indicates that some questions were not effectively constructed, leading to confusion among respondents. This was also shown in other participating countries and was the most prevalent type of error in PaRIS-PCPQ international cognitive testing (3). In Slovenia, most issues associated with poor source question design were linked to cultural and contextual differences. Such issues can lead to biased results. The report notes the importance of cultural adaptation beyond mere translation. Poor design was often linked to a lack of cultural portability, underscoring that validated instruments require contextual refinement to maintain their integrity across diverse populations. The issues identified during cognitive interviews (e.g., confusion or misunderstanding) were pivotal in refining the questions. This indicates that validation in prior studies does not guarantee flawless application in all scenarios, particularly in multilingual and multicultural studies. Maintaining international comparability while addressing local context is a complex challenge. Some of the poor design elements may have persisted because questions were developed with an international audience in mind, which can dilute their relevance or clarity in specific national settings. It is essential to adapt questions to fit the cultural context of the target population. This includes considering local terminologies, customs and healthcare practices. Misunderstandings due to cultural discrepancies can significantly impact the validity of the data collected (11).

Both questionnaires encountered translation errors, which can distort the intended meaning of questions. Similar issues were observed in international cognitive testing (3). Ensuring accurate translations that preserve the original meaning is essential, as well as consultation with native speakers (12, 13).

Some questions did not translate well across different cultural contexts, an issue known as cultural portability which was found as a prevalent issue in the international cognitive testing (3). This underscores the utmost importance of culturally sensitive adaptations that respect local contexts and terminologies (12, 13).

Table 2. Error types revealed after cognitive testing of the PaRIS-PCPQ.

Question content	Round 1			Round 2			Error Type
	N of tests	Tot. diff. score	Ratio	N of tests	Tot. diff. score	Ratio	
Type of practice	3	5	1.7	5	7	1.4	Cultural portability.
Practice offers services without an appointment/ Which type of patients can come without an appointment	3	2	0.7	5	6	1.2	Poor source question design, Translation error, Cultural portability.
Which of the following out-of-hours options does your practice provide	3	3	1.0	5	9	1.8	Poor source question design, Cultural portability, Translation error.
Roles and functions of the nurses	3	3	1.0	5	5	1.0	Poor source question design, Cultural portability.
Scheduled time in practice	3	3	1.0	5	5	1.0	Poor source question design, Translation error, Cultural portability.
How prepared is a practice to manage care?	3	3	1.0	5	7	1.4	Poor source question design, Translation error, Cultural portability.
Access to equipment for managing chronic patients	4	5	1.3	/	/	/	Poor source question design.
Physicians paid in practice	4	6	1.5	/	/	/	Poor source question design, Cultural portability.
Practice receives dedicated payments	4	5	1.3	5	10	2.0	Cultural portability.
Types of medical record kept	4	4	1.0	5	4	0.8	Poor source question design, Translation error.
How are individual patient care plans developed at your practice?	4	6	1.5	5	5	1.0	Poor source question design, Cultural portability.
Practice produces information using computer system	4	3	0.8	5	7	1.4	Poor source question design, Translation error, Cultural portability.
Tasks routinely performed using computer system	3	3	1.0	5	5	1.0	Cultural portability, Translation error.
Review indicators	3	4	1.3	5	6	1.2	Poor source question design, Translation error, Cultural portability.
In charge of coordinating with chronic conditions	3	5	1.7	5	10	2.0	Poor source question design, Translation error.
Self-management support for patients with chronic conditions	3	1	0.3	4	2	0.5	Cultural portability.
Care in practice following chronic conditions	3	4	1.3	/	/	/	Poor source question design, Translation error.
Info about COVID-19	3	2	0.7	/	/	/	Translation error.
Changes in practice due to COVID-19	2	1	0.5	3	2	0.7	Poor source question design.
Salary in COVID-19	2	1	0.5	/	/	/	Poor source question design.
Stressed when managing patients with covid-19	2	1	0.5	2	1	0.5	Poor source question design.
Professional background	4	5	1.3	3	2	0.7	Cultural portability.
Does your practice offer video, phone, or other online techniques for consultations to patients?	3	0	0.0	5	1	0.2	No major difficulties detected in Slovenia.

Legend: N of test = Number of tests, Tot. diff. score = Total difficulty score, Ratio = Total difficulty score / Number of tests.

The cognitive testing highlighted issues with the design of introductions and the sequence of questions. Long and complex introductions were particularly problematic, especially in languages such as Slovenian that require gender-specific language. On the contrary, at the international level, this was the least prevalent issue (3). This finding underlines the importance of continuous testing and refinement of the terminology used in large-scale surveys as well as adaptation to national contexts while ensuring international comparability of results (12). The findings of this study confirm that cognitive interviewing in addition to translation is a crucial step in the development of questionnaires and the adaptation process, especially for developing PROMs and PREMs (14, 15). In large-scale initiatives, it is even more important to do cognitive testing in local languages, since even if the survey instruments used are validated in other contexts, it does not necessarily mean that they have the same face validity in all participating countries. This is why by design, PaRIS ensured that all countries followed a rigorous translation and cognitive testing process, meaning that the final questionnaires were understood by all participating patients, providing comparable data.

Cognitive testing is the most direct way of finding out whether respondents understand questions consistently, have the information needed to answer the questions and can use the response alternatives provided to describe their experiences or their opinions accurately. It does not directly assess the validity of the answers, but cognitive problems will seriously compromise validity and reliability (16, 17). Therefore, we can conclude that cognitive interviewing ensured that the Slovenian version of both PaRIS questionnaires had much better face validity.

Our study has some limitations that must be addressed. Cognitive testing was performed only on specific questions - those questions that were identified and pre-selected for testing in Slovenia by the PaRIS consortium. However, the cognitive complexity of sentences may be different in different languages (e.g. some wording in English sounds less complex than in Slovenian). Also, the testing was adapted to the conditions of the individual interview (time duration, fatigue etc.), therefore not all questions were tested on all participants.

Additionally, during cognitive testing, some participants had difficulty developing rich metacognitive thinking (awareness of their own thoughts and mental processes), which is an important factor in effective cognitive interviewing. Despite encouragement, some participants could not consistently think aloud and were unable to reflect much despite verbal probing. Furthermore, cognitive interviewing was not performed face-to-face, but online (GoToMeeting (video) conference) and by telephone due to COVID-related restrictions, which limits the ability to observe non-verbal communication.

Finally and importantly, cooperating in this international cognitive interviewing study was beneficial since it ensured that the questions which were further tested in the PaRIS survey Field Trial were similar in different countries, which ensures good final data comparability.

5 CONCLUSION

This study describes the cognitive testing of the international PaRIS-PQ and PaRIS-PCPQ in the Slovenian language and in a sample of Slovenian primary care providers and patients. To our knowledge, this is the first time PREMs or PROMs for primary care have undergone cognitive testing in Slovenia, marking a critical step toward better aligning healthcare evaluation tools with local cultural and linguistic contexts. Identified errors enabled the questionnaires to be adapted to the Slovenian context, while keeping consistency with international standards for cross-country comparisons. Through a rigorous process of translation and cognitive testing, we obtained culturally adapted PREMs and PROMs measures in the Slovenian language for family medicine practices, ensuring better validity for any future studies that also use them.

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ETHICAL APPROVAL

The study in Slovenia was approved by the National Ethics Committee (No. 0120-260/2021/3).

CONFLICTS OF INTEREST

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

AVAILABILITY OF DATA AND MATERIALS

The data that support the findings of this study are available from OECD. Restrictions apply to the availability of these data, which were used under license for this study. Data are available from the authors with the permission of OECD.

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PREVALENCE OF SARCOPENIA AMONG SLOVENIAN OLDER ADULTS AND ASSOCIATED RISK FACTORS

PREVALENCA SARKOPENIJE MED STAREJŠIMI ODRASLIMI V SLOVENIJI IN POVEZANI DEJAVNIKI TVEGANJA

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ABSTRACT

Introduction: Sarcopenia is a multifaceted condition affecting between 10 and 16% of the global population, and although multiple classification algorithms exist, no prevalence has been reported for a representative sample of the Slovenian population. Furthermore, multiple behavioural factors, such as malnutrition, physical inactivity, sedentary lifestyle and lower cognitive function, can contribute to the risk of sarcopenia. This study aims to: a) determine sarcopenia prevalence among Slovenian older adults according to different classification algorithms, b) compare the agreement among the algorithms and c) evaluate the relationship between proposed risk factors and sarcopenia.

Keywords:

Sarcopenia
Prevalence
Epidemiology
Classification algorithms
Risk factors

Methods: 654 participants (≥60 years, 30.4% males) have been classified into sarcopenia groups according to eight algorithms, and agreement (Fleiss K) between them was calculated. Additionally, age, sex, nutritional status, physical activity, sedentary levels and cognitive function were assessed as sarcopenia risk/protective factors.

Results: The prevalence of sarcopenia according to EWGSOP2 was 4.1%, ranging from 2.1% to 15.3%, when classified by all eight algorithms. Overall agreement between algorithms was weak (K=.429; 95% CI .414 to .444) with 0.6% of participants classified as sarcopenic by all eight algorithms. Adequate nutrition and physical activity were identified as protective factors, while age, lower cognitive function and sedentary lifestyle were considered risk factors.

Conclusion: Sarcopenia prevalence among the Slovenian general population was lower than in the global population. We can conclude that different sarcopenia algorithms lead to a different prevalence of sarcopenia. It is of great importance to be cautious when comparing prevalences among studies and to further validate the classification algorithms.

IZVLEČEK

Uvod: Čepprav je sarkopenija kompleksna bolezen, ki prizadene med 10 in 16 % svetovnega prebivalstva in obstaja za njo več klasifikacijskih algoritmov, ki vnašajo širok razpon poročane prevalence, ne obstajajo poročila o prevalenci sarkopenije med splošno populacijo slovenskih starejših odraslih. K tveganju za razvoj sarkopenije lahko prispevajo dejavniki življenjskega sloga, kot so neustrezna prehranjenost, gibalna neaktivnost, sedeči življenjski slog in zmanjšana kognitivna funkcija. Namen raziskave je ugotoviti prevalenco sarkopenije med populacijo slovenskih starejših odraslih, ugotoviti ujemanje med različnimi klasifikacijskimi algoritmi in preveriti dejavnike tveganja ali preventivne dejavnike.

Ključne besede:

sarkopenija
prevalenca
epidemiologija
klasifikacijski algoritmi
dejavniki tveganja

Metode: V raziskavi je sodelovalo 654 preiskovancev (≥ 60 let, 30,4 % moških). Uporabljeni so bili testi, ki so predlagani v EWGSOP2 (vprašalnik Sarc-F, jakost stisk pesti, 5-kratno vstajanje s stola, test vstani-in-pojdi, hitrost hoje, električna bioimpedance), preiskovanci pa so bili razvrščeni v skupine sarkopenije glede na osem različnih algoritmov (SDOC, EWGSOP, EWGSOP2, EWGSOP2 s SARC-F, EWGSOP2 brez SARC-F, EWGSOP2 s SARCaIF, IWGS, FNIH). Poleg tega so bili zajeti tudi podatki o starosti, spolu, prehranjenosti (vprašalnik MNA), gibalni aktivnosti in sedentarnih navadah (vprašalnik GPAQ) ter kognitivni funkciji (TMT-a in TMT-b), ki lahko kažejo na tveganje za razvoj sarkopenije.

Rezultati: Prevalenca sarkopenije je 15,3 %, 11,8 %, 4,1 %, 4,4 %, 7,7 %, 7,7 % in 2,1 % ugotovljena z algoritmi SDOC, EWGSOP, EWGSOP2, EWGSOP2 s SARCaIF in EWGSOP2 brez SARC-F, FNIH in IWGS. Ujemanje med algoritmi je nizko (K = 0,429, 95 % IZ od 0,414 do 0,444), in zgolj 0,6 % preiskovancev je sarkopeničnih po vseh osmih algoritmi. Ugotovili smo, da ustrezna prehranjenost in gibalna dejavnost zmanjšujeta tveganje za razvoj sarkopenije in predstavljata preventivna dejavnika, medtem ko so starost, zmanjšana kognitivna funkcija in sedeč življenjski slog dejavniki tveganja in povečujejo tveganje za razvoj sarkopenije.

Zaključek: Med slovensko populacijo starejših odraslih je opaziti manjšo pojavnost sarkopenije kot v svetovni populaciji, ne glede na uporabljen algoritem klasifikacije. Kljub temu je definicijo sarkopenije in s tem klasifikacijske algoritme potrebno poenotiti, poleg tega pa na razvoj sarkopenije vpliva več dejavnikov, ki jih je mogoče preprečiti. Z ustreznimi javnozdravstvenimi intervencijami jih je možno nadzorovati in s tem zmanjšati posledice sarkopenije.

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1 INTRODUCTION

Sarcopenia has been shown to affect between 10 and 16% of the global population based on various classification algorithms (1). Multiple research groups have proposed algorithms for sarcopenia classification (2-7), resulting in discrepancies in the reported prevalence which could be attributed to the continuous revisions of the criteria for defining sarcopenia. The algorithms differ in the proposed methods to evaluate domains of strength, muscle mass or physical performance. Despite efforts to compare and reconcile these algorithms, a universal standard for sarcopenia classification has yet to be established, regardless of its recognition as a disease (8). A unified classification algorithm is needed for multiple reasons: diagnosis confirmation, accurate prognosis and effective treatment plans (9). This multifaceted problem has recently been highlighted and points to various contributing factors including limited measurement methods for muscle mass in large cohorts, lack of consensus, inconsistent evaluation of functional status in older adults and lack of public awareness (10). Sarcopenia prevalence has been assessed in different countries, however, there is no data on sarcopenia prevalence in a representative sample of Slovenian older adults.

In addition to the large prevalence variance and weak agreement between classification methods (11), sarcopenia is a complex condition resulting from various contributing factors. For effective prevention, it is imperative to know the factors that can affect sarcopenia development. The natural ageing process is inevitable and associated with a gradual loss of muscle mass and strength (12) and age has been recognised as the most important risk factor of sarcopenia (13, 14). Furthermore, there are lifestyle behavioural factors (physical inactivity or poor dietary habits) that can significantly contribute to the risk of developing sarcopenia and are modifiable through targeted interventions (15, 16). Malnutrition can be frequently associated with a reduction of muscle mass and muscle strength, but their causal relationship is not yet well established (2, 15). However, the risk of malnutrition increases with age due to inadequate nutritional intake and it has major impacts on individuals' independence and sarcopenia presence (17). Additionally, diminished physical activity with age, especially when coupled with increased physical inactivity, is a first modifiable but still prevalent risk factor of decreased muscle mass and function loss (18). It has been found that low levels of physical activity present a risk factor for sarcopenia onset among community-dwelling adults (19). Beyond physical factors, cognitive decline has been shown to have an association with sarcopenia (20), and the literature highlights the two-way association between cognitive and muscular deterioration, as it has been proposed that cognitive decline and sarcopenia share pathophysiological pathways (21).

This study aims to: a) determine sarcopenia prevalence among Slovenian older adults according to different classification algorithms, b) compare the agreement among the algorithms and c) evaluate the relationship between proposed risk factors and sarcopenia.

2 METHODS

2.1 Study design

This was a cross-sectional study conducted with older adults across 11 (out of 12) Slovenian regions between February 2022 and December 2023. Regional health centres were contacted and invited to take part in the study and to provide their institutions' facilities to conduct the testing.

2.2 Participants and eligibility criteria

The inclusion criteria were: a) minimum age of 60 years and b) signed informed consent.

Exclusion criteria were a) acute illnesses, b) exhaustion, c) cancer in terminal stages, d) infections, e) hospitalisation. Participants were randomly invited to participate via invitation by their chosen general practitioner and they gave preliminary informed consent at the local health centre. Based on region size, a representative sample was randomly selected and contacted to participate in the study via phone calls or e-mails. Altogether 1,184 informed consents were collected, 686 participants accepted the invitation and 654 attended the measurement day.

2.3 Screening protocol

We have followed the revised European working group on sarcopenia in older people (EWGSOP2) algorithm and used proposed tests with an addition of parameters of age, sex, nutritional status, physical activity and cognitive function. The protocol started with the screening tools Sarc-F (22) and Sarc-CalF (23). Muscle strength was assessed with a handgrip strength (HGS) test of the dominant hand using a hydraulic dynamometer (Jamar, Sammons Preston, USA) and a five-repetition sit to stand (5STS) test (3). HGS was measured in a seated position, elbow flexed at 90° and participants were instructed to squeeze the dynamometer three times with maximal effort. An average of three attempts was used for the analysis. In the 5STS test participants were instructed to stand up from the chair to a fully extended position five times as fast as possible with arms on the chest. Total time was measured with a stopwatch in seconds. Muscle mass was estimated with the tetrapolar electrical bioimpedance device BIA 101 Anniversary (Akern Srl, Florence, Italy) in a supine position. Appendicular skeletal mass (ASM), ASM normalised to height (ASM/ht²) and skeletal mass index (SMI) were used in the analysis. Where measures of muscle mass were not

possible, calf circumference was used (cut-off value for low muscle mass for men was ≤ 34 cm and for women ≤ 33 cm). Physical performance was assessed with gait speed over 4 metres and a timed up-and-go (TUG) test over 3 metres. For gait speed, two time measuring gates (Beam trainer timing system, Seedgrov d.o.o., Ljubljana, Slovenia) were set over the course of 4 metres (24). For both tests, an average of two repetitions was used for the analysis.

2.3.1 Nutritional status

The Slovenian version of Mini Nutritional Assessment (MNA) was used to evaluate nutritional status (25). The MNA is an internationally validated tool for assessing the risk of malnutrition and nutritional status in older adults and is scored with a maximum of 30 points, with the following indications: ≥ 24 points - being well-nourished, 17-23.5 points - risk of malnutrition, and < 17 points - undernourished.

2.3.2 Physical activity

Physical activity level and sedentary behaviour were evaluated with the Slovenian version of the Global Physical Activity Questionnaire (GPAQ) (26), which comprises a 16-item assessment of three main domains: work, recreation and transport. Participants determine the intensity, duration and frequency of their physical activity from which we have calculated time spent in moderate to vigorous physical activity (MVPA). One of the items assessed sedentary behaviour over one day in minutes.

2.3.3 Cognitive function

Cognitive function was assessed with a Trail-making test (TMT) (27) with its normative values (28) to evaluate visual search speed and executive function. In TMT-a and TMT-b, participants are asked to connect 25 encircled numbers, or alternating numbers and letters, respectively, in an increasing fashion on a sheet of paper. The completion time (in seconds) for each part is recorded.

2.4 Sarcopenia algorithms

We have included both primary and secondary types of sarcopenia. Participants have been classified regarding the presence of sarcopenia, using eight algorithms validated in the European population (Table 1): Sarcopenia Definition and Outcomes Consortium (SDOC) (5), European working group on sarcopenia in older people (EWGSOP) (2), EWGSOP2 (3), EWGSOP2 with Sarc-CalF, EWGSOP2 without Sarc-F, International working group on sarcopenia (IWGS) (6) and Foundation for the National Institutes of Health (FNIH) (4).

2.5 Sample size calculation

Sample size was calculated at $\alpha=5\%$, error of 3% and expected prevalence of 15% according to the global prevalence data (1). A minimum of 544 participants would be necessary to carry out the present study.

2.6 Statistical analysis

Statistical analysis was conducted in SPSS software (IBM, Chicago, IL, USA), version 29.0. To compare multiple sarcopenia classification algorithms, Fleiss's Kappa test was used. For this, data was grouped into two categories - no sarcopenia (consisting of groups of non-sarcopenic and presarcopenic participants) and sarcopenia (consisting of groups of sarcopenic and severely sarcopenic participants). To interpret the agreement analysis, the following classification categories were considered: 0-0.20 represents no agreement; 0.21-0.39 minimal agreement; 0.40-0.59 weak agreement; 0.60-0.79 moderate agreement; 0.80-0.90 strong agreement; and > 0.90 very strong agreement (29). To calculate risk factors, binary logistic regression was used, and participants were classified using the EWGSOP2 algorithm where the above-mentioned two categories were used. Due to missing values for cognitive function (50.3%), the logistic regression model was calculated separately for each parameter (age, sex, BMI, MNA, sedentary time, cognitive function, MVPA). The significance threshold used was $\alpha < .05$.

3 RESULTS

3.1 Prevalence

Descriptive statistics of the sample (N=654; 30.4% males) are presented in Table 2. All participants had the data to be classified with at least one algorithm.

Table 1. Sarcopenia classification algorithms with cut-off points.

Algorithm name	Algorithm with cut-off points	Sarcopenia	Sarcopenia severity		
SDOC (5)	Physical performance ($<0.8\text{m/s}$) Muscle strength (HGS; M: $<35.5\text{kg}$; F: $<20\text{kg}$)	- physical performance AND - muscle strength	NA		
EWGSOP (severity algorithm) (2)	Muscle mass (BIA: ASM/ht^2 ; M: $<8.87\text{ kg}/\text{m}^2$, F: $<6.42\text{ kg}/\text{m}^2$) Muscle strength (HGS; M: $<30\text{ kg}$, F: $<20\text{ kg}$) Physical performance (gait speed $<0.8\text{ m/s}$)	- muscle mass AND - muscle strength OR - physical performance	- muscle mass AND - muscle strength OR - physical performance		
EWGSOP (2)	Physical performance (gait speed $\leq 0.8\text{m/s}$) Muscle mass (BIA: ASM/ht^2 ; M: $<8.87\text{kg}/\text{m}^2$, F: $<6.42\text{ kg}/\text{m}^2$)	Physical performance (gait speed $>0.8\text{m/s}$) Muscle strength (HGS; M: $<30\text{ kg}$, F: $<20\text{ kg}$) Muscle mass (BIA: ASM/ht^2 ; M: $<8.87\text{kg}/\text{m}^2$, F: $<6.42\text{kg}/\text{m}^2$)	- physical performance AND - muscle strength AND AND - muscle mass	- normal physical performance AND - muscle strength AND - muscle mass	NA
EWGSOP2 (3)	Positive screening test (Sarc-F ≥ 4) Muscle strength (HGS; M: $<27\text{kg}$; F: $<16\text{kg}$ OR 5STS $>15\text{s}$) Muscle quantity or quality (BIA ASM/ht^2 ; M: $<7.0\text{kg}/\text{m}^2$; F: $<5.5\text{kg}/\text{m}^2$) Physical performance (gait speed $\leq 0.8\text{m/s}$ OR TUG $\geq 20\text{s}$)	Positive screening test AND - muscle strength AND - muscle quantity AND/OR - physical performance	Positive screening test AND - muscle strength AND - muscle quantity AND/OR - physical performance		
EWGSOP2 without Sarc-F	Muscle strength (HGS; M: $<27\text{kg}$; F: $<16\text{kg}$ OR 5STS $>15\text{s}$) Muscle quantity or quality (BIA ASM/ht^2 ; M: $<7.0\text{ kg}/\text{m}^2$; F: $<5.5\text{kg}/\text{m}^2$) Physical performance (gait speed $\leq 0.8\text{m/s}$ OR TUG $\geq 20\text{ s}$)	- muscle strength AND - muscle quantity AND/OR - physical performance	- muscle strength AND - muscle quantity AND - physical performance		
IWGS (6)	Muscle quantity (BIA ASM/ht^2 ; M: $<7.23\text{kg}/\text{m}^2$; F: $<5.67\text{kg}/\text{m}^2$) Physical performance (gait speed $<1.0\text{m/s}$)	- physical performance AND - muscle quantity	NA		
FNIH (4)	Muscle quantity (BIA ASMM; M: $<19.75\text{kg}$; F: $<15.02\text{kg}$) Muscle strength (HGS; M: $<26\text{kg}$; F: $<16\text{kg}$) Physical performance (gait speed $<0.8\text{m/s}$)	- muscle strength AND - muscle quantity	- muscle strength AND - muscle quantity AND - physical performance		

Legend: EWGSOP: European Working Group on Sarcopenia in Older People; SDOC: Sarcopenia Definitions and Outcomes Consortium; IWGS: International Working Group on Sarcopenia; FNIH: Foundation for the National Institutes of Health; M: males; F: females; BIA: electrical bioimpedance; ASM/ht^2 : appendicular skeletal mass normalised to height; ASMM: appendicular skeletal muscle mass; TUG: timed up-and-go test; 5STS: five-repetition sit to stand test; HGS: hand grip strength; NA: not applicable

Table 2. Descriptive statistics.

	N	Minimum	Maximum	Mean	Std. deviation
Age	654	60	97	72.45	8.74
Body height (cm)	638	140.4	186.5	163.55	8.53
Body mass (kg)	638	44.0	133.89	77.04	14.28
BMI (kg/m ²)	637	17.35	52.13	28.76	4.78
5STS (s)	590	3.37	41.06	11.11	4.49
TUG (s)	629	3.60	66.97	8.47	5.91
HGS	645	1.00	76.00	27.44	11.32
Gait speed (m/s)	639	.12	2.64	1.14	.39
Calf Circumference (cm)	649	16.4	50.7	36.18	3.50
SARC-F	648	0	10	1.87	2.50
SARC-CalF	648	0	20	3.93	5.14
MNA	649	11.5	30	25.35	4.18
TMT-A (s)	524	13.38	314.70	49.38	31.00
TMT-B (s)	446	24.57	439.91	106.49	62.32
ASM/ht ² (kg/m ²)	621	4.23	11.52	6.78	1.02

Legend: BMI: body mass index; 5STS: five-repetition sit to stand test; TUG: timed up-and-go test; HGS: hand grip strength; MNA: Mini Nutritional Assessment; TMT: trail-making test; SMI: skeletal muscle index; ASM/ht²: appendicular skeletal mass normalised to height

The prevalence of sarcopenia severity was highest and lowest when estimated by SDOC (15.3%) and IWGS (2.1%), respectively (Table 3). We found weak agreement between eight described algorithms on the sample of 613 participants ($K=.429$ (95% CI .414 to .444), $p<.001$). Only 4 (0.6%) participants were classified as sarcopenic with all eight algorithms.

3.2 Protective and risk factors for sarcopenia

Adequate nourishment and physical activity were identified as protective factors, and age, lower cognitive function and sedentary lifestyle as risk factors for sarcopenia. Higher body mass index (BMI) represented a trend of a risk factor.

Table 3. Sarcopenia and sarcopenia severity prevalence.

	EWGSOP severity N (%)	EWGSOP N (%)	EWGSOP2 N (%)	EWGSOP2 without SARC-F N (%)	EWGSOP2 with SARC-CalF N (%)	SDOC N (%)	IWGS N (%)	FNIH N (%)
No sarcopenia	553 (84.6)	546 (83.5)	627 (96.9)	602 (92.0)	625 (95.6)	539 (82.4)	599 (91.6)	567 (86.7)
No sarcopenia	450 (68.8)		547 (83.6)	459 (70.2)	594 (90.8)			
Presarcopenia	96 (14.7)		80 (12.2)	143 (21.9)	31 (4.7)			
Sarcopenia	77 (11.8)	77 (11.8)	27 (4.1)	50 (7.7)	29 (4.4)	100 (15.3)	14 (2.1)	50 (7.7)
Sarcopenia	40 (6.1)		3 (.5)	19 (2.9)	9 (1.4)			15 (2.3)
Severe sarcopenia	37 (5.7)		24 (3.7)	31 (4.7)	20 (3.1)			35 (5.4)
Missing data	24 (3.7)	31 (4.7)	/	2 (.3)	/	15 (2.3)	41 (6.3)	37 (5.7)
Total	654 (100.0)	654 (100.0)	654 (100.0)	654 (100.0)	654 (100.0)	654 (100.0)	654 (100.0)	654 (100.0)

Legend: EWGSOP: European Working Group on Sarcopenia in Older People; SDOC: Sarcopenia Definition and Outcomes Consortium; IWGS: international working group on sarcopenia; FNIH: Foundation for the National Institutes of Health

Table 4. Factors of sarcopenia using logistic regression model.

	95% CI for odds ratio			Sig.
	Odds ratio	Lower	Upper	
Age	1.189	1.153	1.227	<.001
Sex	1.283	.804	2.048	.296
BMI	1.045	1.000	1.092	.049
MNA	.656	.598	.719	<.001
TMT-a	1.026	1.018	1.034	<.001
TMT-b	1.011	1.007	1.016	<.001
Sedentary	1.006	1.004	1.008	<.001
MVPA	.975	.966	.983	<.001

Legend: BMI: body mass index; MNA: Mini Nutritional Assessment; TMT: trail-making test; MVPA: moderate to vigorous physical activity

4 DISCUSSION

This study aimed to determine sarcopenia prevalence among Slovenian older adults according to different classification algorithms and its agreement and we found that sarcopenia is present between 2.1 and 15.3% of participants, while only 0.6% of participants were classified as sarcopenic across all eight used algorithms. The relationship between risk factors has been evaluated and it has been found that adequate nutrition and regular physical activity represent a protective factor, while age, lower cognitive function and sedentary lifestyle represent a risk factor for sarcopenia onset.

Sarcopenia prevalence depends on the classification algorithm being used and was between 2.1% (IWGS) and 15.3% (SDOC) among the general Slovenian population. Our findings are similar to the ones from a Spanish sample of community-dwelling older adults, which reported sarcopenia prevalence between 2.1 and 11.6% according to the EWGSOP2 algorithm, depending on the classification tests being used (30), and to prevalence in other European countries (France, Germany, Switzerland and Portugal) where sarcopenia was found in between 0.7 and 16.8% of older adults using different algorithms (31).

We found sarcopenia prevalence in 15.3% using the SDOC algorithm, which aligns with previous findings from the Hertfordshire cohort study (32,33). However, other population-based cohorts (33) reported lower prevalence for men using this algorithm while omitting the female population. The SDOC algorithm classified only 2% of the sample as sarcopenic among the community-dwelling population from four different European countries, of which there were no sarcopenic participants detected in Germany (31). Importantly, SDOC does not use muscle mass as a classification measure, which could result in higher prevalence in comparison to other classification algorithms.

The focus of the EWGSOP2 algorithm is on inclusion of the muscle strength component at the forefront of the algorithm and introduction to the muscle quality

component, however in practice this one is often omitted. Similarly to the findings from Stuck et al. (31) we found that EWGSOP2 classifies less people as sarcopenic compared to other classifications - in our sample, this amounted to 4.1%. Other studies found even lower prevalences: 2.1% among community-dwelling older adults (31) and 1.1% among population-based cohorts (33). EWGSOP2 is relatively new, therefore not many studies have used it compared to the original EWGSOP which includes the muscle strength measure at a confirmatory level. Using EWGSOP, we found 11.8% prevalence of sarcopenia. Van Ancum et al. (34) pooled the data from multiple cohorts across European countries (the Netherlands, Denmark, United Kingdom, Finland, Estonia and France) and one Australian cohort using both the original EWGSOP and revised EWGSOP2, and also found lower sarcopenia prevalence when classified by EWGSOP2, at 16.7% and 11.4%, respectively. Sarcopenia prevalence using EWGSOP from 45 studies was between 20 and 25% (1), from which we can assume that our sample was less sarcopenic than the average of the global population when classified with either EWGSOP or EWGSOP2.

Swapping Sarc-F with Sarc-CalF in EWGSOP2 resulted in a 0.3% increase in sarcopenia prevalence, from 4.1% to 4.4%. Motivation for this was supported with previous findings, where Sarc-CalF showed enhanced sensitivity (35), higher diagnostic accuracy (36) and was able to detect more truly sarcopenic individuals (37) in comparison to Sarc-F.

Another modification in the EWGSOP2 was omitting the screening test - Sarc-F, based on the hypothesis that all of the screened participants are at risk of sarcopenia. This resulted in a 3.6% increase in sarcopenia prevalence to 7.7%. We can assume that Sarc-F excludes sarcopenic individuals due to the subjective observations of the individual's own physical status. Therefore, Sarc-F might be more suitable to rule out sarcopenia than to detect it (38).

The global prevalence of sarcopenia using FNIIH has been reported to be 15 % and for IWGS 20% (1), however, the Slovenian sample showed 7.7% and 2.1%, respectively.

When comparing the agreement among eight classification algorithms, we have found that only 4 (0.6%) participants were consistently classified as sarcopenic. Weak agreement between algorithms has also been found by Bijlsma et al. (11) and recently by Montemurro et al. (30). The discrepancies could be seen due to different assessment methods (i.e. muscle mass can be estimated with BIA or dual-energy x-ray absorptiometry (DXA)) and different sequences of those within the algorithms. Therefore, algorithms for sarcopenia classification still warrant improvements in consistency to be a diagnostic tool. Indeed, the EWGSOP2 algorithm adds a component of muscle quality and points out a need for a valid assessment method (3).

Lastly, we have assessed individual sarcopenia risk factors and preventive factors, as it has been shown that multimorbidity is a risk factor for sarcopenia (39). The first factor we have assessed is age, as it has been previously shown that this is the primary risk factor for sarcopenia onset (14), which our findings have confirmed. We found adequate nutrition to be the most prominent factor in preventing sarcopenia onset, which aligns with SarcoPhAge findings (40). Even though our study did not focus on nutrition quality, these findings show that sufficient macronutrient intake could be important for overall health. A higher amount of MVPA is a protective factor among our sample, similar to the findings from Japan, where higher MVPA was associated with lower functional disability incidence (41). A recent review also found an association between a sedentary lifestyle and sarcopenia onset (16), similar to our findings where a sedentary lifestyle represents a risk factor for sarcopenia. As physical activity decreases among older adults in Europe (42), we can speculate that sarcopenia will become a more prominent challenge in the future mostly due to physical inactivity. Our results indicate that higher BMI is a risk factor for sarcopenia development. The literature suggests that higher BMI values are also associated with adverse outcomes, especially when accompanying already developed sarcopenia, resulting in sarcopenic obesity which has higher mortality rates (43). The relationship between myokines, which regulate brain functions, such as mood, learning, locomotor activity and neuronal injury protection and skeletal muscle, points to the existence of muscle-brain cross-talk (44). Characterised by the progressive degeneration of muscle mass and function, sarcopenia could be conducive to or be associated with impaired cognitive function, as also observed in the present study. However, it is important to note that the relationship between sarcopenia and cognitive function is yet to be determined. Compared to the findings of a recent meta-analysis (45), the odds ratios were lower in our sample, although they still followed a similar trend: malnutrition is the largest behavioural risk factor (hence, adequate nutrition works as a preventive factor), while

physical activity has positive effects on sarcopenia presence and aging, physical inactivity and cognitive function decline present a risk factor for sarcopenia.

This study has some limitations - although we aimed to recruit a representative sample of the general Slovenian population, we cannot rule out the possibility that the sample is biased towards the more active older adults who are more likely to respond to invitations to participate. However, we tried to avoid this at the preliminary recruitment phase. Secondly, tests for cognitive decline presented a large amount of missing data, therefore we were not able to use multivariate logistic regression models. Thirdly, our findings could be more conclusive if longitudinal study design were applied.

5 CONCLUSIONS

Sarcopenia prevalence in the Slovenian general population, classified by most algorithms (EWGSOP, EWGSOP2, FNIH, IWGS), is lower than global sarcopenia prevalence and similar to the European countries for which data exists, however prevalence strongly depends upon the classification algorithm being used. Physical activity and adequate nutrition were identified as preventive factors while age, cognitive decline, sedentary lifestyle and BMI are risk factors, pointing to possibilities for effective public health interventions. Addressing these methodological inconsistencies could improve sarcopenia identification, while the promotion of an active lifestyle could improve the quality of life of older adults.

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CONFLICTS OF INTEREST

The authors declare that no conflicts of interest exist.

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ETHICAL APPROVAL

Research has been performed in accordance with the Declaration of Helsinki. The study protocol was approved by the Medical Ethics Committee of Slovenia (ID: 0120-76/2021/6).

AVAILABILITY OF DATA AND MATERIALS

The data and materials utilised in this study were collected, anonymised and securely stored in a coded access personal computer at the facilities of the Science and Research Centre, Koper. Requests for data availability should be discussed with the project team and will be considered on a reasonable basis.

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BARRIERS AND FACILITATORS OF FAMILY MEETINGS IN PRIMARY PALLIATIVE CARE: INSIGHTS FROM SLOVENIA

OVIRE IN SPODBUDNI DEJAVNIKI DRUŽINSKIH SESTANKOV V PRIMARNI PALIATIVNI OSKRBI: IZKUŠNJE IZ SLOVENIJE

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ABSTRACT

Background: Within palliative care, family meetings are recognised as the most effective practice for placing the patient and their family at the centre of care, thereby ensuring quality palliative care. The aim of this study was to determine how these meetings are conducted in primary healthcare and to identify the factors influencing them.

Keywords:

Family meetings
Palliative care
Family physicians
Primary care

Methods: Sixteen semi-structured interviews were conducted with family physicians (FP) in Slovenia, who were expressly, and using the snowball method, invited to participate in the study. Transcripts were analysed using the principles of thematic analysis.

Results: It was found that participating FPs frequently discuss diseases, treatment, expectations and goals with patients and families. However, these discussions are seldom structured and fully conducted according to family meeting guidelines, primarily due to time constraints. Barriers to conducting family meetings include patient and family reluctance, the staff's lack of palliative care knowledge, time, and financial challenges. Positive factors include a good doctor-patient-family relationship, an exact diagnosis, the doctor's experience and competence, additional palliative care training and the presence of other team members.

Conclusion: Our research provides a unique insight into the implementation of family meetings at the primary level in Slovenia. FPs recognise numerous benefits of family meetings and consider them meaningful and time efficient. They emphasise that open discussions with the patient and their family are crucial for quality palliative care at the primary level. Considering simpler models of family meetings for the primary level appears sensible. Further research is needed to assess the cost-benefit relationship of family meetings.

IZVLEČEK

Izhodišča: V okviru paliativne oskrbe so družinski sestanki prepoznani kot najučinkovitejša praksa za postavitve pacienta in njegove družine v središče oskrbe, s čimer se zagotavlja kakovostna paliativna oskrba. Namen te študije je bil ugotoviti, kako se družinski sestanki izvajajo v primarnem zdravstvenem varstvu in prepoznati dejavnike, ki vplivajo nanje.

Ključne besede:

družinski sestanki
paliativna oskrba
družinski zdravniki
primarno zdravstveno varstvo

Metode: Izvedenih je bilo šestnajst polstrukturiranih intervjujev z družinskimi zdravniki v Sloveniji, ki so bili namensko in z metodo snežne kepe povabljeni k sodelovanju v študiji. Prepisi intervjujev so bili analizirani z uporabo načel tematske analize.

Rezultati: Ugotovljeno je bilo, da se družinski zdravniki, ki so sodelovali v študiji, s svojimi pacienti in njihovimi družinami pogosto pogovarjajo o boleznih, zdravljenju, pričakovanjih in ciljih za prihodnost. Vendar so ti pogovori redko strukturirani in izpeljani v celoti po smernicah družinskega sestanka, predvsem zaradi časovnih omejitev. Ovire za izvajanje družinskih sestankov vključujejo nenaklonjenost pacienta in družine, pomanjkanje znanja o paliativni oskrbi med osebjem ter časovne in finančne izzive. Spodbudni dejavniki vključujejo dober odnos s pacientom in njegovo družino, natančno diagnozo, zdravnikove izkušnje in kompetence, dodatno usposabljanje v paliativni medicini ter prisotnost drugih članov ekipe.

Zaključek: Naša raziskava ponuja edinstven vpogled v izvajanje družinskih srečanj na primarni ravni v Sloveniji. Družinski zdravniki prepoznajo številne koristi družinskih sestankov in jih smatrajo kot smiselne in časovno učinkovite. Poudarjajo, da so odprti pogovori s pacientom in njegovo družino ključni za kakovostno paliativno oskrbo na primarni ravni. Razmišljanje o preprostejših modelih družinskih sestankov za primarni nivo se zdi smiselno. Potrebne so nadaljnje raziskave za oceno razmerja med stroški in koristnostjo družinskih sestankov.

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1 BACKGROUND

The World Health Organization (WHO) notes that most individuals requiring palliative care prefer to stay at home, underscoring the importance of delivering palliative care within the community as an integral part of primary healthcare (1). The research done in Slovenia supports this WHO indication (2, 3). The primary palliative care team in Slovenia includes a family physician and a nurse; sometimes also administrative support (4). The family physician (FP), as the leader of the interdisciplinary primary care palliative team, is expected to play a crucial role in decision-making, coordination and monitoring of care, aligning with the needs of patients and their families, and facilitating connections with specialised palliative care when necessary (5). A good start is crucial; preferably, this would begin with a family meeting that involves patients, their family and healthcare professionals (6). Early research on family meetings in critical care settings (7, 8) laid the groundwork for the approaches favored by palliative care providers today. This structured gathering includes the patient, their family and healthcare professionals. The meeting's purpose is to exchange information and concerns, clarify care goals, discuss diagnosis, treatment and prognosis, and prepare an advanced care plan (9). One of the models that helps facilitate a family conference is the 7-step family conference framework (10). Effective family meetings require clear and honest communication (11), and it is advisable to involve the patient in choosing topics (12), as the patient's most important concerns often differ from what doctors expect to be important (13). To build trust and establish a collaborative partnership between the patient and the physician, it is also necessary to consider the emotional dynamics of the relationship and empathetically align with the patient (14, 15). Finally, team composition is crucial; an interdisciplinary group of experts, including physicians, nurses and social workers, leads to a more qualitative discussion (7, 11, 16). The Clinical Practice Guidelines for Conducting Family Meetings in Palliative Care involve three steps: preparation, meeting and follow-up (17). In preparation, the meeting's purpose is introduced, key family members are identified and patient permission is sought. During the meeting, ground rules are set and information is exchanged. Follow-up includes documenting decisions, sharing information and initiating follow-up with the primary caregiver (17). Experiences from hospital clinical practice highlight numerous benefits of family meetings (7, 16, 18); they are recognised as best practice in placing the patient and their family at the centre of care (7). The main barriers to integrating family meetings into daily practice include inadequate communication skills, time constraints, unrecognised emotional needs, role ambiguity and lack of reimbursement (7, 19, 20). In Slovenia palliative home

visits (described as visiting a terminally ill patient at their residence and initiating symptomatic therapy) and team consultations (which involve a physician collaborating with experts from other institutions, such as social work centres) are reimbursed by the insurance company (21). A low reimbursement is also provided for the recorded discussions with district nurses, the mobile palliative team, or patients during clinic visits (21). Training in family meetings is part of palliative medicine education, which is increasingly present during undergraduate education in Slovenia (22-24). More extensive training (theoretical and practical) is integrated into postgraduate family medicine specialisation training (25). Our research is the first of its kind in Slovenia to explore the conduct of family meetings at the primary care level and the obstacles that hinder their implementation.

2 METHODS

2.1 Study design and population

We conducted semi-structured qualitative interviews with FPs and FP trainees. Participants were purposively sampled. We invited FP specialist and resident physicians via email or in person and shared the invitation in the Facebook group 'Family Medicine Residents,' which has 460 members. The inclusion criteria were working at the primary care level and consenting to participate in the study; physicians who do not conduct family meetings were excluded. Fourteen physicians met the criteria in the initial sampling round. As saturation had not yet been reached, the additional participants were recruited using snowball sampling. All participants received a study description and a consent form via email, which they signed prior to the interview. Verbal consent was also obtained before each interview.

2.2 Data collection

Semi-structured interviews were conducted in person, over the phone, or via a web-based video conferencing platform by one researcher (M.B.) trained in interviewing methodology during the trainee programme. All interviews were completed between September 2023 and December 2023. Questions were designed to elicit challenges in providing family meetings in primary palliative care, potential barriers and facilitators to a proactive approach in family medicine, and suggestions for optimising the implementation of family meetings in existing workflows. Demographic and practice-related information was self-reported by participants, including gender, training background and age. The sample size was guided by an interim assessment of interview data for thematic saturation, which was reached within 16 interviews (26).

Table 1. Key FDC strategies adapted from Lincoln and Guba.

Rigour criteria	Purpose	Original strategies	Strategies applied in our study to achieve rigour
Credibility	To ensure the results are accurate, credible and trustworthy from the participants' perspective.	<ul style="list-style-type: none"> • Interviewing process and techniques • Establishing investigators' authority • Peer debriefing 	<p>The interview protocol was tested during two induction meetings and through 1-2 pilot interviews.</p> <p>Investigators were equipped with the necessary knowledge and research skills for their roles.</p> <p>Regular debriefing sessions were held with key study members.</p>
Dependability	To ensure the findings of this qualitative inquiry are replicable within the same cohort, coders and context.	<p>Thorough description of the study methods</p> <p>Stepwise replication of the data</p>	<p>We prepared detailed drafts of the study protocol and participants' information.</p> <p>We controlled the coding and inter-coder reliability of the research team.</p>
Confirmability	To strengthen confidence that the results would be validated or confirmed by other researchers.	Triangulation	<p>We applied the following triangulation techniques: data source, investigators, theoretical.</p> <p>Regular investigators meeting.</p>
Transferability	To enhance the extent to which the results can be generalised or applied to other contexts or settings.	<p>Purposeful sampling</p> <p>Data saturation</p>	<p>We used intensity sampling and maximum variation sampling.</p> <p>Quantification of operational and theoretical data saturation.</p>

2.3 Methodological rigour

Lincoln and Guba established strict criteria for trustworthiness in qualitative research: credibility, dependability, confirmability and transferability, known as the "Four-Dimensions Criteria" (FDC) (27). Other studies have used variations of these categories to ensure rigour (28-30). In our study, we systematically adapted these criteria by selecting applicable strategies, as shown in Table 1.

2.4 Analysis

The analysis followed the Framework Method (31-33), which is part of the thematic analysis family and emphasises identifying patterns and contrasts in qualitative data while exploring relationships between different elements. Interview transcripts for each participant were reviewed and consolidated into a matrix organized by broad themes, categories and codes related to family meetings in family medicine palliative care.

This method facilitates the derivation of descriptive and explanatory conclusions centered on key themes. The analytical process included the following steps:

1. Familiarisation: Each transcript was carefully read to immerse the research team in the data, capturing initial impressions and key points.
2. Indexing and Coding: Transcripts were systematically coded, with codes derived both inductively (emerging from the data) and deductively (informed by the research objectives and interview guide).
3. Matrix Development: Codes were organized into a matrix to allow comparison across cases and to facilitate the identification of patterns.
4. Theme Construction: Themes were constructed by clustering related categories, focusing on relationships within the data to ensure both descriptive accuracy and interpretative depth.
5. Consensus and Refinement: Three research team members (M.B., E.Z., L.J.K.) held regular online meetings to iteratively review transcripts and refine the themes, categories and codes. Discrepancies were resolved through discussion until consensus was achieved.

Representative quotations were extracted to illustrate categories and ensure transparency and the grounding of findings in participants' accounts. Used rigour criteria are presented in Table 1. Reporting of qualitative results follows the Consolidated Criteria for Reporting Qualitative Research (COREQ) (33-35). This structured approach ensured that themes and codes were actively constructed and reflected both the depth and breadth of the data, rather than merely summarising surface-level content. Ethical approval to conduct the study was obtained from the National Medical Ethics Committee of the Republic of Slovenia (NMEC), No. 0120-188/2023/3.

3 RESULTS

A total of 16 interviews were conducted among 2 trainees and 14 specialists of family medicine (Table 2). The average age was 44.19 years (with the median age of 41 years, interquartile range 13.5). Interviews lasted up to thirty minutes.

We identified the following themes: Organisation, Facilitators, Barriers, Benefits and Suggestions (Figure 1).

3.1 Organisation

The theme organisation included 4 categories (Frequency, Location, Participants, Time) and 66 codes. Our research revealed that primary care FPs rarely conducted formal family meetings involving the patient, family members and interdisciplinary team. However, they often held meetings in a narrower setting. Such discussions were either spontaneous or planned. "It's better to organise them because during home visits, you usually deal with some acute issues. Of course, it's never wrong to use this time/opportunity if there's no other way. However, it's better to prepare for it, ask yourself a few questions, what concerns you about the patient, do you know the family dynamics, whom you'll ask what..." (FP 3)

Table 2. Participants' characteristics (n=16).

Characteristic	N (%)
Female Gender	13 (81.3)
Male gender	3 (18.7)
Trainee	2 (12.5)
Working only in nursing home (NH)	5 (31.25)
Working only in general practice (GP)	6 (37.5)
Working in NH and GP	5 (31.25)

There were two types of meetings based on whether a conclusion or advanced care plan was accepted. A meeting with an open ending was well described by the following statement: *"It's a first step to talk about death. That it's something that will happen in the future, but we don't know when, and to open up these topics. Often people are shocked at the beginning because they're not used to talking about death and these things. And within a year, we come to some consensus through several discussions."* (FP 10)

FPs led and organised family meetings differently according to their work style and beliefs. Meetings also varied due to different situations and relationships. *"It's like solving equations. I have a model, I know what I need to cover, and I do cover it, but I must catch the thread where they lead me, with their understanding of the diseases."* (FP 7)

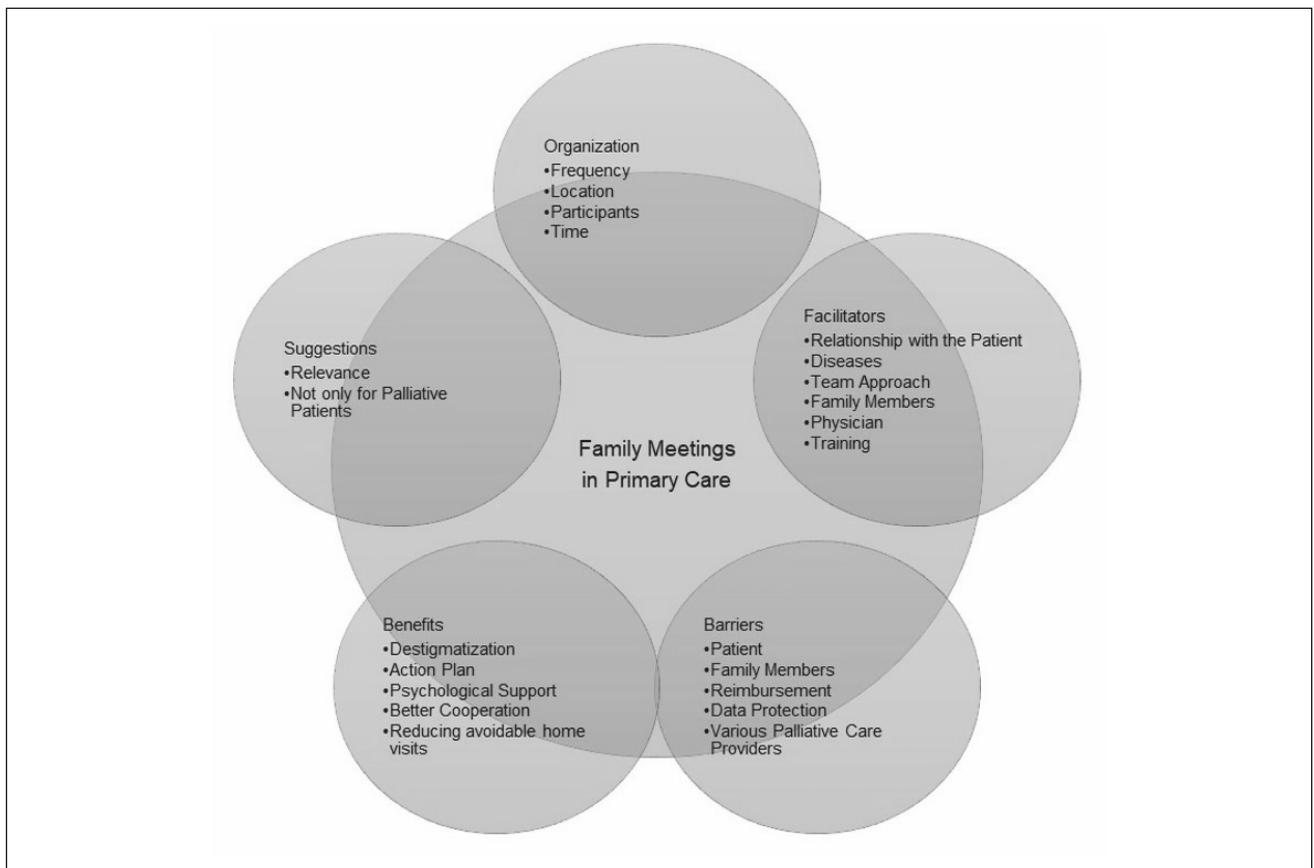


Figure 1. Overview of the main themes and their corresponding categories.

3.2 Facilitators

In this theme we included 6 categories (Relationship with the Patient, Diseases, Team Approach, Family Members, Physician, Training) and 59 codes. FPs found it easier to conduct family meetings when there was trust, which was fostered by a strong patient-physician relationship, patient trust in the institution, and mutual trust among staff.

A common reason for meetings is the need to exchange information. *"... my need for broader insight, meaning how family members experience specific situations. Family meetings are particularly helpful for me in further decision-making and of course for family members who may not understand the situation well ..."* (FP 13)

Another incentive for a meeting was the perceived discord among stakeholders (healthcare team, patient and relatives), such as pressures for futile treatment due to unrealistic expectations. *"I had a case where the husband didn't want to accept that his wife would die. /.../ But the lady accepted her condition. She was okay being at home, resting. The husband insisted on everything, and then we had to stop him."* (FP 9)

On the physicians' side, motivating factors included interest in palliative care, a sense of competence, training, and professional and personal experiences with the dying person.

FPs conducting family meetings with a broader team recognised the presence of colleagues as highly beneficial, as tasks were distributed and the burden was shared.

3.3 Barriers

This theme included 5 categories (Patient, Family members, Reimbursement, Data Protection and Various Palliative Care Providers) and 37 codes. The most significant barrier to conducting family meetings at the primary level was a lack of time. *"You really have to take at least an hour to do this. Most of them, I did them all at the patient's home, so you must drive to them. That's difficult during working hours... and then you go for a home visit after work."* (FP 9)

There was also difficulty in coordinating staff time due to different work schedules for physicians, district nurses and colleagues, and there were no established pathways for collaboration with non-healthcare workers. Coordination in nursing homes was somewhat easier since teams were already formed, but physicians are not part of these teams. *"We must acknowledge that physicians come from different institutions. On paper, we're not considered the same team, but in practice, we must act as if we are. Sometimes coordination works seamlessly, and everything can be arranged, but sometimes it doesn't."* (FP 6)

The challenge of organising meetings and the additional time required often led FPs to conduct meetings with a narrower circle, sometimes alone with the patient and/or relatives, and to communicate the decisions to the team later.

Another barrier for conducting family meetings was that they were not recognised as a professional service by insurance companies and were not paid for. *"I would spend half a day just for a family meeting. If this were recognised as a service that I could bill, more physicians would opt for it. But that's not the case."* (FP 6)

It also happened that the patient or relatives declined a family meeting, and physicians respected their decision, honouring the patient's autonomy and privacy.

3.4 Benefits

Five categories (Destigmatisation, Action Plan, Psychological Support, Better Cooperation, Reducing Avoidable Home Visits) and 54 codes were included in this theme. FPs noticed significant benefits of family meetings. Patients experienced less suffering and found it easier to accept their diseases, while employees experienced less stress and made easier decisions. *"... there were incredibly positive results in terms of better care, more accurate monitoring of disturbing symptoms by healthcare staff, appropriate response to disturbing symptoms, observation of the effect of medications and measures. Consequently, there's significantly less stress experienced by employees, both due to patients and communication with relatives."* (FP 1)

Family meetings were an effective tool for bilateral information delivery and provided a safe space where patients and families could express their emotions and feelings and receive psychological support. *"It's essential to uncover those questions that are important to the patient, not just to me, and to establish trust so that later, if they need anything, they can easily call."* (FP 8)

The family meeting facilitated the establishment of collaboration between the physician and relatives and laid the foundation for an action plan, which is crucial for reducing distress during exacerbations and reducing the unnecessary burden on the system in the future. *"The time spent in the family meeting: I get it back, and so does the system because patients somehow feel that the paths they're turning to are clear, and they know they'll get what they wanted, and they're willing to wait a little. These patients with whom you reach a good agreement, practically never call the emergency service because there's no need for other treatments at the secondary level."* (FP 4)

Finally, FPs also observed a broader effect of such conversations in society: *"After all, they also contribute to destigmatising dying, death, finality, which is good for both relatives and patients and also for the entire healthcare staff dealing with it."* (FP 6)

3.5 Suggestions

This topic included 2 categories (Relevance, Not Only for Palliative Patients) and 24 codes. Palliative care was tailored to the patient, their relatives and their situation, and the approach was highly individual. *“Surely, we have relatives and patients who need it more, even express a desire for it. Perhaps we’re a bit neglectful here too because we don’t actively offer it to those who don’t express the need for it unless we detect any issues. But that doesn’t mean there are no problems.”* (FP 6)

Good practice to avoid unresolved distress was for the physician to implement an open-door policy. However, physicians saw the relevance of family meetings at every major milestone from diagnosing a chronic incurable disease onwards. Especially with the expected decline in cognitive functions, it was advisable to have a family meeting early, while the patient could still express their will.

4 DISCUSSION

The study’s findings offer valuable insights into the perceptions and practices of family physicians (FPs) regarding family meetings in palliative care settings. One of the most important findings is the recognition of family meetings as an essential tool for fostering communication, supporting shared decision-making and alleviating caregiver burden. This aligns with previous research that emphasises the benefits of family meetings in primary care settings (19). However, the study also identifies key barriers that hinder the successful implementation of family meetings. Time constraints remain the most frequently cited challenge in our study, with many FPs reporting difficulty in organising these meetings due to competing demands in their practice. Furthermore, a lack of formal preparation for family meetings, such as advance discussions about the meeting’s goals, involvement of key individuals and a clear care plan, is a significant issue (15, 17). This lack of structure contrasts with guidelines for family meetings in palliative care, highlighting a need for better organisational frameworks and preparation strategies (17). Maintaining continuous care is a vital ethical principle in palliative care, even as patients transition between different levels of care or receive concurrent management from both the FP and the mobile palliative care team (15, 36). However, in Slovenia, tasks are not yet clearly defined, and communication often takes place through reports or family members. A Slovenian study, conducted in a hospital setting, found that despite recognised benefits, family meetings are not always conducted (16). The barriers to conducting family meetings are similar to those encountered in delivering palliative care in primary care, with family physicians identifying a lack of time as the primary obstacle (37). Glajchen and colleagues identify challenges in scheduling meetings and coordinating the interdisciplinary team’s

collaboration in oncology (7). Another barrier is unpreparedness for conversation among patients and their families (7, 18, 19). Oncologists cite also lack of training as a barrier to communication with patients and caregivers (7). In contrast, family physicians assess themselves as having sufficient competence for such discussions (19). Although additional training and a sense of competence are seen as facilitating factors, a lack of experience is not considered a barrier; it is replaced by better preparation for the meeting. This might be due to different roles in care: oncologists concentrate on achieving a cure, whereas family physicians accompany patients from their initial concerns to the end of life (19) and engage in challenging conversations daily. The presence of other team members was recognised as a supportive factor for conducting family meetings (16). Multidisciplinary composition during family meetings leads to more effective discussions and is recommended, but needs more preparation (3, 15, 16, 20, 38). At the primary level, options are limited, and some do not perceive the need for a wider circle of attendees; some include other professionals later as needed or have a separate team meeting with them, while many cite a lack of time as a reason for not organising the meetings (37). This was also noted in hospice care, where they considered the need to respect time constraints, and suggested that a simpler intervention model would be easier to implement in practice (20). Additional research is needed to measure the cost-effectiveness of family meetings (7). Based on the results of our study, it could be argued that family meetings should be recognised as a professional service paid for by the Health Insurance Institute of Slovenia, and consideration should be given to establishing efficient pathways for easier collaboration of different, even non-medical, professionals with general practices. Multidisciplinary collaboration or networking and financial arrangements would not only encourage the conducting of family meetings but also the provision of comprehensive palliative care in primary care (3, 37). Consistent with previous research, FPs recognise family meetings as an effective tool for exchanging information, supporting joint decision-making and reducing caregivers’ burden (7, 18). Like their Australian colleagues, Slovenian FPs also assess the family meetings as economical despite the high time investment (19), since they could help prevent unnecessary strain on hospitals and emergency services (15). An open and honest conversation with appropriate planning minimises the need for complex family meetings (39). Nonetheless, maintaining regular contact is advisable even in stable conditions, with the interval depending on the expected survival, ranging from one month to one year (7, 39). FPs in our study point out a significant need for family meetings for all incurable patients, even if palliative care is not (yet) discussed. This actually confirms the finding of the European Forum for Primary Care that FPs are less likely to recognise impending death in patients with end-stage organ failure and old age or dementia compared to

cancer patients (37). The episodic nature of non-cancerous diseases can lead to delays in recognising the transition to palliative care, and it is encouraging that FPs at least recognise the need for conducting a family meeting (3, 37). This is particularly significant because the greater the number of FPs, the greater the likelihood of home-based end-of-life care for cancer patients, while an increase in non-physician healthcare workers raises the probability of home-based care for other patient groups (40). This indicates that FPs will have more frequent contact with both patients and their relatives and emphasises the importance of family meetings.

4.1 Limitation

A significant limitation is that the sample only includes physicians who already conduct family meetings, potentially overlooking the perspectives of those who do not engage in such practices. This introduces a selection bias, as it may not fully capture the barriers faced by FPs who might not conduct family meetings despite recognising their importance. Furthermore, the study sample is predominantly female, reflecting the local demographic characteristics of family physicians involved in palliative care. Additionally, participants were from six of Slovenia's 12 regions, each with a different organisation of palliative care, which may limit the transferability of the findings to other contexts.

In qualitative research, the value lies in its ability to explore complex social phenomena rather than making generalisable conclusions. The strength of this study lies in its focus on understanding the nuanced experiences of family physicians and the challenges they face in providing palliative care. The study provides a detailed look at the barriers to conducting family meetings, offering insights into the need for better preparation, clearer roles and improved support systems. These findings underscore the importance of family meetings as a practice that can significantly enhance patient care, particularly in primary care settings.

5 CONCLUSION

In conclusion, this study highlights both the challenges and importance of implementing family meetings in primary care. While family physicians often engage in valuable but informal conversations with patients and their families, time constraints and lack of preparation hinder their formalisation as structured family meetings. The study suggests that simplifying these models, offering structured training for family physicians, fostering multidisciplinary collaboration and addressing financial disparities could enhance their integration into routine practice. Further research on the cost-effectiveness of family meetings could support necessary policy changes, ultimately

improving care coordination and benefiting both patients and their families.

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CONFLICTS OF INTEREST

The authors declare that no conflicts of interest exist.

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ETHICAL APPROVAL

Ethical approval to conduct the study was obtained from the National Medical Ethics Committee of the Republic of Slovenia (NMEC), No. 0120-188/2023/3.

CONSENT TO PARTICIPATE

Written informed consent to participate in the research was obtained from all respondents prior to data collection.

AVAILABILITY OF DATA AND MATERIALS

All data and materials used in this study were collected from publicly available sources and are available upon reasonable request.

LLM STATEMENT

During the preparation of this work the authors used ChatGPT in order to improve readability and language of the manuscript. After using this service, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

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SOCIODEMOGRAPHIC DETERMINANTS OF HEALTH LITERACY AMONG UNIVERSITY STUDENTS OF HEALTH SCIENCES IN KOSOVO

SOCIODEMOGRAFSKE DETERMINANTE ZDRAVSTVENE PISMENOSTI MED UNIVERZITETNIMI ŠTUDENTI ZDRAVSTVENIH VED NA KOSOVU

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ABSTRACT

Objective: Our objective was to assess the level and sociodemographic correlates of health literacy (HL) among university students of health sciences in Kosovo.

Keywords:

European Health Literacy Survey Questionnaire (HLS-EU-Q)
Health literacy
Kosovo
Sociodemographic factors
University students of health sciences

Methods: A cross-sectional study was conducted in Kosovo during February-April 2024, including 470 students of health sciences from the universities of Prishtina and Gjakova (=86% females; mean age: 20.7±2.7 years; response rate: 70%). The internationally standardised European Health Literacy Survey Questionnaire (HLS-EU-Q) was self-administered, along with information on sociodemographic factors. Binary logistic regression was used to assess the independent sociodemographic correlates of HL.

Results: Only 7% of the students exhibited "inadequate and/or problematic" HL, whereas about 93% of participants displayed "sufficient and/or excellent" HL. In multivariable-adjusted binary logistic regression models, "inadequate and/or problematic" HL was strongly and positively associated with the male gender only (OR=3.6, 95%CI=1.5-8.9).

Conclusions: We evidenced a relatively high general HL level among university students of health sciences in Kosovo, especially among females. Enhancing HL among future health professionals could guide policies that prioritise embedding health education and resources into higher education institutions, potentially improving students' health behaviours and health outcomes, as a major prerequisite for their future work with patients and communities.

IZVLEČEK

Cilj: Naš cilj je bil oceniti stopnjo in sociodemografske korelate zdravstvene pismenosti med univerzitetnimi študenti zdravstvenih ved na Kosovu.

Ključne besede:

European Health Literacy Survey Questionnaire (HLS-EU-Q)
zdravstvena pismenost
Kosovo
sociodemografski dejavniki
univerzitetni študenti zdravstvenih ved

Metode: Med februarjem in aprilom 2024 smo na Kosovu izvedli presečno študijo, ki je vključevala 470 študentov zdravstvenih ved na univerzah v Prištini in Đakovici (=86% žensk; povprečna starost: 20,7 ± 2,7 leta; stopnja odziva: 70%). Uporabili smo mednarodno standardiziran samoocenjevalni vprašalnik European Health Literacy Survey Questionnaire (HLS-EU-Q), skupaj s podatki o sociodemografskih dejavnikih. Za ocenjevanje neodvisnih sociodemografskih korelatov smo uporabili binarno logistično regresijo.

Rezultati: Samo pri 7% študentov smo zaznali »nezadostno in/ali problematično« zdravstveno pismenost, približno 93% udeležencev pa je izkazalo »zadostno in/ali odlično« zdravstveno pismenost. V modelih multivariatne prilagojene binarne logistične regresije je bila »nezadostna in/ali problematična« zdravstvena pismenost močno in pozitivno povezana samo z moškim spolom (RO = 3,6, 95-% IZ = 1,5-8,9).

Zaključki: Med univerzitetnimi študenti zdravstvenih ved na Kosovu, zlasti pri ženskah, smo dokazali razmeroma visoko splošno zdravstveno pismenost. Povečanje zdravstvene pismenosti med bodočimi zdravstvenimi delavci bi lahko postalo vodilo politik, ki dajejo prednost vključitvi zdravstvenega izobraževanja in virov v visokošolske ustanove, kar bi lahko izboljšalo z zdravjem povezano vedenje in zdravstvene izide študentov, ki so pomemben pogoj za njihovo prihodnje delo z bolniki in skupnostmi.

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1 INTRODUCTION

The Health Literacy (HL) concept was introduced into the field of public health more than four decades ago (1). HL is a multifaceted construct that has led to the development of many definitions throughout history (2-4). According to an integrative approach, the HL construct consists of four dimensions denoting four different types of competencies (ability to: access, obtain or search for relevant health information; understand obtained health information; appraise or process health information, and apply health information to make decisions for improving health) (4, 5). These four HL dimensions are considered assets that are revealed in the domains of healthcare, disease prevention and health promotion (4, 5).

A systematic review has identified over 250 distinct definitions of HL (6), highlighting the enormous complexity of this concept. Yet, in general, HL refers to people's ability to find, understand and use health information for making appropriate health decisions (7). From this perspective, HL encompasses the comprehension and assessment of the adequacy of health-related information, proper medication usage, utilisation of health services, and decision-making regarding self-care and prompt and effective management of various health conditions (8, 9). From a public health viewpoint, the HL concept also includes dimensions which go beyond individual competencies and the medical context (4, 10). From this perspective, Nutbeam has coined a classical model distinguishing between three typologies of HL: functional HL, interactive HL, and critical HL (10), representing different levels of knowledge and skills that progressively support greater autonomy and personal empowerment in the decision-making process related to health matters (4, 10). Based on this public health viewpoint, attempts were made to develop a comprehensive model for measuring HL in general populations, addressing HL as a quite multidimensional and complex concept (11). Hence, the public health perspective of HL was taken forward by Sorensen et al. by focusing not only on the individual's participation in healthcare but also on people's prevention and health promotion activities, thereby considering HL a multifaceted concept (4, 5).

Conversely, it has been convincingly shown that low levels of HL constitute an important risk factor for suboptimal health (6) resulting in the following outcomes: unhealthy behaviours (8, 12); misuse of medications (13); lower participation in screening programmes (4); inadequate disease management skills (14) and deficiency in access to health services which eventually increase morbidity and mortality rates (15, 16), jeopardise quality of life (17) and increase the overall costs of societies (8, 18).

Numerous determinants of HL have been identified, including sociodemographic factors such as age, gender, educational attainment or socioeconomic status, along with other psychosocial and cultural factors (4-6, 8, 19, 20). In general populations, inadequate HL is more prevalent among older individuals and those with lower socioeconomic status, whereas studies have largely not found consistent differences between males and females (4-6, 19). Regarding student populations, in general, levels of inadequate HL are seemingly higher in males (20) and younger individuals (8). Hence, a recent study has reported that the odds of male gender were eight times higher among students with limited HL compared with their counterparts with adequate HL levels (20). Conversely, another recent study has reported that older students had 11% higher odds of exhibiting sufficient HL levels compared with younger individuals (8).

Kosovo, a middle-income country constituting the newest state in Europe, proclaimed its independence in 2008 following a long-standing and devastating war with Serbia (21). Since its independence, Kosovo has been undergoing a rapid process of transformation and deep reforms in all sectors (21). The estimated population of Kosovo consists of about 1.8 million inhabitants, with an average life expectancy of 76.7 years (22, 23), which is one of the lowest in the region (24). Non-communicable diseases (NCDs) affect a large share of the population, with about 22% of individuals aged 18 years and above reporting a chronic disease in 2017 (22, 23). Cardiovascular diseases are the primary cause of the overall burden of disease, followed by cancer and respiratory diseases (22).

However, the information about the levels and determinants of HL in the populations of Western Balkan countries including Kosovo is scarce, especially among university students of health sciences. Measurement of HL among university students in various branches of health sciences is crucial for ensuring they can effectively comprehend and apply health information in their future professional practices, ultimately enhancing patient care and population health outcomes.

With the aim to assess whether future healthcare professionals in Kosovo may need additional training in the field of HL and where there are gaps, the objective of our study was to assess the level of HL among the observed population group as well as define its determinants.

2 METHODS

A cross-sectional study was conducted in Kosovo during February-April 2024, including a representative sample of students attending different branches of health sciences from the universities of Prishtina (the capital) and Gjakova (one of the main regions in Kosovo).

2.1 Sampling and data collection

We decided to invite all students (N=671) from the universities of Prishtina and Gjakova attending studies in one of the following branches: nursing, health management, physiotherapy, or public health.

The survey consisted of self-administration of an anonymous and structured pen-and-paper questionnaire to all students who agreed to participate. Students were invited to fill in the questionnaires during classes by their respective lecturers, without being offered any incentives, while being informed about the aim and procedures of the survey and being expressly guaranteed the anonymity of the survey and the subsequent aggregated data analysis.

2.2 Measurement instruments

The questionnaire included an assessment of the HL and sociodemographic information of participating students. Assessment of HL was based on the internationally standardised European Health Literacy Survey Questionnaire (HLS-EU-Q) (20, 25, 26), which had been already validated in Albanian settings (27). The HLS-EU-Q consists of 47 items measuring students' ability to access, understand, appraise and apply health information across three health domains (healthcare, disease prevention and health promotion) (25, 26). Each item of the instrument was rated on a 4-level Likert scale: "very easy" (score: 4), "fairly easy" (score: 3), "fairly difficult" (score: 2), and "very difficult" (score: 1).

2.3 Observed phenomena

2.3.1 Observed outcome and its derivation

According to the recommendations of developers of the instrument, first a summary score was calculated for each participant (HL-score), ranging from 0-50 (20, 28). Next, the HL-score was grouped into four categories representing four HL levels (HL-level): inadequate HL level (scores: 0-25), problematic HL level (scores: >25-33), sufficient HL level (scores: >33-42), and excellent HL level (scores >42-50). Finally, for the purposes of this study, the four categories were combined into the following two categories: inadequate/problematic HL (scores: 0-33), and sufficient/excellent HL scores (>33-50) (20, 28). Therefore, the observed outcome variable in this study consisted of a binary variable "inadequate/problematic HL" with the values "0=no" and "1=yes".

2.3.2 Explanatory variables

The explanatory variables included all sociodemographic characteristics of study participants: gender (males vs. females), age (18-19, 20, 21, all vs. ≥ 22 years), university institution (University of Prishtina vs. University of Gjakova), branch of study (health management and public health vs. nursing and physiotherapy), place of residence

(urban vs. rural areas), marital status (married vs. single), current employment status (employed vs. not employed), and economic level (not good vs. good).

2.4 Statistical analysis

Standard descriptive statistics methods were used to describe the variables, while binary logistic regression (direct method) was used to assess the association of 'inadequate/problematic HL' with the sociodemographic characteristics of study participants. A simple method with a single reference category was used to create dummy variables. Odds ratios (ORs), their respective 95% confidence intervals (95% CIs) and p-values were calculated. A Hosmer-Lemeshow test was used to assess the goodness-of-fit of the multivariable-adjusted logistic regression models (29). SPSS (version 19.0) was used for all the statistical analyses.

2.5 Ethical considerations

The study was approved by the Ethics Committee of the National Institute of Public Health of Kosovo (Decision: 01/1531, date: 28-12-2023) and by the Ethics Committee of the Faculty of Medicine, University of Gjakova (Decision: 006/82, date: 12-01-2024).

3 RESULTS

3.1 Response rate and description of participants

Of all the invited students (N=671), 113 ($\approx 17\%$ of the target population) did not complete the survey, while a further 88 participants (13% of the total) provided incomplete responses, which were excluded from the analysis. There were no significant differences among respondents and non-respondents regarding gender and age distribution.

The study sample included in the statistical analyses consisted of 470 students (405 females, or $\approx 86\%$ of the overall study sample - Table 1). The final response rate in this study was: $470/671=70\%$. All other characteristics are shown in Table 1.

The HL-score results showed that the mean value was 40.7 ± 5.0 , while the HL-level results showed that out of 470 students, 3 (0.6%) of them exhibited an inadequate, 30 (6.4%) exhibited problematic, 239 (50.9%) exhibited sufficient, and 198 (42.1%) exhibited an excellent HL-level. Overall, only 33 (7.0%) of the students exhibited 'inadequate/problematic HL'.

Table 1. Sociodemographic characteristics of a representative sample of university students of health sciences from Kosovo in 2024 (N=470).

Sociodemographic characteristics	N (%)
Gender	
Males	65 (13.8) ^a
Females	405 (86.2)
Age	
18-19 years	118 (25.1)
20 years	149 (31.7)
21 years	115 (24.5)
≥22 years	88 (18.7)
University	
Prishtina	231 (49.1)
Gjakova	239 (50.9)
Branch of study	
Nursing	364 (77.4)
Health management	19 (4.0)
Physiotherapy	22 (4.7)
Public health	65 (13.8)
Residence	
Urban areas	198 (42.1)
Rural areas	272 (57.9)
Marital status	
Single	446 (94.9)
Married	24 (5.1)
Employment status	
Students not employed	439 (93.4)
Students employed	31 (6.6)
Economic level	
Good	317 (67.4)
Not good	153 (32.6)

Legend: ^a Absolute numbers and their respective column percentages (in parentheses).

3.2 Univariate analysis of association of inadequate/problematic HL with sociodemographic determinants

In crude/unadjusted binary logistic regression models (Table 2), the results showed a statistically significant association between the observed outcome and gender, marital status and employment status. Additionally, the association between inadequate/problematic HL and university institution was marginally statistically significant.

Table 2. Association of inadequate/problematic health literacy with sociodemographic determinants; results from crude (unadjusted) logistic regression models.

Variable	OR (95%CI) ^a	P
Gender		
Female	1.00 (reference)	
Male	3.55 (1.63-7.72)	0.001
Age		0.759 (3) ^b
≥22 years	1.00 (reference)	-
18-19 years	0.73 (0.26-2.02)	0.541
20 years	0.80 (0.31-2.06)	0.640
21 years	0.55 (0.18-1.65)	0.286
University		
Gjakova	1.00 (reference)	
Prishtina	1.89 (0.91-3.94)	0.089
Branch of study		
Nursing and Physiotherapy	1.00 (reference)	
Health Management and Public Health	0.62 (0.21-1.80)	0.375
Residence		
Rural areas	1.00 (reference)	
Urban areas	1.16 (0.57-2.36)	0.688
Marital status		
Single	1.00 (reference)	
Married	3.93 (1.37-11.3)	0.011
Employment		
Not employed	1.00 (reference)	
Students employed	2.82 (1.01-7.91)	0.048
Economic level		
Good	1.00 (reference)	
Not good	1.20 (0.57-2.51)	0.628

Legend: ^a Odds ratios (OR): “inadequate/problematic” health literacy (HL) vs. “sufficient/excellent” HL; ^b Overall p-value and degrees of freedom (in parentheses).

3.3 Multivariate analysis of association of inadequate/problematic HL with sociodemographic determinants

Upon simultaneous adjustment for all sociodemographic characteristics (Table 3), the positive association of the observed outcome with gender persisted. The odds even slightly increased. The only determinant for which the odds increased in the multivariate analysis, besides gender, was university, although the association was only marginally statistically significant. Conversely, the relationships with marital status and employment were no longer statistically significant and their odds considerably decreased (Table 3).

The model of the multivariate association of inadequate/problematic health literacy with sociodemographic determinants as a whole was statistically significant, as the HL test of goodness-of-fit showed that the model fits the data well ($P=0.790$).

Table 3. Multivariate association of inadequate/problematic health literacy with sociodemographic determinants; results from binary logistic regression models^a.

Variable	OR (95%CI) ^b	P
Gender		
Female	1.00 (reference)	
Male	3.65 (1.49-8.92)	0.005
Age		
≥22 years	1.00 (reference)	-
18-19 years	1.01 (0.33-3.15)	0.981
20 years	0.95 (0.33-2.80)	0.932
21 years	0.53 (0.16-1.74)	0.293
University		
Gjakova	1.00 (reference)	
Prishtina	2.07 (0.86-4.99)	0.107
Branch of study		
Nursing and Physiotherapy	1.00 (reference)	
Health Management and Public Health	0.59 (0.16-2.20)	0.432
Residence		
Rural areas	1.00 (reference)	
Urban areas	1.08 (0.52-2.27)	0.831
Marital status		
Single	1.00 (reference)	
Married	1.88 (0.48-7.43)	0.369
Employment		
Not employed	1.00 (reference)	
Students employed	1.96 (0.54-7.16)	0.311
Economic level		
Good	1.00 (reference)	
Not good	1.20 (0.55-2.61)	0.641

Legend: a Models adjusted simultaneously for all variables presented in the table. Hosmer-Lemeshow test: chi-square=4.69; df=8; $P=0.790$; b Odds ratios (OR): “inadequate/problematic” health literacy (HL) vs. “sufficient/excellent” HL.

4 DISCUSSION

4.1 Salient findings

The main finding of this study consists of a relatively high general HL level among university students in Kosovo, especially those from the University of Gjakova. Hence, only 7% of the students exhibited “inadequate and/or problematic” HL. Overall, female students had a remarkably higher HL level compared to males, a finding which was quite consistent and persisted upon adjustment for a wide range of other sociodemographic characteristics. Conversely, economic level, an indicator of social status, was not a significant determinant of general HL.

4.2 Comparison with other studies

The general HL level in our study is a bit higher than a previous report from Albania, which consisted of a similar cross-sectional study applying the same HL instrument in a sample of students pertinent to a range of health sciences (nursing, physiotherapy, midwifery and laboratory technicians) (20). Furthermore, according to this recent report (20), about half of Albanian students had sufficient HL (which is very similar to our estimate), while an excellent HL level was higher than in our study. Hence, on the face of it, the HL levels among university students from Kosovo are higher compared to their counterparts from Albania attending similar study branches (pertinent to health sciences). Apparently, Kosovo has developed a robust curriculum for health sciences that emphasises HL, including practical skills and knowledge about navigating health information (24). Also, in Kosovo, cultural attitudes toward health, well-being and education could play a significant role in promoting HL. Additionally, students in Kosovo may have better access to modern health information technologies, such as e-health platforms or digital libraries, which may engage them more effectively with up-to-date health information, boosting their HL levels. However, our findings on the seemingly high HL levels should be interpreted with caution and replicated in future studies in Kosovo.

The prevalence of adequate (sufficient or excellent) HL in our study was higher than the estimate among Albanian students, as well as among nursing students in Namibia (30). A study including Spanish and French students from different branches reported that only about two in five students had sufficient HL (31). However, nursing students exhibited the best HL levels in that study, which used a different HL measuring scale (31), making it difficult to compare with our study and the previous one from Albania (20). Yet, methodological considerations aside (including especially different measuring HL scales), previous literature on nursing students indicates that around one

third of the surveyed students have problematic or limited HL (31, 32). A recent report from Spain (8) indicated that few nursing students had an inadequate HL level, while one third of them had a problematic HL level.

Regarding another aspect, our finding related to a higher HL level among females compared to males is compatible with a previous study from Albania (20) which reported that, in multivariable-adjusted binary logistic regression models, the only factor significantly increasing the likelihood of limited HL was male gender. Seemingly, females tend to engage more with health-related information in Albanian settings, which may be rooted in their traditional societies imposing certain cultural and social roles. From this perspective, females in Albania and Kosovo may assume more responsibility for health management within families, such as caring for children and elderly relatives. This role could lead to a greater focus on acquiring health knowledge and skills, thereby enhancing their HL levels.

Furthermore, the large European HL survey, employing the same measuring instrument used in our study (HLS-EU-Q), has reported a weak yet positive relationship between female gender and HL level (25, 26). However, a recent study from Spain has reported opposite findings, with female students exhibiting higher levels of insufficient HL (8). On the other hand, some other studies conducted on nursing students have not reported significant gender differences in HL levels (32, 33).

In a previous study from Albania, low social and economic status also increased the likelihood of limited HL, but these associations were not statistically significant in multivariable-adjusted models (20). In our study, economic level was not significantly associated with HL levels even in crude (unadjusted) models.

Of note, the higher prevalence of “inadequate and/or problematic” HL among students who were married compared with those who were single evidenced in our study is explained by the strong confounding effect of gender, with male students (exhibiting lower HL levels) reporting a much higher degree of being married than their female counterparts (displaying significantly higher HL levels). As a matter of fact, upon multivariable adjustment for the other sociodemographic factors including gender, there was no evidence of a significant relationship of HL with marital status.

Conversely, our findings on a positive relationship of age with higher HL levels are intuitive and in line with previous reports from Albania and other countries (8, 20, 34-36). As a matter of fact, in studies involving student populations, older age indicates a more advanced academic year, which has been shown to exhibit a direct linear association with higher HL levels (8, 34-36).

4.3 Strengths and limitations

This study may have some limitations. The first and probably the most important limitation is that the observed outcome is relatively rare. This posed some technical difficulties in the analysis, especially in determinants that had some rare categories (e.g. male gender). However, important results were obtained for planning potential interventions despite this limitation. Second, there is a possibility of selection bias (due to non-response and/or non-valid information provided by almost 30% of the targeted population). Nevertheless, the achieved response rate still provided valuable results. Next, there is a possibility of information bias (likelihood of differential reporting between various sociodemographic groupings). The next potential limitation refers to the measurement of socioeconomic status, which should have combined various economic and social factors of participating students (such as the level and quality of education attained before attending the current studies in health sciences, income, wealth and social status). Finally, the survey design is cross-sectional which does not allow inferences about causality.

Conversely, our study has important strengths. First, for participation in the survey the entire targeted population was invited, and second, the study instrument used was based on a standardised international instrument, previously validated in Albanian settings (27).

4.4 Implications for research and practice

Our study indicates a need to strengthen HL among male students in Kosovo and that the problem seems to be greater at the University of Prishtina. A potential explanation for this regional difference may be the educational environment (curriculum differences, as well as resources and faculty expertise), along with gender dynamics and cultural norms which could influence attitudes towards HL (e.g., different traditional views in these regions may affect how male students perceive health education).

At a broader level, health professionals are essential for patient care at all levels of healthcare services (37, 38). An important component of their work consists of empowering patients and enabling prompt and effective self-care by enhancing their HL skills (37). Therefore, preparation of upcoming health professionals is of paramount importance for addressing the difficulties and needs of patients with inadequate HL levels (37). From this perspective, our study indicates that proper education and training especially of male students from different branches of health sciences is crucial for ensuring they can effectively comprehend and apply health information in their future professional practices, ultimately enhancing patient care and population health outcomes.

Conversely, from a research viewpoint, future studies on HL among health sciences students should explore particularly the impact of curriculum design and cultural factors on HL levels to inform targeted educational interventions for upcoming health professionals.

5 CONCLUSIONS

Our study provides important evidence on the levels and sociodemographic determinants of HL among university students of health sciences in Kosovo, a country which is currently implementing complex and multifaceted political and socioeconomic reforms.

Enhancing HL among university students of health sciences could guide policies that prioritise embedding health education and resources in higher education institutions, potentially improving students' health behaviours and health outcomes, as a major prerequisite for their future work with patients and communities at large.

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CONFLICTS OF INTERESTS

None declared.

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ETHICAL APPROVAL

This study was approved by the Ethics Committee of the National Institute of Public Health of Kosovo (Decision: 01/1531, date: 28-12-2023) and by the Ethics Committee of the Faculty of Medicine, University of Gjakova (Decision: 006/82, date: 12-01-2024).

AVAILABILITY OF DATA AND MATERIALS

All data and materials used in this study are available upon reasonable request.

AUTHORS' CONTRIBUTIONS

Naim Jerliu, Haxhi Kamberi and Genc Burazeri contributed to the study conceptualisation and design, analysis and interpretation of the data and writing of the article. Iris Mone and Pranvera Krasniqi commented comprehensively on the manuscript. All authors have read and approved the submitted manuscript.

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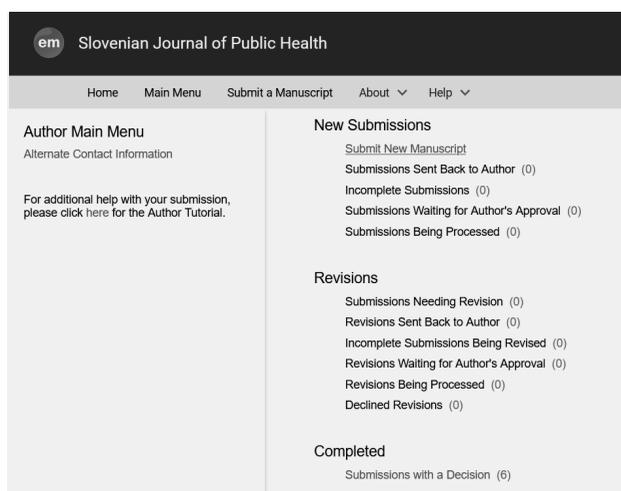
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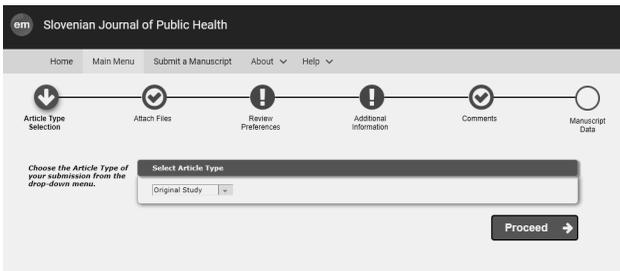
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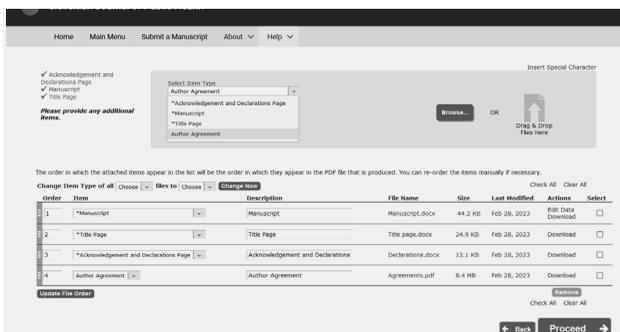


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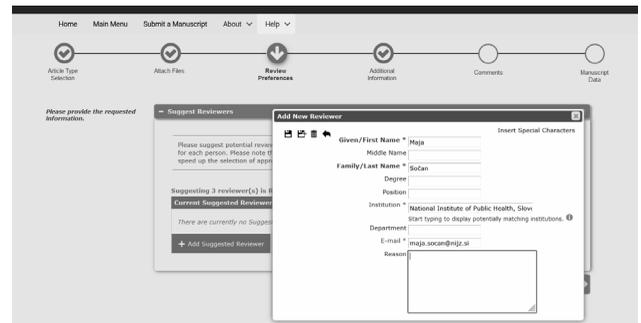


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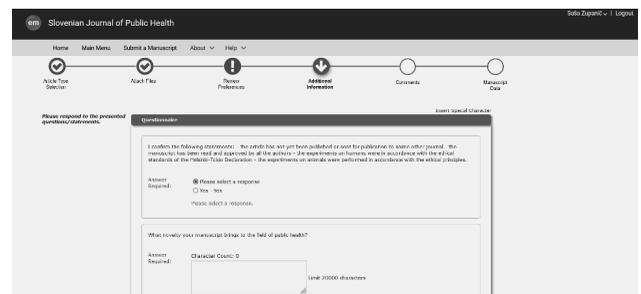
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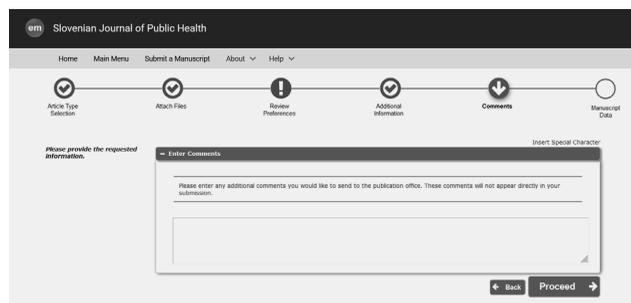
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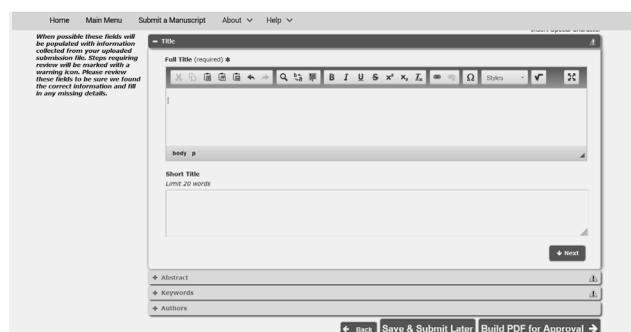
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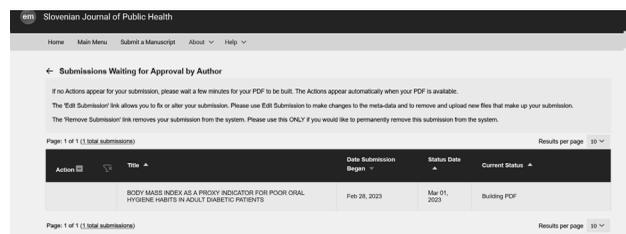
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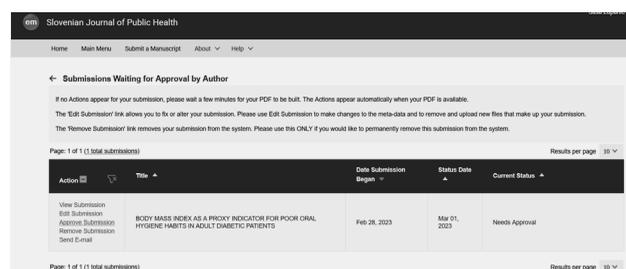


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Book chapter

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Website

Cancer Research UK. Current research into breast cancer [Internet]. 2020 [cited 2022 Dec 14]. Available from: <https://www.cancerresearchuk.org/our-research/our-research-by-cancer-type/our-research-into-breast-cancer/current-breast-cancer-research>

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The names of the authors should be given in the order preferred, with the full addresses of the institutions where the authors are employed. Authors must meet the conditions for authorship. They must contribute to the conception and design or analysis and interpretation of the data, they must intellectually conceive of and critically review the manuscript, and they must agree with the final version of the manuscript. Simply collecting data is not sufficient for authorship. Shared first authorship is allowed for up to two authors. Please give the ORCID numbers of the authors and the email address of the corresponding author.

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Between 3 and 6 keywords should be listed.

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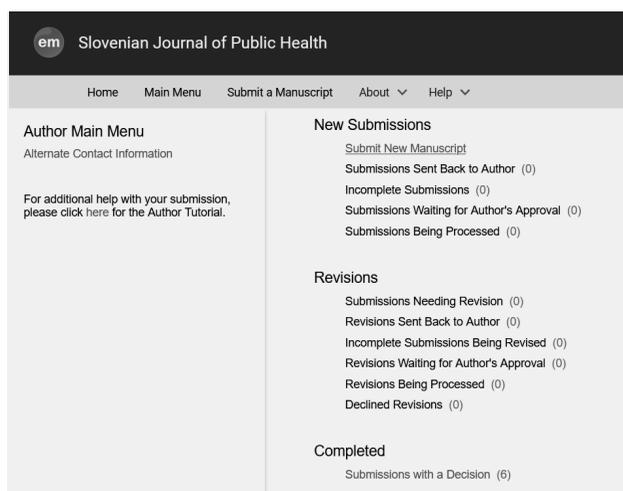
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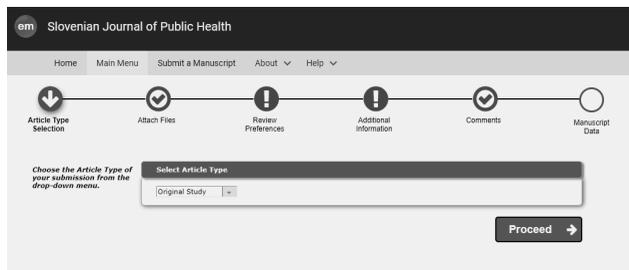
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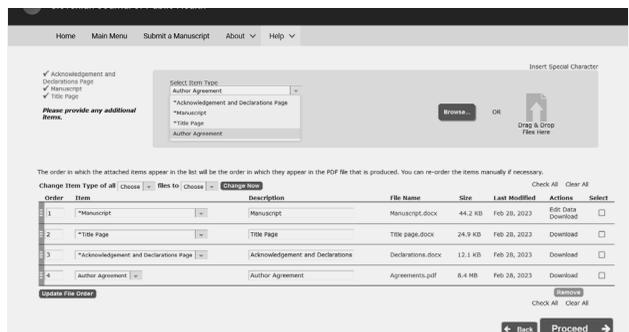


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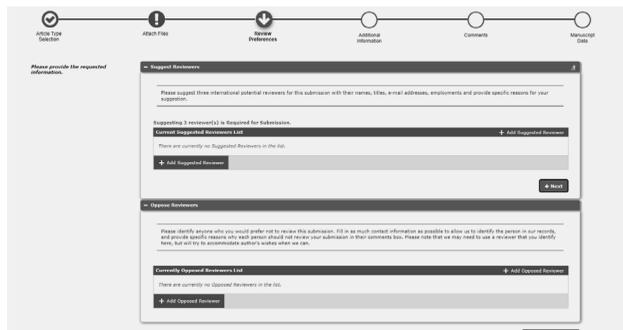


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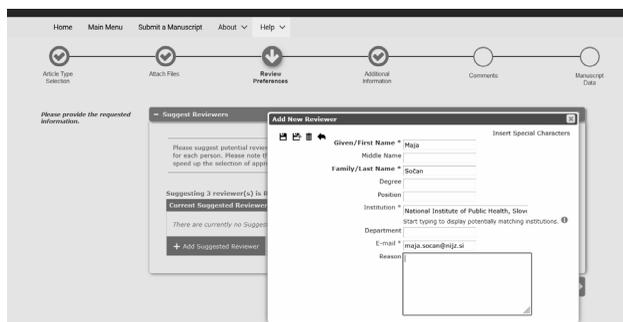


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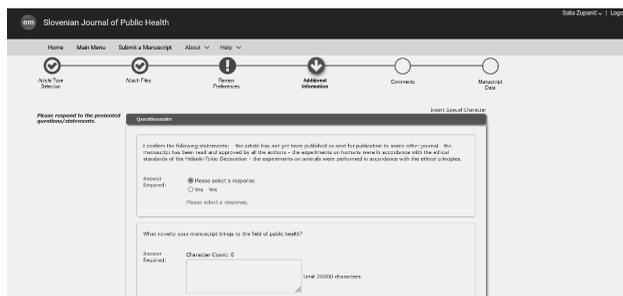


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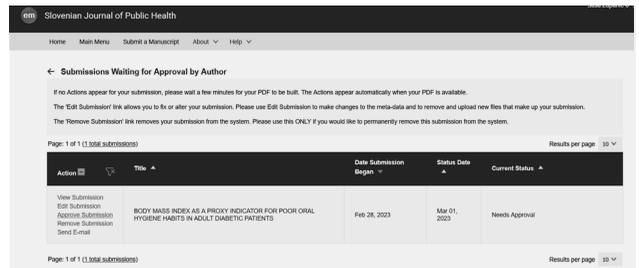
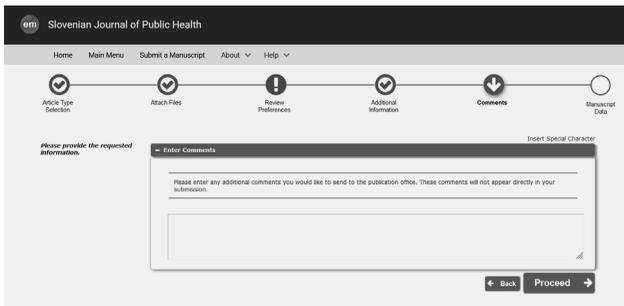


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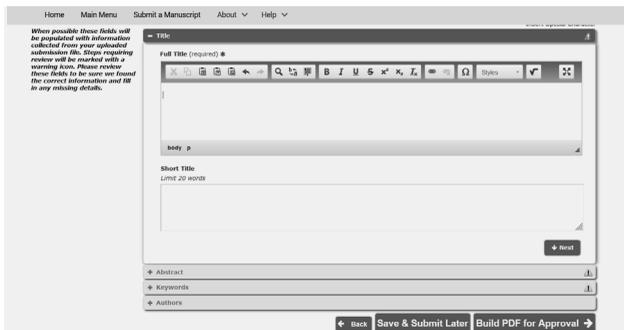
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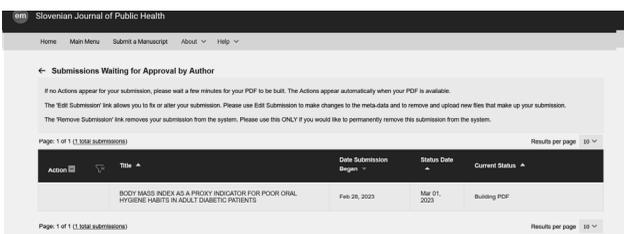
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This argument is increasingly relevant to the topic (2, 3) ...
Several studies (1, 4-8, 12) ...

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Navedite imena vseh avtorjev; v primeru, da je avtorjev šest ali več, navedite prvih šest avtorjev in dodajte kratico et al. Naslov in podnaslov pišite z malimi začetnicami z izjemo prve besede in lastnih imen. Uporabljajte običajno pisavo in se izogibajte ležeči pisavi ali zapisu v navednicah. Naslove revij krajšajte tako kot baza Medline/PubMed. Popoln seznam kratic revij najdete na naslovu National Library of Medicine's [List of Journals Indexed for Medline](#). Naslovov revij, katerih kratic v seznamu ni, ne krajšajte. Če ima objava DOI številko, jo navedite na koncu reference. Primeri navajanja najbolj pogosto uporabljenih vrst objav:

Članek v reviji

Vodička S, Zelko E. Remote consultations in general practice: A systematic review. *Zdr Varst.* 2022 Sep 28;61(4):224-230. doi: 10.2478/sjph-2022-0030.

de Villiers TJ. The role of menopausal hormone therapy in the management of osteoporosis. *Climacteric.* 2015;18 Suppl 2:19-21. doi: 10.3109/13697137.2015.1099806.

Knjiga

Wilkinson IB, Raine T, Wiles K, Goodhart A, Hall C, O'Neill H, et al. *Oxford handbook of clinical medicine.* 10th ed. Oxford: Oxford University Press; 2017. 123 p.

Kaplan SJ. *Post-hospital home health care: the elderly's access and utilization [dissertation].* St. Louis (MO): Washington University; 1995.

Poglavje v knjigi

Goldberg BW. Population-based health care. In: Taylor RB, Robin S, editors. *Family medicine.* 5th ed. Cambridge: Cambridge University Press; 1999. p. 32-36.

Spletna stran

Cancer Research UK. Current research into breast cancer [Internet]. 2020 [cited 2022 Dec 14]. Available from: <https://www.cancerresearchuk.org/our-research/our-research-by-cancer-type/our-research-into-breast-cancer/current-breast-cancer-research>

McNeil DG. Vaccines against HIV, malaria and tuberculosis unlikely, study says. *New York Times.* 2018 Sep 7. [cited 2018 Nov 14]. Available from: <https://www.nytimes.com/2018/09/07/health/vaccines-hiv-malaria-tuberculosis.html>

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Naslovna stran naj zajema sledeče podatke: title / naslov, avtorji, zaposlitve, [ORCID](#) številke avtorjev, e-poštni naslov korespondenčnega avtorja, abstract / izvleček, keywords / ključne besede.

Naslov v angleškem in slovenskem jeziku naj bo informativen in natančen, opisen in ne trdilen (povedi v naslovih niso dopustne). V naslovu naj ne bo kratic.

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Zahvala se naj nahaja na prvem mestu v dokumentu. Vsebuje naj zahvalo vsem sodelujočim pri rokopisu, ki niso prejeli avtorstva rokopisa.

Dokument naj nato zajema še sledeče izjave:

CONFLICTS OF INTEREST

(The authors declare that no conflicts of interest exist.)

FUNDING

(The study was financed by ...)

ETHICAL APPROVAL

(Received from the... ali opis etičnega vidika raziskave)

AVAILABILITY OF DATA AND MATERIALS

(All data and materials used in this study were collected from publicly available sources and are available upon reasonable request.

ali

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.)

LLM STATEMENT

(V LLM izjavi morajo avtorji obvezno navesti morebitno uporabo generativnih jezikovnih modelov (kot je ChatGTP) za izboljšanje jezika in berljivosti rokopisa. Primer: During the preparation of this work the author(s) used [NAME TOOL /SERVICE] in order to [REASON]. After using this tool/service, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the publication.)

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Za SJPH javni komentarji o preprintih niso sprejemljivi kot recenzije.

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V izjavah morajo biti zapisani morebitni finančni ali drugi interesi farmacevtske industrije ali proizvajalcev opreme ter inštitucij, povezanih z rokopisom.

Primere priponek najdete na spletni strani revije.

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