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Martina Klanjčić
Nikola Novaković

CROATIAN PROOFREADING
Dunja Aleraj Lončarić

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Quality Of Life of Persons with Sensory Impairments

[1] **Melani Mihocek** *
[2] **Ana Marija Hošnjak**

[1] **Student at the University of Applied Health Sciences, Zagreb, Croatia**
[2] **University of Applied Health Sciences, Zagreb, Croatia**

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Author for correspondence:
Melani Mihocek
E-mail: melanimihocek@gmail.com

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Abstract

Introduction. Quality of life is a multidimensional concept that includes social, affective, cognitive, and physical domains. People with disabilities include persons with sensory impairments, i.e., the visually impaired, the blind, the hard of hearing, the deaf, and the deafblind. Their diagnosis is a real challenge in everyday life because it hinders them from gathering visual and auditory information from the environment. This affects their abilities and interaction with others, which affects their quality of life.

Aim. To examine how sensory impairment is related to the quality of life and activities of daily functioning.

Methods. The research was conducted using a questionnaire completed by 57 respondents diagnosed with deafness, hearing impairment, low vision, blindness, and deafblindness. Data were collected online, using the snowball method from members of the Association of the Blind, Association of the Deaf, and Association of the Deafblind. The survey consisted of two parts: the first part consisted of general demographic questions, while the second part consisted of selected questions from the WHOQOL-BREF quality of life questionnaire where respondents marked their answers on a five-point Likert scale.

Results. By calculating the mean of all quality of life issues, the results showed that deaf people are the most satisfied with their quality of life, followed by the hard of hearing, visually impaired, and blind people. Deafblind people are the most dissatisfied with the quality of life.

Conclusion. There is a significant difference in the quality of life of people with sensory impairment depending on the category of impairment. The analysis of the results showed a difference in the quality of life concerning the diagnosis of sensory impairment and that people with deafblindness consider their quality of life the worst.

Introduction

Quality of life is an inclusive term used in many fields of science with different meanings. Assessment of quality of life is based on individual experience, expectations, aspirations, value system, and psychophysiological functioning (1). The World Health Organization (WHO) describes the quality of life as an individual's perception of their position in the cultural and value system in which they live and their own goals, expectations, and standards (2). As the authors disagreed on an accurate definition of quality of life, we do not have a universal measuring instrument. Numerous questionnaires tailored to the research topic are used to measure the quality of life (3). The World Health Organization (WHO) has developed two instruments for measuring the quality of life: the World Health Organization Quality of Life Questionnaire (WHOQOL-100) and WHOQOL-BREF. The WHOQOL-100 questionnaire measures the quality of life through 100 items divided into six domains, while WHOQOL-BREF is its abbreviated version of 26 items that is more suitable for everyday use and measures quality of life through 4 domains (2).

We meet people with visual impairments (blind and partially sighted), hearing impaired (deaf and hard of hearing), and deafblind people in our daily practice. These individuals face many obstacles and challenges that they need to overcome. Sensory impairments are obstacles to properly executing basic daily activities such as walking, climbing stairs, moving in traffic, and watching television. These numerous obstacles, which seem banal to other people, affect their daily functioning and quality of life (4-6). The more severe the damage, the more the lifestyle changes, and the person needs to work harder to adapt to the new situation. Due to living with sensory impairment, stress can lead to the risk of depression, anxiety, anger, poor self-image, lack of self-confidence and self-esteem, and feelings of isolation. The quality of life of people with sensory impairment depends on the form of impairment, the availability of a social network, social life, and environmental support (4, 7-9). Visual impairment increases the risk of injury, falls and depression. It limits daily life activities (10), leading to dissatisfaction with social activity and affecting the quality of life and independence (11). Hearing impairment is associated with communication difficulties, depression, social isolation, and poor self-esteem, leading to severe psychosocial and functional problems (10). Older people with double sensory impairment face a higher risk of social and relational problems, depression, cognitive impairment, and poor health than older people with single sensory impairment; the percentage of those with dual sensory impairment increases with age (12-15).

The aim of this research is to examine the satisfaction of visually and hearing-impaired persons in the following domains: health, productivity, safety, accessibility of public institutions and encountering prejudice and discrimination based on their disability. The purpose of the study is to assess the difference in the quality of life depending on the type of impairment.

Methods

Design

The research was conducted as a cross-sectional study.

Participants

A total of 57 respondents participated in the research, members of the Association of the Blind, members of the Association of the Deaf, and members of the Association of the Deafblind. The survey was forwarded to the coordinators in each Association and passed on by the snowball method. All respondents were familiar with the purpose and objectives of the research. The survey was voluntary, anonymous, and conducted during December 2020.

Instrument

An abridged version of The World Health Organization's Quality of Life Questionnaire (WHOQOL - BREF).

The WHOQOL-BREF questionnaire initially consists of 26 items that examine four quality of life domains: physical health, mental health, social relations, and environment. The subscales of this questionnaire have good internal consistency (Cronbach's Alpha is between .66 and .84) (16).

For this research, the questionnaire was created in

Google form. Our survey questionnaire consisted of two parts. The first part dealt with general demographic questions: age, gender, diagnosis, education, and employment status. The second part consisted of 10 closed questions summarized from the WHOQOL-BREF questionnaire. In consultation with staff working with the required group of respondents, ten questions were selected to answer our research objectives, and we made sure that the survey was not too long as some respondents used the help of translators and/or family members due to misunderstandings. Respondents answered these questions using the Likert scale ranging from 1 to 5, where 1 indicates the lowest agreement with an individual item and 5 indicates the highest agreement with the item. The particles of the general quality of life and general health were considered separately.

The last question was open-ended. Respondents could write a personal comment on this question regarding the quality of their lives depending on the sensory impairment.

Results

Sociodemographic data

The study involved 57 respondents whose sociodemographic data are divided by frequencies and percentages in Table 1.

Table 1. **Socio-demographic characteristics of the respondents**

		N	%
Sex	Female	30	53
	Male	27	47
Age	18-30	21	37
	31-40	8	14
	41-50	8	14
	51-60	9	11
	> 60	11	19
Sensory impairment	Hard of hearing	14	25
	Deafness	11	19
	Low vision	9	16
	Blindness	13	23
	Deafblindness	10	17
Education	Elementary School	5	9
	High school	42	74
	Bachelor's/Master's degree	10	17
Working status	Student	8	14
	Employed	21	37
	Unemployed - looking for a job	2	3
	Unemployed - not looking for a job	6	11
	Retired	20	35

Out of 57 respondents most were female (53%), aged 18 to 30. Most of the involved participants have a diagnosis of hearing impairment 25%), followed by blindness (23%), deafblindness (17%), deafness (19%), and low vision (16%). Most participants have completed high school, while there is the least number of participants who have completed primary school. The vast majority are employed (37%) or retired (35%), while the rest are students and unemployed.

Quality of life

Table 2. **Quality of life of people with sensory impairment**

QUESTION	CATEGORY	N		Mean	Median	Mode	Std. Deviation	Min	Max
		Valid	Missing						
To what extent do you feel that your diagnosis interferes with your daily activities?	Hard of hearing	14	0	2.79	3.00	3	0.893	1	4
	Deafness	10	1	2.90	3.00	4	1.197	1	4
	Visual impairment	9	0	3.22	3.00	4	0.833	2	4
	Blindness	13	0	2.92	3.00	2	0.954	2	5
	Deafblindness	10	0	4.30	5.00	5	1.059	2	5
How much are you worried about your health?	Hard of hearing	14	0	2.86	3.00	3	2.027	1	5
	Deafness	11	0	2.55	3.00	1	1.572	1	5
	Visual impairment	9	0	2.44	3.00	3	1.014	1	4
	Blindness	13	0	2.23	2.00	2	1.235	1	5
	Deafblindness	10	0	3.50	3.50	2	1.269	2	5
How positive do you feel about your future?	Hard of hearing	14	0	3.21	3.00	3	1.051	1	5
	Deafness	11	0	3.64	4.00	3	1.120	2	5
	Visual impairment	9	0	3.67	4.00	4	0.866	2	5
	Blindness	13	0	3.77	4.00	4	0.725	3	5
	Deafblindness	10	0	2.70	3.00	3	0.949	1	4
Do you feel limited by your diagnosis?	Hard of hearing	14	0	2.43	2.00	2	0.938	1	4
	Deafness	11	0	2.55	3.00	1	1.368	1	4
	Visual impairment	9	0	3.22	4.00	4	1.302	1	5
	Blindness	13	0	2.69	3.00	2	1.182	1	5
	Deafblindness	10	0	4.30	5.00	5	1.059	2	5
To what extent does the quality of your life depend on medical supplies?	Hard of hearing	14	0	3.43	4.00	5	1.604	1	5
	Deafness	11	0	3.36	3.00	3	1.362	1	5
	Visual impairment	9	0	3.56	4.00	5	1.424	1	5
	Blindness	13	0	3.46	3.00	3	1.198	1	5
	Deafblindness	10	0	1.80	2.00	1	0.789	1	3

How much information is available to you for everyday life?	Hard of hearing	14	0	3.50	3.50	2	1.225	2	5
	Deafness	11	2	2.73	2.00	2	1.009	2	5
	Visual impairment	9	0	3.00	3.00	2	1.118	2	5
	Blindness	13	0	3.62	4.00	4	0.961	2	5
	Deafblindness	10	0	2.30	2.00	1	1.418	1	5
Have you faced discrimination when looking for a job?	Hard of hearing	14	0	2.93	3.00	4	1.385	1	5
	Deafness	11	0	2.27	2.00	2	1.91	1	4
	Visual impairment	9	0	2.33	2.00	1	1.581	1	5
	Blindness	13	0	2.62	2.00	1	1.446	1	5
	Deafblindness	10	0	3.70	4.00	4	1.494	1	5
Did you face prejudice when meeting a stranger?	Hard of hearing	14	0	2.43	2.00	1	1.284	1	5
	Deafness	11	0	3.18	3.00	2	1.079	2	5
	Visual impairment	9	0	2.78	3.00	1	1.394	1	5
	Blindness	13	0	3.15	3.00	3	1.068	1	5
	Deafblindness	10	0	4.50	5.00	5	0.850	3	5
How satisfied are you with the quality of your life on a scale of 1 to 5?	Hard of hearing	14	0	3.79	4.00	4	0.699	3	5
	Deafness	11	0	4.18	4.00	4	0.751	3	5
	Visual impairment	9	0	3.78	4.00	3	0.833	3	5
	Blindness	13	0	4.00	4.00	4	0.707	3	5
	Deafblindness	10	0	2.90	3.00	3	0.738	2	4
On the scale from 1 to 5, how satisfied are you with the accessibility of educational, cultural and sports institutions adapted to you?	Hard of hearing	14	0	3.57	3.00	3	1.089	2	5
	Deafness	11	0	3.91	4.00	4	0.944	2	5
	Visual impairment	9	0	2.33	2.00	2	1.000	1	4
	Blindness	13	0	2.31	2.00	2	0.855	1	4
	Deafblindness	10	0	1.80	1.00	1	1.135	1	4

Participants diagnosed with deafblindness answered that their diagnosis hinders them the most in daily activities compared to other participants with sensory impairment.

Deafblind respondents are concerned about their health the most, while the least concerned are the visually impaired and the blind.

When asked how positive they feel about their future, none of the deafblind people said they feel very positive. Blind people are the most positive about their future.

When asked if their diagnosis limits them, deafblind people answered the most affirmative.

When asked how dependent they are on medical supplies, deaf and visually impaired respondents are the most dependent. Interestingly, deafblind respondents answered that they do not depend on medical aids.

When asked how much information is available for everyday life, respondents diagnosed with deafblindness answered that they have no access to everyday information at all. Blind and hard of hearing respondents were the most satisfied with the access to information.

Most deafblind respondents faced discrimination in seeking employment, while most deaf and visually impaired respondents did not.

Deafblind people were ultimately confronted with prejudice when meeting an unknown person, while deafblind respondents encountered little or no prejudice.

Subjectively dissatisfied with the quality of their lives are deaf respondents, while deafblind respondents are the most dissatisfied.

When asked how satisfied they are with the accessibility of cultural, educational and sports institutions, deaf respondents are the most satisfied, while deafblind people are the most dissatisfied.

Table 3. **Quality of life of respondents according to the diagnosis**

	Diagnosis		Statistics	Standard error
Quality of life of respondents	**hard of hearing**	Arithmetic mean	2.73	0.195
		Standard deviation	0.647	
		Minimum	2	
		Maximum	4	
		Skewness	0.291	661
		Courtesy	0.208	0.279
	deafblindness	Arithmetic mean	3.70	0.153
		Standard deviation	0.483	
		Minimum	3	
		Maximum	4	
		Skewness	-1.035	0.687
		Courtesy	-1.224	1.334
	deafness	Arithmetic mean	3.70	0.153
		Standard deviation	0.426	
		Minimum	2	
		Maximum	3	
		Skewness	-1.566	0.597
		Courtesy	0.501	1.154
	low vision	Arithmetic mean	3.11	0.261
		Standard deviation	0.782	
		Minimum	2	
		Maximum	4	
		Skewness	0.216	0.717
		Courtesy	-1.041	1.400
	blindness	Arithmetic mean	3.08	0.077
		Standard deviation	0.277	
		Minimum	3	
		Maximum	4	
		Skewness	3.606	0.616
		Courtesy	13.000	1.191

The quality of life of the respondents according to the diagnosis is shown in Table 3. Here we see that the respondents with deafness rate the quality of life with 2.73, while the standard deviation is 0.647 (2.73 ± 0.647). The minimum score in this group is 2, and the maximum is 4. Participants with deafblindness assess the quality of life with 3.70, while the standard deviation is 0.483 (3.70 ± 0.483). The minimum score in this group is 3, and the maximum is 4. Participants with hard of hearing rate the quality of life with 3.70, while the standard deviation is 0.426 (3.70 ± 0.426). The minimum score is 2 and the maximum is 3. Respondents with low vision rate the quality of life with 3.11, while the standard deviation is 0.782 (3.11 ± 0.782). The minimum score is 3, and the maximum is 4. Participants with blindness rate the quality of life with 3.08, while the standard deviation is 0.680 (3.08 ± 0.680). The minimum grade in this group is 2, and the maximum is 4.

Table 4. **Quality of life of respondents by items**

Ranks			
Item	Diagnosis	N	Average rank
How satisfied are you with the quality of your life on a scale of 1 to 5?	Hard of hearing	14	29.32
	Deafness	11	36.95
	Visual impairment	9	28.83
	Blindness	13	33.58
	Deafblindness	10	14.00
	In total	57	
On the scale from 1 to 5, how satisfied are you with the accessibility of educational, cultural and sports institutions adapted to you?	Hard of hearing	14	38.07
	Deafness	11	42.77
	Visual impairment	9	22.61
	Blindness	13	22.04
	Deafblindness	10	15.95
	In total	57	
To what extent do you feel that your diagnosis interferes with your daily activities?	Hard of hearing	14	23.39
	Deafness	10	25.20
	Visual impairment	9	29.39
	Blindness	13	24.19
	Deafblindness	10	43.75
	In total	56	
How much are you worried about your health?	Hard of hearing	14	31.43
	Deafness	11	27.00
	Visual impairment	9	26.33
	Blindness	13	22.62
	Deafblindness	10	38.50
	In total	57	

How positive do you feel about your future?	Hard of hearing	14	26.32
	Deafness	11	32.27
	Visual impairment	9	33.39
	Blindness	13	34.46
	Deafblindness	10	18.10
	In total	57	
Do you feel limited by your diagnosis?	Hard of hearing	14	22.29
	Deafness	11	24.14
	Visual impairment	9	32.33
	Blindness	13	25.58
	Deafblindness	10	45.20
	In total	57	
To what extent does the quality of your life depend on medical supplies?	Hard of hearing	14	33.56
	Deafness	11	31.23
	Visual impairment	9	32.32
	Blindness	13	32.31
	Deafblindness	10	13.50
	In total	57	
Did you face prejudice when meeting a stranger?	Hard of hearing	14	20.11
	Deafness	11	29.00
	Visual impairment	9	24.44
	Blindness	13	28.88
	Deafblindness	10	45.70
	In total	57	
Have you faced discrimination when looking for a job?	Hard of hearing	14	30.04
	Deafness	11	24.14
	Visual impairment	9	24.39
	Blindness	13	27.38
	Deafblindness	10	39.15
	In total	57	
How much information is available to you for everyday life?	Hard of hearing	14	34.21
	Deafness	11	23.91
	Visual impairment	9	27.67
	Blindness	13	36.31
	Deafblindness	10	19.00
	In total	57	

	How satisfied are you with the quality of your life on a scale of 1 to 5?	On a scale from 1 to 5, how satisfied are you with the accessibility of educational, cultural and sports institutions adapted to you?	To what extent do you feel that your diagnosis interferes with your daily activities?	How much are you worried about your health?	How positive do you feel about your future?	Do you feel limited by your diagnosis?	To what extent does the quality of your life depend on medical supplies?	Did you face prejudice when meeting a stranger?	Have you faced discrimination when looking for a job?	How much information is available to you for everyday life?
Chi-Square	13.263	22.710	12.278	6.208	7.860	14.327	11.166	15.515	5.978	9.167
df	4	4	4	4	4	4	4	4	4	4
Asymp. Sig.	0.010	0.000	0.015	0.184	0.097	0.006	0.025	0.004	0.201	0.057

Participants with different sensory impairments statistically significantly differ in the items that examine their satisfaction with the quality of life (χ^2 =13.263, *p*=0.010) and satisfaction with the accessibility of educational, cultural and sports institutions adapted to them (χ^2 =22.710, *p*=0.000). They also statistically significantly differ in the item that examines how much the diagnosis interferes with their daily activities (χ^2 =12.278, *p*=0.015) and in the item that examines whether their diagnosis hinders/limits them (χ^2 =14.327, *p*=0.006). Furthermore, participants with different sensory impairment statistically significantly differed depending on medical devices (χ^2 =11.166, *p*=0.025) and coping with prejudice when meeting an unknown person (χ^2 =15.515, *p*=0.004).

Table 5. **Quality of life of respondents by items**

	Ranks					
Item	Diagnosis	N	Average rank	Sum of ranks	Mann-Whitney U	*p*
How satisfied are you with the quality of your life on a scale of 1 to 5?	Hard of hearing	14	15.39	215.50	29.500	0.016
	Deafblindness	10	8.45	84.50		
	In total	24				
	Deafness	11	14.73	162.00	14.000	0.003
	Deafblindness	10	6.90	69.00		
	In total	21				
	Blindness	13	15.42	200.50	20500	0.004
	Deafblindness	10	7.55	75.50		
	In total	23				

On the scale from 1 to 5, how satisfied are you with the accessibility of educational, cultural and sports institutions adapted to you?	Hard of hearing	14	14.57	204.00	27.000	0.023
	Visual impairment	9	8.00	72.00		
	In total	23				
	Hard of hearing	14	18.00	252.00	35.000	0.006
	Blindness	13	9.69	126.00		
	In total	27				
	Hard of hearing	14	16.07	225.00	20.000	0.002
	Deafblindness	10	7.50	75.00		
	In total	24				
	Deafness	11	13.82	152.00	13.000	0.004
	Visual impairment	9	6.44	58.00		
	In total	20				
	Visual impairment	11	17.50	192.50	16.500	0.001
	Blindness	13	8.27	107.50		
	In total	24				
	Deafness	11	15.09	166.00	10.000	0.001
	Deafblindness	10	6.50	65.00		
	In total	21				
To what extent do you feel that your diagnosis interferes with your daily activities?	Hard of hearing	14	8.93	125.00	20.000	0.002
	Deafblindness	10	17.50	175.00		
	In total	24				
	Deafness	10	7.20	72.00	17.000	0.011
	Deafblindness	10	13.80	138.00		
	In total	20				
	Visual impairment	9	6.94	62.50	17.500	0.022
	Deafblindness	10	12.75	127.50		
	In total	19				
	Blindness	13	8.77	114.00	23.000	0.008
	Deafblindness	10	16.20	162.00		
	In total	23				
Do you feel limited by your diagnosis?	Hard of hearing	14	8.57	120.00	15.000	0.001
	Deafblindness	10	18.00	180.00		
	In total	24				
	Deafness	11	7.41	81.50	15.500 the most common	0.004
	Deafblindness	10	14.95	149.50		
	In total	21				
	Blindness	13	8.62	112.00	21.000	0.005
	Deafblindness	10	16.40	164.00		
	In total	23				

To what extent does the quality of your life depend on medical supplies?	Hard of hearing	14	15.36	215.00	30.000	0.019
	Deafblindness	10	8.50	85.00		
	In total	24				
	Deafness	11	14.27	157.00	19.000	0.01
	Deafblindness	10	7.40	74.00		
	In total	21				
	Visual impairment	9	13.44	121.00	14.000	0.01
	Deafblindness	10	6.90	69.00		
	In total	19				
	Blindness	13	15.69	204.00	17.000	0.002
	Deafblindness	10	7.20	72.00		
	In total	23				
Did you face prejudice when meeting a stranger?	Hard of hearing	14	8.54	119.50	14.500	0.001
	Deafblindness	10	18.05	180.50		
	In total	24				
	Deafness	11	7.68	84.50	18.500	0.008
	Deafblindness	10	14.65	146.50		
	In total	21				
	Visual impairment	9	6.50	58.50	13.500	0.008
	Deafblindness	10	13.15	131.50		
	In total	19				
	Blindness	13	8.65	112.50	21.500	0.005
	Deafblindness	10	16.35	163.50		
	In total	23				

Post-hoc analysis of the Mann-Whitney test found that there were statistically significant differences in quality of life satisfaction between participants diagnosed with hearing impairment and deafblindness *(U=29.500, p=0.016)*, deafness and deafblindness *(U=14.000, p=0.003)* and between subjects diagnosed with blindness and deafblindness *(U=20.500, p=0.004)*.

Post-hoc analysis of the Mann-Whitney test found that there are statistically significant differences in satisfaction with the accessibility of educational, cultural and sports institutions adapted to people with sensory impairment between respondents diagnosed with hearing impairment and low vision *(U=27.000, p=0.023)*, hearing impairment and blindness (*U*=35.000, *p*=0.006), hearing impairment and deafblindness *(U=20.000, p=0.002)*, deafness and low vision (*U*=13.000, *p*=0.004), low vision and blindness *(U=16.500, p=0.001)* and among respondents who are diagnosed with deafness and deafblindness *(U=10.000, p=0.001)*.

Post-hoc analysis by Mann-Whitney test found that there are statistically significant differences in the item that examines how much the diagnosis interferes with daily activities between participants diagnosed with hearing impairment and deafblindness (*U*=20.000, *p*=0.002), deafness and deafblindness (*U*=17.000, *p*=0.011), low vision and deafblindness (*U*=17.500, *p*=0.022) and among participants diagnosed with blindness and deafblindness (*U*=23.000, *p*=0.008).

Post-hoc analysis of the Mann-Whitney test showed that there are statistically significant differences in the item examining how limited they feel because of their diagnosis in participants with hearing impairment and deafblindness (*U*=15.000, *p*=0.001), with deafness and deafblindness (*U*=15.500 *p*=0.004), and among participants diagnosed with blindness and deafblindness (*U*=21.000, *p*=0.005).

Post-hoc analysis by Mann-Whitney test found that there are statistically significant differences in medical device dependence between subjects diagnosed with hearing impairment and deafblindness (U=30.000, p=0.019), deafness and deafblindness (U=19.000, p=0.01), low vision and deafblindness (U=14.000, p=0.01) and between participants diagnosed with blindness and deafblindness (U=17.000, p=0.002).

Post-hoc analysis of the Mann-Whitney test found that there are statistically significant differences in coping with prejudice when meeting an unknown person between participants diagnosed with hearing impairment and deafblindness (U=14.500, p=0.001), deafness and deafblindness (U=18.000, p=0.008), low vision and deafblindness (U=13.500, p=0.008) and among participants diagnosed with blindness and deafblindness (U=21.500, p=0.005).

In the last question of the questionnaire, respondents could freely write their thoughts on their quality of life. Here are their answers (without proofreading):

- Without the services of an interpreter, I would not be able to do my daily work and solve life situations.
- Unavailable information, untranslated shows, not enough news, not enough translators because people don't want to do it, or the minimum wage.
- I am a deafblind girl from birth. I am grateful to my parents, relatives, teachers, assistants-translators who, with their hard work, commitment, and sacrifice, made it possible for me to live with dignity, quality and surrounded by love.
- More attention should be paid to the employment of people with disabilities (deafness).
- Simplify the process of getting a guide dog.
- I am bothered by people's ignorance and lack of information about hearing impairment or deafness, and I believe that they should not be discriminated against in their work.
- The need for a communication intermediary (translator of Croatian sign language).
- The association of which I am a member helps improve the quality of life.
- Due to ageing and health, I fear the future, and I would not want to remain a "burden" to my children. I didn't think about the future before, and now everything comes to my mind due to my deteriorating health and psychophysical condition. I feel more and more lonely and I withdraw into myself, and I would like to be as active as I used to be since this is a cure for depression.
- I don't think the government cares enough about deaf and deafblind people. There is not enough accessibility of information, and deafblind people have to fight for themselves. We would all be happy if more information is available to enable us to live a better life (e.g., health, social and other rights). The problem is small pensions, and the cost of living is high.
- There are significant individual differences in perceptions of quality of life concerning sensory impairments. I feel like living a fulfilled life because I have entirely accepted my disability and I am supported by family and friends, making me happy with my life. What is missing are rehabilitation services for the visually impaired in local communities. Many services are centralized, and many rehabilitation institutions are located in Zagreb, complicating the rehabilitation process after the damage occurs. Also, many jobs are not adapted for people with disabilities and are still not available.

Discussion

The aim of this study was to examine the satisfaction of deaf, blind and deafblind people with their health, productivity, security, accessibility of public institutions and meeting prejudice and discrimination considering their disability. As far as the authors know, few research papers in the Republic of Croatia determine the quality of life of people with various sensory-perceptual impairments, which could be due to an insufficient sample population or differences in measurement methods. Further clarifications and discussions on research design, participants, tools and results are needed.

Most of the studies we reviewed support the idea that the deterioration of hearing and vision is associated with a deterioration in the quality of life and that the quality of life of deafblind people is worse than in people with only one of the impairments, which is consistent with our results (17). Possible explanations include the following: (1) activity limitations: sensory impairments interfere with basic self-help skills in adult daily life, such as bathing and feeding, and also interfere with more complex daily activities such as shopping and financial transactions, causing functional impairment and deteriorating quality of life; (2) less social resources: sensory impairments interfere with communication and interaction with others, causing social isolation and lack of self-perception and social support, which affects the quality of life; and (3) fewer psychological resources: due to disability and social isolation, people with sensory impairments are prone to adverse mental reactions, such as anger and depression, resulting in a low quality of life (18-21). Based on these explanations, future studies should examine whether better social support and easier access to medical, educational and cultural content are affected by mitigating the harmful effects of sensory impairment on quality of life.

Raina and his colleagues (2004) described how respondents with visual and hearing impairments reported the most limitations in their daily life activities, which is in line with our results; however, they were followed by visually impaired people and then people with hearing impairment, while our results are reversed. Elderly deafblind people were also more likely to require assistance in their daily activities than all other subjects with sensory impairment (22).

A study conducted by Vuletić, Šarlija and Benjak (2016) examined the subjective quality of life of 78 blind and 64 visually impaired people. Respondents answered questions about the standard of living, health, achievement in life, close relationships, security, community connection and future security using a ten-point Likert scale where 0 indicates complete dissatisfaction and 10 completes satisfaction. Their results showed that blind and partially sighted people were most satisfied with close relationships and least satisfied with future security, while our results showed they were most satisfied with employment and least satisfied with cultural events (community connection). The results of this study showed a statistically significant difference in the average score by type of impairment: blind people described a lower subjective quality of life than the visually impaired, which confirms our hypothesis that there is a significant difference in the quality of life with sensory impairment according to the category of impairment (23).

A study conducted by Sign Health (2013) involved 533 deaf respondents. Their health, lifestyle and access to health services were researched. One-third of the deaf (37%) were currently employed full time, 19% part-time, 9% were retired, 3% were students, while 12% of respondents were not employed at all. In our study, 55% of deaf respondents were employed full time, 36% were retired, and 1% was a student. In both surveys, only about half of the deaf respondents were employed. These results prove that employment is a problem for the deaf, among other things. Namely, deaf people are exposed to being misunderstood by employers because employers are not familiar with their methods of communication and consequently do not know how to establish communication (24). In a study conducted by Hersh (2013) 27 deafblind people from six different countries were interviewed. Discussed topics were barriers to communication with the people around them and inadequate support from society. Participants used a variety of communication strategies, from sign language and palm writing to lip reading and hearing aid use. The research results showed that all deafblind participants in all countries were interested in participating and contributing to the society. However, communication is an obstacle. In communicating with other people, they noticed that people do not have the patience to repeat what is said to them, even though they try to understand them. Sometimes they can be offended if they are not answered. The participant stated that they had lost friends or treated them differently due to increasingly evident sensory impairment, which resulted in withdrawal and a lack of self-confidence. It was concluded that barriers to communication, information and mobility can have severe emotional and social consequences, such as depression and isolation. They can also limit decision-making, reduce functional independence, and perform daily life tasks, resulting in poor quality of life. These results suggest that deafblind people consider their quality of life as poor (25).

Limitations of the study

As a limitations of the study, we should mention the small number of respondents and insufficient understanding of the meaning of specific issues. Therefore, some respondents needed the help of an assistant/translator/family member to complete it, which could also be a significant obstacle in answering questions. In the future, it is necessary to research a larger sample of respondents to improve the existing multidisciplinary or monodisciplinary approach to people with sensory impairments to improve their quality of life. Furthermore, the cross-sectional study for this area of research is inadequate to establish cause-and-effect relationships because it cannot demonstrate the actual causal relationship between sensory impairment and quality of life or determine whether the relationship changes over time.

Conslusion

This research proved a significant difference in the quality of life of people with sensory impairment due to the impairment category and that deafblind people consider their quality of life the worst. The results show that blind and partially sighted people are the most positive about their future and are the most satisfied with employment, while they are least satisfied with personal participation in cultural events, i.e., connection with the community. Deaf and hard of hearing people are most satisfied with employment, while on the other hand, they state that they are most dependent on medical aids (hearing aids). People with deafblindness state that their diagnosis dramatically interferes with their daily activities and are the most concerned about their health. They state that they are the most dissatisfied with the accessibility of educational, cultural and sports centers adapted to them. By calculating the mean value of all quality of life questions, the results showed that hard of hearing are the most satisfied with their quality of life. They are followed by deaf, visually impaired, and blind people, while deafblind people are the most dissatisfied with the quality of life.

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KVALITETA ŽIVOTA OSOBA SA SENZORNIM OŠTEĆENJIMA

Sažetak

Uvod. Kvaliteta života definirana je kao višedimenzionalni koncept koji obuhvaća društvene, afektivne, kognitivne i fizičke domene. U osobe s invaliditetom spadaju osobe sa senzornim oštećenjem, tj. slabovidni, nagluhi, slijepi, gluhi i gluhoslijepi. Njihova dijagnoza predstavlja pravi izazov u svakodnevnom životu jer ih ometa u prikupljanju vizualno-auditivnih informacija iz okoline. To utječe na njihove sposobnosti i interakciju s drugima, što posljedično utječe na kvalitetu života.

Cilj. Ispitati kako je senzorno oštećenje povezano s kvalitetom života i aktivnostima svakodnevnog funkcioniranja bio je cilj ovoga istraživanja.

Metode. Istraživanje je provedeno s pomoću anketnog upitnika koji je ispunilo 57 ispitanika s dijagnozom nagluhosti, slabovidnosti, gluhoće, sljepoće i gluhosljepoće. Podaci su prikupljeni putem interneta i metodom snježne grude, a sudjelovali su članovi udruge slijepih Hrvatskog saveza slijepih, članovi udruge gluhih Hrvatskog saveza gluhih i nagluhih i članovi Saveza gluhoslijepih osoba „Dodir”. Anketa se sastojala od dva dijela: prvi dio sastojao se od općih demografskih pitanja, dok su drugi dio sačinjavala odabrana pitanja iz upitnika kvalitete života Svjetske zdravstvene organizacije WHOQOL-BREF gdje su ispitanici svoje odgovore označavali na petostupanjskoj Likertovoj ljestvici.

Rezultati. Izračunom srednje vrijednosti svih pitanja o kvaliteti života rezultati su pokazali da su gluhe osobe najzadovoljnije kvalitetom života. Zatim slijede nagluhe, slabovidne i slijepe osobe, dok su gluhoslijepe osobe najnezadovoljnije kvalitetom života.

Zaključak. Postoji značajna razlika u kvaliteti života osoba sa senzornim oštećenjem s obzirom na kategoriju oštećenja. Analizom rezultata utvrđeno je da postoji razlika u kvaliteti života s obzirom na dijagnozu senzornog i motoričkog oštećenja te da osobe s gluhosljepoćom svoju kvalitetu označavaju kao najlošiju.

Ključne riječi: senzorno oštećenje, kvaliteta života

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Attitudes of Nursing Students and Non-Medical Students Toward Vaccination

[1,2]Iva Marija Stipandić
[2] Janko Babić

[1] Health Center Zagreb-Istok, Zagreb, Croatia
[2] University of Applied Health Sciences, Zagreb, Croatia

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Author for correspondence:
Iva Marija Stipandić
Health Center Zagreb-Istok
Grižanska 4, Zagreb, Croatia
E-mail: iva20marija@gmail.com

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Keywords: vaccination, education, attitudes, medicine, students

Abstract

Introduction. Despite the scientifically proven positive effect on the population, vaccination remains a major public health problem. The biggest problem at the moment is that attitudes are based on other people's opinions or various scientifically unfounded information obtained via the Internet.

Aim. The aim of this study was to examine the attitudes and level of knowledge about vaccination of nursing students and non-medical students in Croatia and establish whether there is a difference between them.

Methods. The study involved 961 nursing and non-medical students from Croatia, aged between 18 and 53 years. The research was conducted using an online questionnaire program 'Google Forms' which consisted of 33 questions and was completely anonymous.

Results. The study shows that nursing students have better knowledge of vaccinations and vaccines. They also have a statistically more positive attitude towards vaccination in comparison to non-medical students. When it comes to obtaining information about vaccines, as in existing studies from around the world, the participants in this study stated that they first turn to doctors and nurses for information related to vaccination and its side effects.

Conclusion. The results of this study show that nursing students have better knowledge. Also, there was a statistically significant difference between the attitudes of nursing students and students of non-health studies, but the numerical difference is very small, which actually shows a very small difference in attitudes. Educational and health institutions play an important role in forming attitudes, as well as the importance of presenting accurate, clear, and proven information.

Introduction

Vaccination has greatly contributed to the social and economic development of society at the global level by reducing hospitalizations, reducing the need for expensive medical procedures, reducing epidemics and permanent disability by limiting the long-term effects of disease, reducing productivity and absenteeism (1). Vaccination or active immunization is a process that achieves immunity over time through the injection of live, inanimate or genetically modified antigens (2). This achieves a specific immunity that protects a person from a particular infectious disease. Passive immunization involves the intake of specific ready-made antibodies (IgG, IgA, IgM, and other plasma proteins) for current protection against infection or the development of an infectious disease (3). Immunization represents a key component of primary health care and an indisputable human right. It is also one of the most profitable investments in health care. Vaccines are also crucial to preventing and controlling the epidemic of infectious diseases. An optimal vaccination program and implementation achieves individual protection and collective immunity for human-to-human-transmitted diseases, and if sufficient coverage of the population by vaccination is achieved, disease transmission will be interrupted (4). In Croatia, vaccination is available to everyone and is defined by the Law on the Protection of the Population from Infectious Diseases (5). Most vaccines today are free and covered by the mandatory national vaccination program. The mandatory vaccination program in Croatia is implemented continuously throughout the year and prescribes diseases against which vaccination is mandatory with the aim of reducing disability and mortality; prescribes procurement, distribution, storage of vaccines, deadlines, vaccines of certain characteristics, time intervals between the application of individual vaccines, contraindications, method of documenting implementation, and reporting adverse reactions (6). Despite tremendous progress, large numbers of people worldwide, including nearly 20 million newborns, still lack access to vaccines. According to the World Health Organization, about 2.5 million deaths a year are still caused by vaccine-preventable diseases, mostly among African and Asian in all age groups (7). On the other hand, more developed countries have a problem with the anti-vaccination movement and the downward trend in vaccination. Unfortunately, although the availability of a variety of information on the Internet has its advantages, it also has some disadvantages. On the Internet, people can come across a lot of untrue and unfounded articles, and thus a variety of information about vaccines promoted by various anti-vaccination groups. There exists mistrust toward the health system and concerns about the efficacy and safety of vaccines. Based on the report of the Croatian Institute of Public Health, it can be concluded that due to the continuous decline in vaccination in the period from 2011 to 2017, the level of collective immunity has been endangered, primarily among preschool children (8). In the last two years, the negative decline in vaccination has stopped, which is a good sign, and if this positive trend continues it should be possible to avoid epidemics of infectious diseases which have been a serious threat in recent years.

Aim

The purpose of this study is to examine the attitudes and level of knowledge about vaccination of nursing and non-medical students in undergraduate and graduate professional and university studies in Croatia and establish whether there is a difference between them.

Specific goals:

1. Examine the difference in attitudes about vaccination and vaccines among students according to the type of study
2. Compare the level of knowledge about side effects among students according to the type of study
3. Examine students' perceptions of who influences their attitudes about vaccination the most

Hypothesis

1. Nursing students have a more positive attitude towards vaccination than non-medical students
2. Nursing students are better educated and informed about the vaccination calendar than non-medical students
3. There is no difference in knowledge between nursing students and non-medical students about the connection between vaccines and disease
4. Regardless of the type of study, students perceive that educational institutions and the internet have the greatest impact on their attitudes towards vaccination
5. Regardless of the type of study, students received most information and advice from physicians and nurses

Methods

Using the online program ‘Google Forms’, respondents filled in a questionnaire which was created for the purposes of this study. The participants completed the questionnaire in the period from October 2019 to March 2020. 33 questions needed to be answered, which took about 5 minutes to complete, and participation was completely anonymous and voluntary. Each participant could withdraw from the survey at any time. The first part of the questionnaire asked for general information about the respondents (age, gender, and type of study). The second part of the questionnaire consisted of statements related to the students’ attitudes towards vaccination. Participants gave their answers on a Likert scale from 1 to 5. They had to respond to individual statements by choosing one of the following options: 1 - strongly disagree, 2 - disagree, 3 - neither agree nor disagree, 4 - agree, 5 - strongly agree. The rest of the questionnaire referred to the students’ knowledge of vaccination. They were offered yes/no answers and supplementary questions. For statistical data processing, Microsoft Excel 2010 and the statistical program SPSS 21 (IBM SPSS Statistics for Windows) were used, along with methods of descriptive and inferential statistics.

Results

The study involved 961 nursing and non-medical students from Croatia. According to the gender of the respondents, the largest number of respondents was female (N=785, 81.7%), while 176 were male (18.3%). The age range of participants is between 18 and 53 years, with an average age of 22 years. Table 1 shows the type of study: the sample consisted of 455 (47.3%) nursing students and 506 (52.7%) non-medical students.

Table 1. **Participants according to the type of study**

		N	%
STUDY	Nursing studies	455	47.3
	Non-medical studies	506	52.7
	Total	961	100

Regardless of the type of study, 796 of all respondents are in favour of mandatory vaccination for vaccines listed in the vaccination calendar, while the remaining 165 believe that vaccination should not be mandatory. The first hypothesis was that nursing students had a statistically significantly more positive attitude toward vaccination than non-medical students. This hypothesis was tested and confirmed by a nonparametric method via the chi-square test. Table 2 shows that a statistically significant difference in attitudes towards vaccination was obtained with regard to the type of study (chi-square=13.09, df=1, $p<0.01$), with nursing students significantly more supportive of the claim that vaccination should be mandatory (87.5%), as opposed to non-medical students (78.7%).

Table 2. **Students' responses to the question "Should vaccination be mandatory?" according to the type of study**

Should vaccination be mandatory for vaccines listed in the vaccination calendar?						
	YES	%	NO	%	TOTAL	%
Nursing studies	398	87.5	57	12.5	455	100
Non-medical studies	398	78.7	108	21.3	506	100
Total	796		165		961	
Chi-square	13.09*					
df	1					

p < 0.01

Table 3 shows that 550 of the total number of respondents stated that they had knowledge about the vaccination calendar, while the rest stated that they did not have sufficient knowledge (N=411).

Table 3. **Students' responses to the question: "I am well informed about the vaccination calendar and what are certain vaccines used for?" according to the type of studies**

I am well informed about the vaccination calendar and what are certain vaccines used for?						
	YES	%	NO	%	TOTAL	%
Nursing studies	341	74.9	114	25.1	455	100
Non-medical studies	209	41.3	297	58.7	506	100
Total	550		411		961	
Chi-square	110.76*					
df	1					

p < 0.01

The second hypothesis claims that nursing students are better educated and instructed in the vaccination calendar than non-medical students. The chi-square test resulted in a statistically significant difference according to the type of study (chi-square=110.76, df=1, *p*<0.01), with nursing students (74.9%) significantly more informed about the vaccination calendar and what certain vaccines are used for in comparison to non-medical students (41.3%). Furthermore, it can be seen that the majority of all students do not agree that the vaccination calendar in Croatia is too extensive (N=841), while the remaining students (N=120) agree with such an assessment. Depending on the type of study, there is a statistically significant difference (chi-square=6.27, df=1, *p*<0.05) between nursing students (9.7%), who believe significantly less strongly that the vaccination calendar in Croatia is too extensive, and students of non-medical studies (15%). On the question about the risk of new vaccines over old ones, there is no statistically significant difference with regard to the type of study (chi-square=0.21, df=1, $p>0.05$). Nursing students (53.4%) show greater knowledge about the side effects of vaccines than non-medical students (34.4%). According to the type of study, there is a statistically significant difference (chi-square=35.28, df=1, $p<0.01$). As part of this question, all students who answered positively (N=417) were also able to answer an open-ended question and write about the side effects of the vaccine. Most of them wrote: pyrexia (fever), local redness and pain at the injection site, allergic reactions (rash, urticaria, and anaphylactic shock), headache, nausea, vomiting and gastrointestinal problems. Most of the side effects written by students correspond to the register of side effects of vaccines, which indicates good knowledge among the students who provided a positive answer to this question. The third hypothesis (zero) says that there is no difference in knowledge between nursing students and non-medical students about the connection between vaccines and disease. Nursing students (M=2.13, sd=1.00) are statistically significantly less likely to think that vaccines cause other diseases (t=-2.05. df=959, $p<0.05$) than students of non-health studies (M=2.27, sd=1.10). The t-test also shows that nursing students (M=1.64, sd=0.97) are statistically significantly less likely (t=-3.26. df=959, $p<0.01$) to believe that vaccines cause autism than non-medical students (M=1.87, sd=1.14). Regardless of the type of study, the ratio of all students who would vaccinate their children (N=890) according to the mandatory vaccination calendar is significantly higher than the number of students who said they would not do so (N=71). Considering the type of studies, nursing students are more likely to agree to the vaccination of their children with the mandatory vaccine (95.2%) than non-medical students (90.3%), with a statistically significant difference (chi-square=8.23, df=1, $p<0.01$). In comparison with the previous question, where the majority of students provided a positive answer, the responses to this question were divided. Regardless of the type of study, 504 students would vaccinate their children with an additional vaccine that is not on the list of the mandatory vaccination calendar, while the remaining students would not (N=459). Nursing students (60.4%) are statistically significantly (chi-square=22.14, df=1, $p<0.01$) more in favour of vaccinating their own children with an optional vaccine than non-medical students (45.3%). Regardless of the type of study, the majority of 874 students oppose the abolition of the mandatory vaccination calendar, while 87 are in favour of abolishing it. Comparing the attitudes with respect to the type of study, there is a statistically significant difference (chi-square=10.21, df=1, $p<0.01$), with non-medical students (11.9%) significantly more in favour of abolishing the calendar than nursing students (5.9%). 605 students believe that children who have not been vaccinated should be forbidden to enrol in kindergarten, and 356 believe that the ban should not be introduced. When students are divided by the type of study, there is no statistically significant difference (chi-square=1.02, df=1, $p>0.05$). Of the total number of students, 511 think that parents who did not vaccinate their children should be fined, while 450 disagree. Regarding the type of study, there is no statistically significant difference in attitudes (chi-square=0.61, df=1, $p>0.05$). Most of the students stated that they had never been vaccinated against influenza (N=779), while 182 had been vaccinated at least once in their lives. When students are divided by the type of study, there is no statistically significant difference (chi-square=0.92, df=1, $p>0.05$). In the next part of the study, the respondents were able to choose from seven answers when asked to indicate who had the greatest influence on their opinion about vaccination (Table 4). The fourth hypothesis was partially confirmed by descriptive data, which shows that students perceive that their attitudes about vaccination are mostly influenced by health facilities and the internet. The hypothesis was not fully confirmed, as students stated that they were mostly influenced by educational (35.1%) and health institutions (27.4%).

Table 4. **Influences on students' opinions about vaccination regardless of the type of study**

Of the following, who or what has had the greatest influence on your opinion about vaccination?		
	N	%
Educational institutions	337	35.1
Healthcare facilities	263	27.4
No one	142	14.8
Family / friends	114	11.9
Internet	59	6.1
Multiple answers	35	3.6
TV / newspaper	11	1.1
Total	961	100

The fifth hypothesis was that regardless of the type of study, students received most information and advice from doctors and nurses. This hypothesis was not fully confirmed, as a large percentage of students stated that they sought or received most advice from a doctor (39.8%), or that they had never sought or received any advice or information (21.5%). Of the seven possible answers to the question shown in Table 5, nurses as a source of information are only in the 6th place, with 3.9%, while the fewest number of students selected the answer "Pharmacist" (1.1%).

Table 5. **Sources of information and advice about vaccinations and vaccines regardless of the type of study**

You have asked for or received information and advice about vaccines and vaccination from the following sources:		
	N	%
Doctors	382	39.8
I have never asked for or received any advice or information	207	21.5
Via the Internet / TV / newspaper	116	12.1
Croatian Institute of Public Health	114	11.9
Family members / friends	94	9.8
Nurses	37	3.9
Pharmacist	11	1.1
Total	961	100

Nursing students (M=4.65, sd=0.70) statistically significantly (t=3.79, df=959, $p<0.01$) more strongly believe that vaccines help prevent infectious diseases when compared to non-medical students (M=4.44, sd=0.95). Regarding the question of vaccination benefits, the t-test (t=4.10, df=959, $p<0.01$) also shows that nursing students (M=4.55, sd=0.82) statistically significantly more strongly believe that the benefit of vaccination is greater than its side effects when compared with non-medical students (M=4.28, sd=1.11). The answers to the question about the safety of vaccination (t=3.93. df=959, $p<0.01$;) show that nursing students (M=4.19, sd=0.90) significantly more strongly believe that vaccines are safe and well-controlled when compared with non-medical students (M=3.92, sd=1.14). Students of non-medical studies (M=2.61, sd=1.33) statistically significantly more strongly believe that the pharmaceutical industry has more benefits from vaccines than the general population when compared with nursing students (M=2.21, sd=1.22; t=-4.86, df=959, $p<0.01$).

Table 6. **Students' responses to the question about the connection between vaccines and autism and other diseases**

	Vaccines cause some other diseases		Vaccines cause autism	
Mean	2.21		1.76	
Median	2.0		1.0	
Mode	1		1	
Standard deviation	1.06		1.07	
Minimum	1		1	
Maximum	5		5	
	Nursing studies	Non-medical studies	Nursing studies	Non-medical studies
Arithmetical mean	2.13	2.27	1.64	1.87
Standard deviation devijacija	1.00	1.10	0.97	1.14
Total	961		961	
t	- 2.05		- 3.26	
df	959		959	
	$p<0.05$		$p<0.01$	

Discussion

This study analysed differences in attitudes and basic knowledge between nursing students and non-medical students in Croatia. Regardless of the type of studies, students generally have positive attitudes toward vaccination, which supports claims that people with a higher level of education are more in favour of vaccination than people with a lower level of education (9). When the types of study are taken into consideration, the difference in arithmetic means is significant (which is not unexpected, considering the sample size), but it is numerically very small, which means that it shows a very small difference in attitudes. The study also shows that nursing students have a more positive attitude towards compulsory vaccination with vaccines listed in the vaccination calendar, which in Croatia consists of a three-year vaccination program (2019-2021) (10). The results show that nursing students are better informed about vaccines and the vaccination calendar. Such results are to be expected if one takes into consideration that nursing students undergo additional education and practice. We can conclude from this that additional education and national programs would help change the thinking of individuals advocating for the anti-vaccination movement, and thus reduce the spread of infectious diseases. Many studies, especially in recent years, have examined the attitudes of the population toward vaccination. The main reason for this is numerous media articles and public statements of people who express their scientifically unfounded opinions about the harmfulness of vaccination. Disclosure of such information that has not been scientifically proven is very harmful and threatens the implementation of one of the most important public health programs in any country – the protection of public health through vaccination (5). Information sources represent a very important link in education. Information used by students and the rest of the population should be reliable and based on verified facts. According to a 2015 study by Kulić, the most commonly used sources are doctors, followed by the Internet and nurses (11). Table 5 confirms this, showing that doctors and the Internet were sources of information for most of the respondents. It is interesting to note that few of the respondents selected the answer "Nurses", which is only in sixth place. Also, considering the general interest in the topic of vaccination and the level of education of the respondents, it is very alarming that the majority of all participants stated that they had never asked for or received advice and information about vaccination. Another study from 2005 found that the results of searching for the word "vaccination" on the Internet consist of 60% of anti-vaccination content (12). The negative attitudes of the respondents mostly stem from a lack of information about the serious consequences of the diseases against which vaccination is carried out, both for individuals and the community as a whole. The key to better understanding and building trust lies in a system of training professionals to be able to answer all questions and monitor the effects of vaccination, as well as in educating the general public. At the same time, more emphasis needs to be placed on verified and credible sources of information that are neglected today. Such efforts will help strengthen the bond of trust between medical workers and patients, as well as provide a way to change negative beliefs about vaccination through arguments. It is important to inform the public about the consequences of avoiding vaccination, especially the fact that being unprotected is of greater risk than being protected (13). Students, regardless of the type of studies, mostly agreed with the statement that the benefits of vaccination are significantly greater than its side effects, but when comparing attitudes by type of studies, nursing students have a more positive attitude. A similar study shows that 100% of physicians surveyed in Croatia, 76% in Romania, 75% in France, and 55% in Greece believe that the benefits of vaccination outweigh the possible side effects (14). A study from 2007 has shown that reactions to vaccines can be expected in most cases (15). Most often, these side effects are mild and mainly include fever, irritability, local redness and pain at the injection site, allergic reactions (rash and urticaria), headache, nausea, vomiting and gastrointestinal problems. Healthcare professionals consider these side effects to be very mild and insignificant, while opponents of vaccination say more attention should be paid to them. Most of the participants stated that they knew which side effects vaccines cause. The development and approval process of vaccines is time-consuming and complex, and includes the analysis of appropriate vaccine quality, its effectiveness, and safety of application. Vaccine safety is continuously evaluated by monitoring for adverse reactions during the clinical trial, and especially after the start of administration. If clinical trials prove that the risk outweighs the benefits, such a vaccine cannot be marketed. In Croatia, the Agency for Medicinal Products and Medical Devices is responsible for approving and checking the quality of all medicines, including vaccines on our market. During 2018, a total of 212 side effects after vaccination were reported in Croatia (16). Most reports were related to mild side effects, such as fever, redness, and swelling at the site of application (16). Any reaction that occurs after vaccination does not necessarily mean a cause-and-effect relation. For some side effects, such as a local reaction at the site of vaccination, it is easy to determine the cause-and-effect relation. For others, such as fever after vaccination, it is difficult to determine whether the cause is a vaccine or a disease independent of vaccination. Regarding the statement that vaccines cause autism, students stated that they somewhat disagree, although nursing students agree with this statement to a lesser degree than students of non-medical studies (Table 6). Although there is a statistically significant difference in favour of nursing students, these results are very encouraging because non-medical students also showed a high degree of disagreement with this scientifically unproven claim. On the statement that vaccines cause some other diseases, the statistics were similar to the previous statement. There is enough evidence to reject the null hypothesis according to which there is no difference in attitudes between nursing and non-medical students regarding the connection between vaccination-related diseases (Table 6). In 2011, the American Institute of Medicine conducted a thorough review of the professional and scientific literature with the aim of determining the association of various vaccines (17). Regardless of the vaccine ingredients and certain side effects, they concluded that no vaccine was associated with autism and that vaccines were generally safe for use in children and adults, as well as that (other) serious side effects are rare (16). Another study by Geber and Offit presented research conducted around the world based on the link between vaccines and autism (18). Theories for this putative association have centred on the measles-mumps-rubella (MMR) vaccine, thimerosal, and the large number of vaccines currently administered. However, both epidemiological and biological studies fail to support these claims (18).

Conclusion

This study showed a statistically significant difference in attitudes and knowledge between nursing students and non-medical students. Although both groups of students showed positive attitudes towards vaccination in most cases, nursing students had statistically significantly more positive attitudes and better knowledge. Such results are not too surprising considering that nursing students undergo additional education during their schooling. Different international studies, including this one, found that students stated that doctors and nurses are the first to be approached for information related to vaccination and its side effects. Additional education and a sense of trust of both students and the general population towards health care staff would significantly change the negative attitude towards vaccination and thus help maintain group immunity and prevent the spread of infectious diseases. Therefore, it is necessary to invest in programs and education about vaccination of both the population and health professionals because they have an important role in forming attitudes as well as presenting accurate, clear, and proven information.

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STAVOVI STUDENATA SESTRINSTVA I STUDENATA NEZDRAVSTVENIH STUDIJA O CIJEPLJENJU

Sažetak

Uvod. Bez obzira na znanstveno dokazani pozitivan učinak na populaciju, cijepljenje i dalje predstavlja veliki javnozdravstveni problem. Najveći je problem što se stavovi baziraju na raznim znanstveno neutemeljenim informacijama.

Cilj. Cilj ovog istraživanja bio je ispitati stavove i razinu znanja o cijepljenju studenata sestrinstva i nezdravstvenih studenata u Republici Hrvatskoj te postoji li razlika između njih. Metode. U istraživanju je sudjelovao 961 student sestrinstva i nezdravstvenih studija s područja Republike Hrvatske, u dobi između 18 i 53 godine. Istraživanje je provedeno putem online upitnika sastavljenog u programu Google obrasci koji se sastojao od 33 pitanja te je bio u potpunosti anoniman.

Rezultati. Istraživanje je pokazalo kako su studenti sestrinstva bolje upućeni u cjepiva i cijepljenje naspram nezdravstvenih studija. Kada je u pitanju informiranje o cjepivima, u istraživanjima diljem svijeta, pa tako i ovom, studenti su naveli kako su stručne osobe (liječnici i medicinske sestre) oni kojima se prvima obraćaju za informacije povezane s cijepljenjem i nuspojavama cjepiva.

Zaključak. Ovo istraživanje pokazalo je bolje znanje studenata sestrinstva o cjepivima. Također je dokazana i statistički značajna razlika u stavovima studenata sestrinstva i studenata nezdravstvenih studija, ali je brojčana razlika vrlo mala, što zapravo iskazuje vrlo malu razliku u stavovima. Vrlo je važno ulagati u programe i edukaciju o cijepljenju, kako studenata tako i cijele populacije. Veliku ulogu u formiranju stavova imaju obrazovne i zdravstvene ustanove, kao i važnost u prezentiranju točnih, jasnih i dokazanih informacija.

Ključne riječi: cijepljenje, obrazovanje, stavovi, medicina, studenti

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Coping with Stress of Nurses Employed in the Internal Medicine and Surgical Departments

[1] **Danijela Kundrata**
[2] **Zrinka Pukljak**
[1] **Marin Repustić**
[2,3,4] **Cecilija Rotim**
[2,5] **Adriano Friganović**
[2] **Biljana Kurtović**

[1] **Department for Ensuring and Improving the Quality of Healthcare, General Hospital „dr. Ivo Pedišić", Sisak, Croatia**
[2] **University of Applied Health Sciences, Zagreb, Croatia**
[3] **Rotim Polyclinic, Zagreb, Croatia**
[4] **Faculty of Dental Medicine and Health, Josip Juraj Strossmayer University of Osijek, Osijek, Croatia**
[5] **Department of Anesthesiology and Intensive Medicine, University Hospital Centre Zagreb, Zagreb, Croatia**

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Author for correspondence:

Danijela Kundrata

Department for Ensuring and Improving the Quality of Healthcare

General Hospital „dr. Ivo Pedišić"

Josipa Jurja Strossmayera 59, Sisak, Croatia

E-mail: dkurtovic2001@yahoo.com

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Abstract

Introduction. Stress is a state of tension that arises when events or requests from the environment are assessed as threatening or too demanding. In the process of coping, we use different cognitive and behavioral strategies. Problem-oriented coping involves strategies aimed at changing or removing stressors. Emotion-focused coping encompasses stress-induced arousal management strategies. No coping strategy is universally effective, but the success of coping is assessed in the interaction of an individual's characteristics and a stressful situation. The prevalence of individual coping patterns among nurses may depend on their workplace.

Aim. To determine nurses in the internal medicine and surgical departments of two Croatian hospitals cope with stress.

Methods. The participants were 163 nurses from the internal medicine and surgical departments of the Sisak General Hospital "Dr. Ivo Pedišić" and the General Hospital Karlovac. The measuring instruments used are the Questionnaire on how to deal with stress and the Scale for assessing the importance of events and the possibility of control.

Results. The most common ways of coping with stress are planned problem solving, seeking social support, and self-control, while the rarest way of coping is avoidance. Nurses perceive the success of coping with stress as moderate, and the degree of control over stressful situations as rather low. Stressful situations are most often perceived as a threat, and least often as a challenge. With the perception of a greater degree of control over the situation, they more often choose to accept responsibility as a way of coping. In internal medicine departments, stressful events are assessed as significantly more disturbing than in surgical departments.

Conclusion. The results confirm that for further education of nurses on successful coping with stress, it is important to examine and further explore cognitive processes in selecting ways of coping: the meaning they attach to the situation, assessing control over the situation, and self-assessing coping success.

Introduction

Multiple studies have shown that significant levels of workplace stress exist among nurses (1-6). At the individual level, stress of nurses leads to a number of physical and emotional symptoms, and favors the development of professional burnout while significantly compromising the quality and efficiency of provided health care (7-10). Also, when there is dissatisfaction with the workplace and the volume of work, it is difficult to retain skilled and qualified nurses (11-14). A large number of international (15-22) and Croatian studies (23-30) have researched the sources of stress in the workplace of nurses. Such research provides insight into what happens to nurses during the work process, but provides no insight into how they cope with that and how successful the coping mechanisms they use are in dealing with stress. This is important because modern theories of stress emphasize the difference between potential stressors and stress as a comprehensive reaction of the organism. The most famous is the theory of stress by Lazarus (31), which points out that the stress of a situation depends not only on the characteristics of what is happening, but also on the characteristics of the person experiencing stress. The same situational circumstances have different meanings for different people because a person's level of stress depends on their cognitive assessment of the situation. Two processes are crucial: assessing the importance and significance of a situation and assessing the possibility of controlling the situation (31). If an event is assessed as important and threatening, we attach stressful significance to it. We perceive it as a *loss* (we estimate that some permanent damage has occurred), a *threat* (we estimate that some damage is very likely to happen) or as a *challenge* (we estimate that there is a possibility of both a positive and a negative outcome). Depending on the assessment of the possibility of control over the situation, the person selects the ways in which they confront it. Coping is a process, and it involves the application of a variety of cognitive and behavioral strategies with the goal of overcoming or reducing stressors, or improving coping with them. Lazarus and Folkman (31) divide ways of coping with stress into problem-oriented coping, emotion-focused coping, and coping by avoidance.

Emotion-focused coping involves expressing, mitigating, and/or controlling emotional reactions in order to more easily cope with the excitement caused by a stressful situation. By facing stress in this way, we try to change how we think about the stressor and/or how we feel about it. These ways of coping are more appropriate in situations where we have little control over the situation.

Problem-oriented coping is the mechanism by which we try to act on the stressor, to change the situation by solving the problem and/or taking action. It is appropriate for situations where there is a possibility of control.

Coping by avoidance refers to the cognitive, emotional, or distancing actions in relation to a source of stress or our mental and physical reactions to a stressor. In everyday life, we most often use problem-oriented coping and emotion-focused coping, so we try to affect the situation and change the way we think about it and how we feel about it. Usually, however, one type of coping dominates, and this is called the preferred response style (31).

In line with their interactive approach, Lazarus et al. point out that none of the ways of coping is universally effective in itself. It makes sense to evaluate the success of a way of coping only in a temporal perspective (a way of coping that helps us in the short term can be harmful in the long run) and in relation to a specific situation and a specific person.

Research on how nurses deal with stress is conducted in order to gain insight into the prevalence of different ways of coping and assess their effectiveness (32-36), but these are rare in Croatia (37,38). They are important because they can contribute to the organization of systematic education of nurses on the development and selection of effective coping strategies, which on a personal level can help them regulate stress responses, and thus contribute to maintaining and improving the quality of health care.

Aim

To determine how nurses in the internal medicine and surgical departments in two Croatian hospitals experience the stressful situations they encounter, and which coping methods they most often use.

Specific aims

1. To determine the stressful situations experienced by nurses, the meaning they attach to them, and the assessment of the possibility of control and the success in coping with stress.
2. To determine the frequency of individual ways of coping.
3. To examine the relationship between coping patterns and the importance that participants attach to a stressful situation with an assessment of anxiety, controllability, and coping success.
4. To examine whether there are differences in stress, control, and coping performance with regard to the nurses' workplace.

Methods

Participants

The participants were 163 nurses employed in the internal medicine and surgery departments of the Sisak General Hospital "Dr. Ivo Pedišić" and the General Hospital Karlovac.

Ethics

The study was approved by the Ethics Committee of the Sisak General Hospital "Dr. Ivo Pedišić", (registration number: 2176-125-04-3476-5/16) and General Hospital Karlovac, (registration number: 01-12-85/1). Nurses were invited to voluntarily participate in the study. Forms with information on the study were provided to the participants together with questionnaires. Participants were able to stop participating in the study at any time, and they were informed that the study was anonymous and numerically coded for identity protection purposes.

Instruments

Event Assessment and Control Possibility Scale included elements of Lazarus' model of stress. The scale was created for the purposes of this study. Participants were asked to recall events at work that had upset them the most in the past week. Participants were asked to assess whether the event was a *loss* for them (injury, disappointment, loss of someone or something valuable, loss of self-esteem, respect for others, etc.), *threat* (threat, facing some kind of danger or concern about how something will end; potential loss of a person or something of value, potential loss of self-esteem, respect for others, etc.) or *challenge* (facing an opportunity for profit, gain, further development, improvement, well-being). After that, the respondents were asked the following: "On a scale from 0 to 3, circle the number that shows how much the event you remembered upset, worried, or frightened you, depending on how stressful the experience was." Using these instructions, participants assessed how disturbing the event was for them. Then, also on a scale from 0 to 3, they assessed how much they thought they themselves influenced the onset of that event and to what degree they thought they had successfully coped with that event.

The Ways of Coping Questionnaire (WOC) (39) consists of 66 statements about cognitive and behavioral efforts used to manage a specific stressful event (from "0 - not applicable or not used" to "3 - used to a great extent") divided into eight subscales: coping by confrontation, planned problem solving, distancing, self-control, seeking social support, accepting responsibility, avoiding problems, positive reassessment. Such strategies are in this questionnaire viewed as a consequence of the characteristics of the situation and the cognitive processes during it, rather than as a lasting personal coping style (40). Cronbach's α coefficient of internal reliability in this study was 0.92.

To determine the frequency of use of each coping strategy, the average value of responses for each scale was calculated by dividing the total gross score of the scale by the number of claims, according to the Manual of the Stress Management Questionnaire (39).

The questionnaire on how to deal with stress was ordered from a publishing house that has the right to distribute its translation in Croatia.

Statistical data processing was performed using IBM SPSS Statistics 23.

Procedure

The study was conducted in two hospitals, lasting 15 to 20 minutes, which was enough to give instructions to participants and for them to fill in the questionnaires. Participants were provided with personal space to complete the questionnaires independently. Participants first completed the Event Assessment and Control Possibility Scale. Participants then completed a Ways of Coping Questionnaire, taking into account the ways of coping used in the situation they recalled in the first part of the survey. After filling in the questionnaires, the participants put them in a box prepared for that purpose so that the researcher would not have an insight into their order.

Results

The majority of the total of 149 participants (91%) were female, and 14 participants (0.9%) were male. As shown in Table 1, most respondents have a high school education and are in a relationship. The average age is 37, and the average number of the years of work experience is 16.

Table 1. **Descriptive indicators**

		f	%	M	SD	MIN	MAX
age		163		37.30	10.6	20	59
education	secondary school	104	63.8				
	higher education	59	39.2				
relationship	in a relationship	107	65.7				
	single	56	34.3				
years of experience		163		15.9	11.05	1	40
hospital	Sisak	99	60.7				
	Karlovac	64	39.3				
department	internal medicine	81	49.7				
	surgery	82	50.3				

Participants assessed the stress of the stressful event they recalled on a scale of 0–3 as quite high (M = 2.07, SD = 0.758), the control assessment was relatively low (M = 0.76, SD = 0.838), and the assessment of success in coping with a stressful situation is average (M = 1.65, SD = 0.774). For the majority of respondents, the stressful event they recalled represented a threat (N = 69, 42.3%), somewhat less often a loss (N = 57, 35%), and least often a challenge (N = 35, 21.5%).

According to the results shown in Table 2, nurses most often use planned problem solving, seeking social support, and self-control as ways of coping. Escape or avoidance is the least used coping strategy.

Table 2. **Average results of using certain coping methods from the Questionnaire on Coping with Stress (WOC)**

	MIN	MAX	M	SD
confrontation	0.00	2.50	1.22	0.58
distancing	0.00	3.00	1.20	0.59
self-control	0.14	2.71	1.33	0.53
seeking social support	0.00	2.83	1.29	0.62
acceptance of responsibility	0.00	2.75	0.91	0.63
escape - avoidance	0.00	2.88	0.69	0.53
planned problem solving	0.00	3.00	1.50	0.65
positive reassessment	0.00	2.57	0.99	0.57

To determine whether there are differences in the chosen ways of coping depending on the importance that nurses attach to the situation (loss, threat, challenge), a series of variance analyses were conducted. A statistically significant difference was found only in the use of the strategy of accepting responsibility (F = 3.25, $p<0.05$). Post-hoc analysis by Scheffe's test showed that this difference refers to more frequent acceptance of responsibility when the situation is perceived as a loss (M = 1.07) than when it is perceived as a threat (M = 0.78).

To determine the relationship of coping mode with anxiety assessment, controllability, and coping success, the correlations shown in Table 3 were calculated.

Table 3. **Correlation coefficients (Pearson's r) between measured variables (N = 163)**

	Variables	1	2	3	4	5	6	7	8	9	10
1	stress / anxiety	1									
2	control	0.01	1								
3	coping performance	-0.15	-0.13	1							
4	confrontation	-0.07	-0.17	-0.04	1						
5	distancing	0.06	0.01	-0.10	-0.03	1					
6	self-control	0.09	-0.02	-0.05	-0.26**	-0.14	1				
7	seeking social support	0.09	-0.02	-0.05	-0.23**	-0.14		1			
8	acceptance of responsibility	-0.11	0.29**	0.05	-0.34**	-0.30**	-0.15	-0.15	1		
9	avoidance	0.12	-0.06	-0.12	-0.04	-0.03	-0.30**	-0.30**	-0.12	1	
10	problem solving	-0.05	-0.13	0.17*	-0.15	-0.26**	-0.12	-0.12	-0.24**	-0.26**	1
11	positive reassessment	-0.05	0.08	0.11	-0.14	-0.21**	-0.21**	-0.21**	0.18*	-0.02	-0.08

** = $p < 0.01$; * = $p < 0.05$

Although low, a statistically significant correlation was found between the assessment of control over the situation and the acceptance of responsibility. The higher the assessment of control over the situation, the more often nurses use accepting responsibility as a way of dealing with a stressful situation.

The last problem of the study was related to determining the differences in the measured variables between nurses from different departments. The results of t-tests are shown in Table 4. There was a statistically significant (t = 2.31, $p<0.05$) difference in the assessment of anxiety of nurses in the internal medicine department compared to the assessment of anxiety in participants from the surgical department.

However, no differences were found in the assessment of the possibility of control and the success of coping between the participants from the internal medicine and surgical departments.

Table 4. **T-test values for differences in assessment of anxiety, control, and coping performance between internal medicine (N = 81) and surgical departments (N = 82)**

	anxiety		control		coping performance	
	M	SD	M	SD	M	SD
internal medicine departments	2.21	0.72	0.72	0. 81	1.65	0.74
surgical departments	1.94	0.78	0.80	0. 87	1.65	0.80
t	2.31*		- 0.67		0.07	
df	161		161		161	

*$p<0.05$

Discussion

The purpose of this study was to examine the most common ways of coping with stress in nurses from two different departments in accordance with the Lazarus model of stress, and to determine the relationship between coping with the assessment of anxiety, ability to control and cope with stress, and the importance that is attached to stressful situations.

Nurses have been found to assess stressful workplace events as quite disturbing, which is consistent with existing research (34,37).

The assessment of control over stressful situations is relatively low, and the success of coping was assessed as average. Most respondents experienced a stressful event as a threat, slightly less as a loss, and least of all as a challenge. These results contribute to elucidating the processes related to the experience of stress in nurses, given that according to our knowledge no previous studies have been conducted in Croatia on the subjective assessment of control and success of coping with stress and the importance that nurses attach to these stressful situations.

Such findings point to the need for further research and education of nurses on the effective selection of stress management strategies. Studies on the sources of stress at work among nurses have prevailed so far (23-30). These findings are useful in the case of stressors that can be controlled and/or avoided. However, the results of this study show that nurses assess control over stressful situations as low. This is understandable because we can assume, although this was not examined in the study, that some stressors are related to the characteristics of workplaces and patients in internal and surgical departments, and these are often stressors that cannot be avoided an/or significantly altered. However, it should be emphasized that the first spontaneous assessment of the situation and the perception of control over it can be more or less realistic. Some people underestimate and some overestimate the degree of control over a given situation. In both cases, selecting coping strategies is less effective in reducing the stressful experience.

The finding that nurses most often perceive stressful events as a threat, and least of all as a challenge, also emphasizes the importance of education about the possibilities of constant re-assessment, i.e. cognitive management of stressful situations. Whether we perceive a situation as a threat or a challenge depends on whether we estimate that there is a greater chance of negative outcomes of the situation or whether we also consider the possibility of a positive outcome. By encouraging nurses to re-evaluate stressful situations after the first spontaneous assessment, be as realistic as possible in assessing control of the situation, and focus more attention on potential positive outcomes when the situation has not yet occurred, it is possible to alleviate stress and the meaning of some situations, changing them from a threat to a challenge. This significantly changes both emotional response and behavior in stressful situations and can contribute to better coping with stress (41), and thus better quality of nursing care.

The scale of assessing the importance of the event and the possibility of control predicts that respondents choose only one of the possible meanings of the event (loss, threat, challenge), but it is possible that some respondents could experience a situation as loss (e.g. a close colleague is dismissed) and as a threat (e.g. the respondent worries whether they will bear sanctions for the same omission that led to their colleague's dismissal). The results were processed under the assumption that the respondents opted for the meaning that dominated their experience.

Low correlations were found between different ways of coping, which is in line with expectations because in constructing the questionnaire the authors received an eight-factor structure according to which each of the examined ways of coping (coping by confrontation, planned problem solving, distancing, self-control, seeking social support, problem avoidance, positive reassessment) is a special independent factor, i.e. a measure of coping (39).

The results show that nurses use planned problem solving, seek social support, and self-control as the most common ways of coping, while the least used method is escape or avoidance. This is in line with expectations and previous studies conducted in Croatia (37,38,43), as well as with most international research (42,43). The dominance of planned problem solving is probably due to the fact that the health care process is action-oriented and directly addresses everyday professional challenges. In order to successfully achieve the goals of health care, ample planning, analysis, and organization of the work environment is needed, which is all part of planned problem solving as a strategy for dealing with stress.

Seeking social support as the second most common way of coping is in line with the results of existing studies, which show that social support, especially when it comes from co-workers and superiors, is one of the most important elements in preventing burnout of nurses (44).

Avoidance strategy consists of avoiding dealing with a stressful situation and denying the problem by turning to other activities. It can be effective in the short term, especially if we have no control over the situation, but if there is control, it is associated with poorer adjustment in the long run (40). Therefore, the finding that nurses use it the least speaks about their tendency to be active and mature.

Participants rely more frequently on acceptance of responsibility when they perceive a stressful situation as loss than as a threat. This is in line with one of the assumptions of Lazarus' model, according to which the choice of the coping model depends on the meaning a person attaches to the situation.

Comparisons of the results of participants from different departments showed that nurses of internal medicine departments assess their stressful events as significantly more disturbing than their colleagues from surgical departments, which suggests that the degree of stress depends on the characteristics of the work environment and the type of patients nurses work with. There is a lack of studies comparing the stressful experiences of nurses of these two departments, but existing studies show high levels of stress and burnout in internal medicine departments (45-47). When comparing the behavior of nurses from different departments in stressful situations, certain differences were also found (48,49), which is important when planning programs and interventions in order to alleviate workplace stress for nurses, as well as for nurses' adaptation to the specifics of the workplace (50).

This study has certain limitations, which is why any generalization about the entire nursing population should not be done lightly. Participants are employees of only two hospitals, and in future studies it would be desirable to include more participants from other hospitals with the same departments. The situation in other departments should also be examined, and additional personal variables should be explored, such as the quality of interpersonal relationships and elements of emotional control, which some studies have shown to be important predictors of stress perception and coping success (51).

Conclusion

Based on the results of this research, we can conclude that nurses experience quite disturbing stressful situations in the workplace. The participants have the impression that their control over such situations is quite low and their coping performance is mediocre. Stressful situations are most often perceived as a threat, and least often as a challenge.

Planned problem solving, seeking social support, and self-control are the most common ways of coping the participants use, while avoiding dealing with a stressful situation is the least used strategy. The strategy of accepting responsibility is more frequently used when a stressful situation is perceived as a loss rather than when it is perceived as a threat. The higher the assessment of control over the situation, the more likely a person will choose to accept responsibility as a coping strategy. Nurses of the internal medicine departments assess their stressful events as significantly more disturbing than their colleagues from the surgical departments.

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SUOČAVANJE SA STRESOM MEDICINSKIH SESTARA ZAPOSLENIH NA ODJELIMA INTERNISTIČKIH I KIRURŠKIH DJELATNOSTI

Sažetak

Uvod. Stres je stanje napetosti koje nastaje pri procjeni događaja ili zahtjeva iz okoline kao prijetećih ili prezahtjevnih. U procesu suočavanja primjenjujemo različite kognitivne i ponašajne strategije. Suočavanje usmjereno na problem obuhvaća strategije usmjerene mijenjanju ili uklanjanju stresora. Suočavanje usmjereno na emocije obuhvaća strategije reguliranja pobuđenosti izazvane stresom. Nijedan način suočavanja nije univerzalno djelotvoran, već se uspješnost suočavanja procjenjuje u interakciji osobina pojedinca i stresne situacije. Zastupljenost pojedinih načina suočavanja kod medicinskih sestara djelomično može ovisiti o vrsti službe u kojoj rade.

Cilj. Ispitati načine suočavanja sa stresom medicinskih sestara u internističkim i kirurškim službama dviju hrvatskih bolnica.

Metode. U istraživanju su sudjelovala 163 ispitanika, medicinske sestre i medicinski tehničari iz internističkih i kirurških službi Opće bolnice „Dr. Ivo Pedišić" i Opće bolnice Karlovac. Upotrijebljeni su mjerni instrumenti Upitnik o načinu suočavanja sa stresom i Skala procjene važnosti događaja i mogućnosti kontrole.

Rezultati. Najčešći su načini suočavanja medicinskih sestara plansko rješavanje problema, traženje socijalne podrške i samokontrola, a najrjeđi izbjegavanje. Uspješnost suočavanja sa stresom doživljavaju osrednjom, a stupanj kontrole nad stresnim situacijama prilično niskom. Stresne situacije najčešće doživljavaju kao prijetnju, a najrjeđe kao izazov. Uz percepciju većeg stupnja kontrole nad situacijom, češće biraju prihvaćanje odgovornosti kao način suočavanja. U internističkim službama stresni događaji procjenjuju se znatno više uznemirujućima nego u kirurškima.

Zaključak. Rezultati potvrđuju kako je za edukaciju medicinskih sestara o uspješnom suočavanju sa stresom važno ispitati i dalje istraživati kognitivne procese pri odabiru načina suočavanja: značenje koje pridaju situaciji, procjenu kontrole nad situacijom i samoprocjenu uspješnosti suočavanja.

Ključne riječi: medicinske sestre, stres u sestrinstvu, načini suočavanja

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The Knowledge and Photoprotective Behaviour of the Hungarian Population in Relation to Skin Cancer

[1] **Bence Szabados**
[2] **Mónika Ferenczy**

[1] **APN Student, University of Pécs, Faculty of Health Sciences, Pécs Campus, Institute of Nursing Sciences, Basic Health Sciences and Health Visiting, Hungary**
[2] **University of Pécs, Faculty of Health Sciences, Szombathely Campus, Institute of Nursing Sciences, Basic Health Sciences and Health Visiting, Hungary**

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Author for correspondence:

Mónika Ferenczy

University of Pécs, Faculty of Health Sciences, Szombathely Campus, Institute of Nursing Sciences, Basic Health Sciences and Health Visiting

14. Jókai str., Szombathely, Hungary

Tel: +36-94/311-170

Email: monika.ferenczy@etk.pte.hu

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Abstract

Introduction. The carcinogenic ultraviolet range of sunlight plays a major role in the development of malignant skin tumours with a steadily increasing incidence. It shows a significant upward trend in our country, with 2,742 new cases registered in 2016, nearly 15% of which were under 40 years of age. With conscious behaviour and the use of sunscreen products, the incidence of skin tumours can be reduced. The aim of the study is to assess the Hungarian population's knowledge about skin cancer and attitudes towards sun protection.

Methods. Quantitative cross-sectional study was conducted in a dermatology clinic and among 7th and 8th-grade students and 11th and 12th-grade students of two high schools. The self-administered questionnaire used in the study included questions on socio-demographic data, addictions, skin type, family history of skin cancer, sunburns, sunbathing habits, sunscreen use, knowledge about sun protection and skin cancer, screening and self-testing.

Results. 83.9% of respondents (N=356) have experienced sunburn 3 or more times, and 27.8% use sunscreen regularly (N=118). 62.7% of respondents (N=266) have never had a skin cancer/melanoma screening. A significant association was found between education, gender and sunscreen use ($p<0.001$). A significant association was also found between risky behaviour and going to a tanning salon ($p<0.001$).

Conclusions. The Hungarian population has a lack of knowledge about skin cancer. The results indicate that more emphasis should be placed on increasing the knowledge and awareness of the population about sun protection and on developing good habits, starting at the primary and secondary level.

Introduction

The increasing incidence of malignant skin tumours (basocellular carcinoma/basalioma/basal cell carcinoma, spinocellular carcinoma/spinalioma/spinocellular carcinoma/stem cell cancer, melanoma malignum/pigmented skin cancer) is associated with a significant role of the carcinogenic ultraviolet range of sunlight, as confirmed by in vitro and in vivo studies. With conscious behaviour and the use of sunscreen products, the incidence of skin tumours can be reduced. Basocellular carcinomas and spinocellular carcinomas are the most common malignant tumours in humans. Because of its local invasiveness and frequency, basal cell carcinoma is considered to be of major importance, although it rarely metastasises. Spinocellular carcinoma metastasises more frequently, although not as frequently as the most aggressive pigment cell-derived melanoma malignanum. The latter accounts for a small proportion of skin tumours, but is responsible for a large proportion of deaths. The incidence of skin tumours is increasing significantly worldwide. Epithelial tumours are more prevalent in the older population, but nowadays their first appearance is occurring at younger and younger ages. Malignant melanoma occurs at all ages, but is most common in middle-aged people. The causal role of these malignant skin tumours is due to ultraviolet radiation from sunlight, as evidenced by the fact that they occur mainly on skin surfaces exposed to sunlight and that they are more common in geographical areas with higher sunshine hours (1). Contrary to popular belief, the risk of developing it is increased by the use of a tanning salon. In addition to epidemiological data, in vitro studies and animal experiments show that UV radiation is completely carcinogenic, i.e., it can induce the whole process of carcinogenesis: it causes mutations, promotes the survival and division of mutant cells, and is also an inflammatory and immunosuppressive agent. Reducing the amount of UV radiation to the skin is a very important part of the primary prevention of tumours, which are becoming more and more common. This can be achieved through social and individual habits and the use of sunscreens (2-4). UV radiation is thought to play a role of about 65% in the development of melanoma malignancies, and of particular importance, sunburns suffered during childhood and intermittent exposure to strong radiation (e.g. holidays in the Mediterranean or tropical climates) significantly increase the risk of developing melanoma. For basocellular carcinoma and spinocellular carcinoma, where the incidence of tumours is about 90% due to sunlight, the incidence is proportional to the total amount of sunlight received during a lifetime (cumulative exposure). The UVB content of sunlight is highest at midday, so minimising exposure to the sun and protecting the skin with clothing (long-sleeved clothing, hats) is essential to reduce the risk. In addition, sunscreen creams can be used as sun protection. A high number of nevus means an increased risk of melanoma. In children, the use of sunscreen reduces the number of moles and strict sun protection reduces the appearance of melanoma (5). Sunbathing and tanning salons are still fashionable in some circles of society because tanned skin is considered a ‚status symbol'. Educating the public about the harms of excessive sunbathing is a matter of health education. Primary care workers have a key role to play in this (6). According to WHO data, the incidence of melanoma and non-melanoma skin cancers has been steadily increasing over the past decades. Approximately 2 to 3 million non-melanoma skin cancers and 132,000 melanomas occur annually worldwide. The incidence of skin cancer is the third highest of all cancers (7). In Hungary, the incidence of melanoma (C43) has shown a significant upward trend, with the National Cancer Registry reporting 1,255 new cases in 2001, 2,384 in 2013, 2,742 in 2016 and 2,778 in 2018. It is also noteworthy that in 2001, 2013, 2016 and 2018, nearly 15% of cases were under 40 years old (8). Basal cell carcinoma and squamous cell carcinoma, which are three to four times more common overall, account for 99% of non-melanoma skin cancers (9). According to the National Cancer Registry statistics, 9,728 non-melanoma skin cancers (C44) were diagnosed in Hungary in 2001, 14,928 in 2013, 16,419 in 2016 and 17,877 in 2018. Based on these figures, significant growth is forecast for the future in our country as well (8). The skin of children, adolescents and young adults is more vulnerable than that of adults, and childhood sunburns may contribute to the development of adult melanoma (10), therefore, it is important to start health education in these age groups (11). The foundations of health can be established in childhood, and it is important to reduce and stop negative health behavioural trends and to strengthen and increase positive ones (12). In the context of health education, the promotion of healthy lifestyles is a priority: reducing the enjoyment of natural UVB sources and sun exposure. Long-term results can be achieved through the involvement and active participation of individuals and communities (13). The public should be educated about the harms and consequences of excessive sun exposure and advised to enjoy the sun in moderation, wear appropriate clothing and use regularly the excellent sunscreens available to counteract the harmful effects of UVB radiation (11,14,15).

Objectives

The aim of our study was to assess the knowledge and attitudes towards skin cancer and sun protection among the Hungarian population. We also assessed separately the knowledge and behaviour of primary and secondary school students with regard to sun protection.

Methods

The questionnaire used for the survey was completed anonymously. It contained 43 questions, including both closed and open questions. The survey covered the following areas: socio-demographic data, questions on harmful addictions, skin type, family history of skin cancer, knowledge about skin cancer, tanning bed use, sun protection, dermatological screening and self-examination. Anyone who attended the dermatological examination could take part in the survey without any restrictions. Our quantitative, cross-sectional, descriptive study was conducted in Hungary, in the dermatology clinic of Szentendre between August and December of 2019, and in two primary and high schools in the town. Our target group was the population attending the dermatology clinic of the town of Szentendre, as well as primary and high school students. A number of primary school students was 100, secondary school students was 105 and the number of people attending the clinical examination was 219, of which 4 were only included in the total because they were still at university or college at the time of the survey. We used a non-random, expert sample of individuals who attended the dermatology clinic in Szentendre during office hours, and who agreed to fill in the questionnaire and completed it in full. We excluded individuals who did not complete it. Among the primary school students, the 7th and 8th grade students of the school were selected. Those who did not complete it were excluded. Among the secondary school students, we selected students in grades 3 and 4 of the gymnasium and excluded those who filled it in incompletely. A total of 500 questionnaires were distributed for the survey, and 440 completed questionnaires were returned. Out of the 440 questionnaires, 424 were suitable for statistical processing (excluding 16 incomplete questionnaires, their responses were not taken into account). This constitutes the sample size. (N=424). Our survey was conducted using a self-administered questionnaire. The distributed questionnaires were filled out anonymously and independently, following the rules of the Helsinki Declaration (16).

Statistics

Within the framework of descriptive statistics, the mean, standard deviation, and absolute and relative frequencies were calculated, and chi-square test was used as a mathematical statistic. The strength of association was measured using the Cramer V contingency coefficient. Results were considered significant at $p<0.05$. Statistical analyses were performed using Excel 2010 (17-19).

Results

Socio-demographic data

Among the participants, 53.3% (N=226) were women and 46.7% (N=198) were men. The mean age was 30.86 years (SD±19.11) in the study population. The youngest respondent was 12 years old and the oldest was 80 years old. The proportion of young people under 18 years (12-17 years) was 39.2%. (N=166). A number of people attending the dermatology clinic was 219. In terms of educational attainment, 24.1% (N=102) of the 18+ respondents had completed high school and 21.2% (N=90) had completed college/university. The proportion of respondents with only primary education is low (5.4%, N=23). Nearly the same proportion of primary (23.6%, N=100) and high school (24.8%, N=105) students were surveyed. In terms of the place of residence, 66.7% of respondents (N=283) live in a town and 26.2% (N=111) in a village. 7.1% of respondents (N=30) live in the capital.

Prevalence of skin type

The majority of respondents (53.5%, N=227) have the Fitzpatrick II skin type according to the internationally recognized Fitzpatrick scale, i.e., they are white and their skin is usually sunburned and difficult to tan. The data suggest that the majority of those who completed the questionnaire have a skin type that is at increased risk of developing skin cancer (Figure 1).

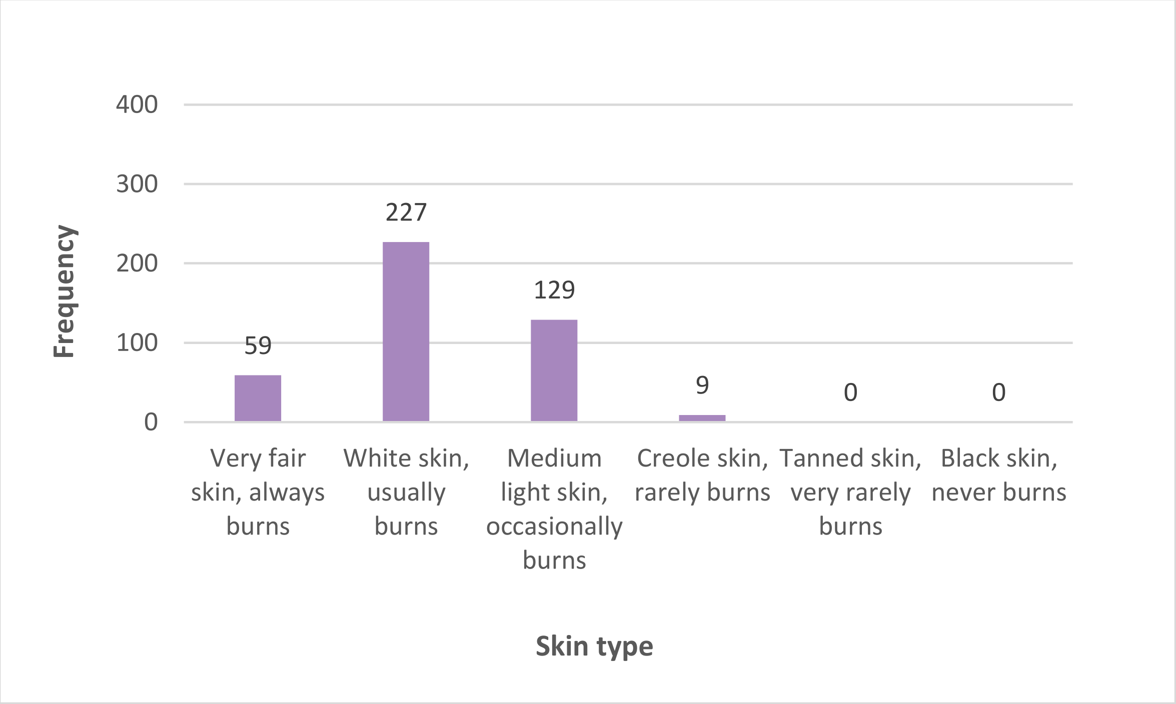

Figure 1. **Distribution of Fitzpatrick skin type in the study sample**

Characteristics of family history of skin cancer

9% of respondents (N=38) said they had a family history of some type of skin cancer. Of those with a positive family history of skin cancer, the most common were grandparents (50%, N=19) and parents (44.7%, N=17).

Knowledge about skin cancer

Based on the responses, 99.1% (N=420) of respondents had heard of skin cancer. The most common source of information about skin cancer was the media (83.3%, N=350). Only 0.9% (N=4) had never heard of skin cancer in their lifetime, all of them were primary school students. More than half (55.7%, N=236) of the respondents correctly knew that melanoma malignum was associated with moles. (Figure 2). The majority of respondents came from the dermatology clinic (64.4%, N=152).

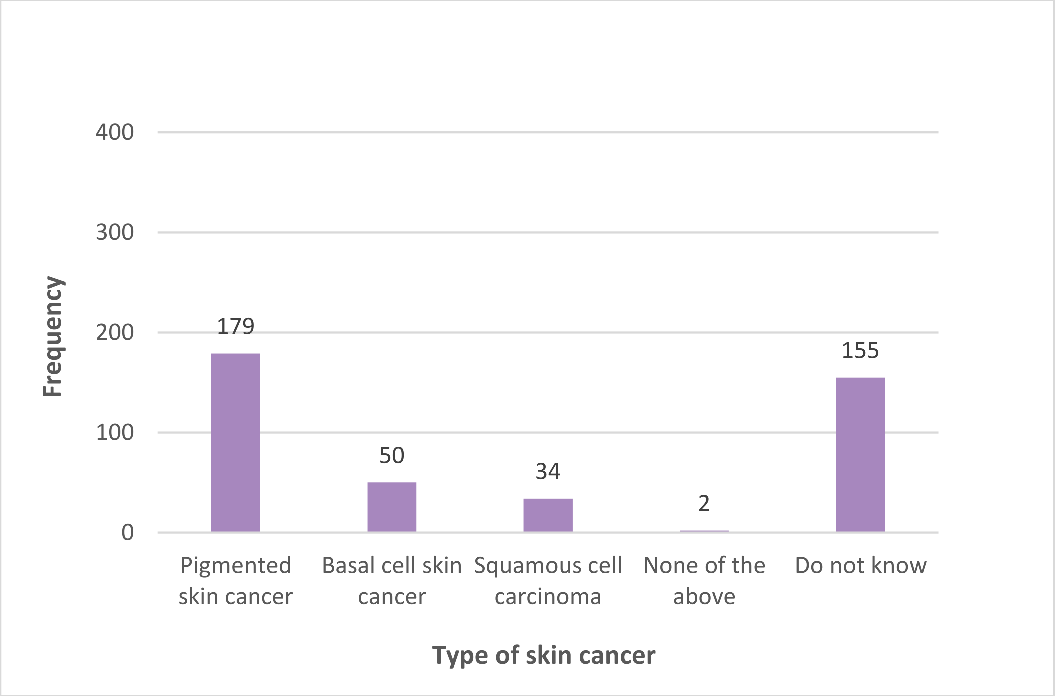

Figure 2. **Frequency of responses on the type of skin cancer associated with moles (N=424)**

Those with a college, university (72.2%, N=65) and secondary education (73.5%, N=75) over the age of 18 were more likely to have the appropriate answer than those with primary education (43.5%, N=10). A higher proportion of primary school students (44%, N=44) gave a good answer to this question than high school students (38.1%, N=40). Only 42.5% of respondents (N=180) were aware that melanoma is the most dangerous type of skin cancer. Only 21.5% (N=91) of the individuals surveyed knew correctly that tanning salons work mostly with UVA content. A slightly higher proportion (27.6%, N=24) of those who use a tanning salon knew the correct answer than those who answered „no" to this question (19.9%, N=67). 87,3% of the survey participants (N=370) knew that UV radiation can cause skin cancer, but far fewer were aware that childhood sunburns increase the risk of developing skin cancer. Only 63.4% of respondents (N=269) answered this question correctly. 19,3% of those under the age of 18 years (N=32) we studied (N=166), did not know correctly that tanning salon use increases the risk of skin cancer. All but 1 of the 7 questions on the leading symptoms of skin cancer were answered correctly. Only 5% (N=21) completed it correctly. The most common combination of responses to this question was asymmetric or irregular-edged skin lesions/moles and colour and/or shape changes of the mole. (28,5%, N=121).

Tanning salon use in the study population

20.5% of respondents (N=87) go to a tanning salon. 66.7% of the respondents (N=58) go to a tanning salon on a weekly basis. 21.7% of women (N=49) and 19.2% of men (N=38) of the respondents go to a tanning salon. 61.2% of women (N=30) and 16.3% (N=8) of men go to a tanning salon once a week, and 73.7% (N=28) of men and 10.5% (N=4) of women go to a tanning salon more than once a week. Among the children under 18 years of age in our study (N=166), 8.4% (N=14) go to a tanning salon with some regularity. Of the under-18 respondents we surveyed, 50% (N=7) went to a tanning salon once a week and 42.9% (N=6) went several times a week. By skin type, tanning bed use was highest (30.5%, N=18) among those most at risk of developing skin cancer (Fitzpatrick skin type I). Risky behaviour is sunbathing at inappropriate times on a regular basis. The results of our study show a significant association between risky behaviour (regular sun exposure at inappropriate times) and tanning bed use, with a medium association between the variables ($p<0.001$, C=0.48 χ^2=98,36). Among sunbathers with risky behaviour, 42,1% (N=80) also regularly use a tanning bed, while only 3% (N=7) of those with non-risky behaviour regularly use a tanning bed.

Knowledge and behaviour related to light protection

67% of respondents (N=284) answered correctly to the question that sunscreen with a factor of 30 or more can provide adequate protection against the harmful effects of sunlight. Less than half of the respondents (45.5%, N=193) knew correctly that they should apply sunscreen with the right SPF at least half an hour before sun exposure. Surprisingly, there was also a response that sunscreen should be applied after sun exposure (2.6%, N=11). The results of the survey show that almost all respondents have experienced sunburn after sun exposure (95.3%, N=404), 2.7% (N=11) once, 13.4% (N=54) twice, 83.9% (N=339) three or more times. Among primary school students 65% (N=65) and among high school students 77.1% (N=81) had experienced 3 or more sunburns in their lifetime, which is certainly a remarkable figure. By gender, 44.7% of female respondents (N=101) always use sunscreen and 11.1% (N=25) never use sunscreen. The same results for men show that only 8.6% (N=17) always use sunscreen, while 38.4% (N=76) never use it. The results show that statistically significantly more women use sunscreen than men, with a medium relationship between the variables ($p<0.001$, C=0.45 $\chi^2=86.42$) (Figure 3).

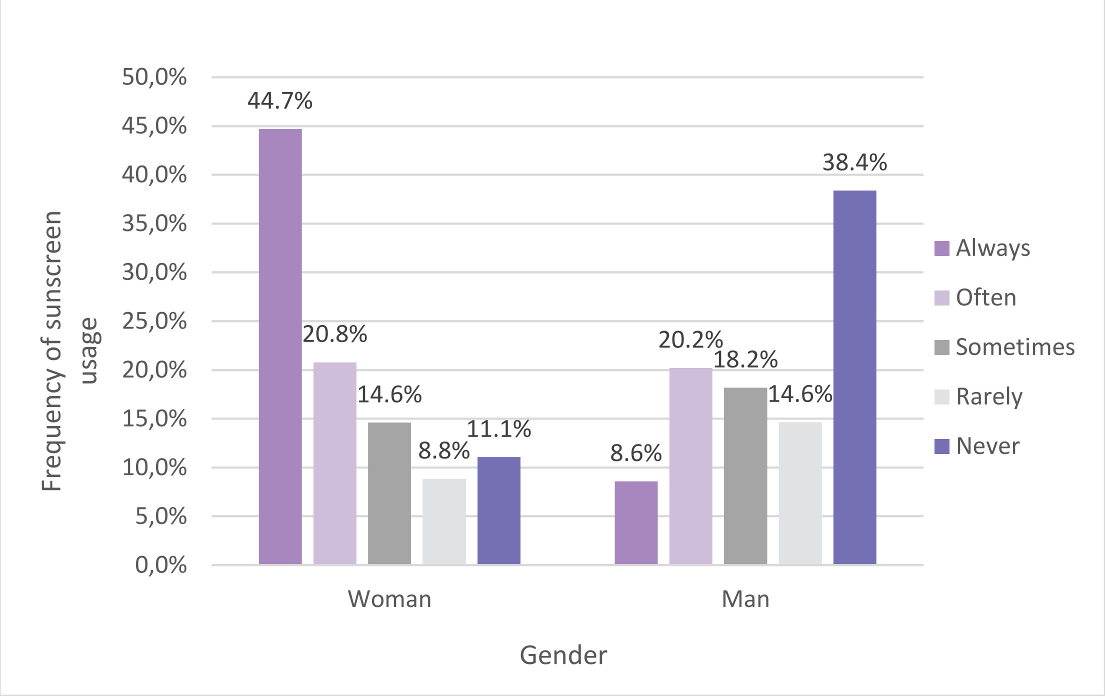

Figure 3. **Frequency of sunscreen use by gender**

Regarding education, significantly more people with higher education over the age of 18 use sunscreen than those with lower education, a strong relationship was found between the variables ($p<0.001$, C=0.87, $\chi^2=83.05$) (Figure 4).

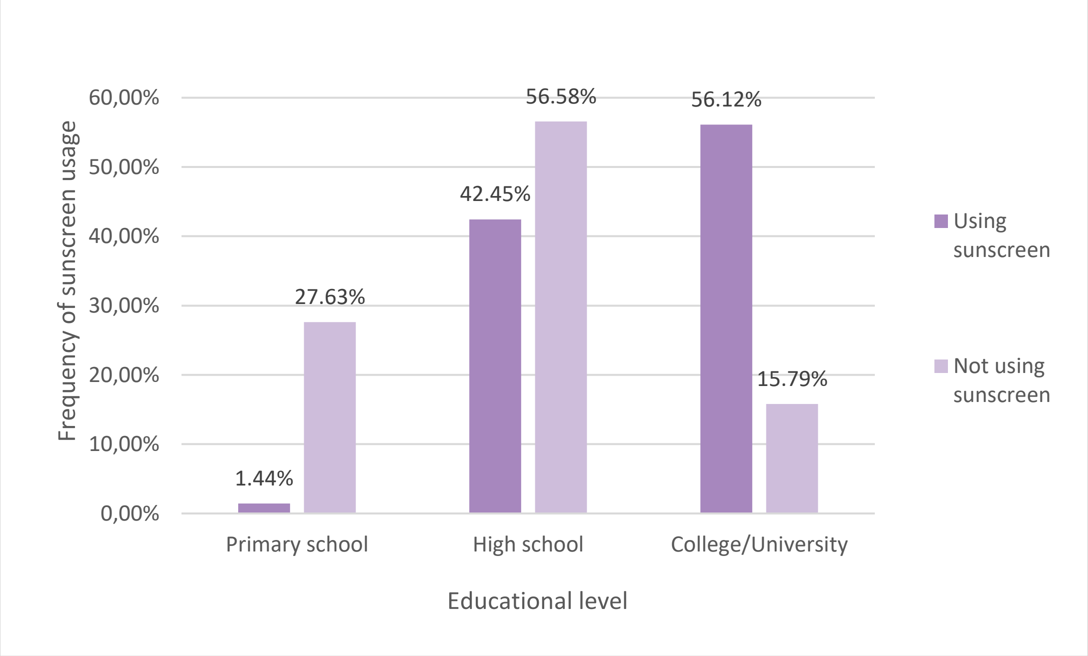

Figure 4. **Usage of sunscreen by educational level among respondents aged 18 and over**

Our results show that there is no significant difference in regular sunscreen use between primary and high school students (*p*=0.390, C=0.14, χ^2=4.115). In terms of responses, 30% of primary school students (N=30) and 24.8% of high school students (N=26) always use sunscreen, 22% of primary school students (N=22) and 25.7% of high school students (N=27) never use sunscreen (Figure 5).

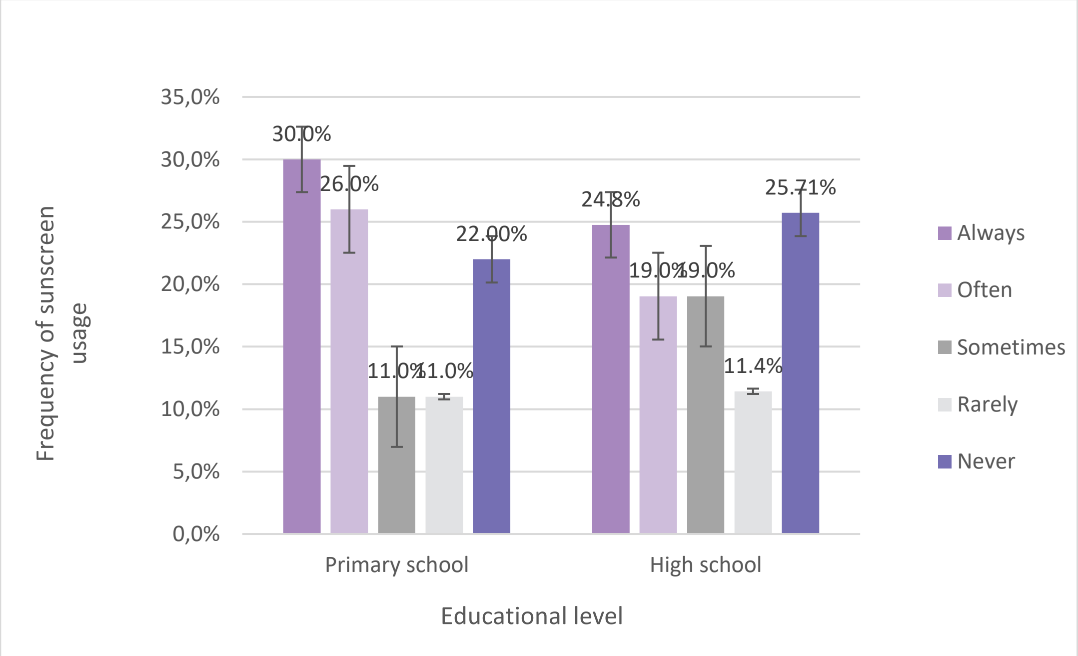

Figure 5. **Frequency of sunscreen use among primary and high school students (N=205)**

Examination of attitudes towards screening

The majority of respondents (89.4%, N=379) had heard of skin cancer screening, also known as skin cancer/melanoma screening. Approximately the same number (88%, N=373) knew that melanoma screening is performed exclusively by a dermatologist. However, the results of the survey confirm that only 37.3% (N=158) of people have had a skin cancer/melanoma screening in their lifetime, which is a very low rate. 55.7% (N=88) had visited the dermatologist randomly (no fixed frequency) for screening, and 62.7% (N=266) had never been to the dermatologist, which is a worrying figure. Of those who had been for a check-up, just over a quarter (25.3%, N=40) had attended the recommended annual check-up. There was not a big difference in attendance by gender, with 37.6% of women (N=85) and 36.9% of men (N=73) attending the screening. Higher prevalence rates are found among college/university (63.3%, N=57) and secondary (59.8%, N=61) graduates aged 18 and over. Only 34.8% (N=8) of high school leavers aged 18 years and over have had at least one screening test in their lifetime, 89% (N=89) of primary school students and 80% (N=84) of high school students have never had a skin cancer/melanoma screening in their lifetime.

Discussion

In the course of our research, we aimed to assess the knowledge about skin tumours of the involved people in this survey, as well as their sun protection habits. We wanted to include primary and secondary school students in our study because our experience has shown that they are even more vulnerable (1) than adults, yet they do not exhibit adequate sun protection behaviour or have comprehensive knowledge about skin cancer. Our results show that individuals with higher education use sunscreen significantly more often than those with lower levels of education. The same result was obtained by Elizabeth Thomas-Gavelan and colleagues, who also found that sunscreen use was significantly associated with the education level of the individual (20). Only 11.1% of the women surveyed never use sunscreen, while the rate is much higher for men (38.4%). Antonov and colleagues in Germany found that a similar proportion of women never used sunscreen, but there was a much lower proportion of men (15%) (21). The results of our study showed that women used sunscreen significantly more often than men. The same finding was made by Lee Andrew et al., Who found that women used significantly more sunscreen than men (22). Our study shows that the Hungarian population, including the young age group, does not have sufficient knowledge about skin cancer. This is supported by the fact that slightly more than half (55.7%) of the participants in the survey correctly knew that melanoma malignum is associated with moles. However, this rate is better than that found in research conducted in the United States of America, where scientific work by Adriane A. Levin and colleagues found that only 29.3% of Americans who participated in the study knew the answer to this question correctly (23). A further lack of knowledge is indicated by the fact that only 42.5% of the Hungarian population knew correctly that melanoma is the most dangerous type of skin tumour. Compared to the US survey, there is no significant difference, with 41.4% of US respondents answering the same (23). Overall, the Hungarian population's knowledge about skin cancer is incomplete. Therefore, it is essential to increase the knowledge of lay people that skin cancer is one of the most treatable malignancies, of course, if detected in time. Regular check-ups and awareness of the warning signs are essential. According to the results of the survey, 95.3% of the Hungarian population have experienced sunburn in their lifetime. In comparison with an international study, Antonov and colleagues obtained similar results, with 97% of respondents in the German population (21). It is of serious concern that the most vulnerable age group also has a high rate of sunburn, with 65% of primary school students and 77.1% of high school students having experienced three or more sunburns. Our study showed that there was no significant difference between primary and high school children in terms of sunscreen use. Gellén et al. surveyed primary and high school students in Debrecen, Hungary, and found that primary school students use sunscreen more often than high school students (24). It is important to introduce children to good sunbathing habits as early as possible and to make them aware of the dangers.

20.5% of people surveyed go to a tanning salon, which is a high proportion. Those who used tanning beds were most at risk (30.5%) of developing skin cancer (Fitzpatrick skin type I). We would highlight the surprising and disheartening data that 8.4% of the children under 18 (12-17-year-olds in the study) use a tanning salon with some regularity. Of the children who go to a tanning salon, 50% go once a week and 42.9% go more than once a week. Boniol et al. found that tanning bed use increases the risk of developing melanoma by 20%. When they started using before the age of 35, the risk of developing pigmented skin cancer doubled (25). 12% of the respondents under 35 in our survey use tanning beds with some regularity. Our results show a significant association between risky behaviour and tanning bed use. In an Austrian study, Daniel Haluza and colleagues also came to the same conclusion (26). In our study, we found that 62.7% of respondents had never been screened for skin cancer/melanoma, and only 25.3% had attended the recommended annual screening.

Conclusion

In order to increase the participation rate, it is necessary to promote responsible health behaviour, raise awareness, motivate people to take part in screening and explain the risks of not being screened. To further improve our morbidity and mortality indicators, it is of paramount importance to emphasise primary and secondary prevention for the population. Learning good sun protection and sunbathing habits from an early age in preschool children has become a key issue, and awareness campaigns should be launched to increase lay awareness of the early signs of skin tumours (27).

Acknowledgements

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ZNANJE I FOTOZAŠTITNO PONAŠANJE MAĐARSKE POPULACIJE POVEZANO S RAKOM KOŽE

Sažetak

Uvod. Kancerogeni ultraljubičasti raspon Sunčeve svjetlosti igra važnu ulogu u nastanku malignih tumora kože sa sve većom incidencijom. Učestalost malignih melanoma pokazuje znatan, rastući trend u Mađarskoj, gdje je 2016. registrirano 2742 novooboljelih osoba, od kojih je gotovo 15 % bilo mlađe od 40 godina. Svjesno ponašanje i upotreba kreme za sunčanje može smanjiti učestalost tumora kože. Cilj je istraživanja procijeniti znanje Mađarske populacije o raku kože i njihov stav prema zaštiti od štetnih Sunčevih zraka.

Metode. Kvantitativna studija presjeka provedena je u dermatološkoj klinici, kao i među učenicima 7. i 8. razreda te 11. i 12. razreda dviju gimnazija. Primijenjen je upitnik koji su sudionici samostalno ispunili s pitanjima koja su se odnosila na sociodemografske podatke, štetne navike, tip kože, obiteljsku anamnezu raka kože, broj opeklina, navike sunčanja, upotrebu krema za sunčanje, znanje o zaštiti od sunca i raku kože, kontrolni pregled madeža i samopregled.

Rezultati. Opekline od sunca tri ili više puta imalo je 83,9 % ispitanika (N = 356), 27,8 % redovito koristi kremu za sunčanje (N = 118), a 62,7 % ispitanika (N = 266) nikada nije bilo pregledano za rak kože / melanom. Pronašli smo značajnu povezanost između razine obrazovanja, spola i upotrebe kreme za sunčanje ($p < 0,001$). Utvrdili smo značajnu korelaciju između rizičnog ponašanja (redovito sunčanje u pogrešno vrijeme) i odlaska u solarij ($p < 0,001$).

Zaključak. Mađarsko stanovništvo ima nepotpuno znanje o raku kože. Rezultati pokazuju da je potrebno staviti veći naglasak na povećanje znanja i svjesnosti populacije o zaštiti od sunca i razvijanju dobrih navika, počevši od osnovne i srednje škole.

Ključne riječi: rak kože, zaštita od sunca, kontrolni pregled madeža, samopregled, znanje

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Awareness of Testicular Cancer Among the Male Population in the Republic of Croatia

[1] **Antonija Strojny**
[2] **Mara Županić**

[1] **Department of Urology, Clinical Hospital Sveti Duh, Zagreb, Croatia**
[2] **University of Applied Health Sciences, Zagreb, Croatia**

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Author for correspondence:
Antonija Strojny
Department of Urology, Clinical Hospital Sveti Duh
Sveti Duh 64, 10000 Zagreb, Croatia
E-mail: strojnyantonija7@gmail.com

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Keywords: testicular cancer, information, Croatian rural and urban area, prevention

Abstract

Testicular cancer is the most common tumour in men of reproductive age. The incidence has increased in the last few years, both globally and in the Republic of Croatia. No studies have been conducted in the Republic of Croatia that show the level of knowledge about testicular cancer, so this study was conducted to examine the knowledge and attitudes of the male population about testicular cancer, to determine whether there are differences in knowledge and attitudes between members of the male population from rural and those from urban areas, and to examine how to increase the awareness of the male population about the prevention of testicular cancer. A cross-sectional survey was conducted among 200 respondents from rural and urban areas of the Republic of Croatia. The study was conducted using an anonymous survey questionnaire. Knowledge of risk factors, clinical presentation, diagnosis and treatment methods, and self-examination was examined. The results did not show a significant difference in the knowledge and attitudes between participants from rural and those from urban areas. However, the overall level of knowledge about testicular cancer has been shown to be low and efforts need to be made to improve prevention programs to protect the health of the male population.

Introduction

Testicular cancer is the most common solid malignant tumour in younger men (1). Since testicular cancer occurs in the younger population, men do not take the symptoms of the disease seriously. Unfortunately, testicular cancer cannot be prevented, but it is important to encourage the male population to detect the disease early in order to reduce the risk of mortality and improve the quality of life since the incidence of testicular cancer is highest among the reproductive population. Testicular tumours account for only 1% of malignancies in men, but solid tumours are most common in men between the ages of 15 and 35 (2). A large increase in morbidity has been observed in Finland, Slovakia, Slovenia and Croatia (3). In the Republic of Croatia, testicular cancer is most often diagnosed in the age group of 20 to 34 years (51% of all cases), and the lowest number is diagnosed in those of over 60 years of age. Due to the growing incidence, environmental factors are believed to play a role in the development of testicular cancer, in addition to genetic factors. Risk factors for testicular cancer include cryptorchidism, considered the most important factor, Klinefelter's syndrome, a family history of testicular cancer among first-degree relatives and the existence of a contralateral tumour.

Testicular malignancy is usually presented as a unilateral lump or painless mass. Testicular enlargement is the most important sign of testicular tumours. Dull pain is less common, and acute pain has been reported in 10% of patients. A greater number of patients with disseminated disease have symptoms arising from metastatic disease. Testicular tumour is most often detected by clinical examination, testicular ultrasound, MR and CT. Serum tumour markers AFP, βHCG and LDH are important prognostic factors. In bilateral testicular tumours, radical orchidectomy is performed. In the case of tumours of one testicle, a partial orchidectomy is performed, thanks to which the functional tissue of the testis and male fertility are preserved. During the operation, a biopsy for pathohistological analysis must be taken. Further treatment depends on the stage of the disease and includes chemotherapy and radiotherapy. Testicular cancer and metastatic disease are also associated with elevated inflammatory markers and systemic inflammation, which can significantly impair spermatogenesis. It is recommended that men wait at least three months after completing chemotherapy before conceiving a child. After radiotherapy, complete recovery of spermatogenesis is possible, but this depends on the radiation dose. Infertility in the case of removal of one testicle is rare. An average study conducted on 680 patients after testicular cancer treatment assessed the fertility of patients after orchidectomy who were treated with chemotherapy, radiotherapy, and chemotherapy in combination with radiotherapy (4). In 77% of men, conception is achieved naturally.

Treatment of testicular cancer diagnosed at an early stage has been associated with positive results including prolonging survival and minimizing morbidity caused by treatment methods. The cure rate is about 96%, which significantly affects survival. However, more than 50% of cases are diagnosed in the metastatic phase of the disease. Once the cancer has spread to the lymph nodes, the survival rate is significantly reduced.

Testicular self - examination has been shown to increase the rate of early detection of cancer, but there are insufficient data to suggest that this improves long - term survival (5). Testicular self-examination is short, easy to learn and apply, safe and economical, and non-invasive. It is recommended at least once a month, starting from the beginning of puberty. The role of self-examination in screening for testicular cancer is still a matter of debate. For the purpose of making an early diagnosis, the American Cancer Society and the American Urological Society recommend that doctors include a testicular examination as part of their routine examination. Some organizations, such as the Canadian Task Force, do not recommend regular self-examinations because they can cause anxiety and unnecessary visits to the doctor (6). Some believe that self-examination can lead to a false positive diagnosis, which may then lead to performing unnecessary invasive procedures to confirm the diagnosis of cancer. However, self-examination is a useful method for early diagnosis due to the very small number of men involved in preventive health care. Although some studies believe that self-examination is not highly effective in diagnosing testicular cancer, other studies advocate conducting testicular self-examination because of its practicality and simplicity. The health beliefs model explains the relationship between an individual's attitudes and behaviours and the impact of personal motivation on health behaviours. It is considered a health behaviour that is the integration of individual perception and values that lead an individual to a certain goal and is directly related to the onset of the disease. Self-examination is a behaviour that promotes health. Nurses can identify the beliefs and attitudes of the population and develop an initiative to change these attitudes and achieve responsible behaviour necessary for overall health.

Methods

Study design

Cross-sectional study.

Participants

The study was conducted among the male population of urban and rural areas of Croatia. It was conducted on 200 respondents in the period from 1 April 2021 - 20 September 2021. According to the place of residence, 112 respondents live in urban areas, and 88 of them live in rural/suburban areas. Of the total number of respondents, most respondents have secondary education, and the smallest number of respondents have primary education. The most represented respondents in the study are in the age group between 18 and 35, and the smallest number of respondents is older than 60.

Statistics

The study was conducted by having respondents fill out a questionnaire. Respondents who agreed to participate in the survey were informed about the purpose and the anonymity of the survey. The study used non-probabilistic sampling in which respondents recruited new samples through a network of acquaintances, where a chain of recommendations using the "snowball method" was used. Respondents from the work environment were encouraged to forward the questionnaire to male friends, colleagues and family members. In order to ensure the privacy and reliability of the answers, the survey questionnaires were distributed individually to the study participants in sealed envelopes. The participants returned the completed survey questionnaires in the same way. Statistical data processing was performed using the Microsoft Office Excel program. The data are presented in graphs. Descriptive statistical methods were used to describe frequency distribution.

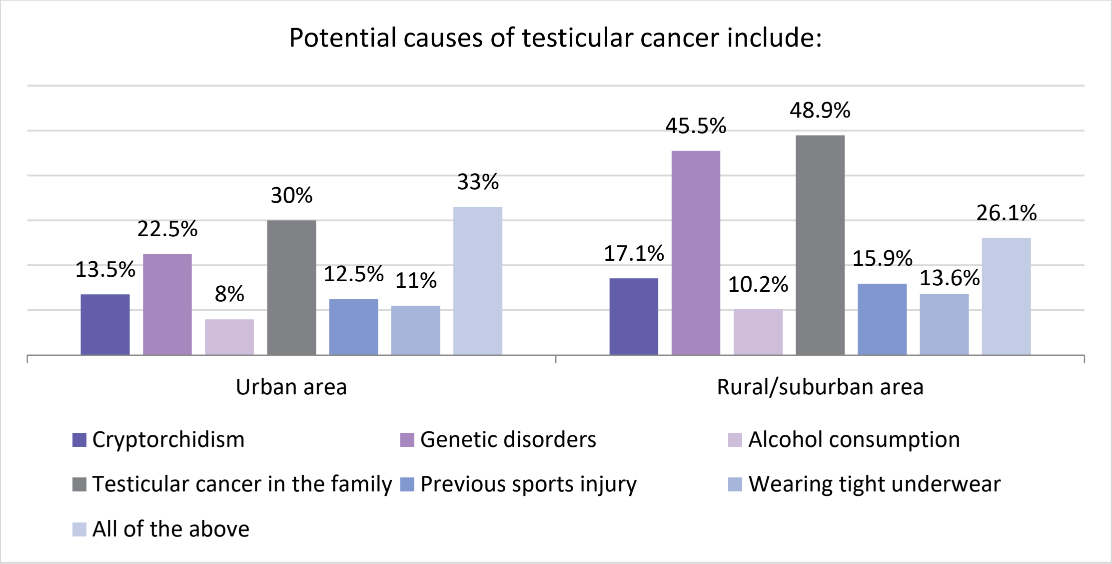
Instrument

The research questionnaire was compiled independently. Respondents were asked 19 closed-ended questions. The first part of the survey referred to sociodemographic data (age, education, level of education, place of residence, marital status). The second part of the survey questionnaire deals with questions related to cancer and testicular self-examination.

Results

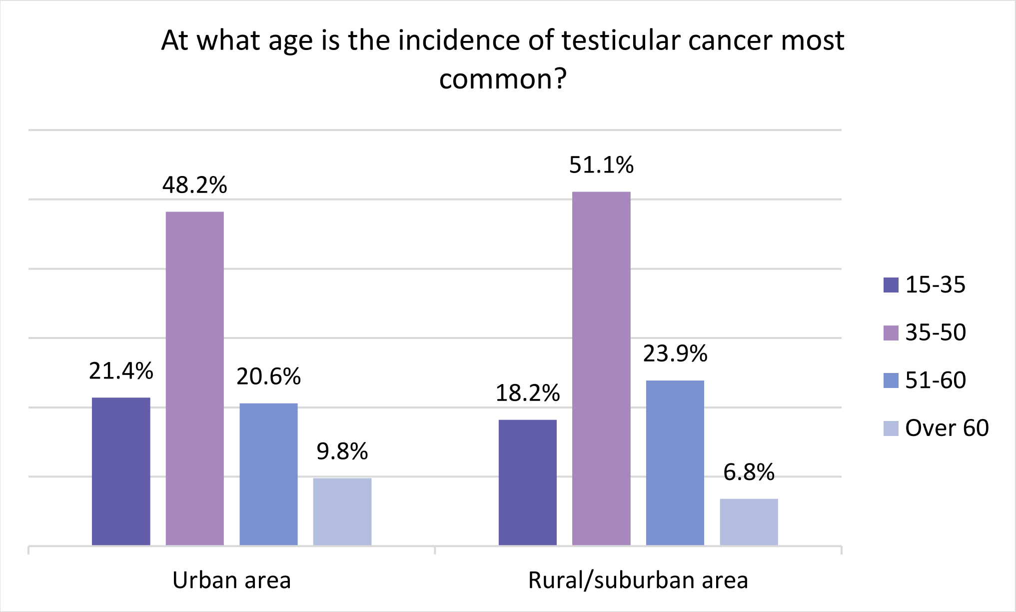
The most represented respondents in the study are in the age group between 18 and 35 years (73.5%). The average age of all respondents is 32.2. Of the total number of respondents, the majority have secondary education (60.5%), and only 1.5% of respondents have primary education. According to place of residence, 112 (56%) respondents live in urban areas, and 88 (44%) live in rural/suburban areas. 44.5% of respondents are single, 29.5% of respondents live in a cohabitation relationship and 22.5% of respondents were married. Divorced respondents represent the smallest share (3.5%).

When testing knowledge about testicular cancer risk factors, respondents were offered a choice of claims and could select one or more of them. The fewest number of respondents (12.5%) consider alcohol consumption to be a risk factor. 40 (20%) respondents believe that the cause is cryptorchidism, and 84 (42%) respondents believe that genetic disorders are responsible for the development of testicular cancer. Testicular cancer in the family is mentioned as a risk factor by 102 (51%) respondents, and 39 (19.5%) believe that the cause is a previous sports injury. 34 (17%) respondents believe that wearing tight underwear is a risk factor. 60 (30%) respondents answered that all these factors play a role in the development of testicular cancer. The responses of respondents from rural and urban area are shown in Graph 1. The graph shows that respondents from rural areas are more informed about risk factors in comparison with respondents from urban areas.



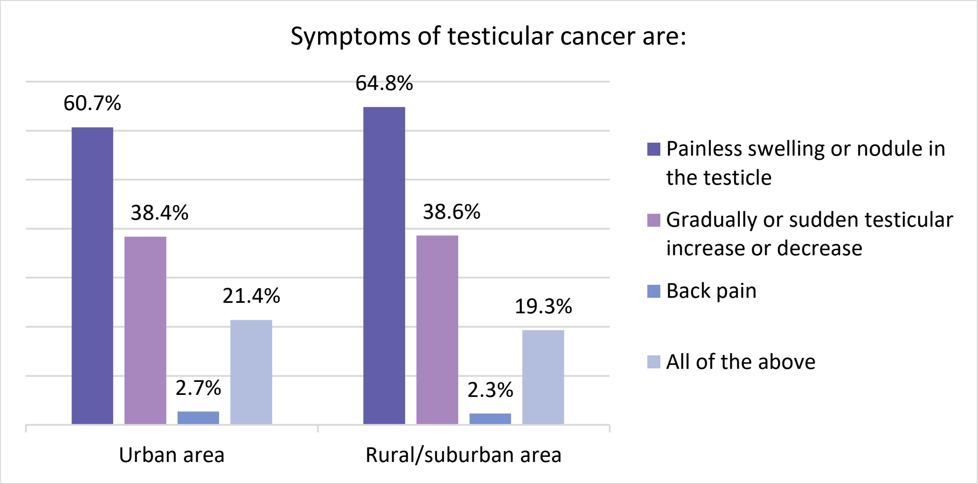
Graph 1. **Distribution of respondents from urban and rural areas according to the answers on risk factors for the development of testicular cancer**

The prevailing opinion among the respondents is that testicular cancer most often affects men between the ages of 35 and 50. 99 (49.5%) respondents selected this statement. 40 (20%) respondents believe that the incidence is highest in men aged between 15 and 35, and almost the same number of respondents, 44 (22%), believe that testicular cancer most often occurs between the ages of 51 and 60. Only 17 (8.5%) respondents believe that the development of testicular cancer is most common at the age of 60 or above. According to the results shown in Graph 2., respondents from rural and urban areas have equal knowledge about the age incidence of testicular cancer.



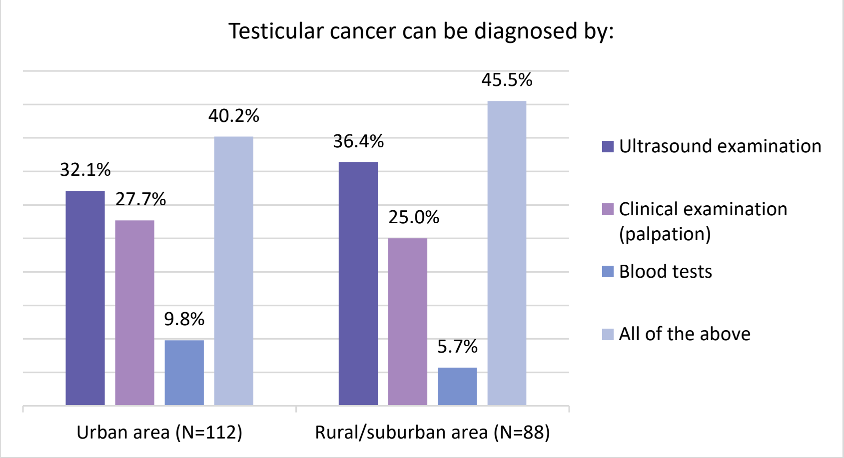
Graph 2. **Distribution of respondents from urban and rural areas according to the answers on the age incidence of testicular cancer**

Respondents were able to select multiple answers when testing their knowledge of testicular cancer symptoms. The largest number of respondents, 125 of them (62.5%), believe that the symptom of testicular cancer is painless swelling or a nodule in the testicle, and only 5 (2.5%) believe that the symptom is back pain. 77 (38.5%) respondents believe that it is presented by a gradual or sudden increase or decrease in the testicles. 41 (20.5%) respondents believe that all these symptoms may occur. One respondent from a rural area did not answer the question. Graph 3 shows that there is no significant difference in knowledge between the urban and the rural population.



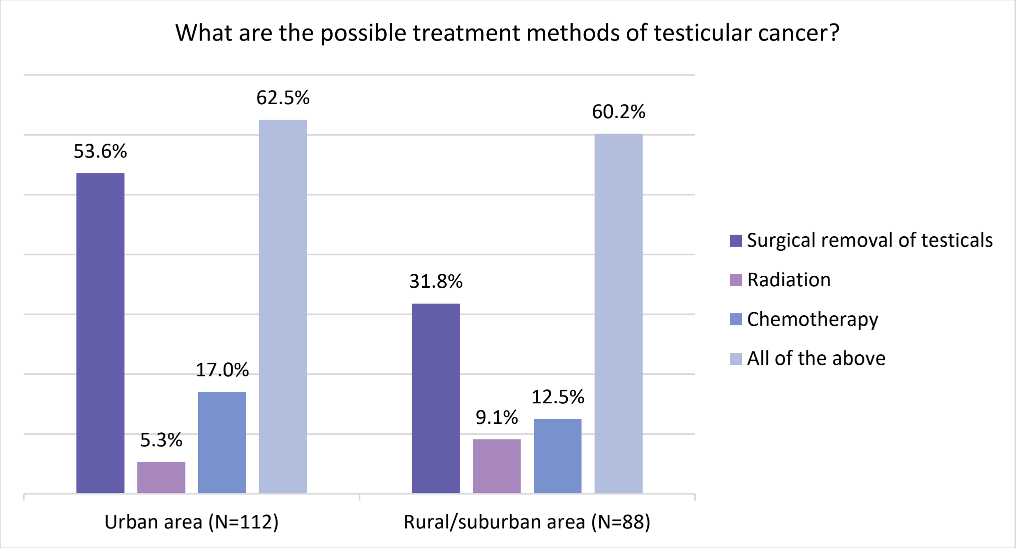
Graph 3. **Distribution of respondents from urban and rural areas according to the answers on the symptoms of testicular cancer**

68 (34%) respondents agreed that ultrasound examination of the testicles is a diagnostic method for testicular cancer, and 53 (26.5%) of them believe that a clinical examination is necessary for diagnosis. 16 (8%) respondents believe that laboratory blood testing is a diagnostic method. 85 (42.5%) respondents believe that all three diagnostic methods are needed for diagnosis. Respondents were offered the possibility of multiple answers. Comparing the responses of the population from urban and rural areas, a slight difference in knowledge is noticed, as seen in Graph 4.



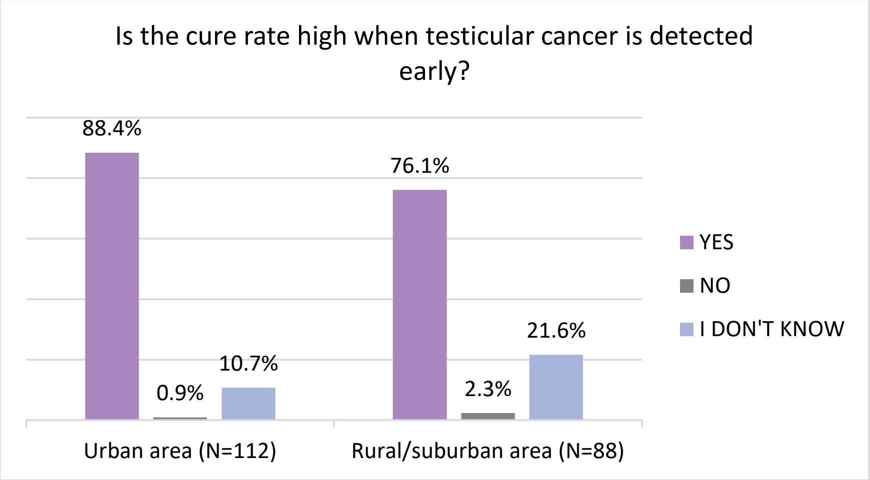
Graph 4. **Distribution of respondents from urban and rural areas according to the answers on the diagnosis of testicular cancer**

63 (31.5%) respondents believe that surgical removal of the testicles is one of the treatment methods. 14 (7%) respondents believe that radiation can be used in treatment, and 30 (15%) respondents believe that chemotherapy is a treatment option. 120 (60%) respondents believe that all treatment methods are applicable to testicular cancer. Respondents were able to give multiple answers to the question. There is a significant difference in the responses of the rural and urban population to the operative removal of the testicles. Respondents from the urban areas are more informed about surgical testicular removal as a treatment method.



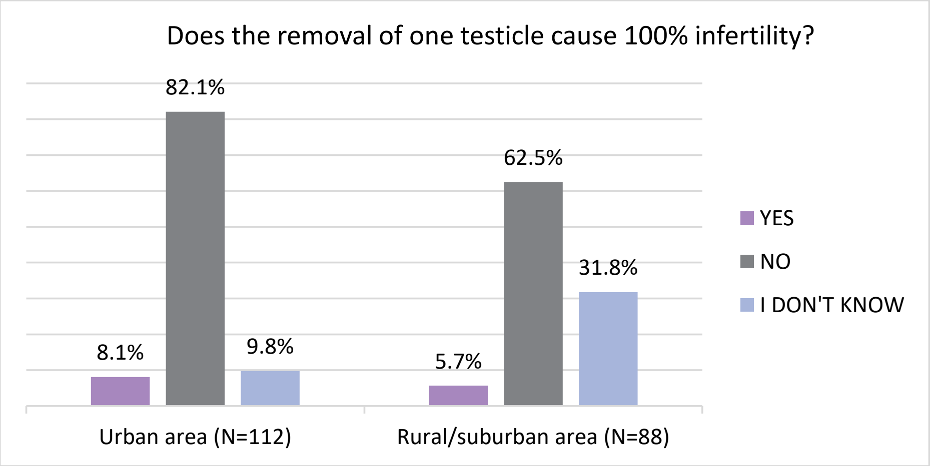
Graph 5. **Distribution of respondents from urban and rural areas according to answers about methods of testicular cancer treatment**

The largest number of respondents, 166 of them (83%), believe that testicular cancer has a high cure rate if detected at an early stage. A significantly smaller number of respondents, 31 (15.5%) do not know whether the detection of testicular cancer at an early stage affects the cure rate, and only 3 (1.5%) respondents believe that early detection of testicular cancer does not affect the high cure rate. The rural population is less informed about the importance of early diagnosis compared to the urban population as shown in Graph 6.



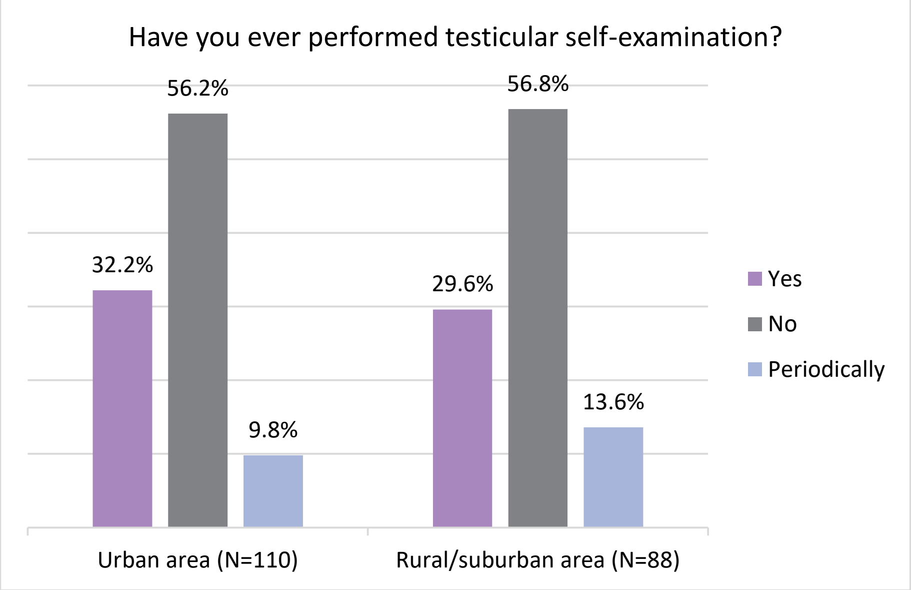
Graph 6. **Distribution of respondents from urban and rural areas according to the answers on the cure rate of testicular cancer**

147 (73.5%) respondents believe that the removal of one testicle does not cause 100% infertility, and 39 (19.5%) respondents are unsure. Only 14 (7%) respondents believe that the removal of one testicle leads to 100% infertility. There is a significant difference between respondents from rural and urban areas. Respondents from rural areas are less informed about 100% infertility as a result of removing one testicle than respondents from urban areas. The difference in responses is shown in Graph 7.



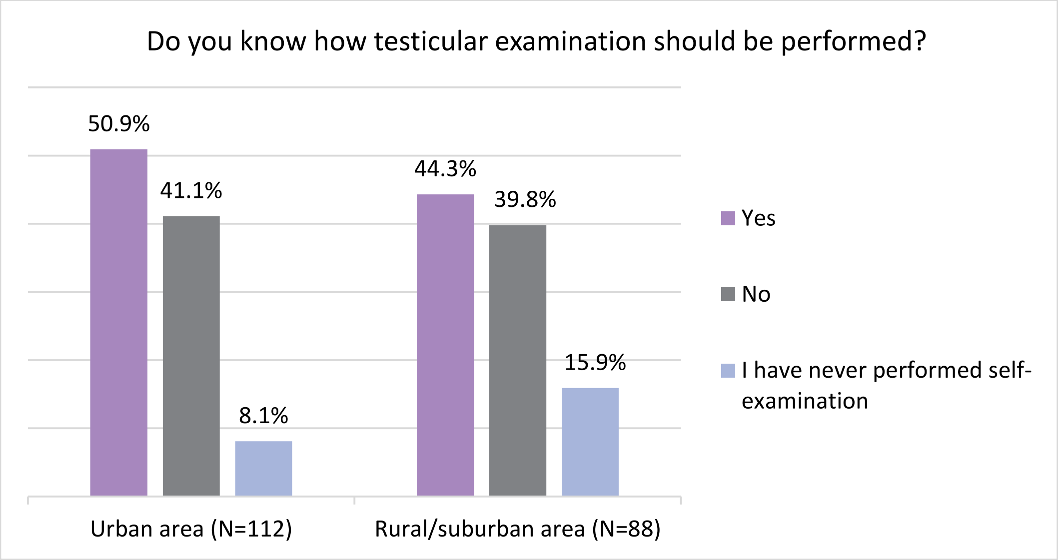
Graph 7. **Distribution of respondents from urban and rural areas according to the answers on infertility caused by testicular removal**

60 (30%) respondents stated that they perform testicular self-examination, and 23 (11.5%) respondents that they perform it occasionally. 115 (57.5%) respondents have never performed testicular self-examination. 2 (1%) respondents did not answer the question.



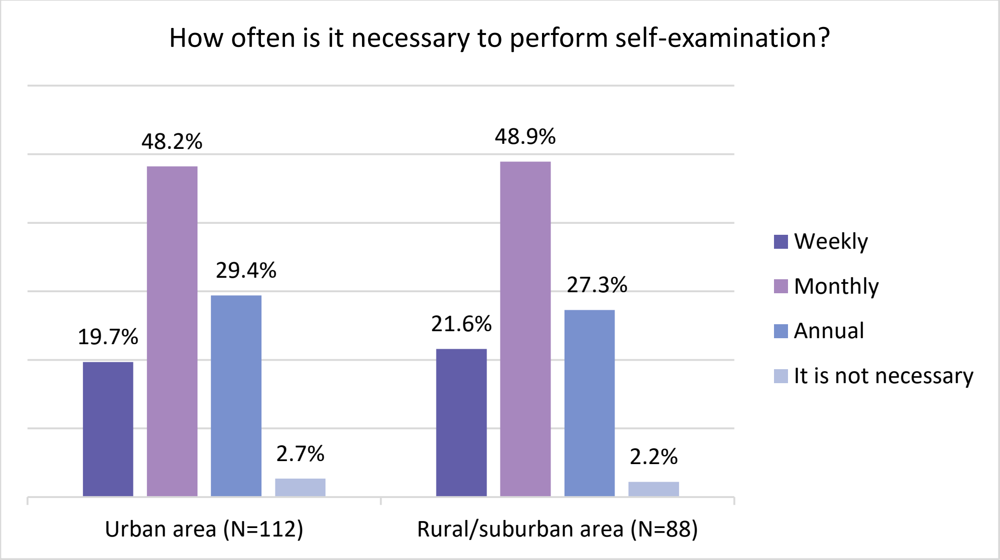
Graph 8. **Distribution of respondents from urban and rural areas according to the answers on the conduct of testicular self-examination**

Of the total sample, 96 (48%) respondents state that they know how to perform testicular self-examination, followed by 81 (40.5%) respondents who are not familiar with performing self-examination. 23 (11.5%) respondents stated that they had never performed a testicular self-examination.



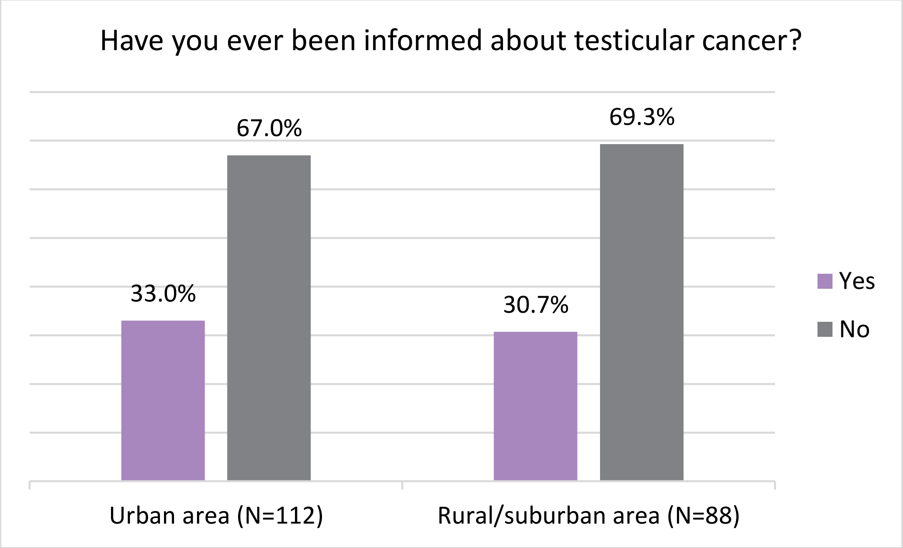
Graph 9. **Distribution of respondents from urban and rural areas according to the answers on the knowledge of performing testicular self-examination**

97 (48.5%) respondents believe that testicular self-examination should be performed once a month, while 57 (28.5%) respondents believe that it is necessary to perform it once a year. 41 (20.5%) respondents believe that testicular self-examination is important once a week, and the smallest number of respondents, 5 of them (2.5%) believe that it is not necessary.



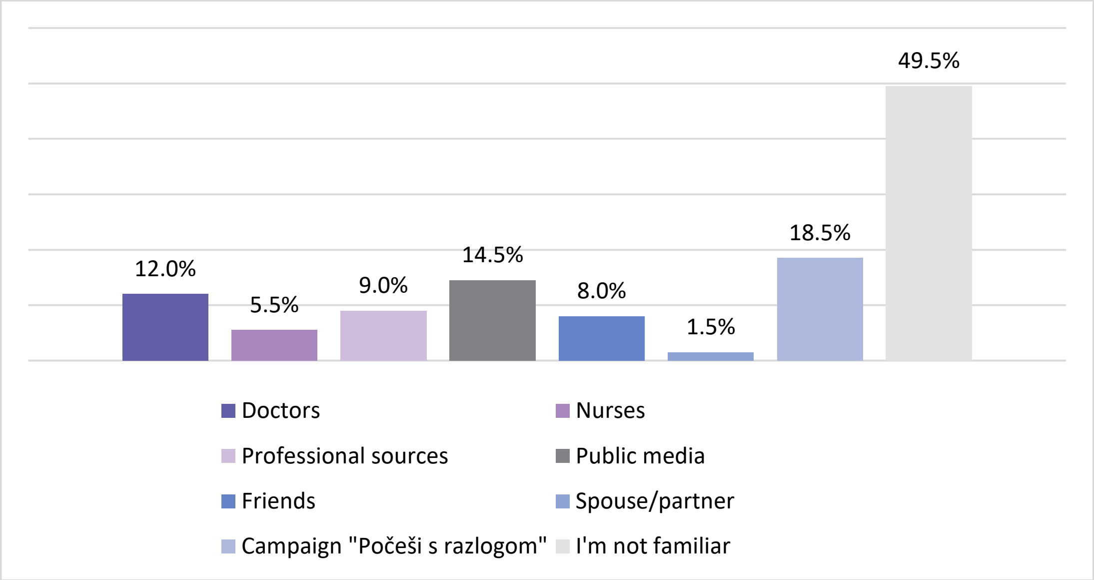
Graph 10. **Distribution of respondents from urban and rural areas according to the answers on the regularity of testicular self-examination**

Of the total sample, 136 (68%) respondents had never been informed about testicular cancer, as opposed to 64 (32%) respondents, who had. The answers of respondents from rural and urban areas are almost equal, as shown in Graph 11.



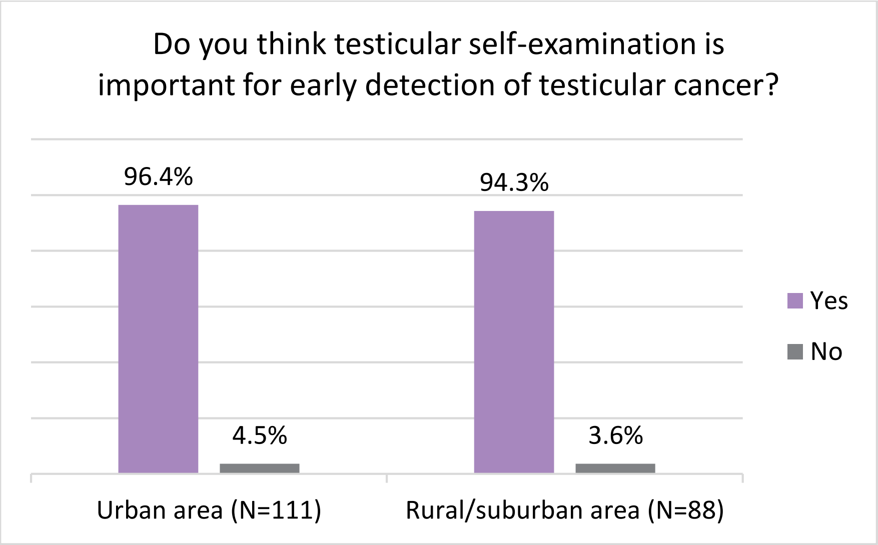
Graph 11. **Distribution of respondents from urban and rural areas according to the answers on the level of knowledge about testicular cancer**

The majority of the respondents state that they are not familiar with this malignant disease. Self-examination of the respondents was mostly encouraged by the "Počeši s razlogom" campaign and the media, while the lowest percentage of respondents received information from partners and health workers, as seen in Graph 12.



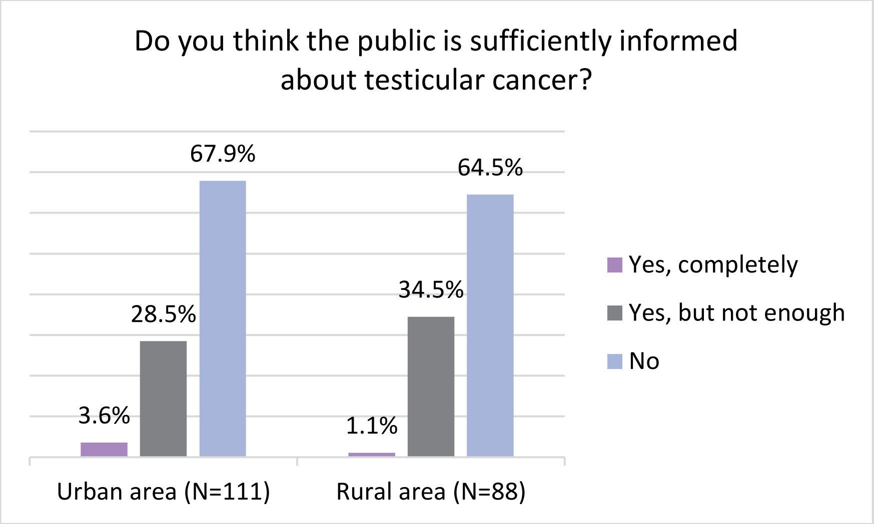
Graph 12. **Distribution of subjects in the total sample according to the sources of information about testicular cancer**

190 (95%) respondents believe that testicular self-examination is important for early detection of testicular cancer, and only 9 (4.5%) respondents believe that it is not important. One respondent did not answer the question. Graph 13 shows the responses of the rural and urban population.



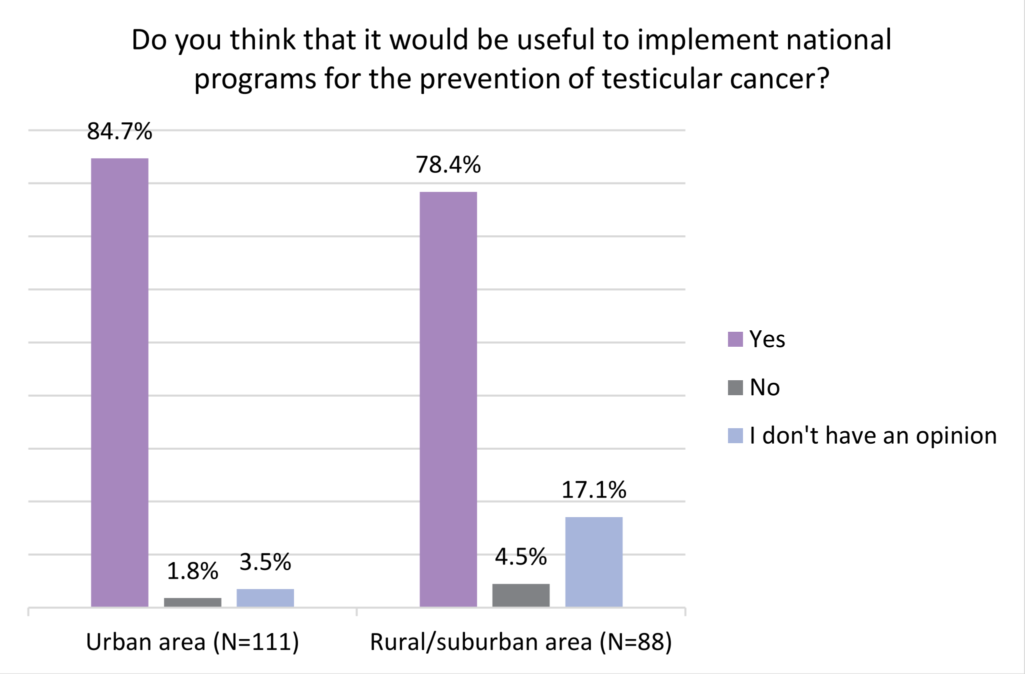
Graph 13. **Distribution of respondents from urban and rural areas according to the answers on information about testicular cancer**

Of the total sample, 62 (31%) respondents felt that the public was informed about testicular cancer, but not enough. 6 (3%) respondents agree that the public is fully informed. The largest number of respondents, 131 (65.5%) believe that the public is not sufficiently informed. One respondent did not answer this question. Respondents from urban and rural areas provided almost identical answers to these questions, which is shown in Graph 14.



Graph 14. **Distribution of respondents from urban and rural areas according to the answers on public information about testicular cancer**

The implementation of the national prevention program is desirable for 163 (81.5%) respondents, and only 6 (3%) respondents do not consider their implementation useful. 30 (15%) respondents do not have an opinion on the implementation of the national prevention program. Respondents from rural and urban areas believe that the implementation of a national prevention program is necessary, but it is also evident that compared to the urban population, the rural population has no opinion on the implementation of the national prevention program, with a share of 17.1%. The differences in responses are shown in Graph 15.



Graph 15. **Distribution of respondents from urban and rural areas according to the answers on the usefulness of implementing national prevention programs**

Discussion

Given that the incidence rate shows a steady growth trend, including Croatia, it is important to examine the knowledge of the male population about testicular cancer. The results of this study indicate that respondents have different perceptions about risk factors, treatment, and clinical presentation of testicular cancer. Studies conducted in different parts of the world have highlighted the relatively low level of awareness among men of risk factors and signs and symptoms of testicular cancer (7). Men need to be aware of risk factors. A review of existing literature shows that approximately 20-30% of men with testicular cancer delay medical care for more than 3 months after the onset of symptoms (8). Cryptorchidism as the most relevant risk factor is not recognized as such. However, genetic disorders and testicular cancer in the family are considered relevant, especially in respondents living in rural areas. Knowledge of risk factors is important because of the motivation for testicular self-examination. According to a study by Ugobom and Aburom, only a small number of individuals believe that testicular self-examination may help in the early detection of testicular cancer (9). This study showed different results. Despite a high level of awareness and importance of self-examination, only 30% of respondents practiced it. Men do not perform testicular self-examination due to a number of factors including lack of knowledge, fear of cancer, feelings of shame, and insufficient free time (10). Studies show that men have basic knowledge of testicular cancer but lack knowledge of testicular self-examination (11). This suggests that awareness of testicular cancer does not necessarily increase the practice of testicular self-examination. It has also been shown that men at risk for testicular cancer are not educated and do not know how to perform testicular self-examination (12). In this study, respondents from rural and urban areas state both that they know how to perform self-examination and that they are not familiar with it. Abnormalities in the structure of testicles, which may indicate cancer, can be noticed through self-examination. For this reason, it is advisable for men to perform regular self-examination. Self-examination should be performed once a month, with which 48.5% of respondents agree in this study. According to numerous studies, men in the risk group (under 35) have never performed testicular self-examination, and very small number of respondents knew that men in the age of 18-50 should perform testicular self-examination every month (13). Most malignancies are considered to have the highest incidence in old age, but the development of testicular cancer is associated with younger age. This study demonstrated a lack of knowledge about the age incidence of testicular cancer. Most respondents (49.5%) believe that it develops between the ages of 35 and 50, and only 20% of respondents believe that the incidence of testicular cancer is most common between the ages of 15 and 35.

Treatment with chemotherapy and radiotherapy in men causes damage to the gonads. In a study by Matos et al., half of the patients wanted to have children after testicular cancer treatment. However, according to the results of the study, fertility rate was lower after treatment (14). Given the detrimental effects of treatment methods on fertility, it is important to research the level of knowledge of the male population about this issue after testicular removal. The results of this study show that the respondents from the total sample were familiar with the fact that the removal of one testicle does not cause 100% infertility. The answers highlight 31.8% of respondents from rural areas who are not familiar with the problem of infertility in the case of removal of one testicle. Cornet et al., estimate that the incidence of testicular cancer in Europe will increase by 25% by 2025 (15). They also point out that Croatia, along with Slovenia and Norway, is the country with the highest risk. Due to the above data, it is important to improve preventive health care of the male population in Croatia. This study sought to determine how respondents were informed about testicular self-examination. Awareness of 18.5% of respondents was influenced by the campaign "Počeši s razlogom" for early detection of testicular cancer, and 14.5% of respondents were informed through public media. The results of this study show that the respondents were not sufficiently informed about self-examination, which is why other preventive programs should be developed with an emphasis on testicular self-examination. Also, nurses are listed as the second least represented group credited with educating men about self-examination. It is known that nurses often perform the function of promoters for improving and maintaining the health of the population and therefore should be actively involved in the implementation of prevention programs. 1.5% of respondents state that their spouse/partner had an impact on them conducting self-examination. Studies have shown that partner attitudes and behaviour are associated with greater awareness and motivation in the context of cancer screening (16). Women who are sufficiently informed about testicular cancer can motivate men to perform self-examination. Given the above, it is desirable to attract the attention of women in the implementation of prevention programs.

The goal of any cancer screening program is to diagnose the disease at an early stage, which affects survival. It has been found that the implementation of a national program for screening and early detection of cancer can significantly reduce mortality (17). Encouraging participation in prevention programs is key to promoting men's health and is aimed at early detection of testicular cancer. An integral part of prevention is informing the population about the disease. The results of this research show that the public is insufficiently informed about testicular cancer, which is supported by the answers of 65.5% of respondents. 81.5% of respondents believe that it would be useful to implement national prevention programs for early detection of testicular cancer, given that it has not yet been developed in Croatia.

In most countries, health policy is focused primarily or exclusively on women's health, and men's health is often neglected. Although they do not contribute to the mortality rate directly, male-specific health problems are becoming more common. Health policy must improve the provision of information on men's health, develop information and confidentiality programs, and promote the development of preventive measures for the main causes of mortality and morbidity in men, including preventive health examination. Given that testicular cancer occurs in men of reproductive age, it is desirable that education be conducted as part of the curricula of high schools and universities in cooperation with primary care health professionals. It is also important to strengthen the role of public media in raising awareness about testicular cancer.

Conclusion

Testicular cancer is associated with a high morbidity rate and a negative impact on quality of life. Therefore, attention should be paid to the health of the male population and promote it in order to achieve better health outcomes.

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INFORMIRANOST O KARCINOMU TESTISA MEĐU MUŠKOM POPULACIJOM U REPUBLICI HRVATSKOJ

Sažetak

Karcinom testisa najčešći je tumor kod muškaraca reproduktivne dobi. Incidencija se povećala posljednjih nekoliko godina, kako na globalnoj razini tako i u Republici Hrvatskoj. U Republici Hrvatskoj nisu provedene studije koje pokazuju razinu informiranosti populacije o karcinomu testisa, stoga je provedeno ovo istraživanje čiji je cilj bio ispitati znanje i stavove muške populacije o karcinomu testisa, utvrditi postoje li različitosti u znanju i stavovima muške populacije iz ruralnog i urbanog područja te ispitati na koji način povećati informiranost muške populacije o prevenciji karcinoma testisa. Među 200 ispitanika iz ruralnog i urbanog područja Republike Hrvatske provedeno je presječno istraživanje. Istraživanje je provedeno ispunjavanjem anonimnoga anketnog upitnika. Ispitano je znanje o rizičnim čimbenicima, kliničkoj prezentaciji, dijagnostici i metodama liječenja te provođenju samopregleda. Rezultati nisu pokazali značajnu razliku između znanja i stavova populacije iz ruralnog i urbanog područja. Međutim, pokazalo se da je ukupna razina znanja o karcinomu testisa niska te da je potrebno ulagati napore u unaprjeđenje preventivnih programa u svrhu zaštite zdravlja muške populacije.

Ključne riječi: karcinom testisa, informiranost, hrvatsko ruralno i urbano područje, prevencija

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Implications of Work in the Covid Isolation Ward and the Central Emergency Department on the Life and Work of Nurses

[1] **Jadranka Pavić**
[2] **Marija Vučko**
[1] **Franjo Liška**

[1] **University of Applied Health Sciences, Zagreb, Croatia**
[2] **Clinical Hospital „Sveti Duh", Zagreb, Croatia**

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Author for correspondence:
Jadranka Pavić
University of Applied Health Sciences, Zagreb, Croatia
Mlinarska cesta 38, Zagreb, Croatia
E-mail: jadranka.pavic@zvu.hr

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Abstract

Nurses as the largest group of health workers are at the forefront of the health system's response to the pandemic. In order to control the spread of infection in patients with suspected or confirmed infection, the need for the formation of COVID isolation wards was emphasized. The situation required rapid adaptation to new working conditions, which affected the psychophysical condition and professional and private life of nurses who were actively involved in the care of patients with suspected or confirmed SARS-CoV-2 infection. The aim of the paper is to identify the most common problems faced by nurses working in COVID isolation wards and central emergency departments. Based on the obtained results, the biggest problems in working with SARS-CoV-2 positive patients were working in 12/24-hour shifts (82%), working in protective clothing (74%) and lack of staff (88%). Also, problems were present due to the frequent reorganization of work and the absence of members of the already experienced team due to illness (76%). Working with SARS-CoV-2 suspected/positive patients negatively affected job satisfaction (46%) as well as did frequent isolation from family (58%). Research has shown that working with SARS-CoV-2 suspected/positive patients has changed the private lives of nurses (74%), and has negatively affected physical health (78%), as well as mental health (70%), of our respondents. Despite difficult working conditions, satisfaction was shown with the knowledge and experience of working with highly contagious patients in isolation conditions (64%), strengthened sense of teamwork (66%) and meeting team members who are extremely dedicated and good colleagues (72%).

Introduction

In the last two decades, several epidemics caused by viruses, such as severe acute respiratory coronavirus syndrome (SARS-CoV) from 2002 to 2003, and H1N1 influenza in 2009, have had a significant impact on global health. Since COVID-19 was declared a pandemic, the virus has spread to 223 countries with more than 138 million cases, and more than 2.9 million deaths have been reported globally. The current WHO estimate of the global mortality rate of COVID-19 is 2.2% (1). According to the CNIPH (Croatian National Institute for Public Health), from the beginning of the epidemic until 14 November 2021, 9,880 people died of SARS-CoV-2 infection in Croatia (2).

Although experts have long predicted a large-scale pandemic such as COVID-19, health systems have differed in the context of preparedness, management and monitoring (2). The biggest problems were the allocation of the necessary resources and equipment needed to combat the spread of the virus. As this is a new infection, a lack of understanding of the signs and symptoms of SARS-CoV-2 and an incorrect treatment can accelerate the spread of the infection in the health system (3).

Nurses are the most vulnerable group of health care professionals caring for patients with COVID-19 and have been at the forefront of the pandemic since its beginning. The COVID-19 pandemic has led to a sharp shift in nursing practice to meet the sudden and increased demand for pandemic-related care. During the pandemic, nursing care has gone through a period of change. There are changes in the provision of health services, organizational structure and professional relationships. The roles of nurses are numerous. They conduct health education that includes strategies to prevent infection (regular hand washing, avoiding touching mucous membranes with dirty hands, cancelling group activities) and early detection of infection. Furthermore, they monitor and prevent nosocomial infections. Standard precaution measures are applied (hand hygiene, wearing protective masks, wearing personal protective equipment, disinfecting rooms and objects), and educating patients and healthcare staff. They also provide care for patients in isolation wards. Nurses are exposed to the virus on a daily basis and encounter a variety of psychophysical complications. There are 3.8 million nurses in the United States and 20 million in other parts of the world, and yet there is a need for many more nurses (4). Nurses who have cared for patients with suspected and confirmed SARS-CoV-2 infection since the beginning of the pandemic have had to become familiar with new diagnostic and therapeutic procedures and protocols. They are actively involved in caring for patients and remain key actors in stopping the pandemic. Several viral diseases are known to have an effect on healthcare professionals, which is currently also observed in SARS-CoV-2 infection (4). In the first cases in China, 29% of patients with SARS-CoV-2 infection were healthcare professionals and were presumed to have contracted the disease in hospitals. Deaths among health professionals are rare and mostly affect people over the age of 50. With the growing understanding and prevention of the disease, the proportion of health workers suffering from COVID-19 in the hospital has decreased (3). Safety at work is crucial because healthcare professionals are faced with the risk of infection on a daily basis. Healthcare professionals during care for patients with SARS-CoV-2 infection must be fully protected with appropriate personal protective equipment to prevent the risk of infection. It is important that health facilities have appropriate infection control protocols and personal protective equipment in sufficient quantities for staff caring for patients with suspected or confirmed SARS-CoV-2 infection. Risk categories for exposure in the health system are often based on the type of contact established and whether personal protective equipment is used consistently and appropriately.

The impact of the pandemic on the health of nurses

The high prevalence of SARS-CoV-2 infection in the world population and the characteristics of the disease have contributed to the development of psychological problems. According to a longitudinal study on the Chinese population, during the onset and peak of the epidemic, the symptoms of posttraumatic stress disorder were found to decrease significantly after four weeks (5). However, psychological problems affected not only the general population but also health workers. Nurses' reactions to stress during a pandemic must be viewed from the perspective of health and safety at work. Stress and burnout of nurses were recognized as a hazard to work even before the pandemic. Characterized by feelings of exhaustion, burnout is thought to be the result of chronic work stress that an individual is unable to manage (6). The onset of the COVID-19 pandemic increased stress at work, jeopardizing the mental health and well-being of nurses (7). Research from China and Italy has shown that nurses that are directly involved in the health care of patients with COVID-19 are at increased risk of mental health problems compared to other health professionals (3).

Between March 20 and April 10, 2020, the American Nurses Association (ANA) conducted a national survey during the early stages of the pandemic in the United States. A total of 32,000 nurses responded to a survey that asked questions about their professional needs and concerns about the pandemic. 74% of respondents stated that their greatest stress is the lack of appropriate personal protective equipment, and 64% of respondents stated concerns about the safety of their family and friends. More than 85% expressed fear of going to work (8).

Nurses experience fear of developing infections, fear of not providing adequate care to patients due to inadequate organization, insufficient staff and lack of work equipment, fear of transmitting the virus to family and friends, and fear of stigmatization. Also, the stress in the workplace is associated with increased patient mortality, an increase in the number of patients, a high workload, and inadequate organizational support. It is necessary to take into account the psychological and physiological impact of the pandemic on nurses. Pandemic-related stressors can significantly affect their psychophysical functioning (4).

Studies have shown that psychological effects during a pandemic period can last a long time and negatively affect psychological well-being, and can cause post-traumatic stress disorder, depression, and stress in healthcare professionals. Batra et al. conducted a meta-analysis to show the impact of COVID-19 on the psychological well-being of health professionals (9). Major factors including anxiety, stress, depression, insomnia, and burnout were identified, and higher levels of anxiety and depression were more prevalent among women than men, and nurses compared to physicians (9).

Aim

The aim of the study was to determine the most common problems faced by nurses working in COVID isolation wards and the central emergency department where SARS-CoV-2 positive or suspected patients are stationed and to determine the implications of working in COVID isolation wards on the life and work of nurses.

Methods

The research was conducted from 1 April to 30 April 2021 at the Clinical Hospital “Sveti Duh” in Zagreb. The study involved 50 nurses working in isolation wards and at the central emergency department. All subjects worked with SARS-CoV-2 suspected/positive patients. The survey questionnaire was anonymous, and it did not provide a place to enter the names and surnames of the participants, and the nurses decided whether they wanted to fill it out. The completed questionnaires were placed by the respondents in an envelope for the whole group of respondents.

The research was conducted by filling out a structured survey questionnaire. The research was approved by the Ethics Committee of the Clinical Hospital “Sveti Duh”.

The survey questionnaire was constructed for the purposes of this research and contains two parts. The first part of the questionnaire includes information about the respondents - education, age, frequency of illness and mode of infection. The second part of the questionnaire refers to questions related to work in the COVID isolation ward, namely the assessment of the complexity of work in the isolation ward and the impact of work in the isolation ward on personal, family and business life.

Statistical data processing was performed using the Microsoft Office Excel program and descriptive statistical methods were used to describe frequency distribution. The data are shown in a tabular view.

Results

Sociodemographic data

The study involved 50 respondents. The most represented are respondents in the age group between 25 and 29 years - 14 respondents (28%). The smallest number of respondents, 2 (4%), belongs to the age group between 45 and 49 years. The average age of all respondents was 32.3 years. The largest share among the respondents are nurses with completed high school education, and the smallest share make up the respondents with graduate degree education. Out of 50 respondents, 32 (64%) have high school and 15 (30%) have an undergraduate diploma. The smallest share in the sample of respondents was with graduate degree education, 3 of them (6%). Furthermore, out of 50 respondents, 23 (46%) had COVID-19, of which 15 (71.4%) developed an infection at work and 2 (8.7%) of the surveyed respondents developed the disease while they were in self-isolation as a family contact.

Work at the isolation ward of the Clinical Hospital "Sveti Duh"

Table 1. **Assessment of the complexity of work in the isolation ward**

	1 I don't agree at all	2 Generally, I disagree	3 I neither agree nor disagree	4 Generally, I agree	5 I totally agree
1. Working in protective clothing at the COVID isolation ward/ emergency department is very strenuous.	0%	6%	2%	18%	74%
2. I spend more time in protective clothing than expected.	2%	10%	16%	22%	50%
3. Due to the dynamics of work in the COVID isolation ward/ emergency department, there is no time for proper exchanges between working in protective clothing and rest.	10%	12%	6%	20%	50%
4. The intensity of work in the COVID isolation ward/ emergency department has increased due to the lack of nurses (reorganization of work, illness, self-isolation, etc.)	0%	4%	4%	30%	58%
5. Absence of team members in the COVID isolation ward/ emergency department due to reorganization of work and illness complicates the work process.	0%	0%	8%	20%	56%

6. It takes more time to complete a task with new staff in the COVID isolation ward/emergency department due to a lack of shared work experience.	0%	4	16	26%	54%
7. There are enough protective materials and means to work in the COVID isolation ward/ emergency department.	6%	10%	12%	34%	38%
8. Work in extraordinary circumstances at the COVID isolation ward/emergency department revealed certain shortcomings in the organization of the service.	4%	8%	8%	36%	44%
9. Working in 12/24-hour shifts at the COVID isolation ward/ emergency department is extremely mentally and physically difficult.	0%	0%	18%	16%	66%
10. Working in extraordinary circumstances in the COVID isolation ward/emergency department creates frequent conflicts in the team.	22%	22%	22%	22%	12%

37 (74%) respondents fully agree with the statement that working in protective clothing in COVID isolation wards/emergency department is very strenuous. None of the respondents answered that they did not agree with the statement at all. Furthermore, 25 (50%) respondents believe that they spend more time in protective equipment at work than expected. 11 (22%) respondents mostly agree, and a smaller number of respondents, 5 of them (10%), generally disagree with the statement. Only one respondent completely disagrees.

To the statement of the extent to which the dynamics of work in the COVID isolation ward/emergency department affect the proper exchange between working in protective clothing and rest, 25 (50%) respondents fully agree that more time is spent in protective clothing than expected. Two respondents did not respond to this statement.

To the statement "The intensity of work in the COVID isolation ward/emergency department has increased due to the lack of nurses", the largest number of respondents, 29 (58%), answered that they fully agree with the statement. An equal number of respondents, 2 of them (4%) generally disagree with this statement and believe that neither is true. None of the respondents agreed with the stated statement, and 4 respondents did not answer at all.

28 (56%) respondents fully agree with the statement that the absence of members of the already well-coordinated team complicates the work process. None of the respondents answered that the statement did not apply to them at all, and 16 respondents did not answer the statement. 27 (54%) respondents agree that it takes more time to complete tasks with new staff due to a lack of shared work experience. The smallest number of respondents, 2 of them (4%)

generally disagree with this statement.

19 (38%) respondents fully believe that there are enough protective materials and resources to work in the COVID isolation ward / emergency department. 3 (6%) respondents disagree with this statement.

22 (44%) respondents believe that working in extraordinary circumstances revealed certain shortcomings in the organization of the service. They are followed by 18 (36%) respondents who mostly agree with the statement.

33 (66%) respondents fully believe that working in 12/24-hour shift is extremely physically and mentally difficult. None of the respondents answered that they generally or completely disagree with the statement.

6 (12%) respondents fully agree with the statement that working in extraordinary circumstances in the isolation COVID ward/emergency department creates frequent conflicts in the team. Equal number of respondents, 11 of them (22%) agree equally with the other statements.

Table 2. **Impact of work in the isolation ward on personal, family and business life**

	1 It doesn't apply to me at all	2 Mostly it doesn't apply to me	3 I don't know - I can't evaluate	4 It mostly applies to me	5 It completely applies to me
1. Working in extraordinary circumstances strengthened my sense of teamwork.	8%	16%	10%	30%	36%
2. Working in extraordinary circumstances has created additional security and self-confidence in my daily work.	8%	16%	22%	24%	30%
3. Working in extraordinary circumstances has revealed to me people who are extremely dedicated and good colleagues.	4%	6%	16%	34%	38%
4. Working in extraordinary circumstances provided me with experience and knowledge in working with highly contagious patients in isolation conditions.	8%	8%	18%	28%	36%
5. Working with SARS-CoV-2 suspected/positive patients has negatively affected my job satisfaction.	14%	16%	24%	24%	22%
6. Because of my work with SARS-CoV-2 suspected/positive patients, I am often isolated from my family.	12%	14%	16%	32%	26%
7. The experience of working with SARS-CoV-2 suspected/positive patients has made me aware of the value of community.	20%	22%	12%	28%	18%
8. Working with SARS-CoV-2 suspected/positive patients has changed my private life.	8%	8%	10%	36%	38%
9. Working with SARS-CoV-2 suspected/positive patients has negatively affected my physical health.	2%	8%	12%	38%	40%
10. Working with SARS-CoV-2 suspected/positive patients has negatively affected my mental health.	12%	8%	10%	28%	42%

To the statement that working in extraordinary circumstances has strengthened their sense of teamwork, 66% of respondents say that it fully or mostly applies to them, while 24% believe that it does not apply to them at all or that it applies to them mostly, and 10% are undecided.

18 (36%) respondents agree with the statement that working in extraordinary circumstances has created additional security and self-confidence in their daily work, and the smallest number of respondents, 4 (8%) believe that the statement does not apply to them at all. With the statement that through their work in extraordinary circumstances, they discovered people who are self-sacrificing and good colleagues, the largest number of respondents, 72% of them, completely or mostly agree that it refers to them. The smallest number of respondents, 4 (8%), do not agree with the statement at all.

For the statement "Working in extraordinary circumstances provided me with experience and knowledge in working with highly contagious patients in isolation conditions", 64% of respondents believe that it fully or mostly refers to them, while 16% disagree or mostly disagree and 18% are hesitant.

Furthermore, for the statement "Working with SARS-CoV-2 suspected/positive patients negatively affected my job satisfaction", 46% respondents stated that it fully or mostly applies to them, while in one third of the respondents (30%) there was no negative impact, and they state that the statement does not apply to them at all or that it mostly applies to them.

To the statement "Because of my work with SARS-CoV-2 suspected/positive patients, I am often isolated from my family", 58% of respondents answered that the statement fully or mostly applies to them, 24% cannot assess, while 30% do not agree with the abovementioned statement. Responses to the statement "The experience of working with SARS-CoV-2 suspected/positive patients has made me aware of the value of community" were polarized in equal proportions: 46% of respondents answered affirmatively (It completely applies to me/ It mostly applies to me), while 44% of respondents gave a negative answer (It doesn't apply to me at all/ Mostly it doesn't apply to me). Most respondents (74%) stated that working with SARS-CoV-2 suspected/positive patients changed their private lives, while in 16% of them working conditions had no impact on their private life and 10% could not give an assessment. Working with SARS-CoV-2 suspected/positive patients negatively affected the physical health of the majority (78%) of respondents. A similar range of responses is to the statement "Working with SARS-CoV-2 suspected/positive patients has negatively affected my mental health" in which 70% of respondents state that it applies completely or mostly to them, while 20% believe that the statement completely or mostly does not apply to them and 10% cannot give an estimation.

Discussion

Nurses are at the forefront of the care of hospitalized patients with suspected or proven SARS-CoV-2 infection. As such, they have a high risk of infection and psychophysical consequences. The aim of this research was to investigate the implications of working in COVID isolation wards and the emergency department of the Clinical Hospital "Sveti Duh" in Zagreb.

Personal protective equipment is one of the most significant challenges faced by the health system during the COVID-19 pandemic. It presents challenges to both the supply and implementation of security measures to protect the health of the health personnel. According to the obtained data, it is evident that the work in protective clothing in COVID isolation wards is extremely hard for most of the respondents and that they spend more time in it than expected.

Numerous studies have shown that nurses lack health system support in terms of lack of personal protective equipment and hand sanitizers, which is crucial for the protection of health professionals (10). A qualitative study conducted by He et al. using an in-depth interview on a sample of 10 Chinese nurses in February 2020 found that nurses worked without personal protective equipment or with inadequate protective equipment (11). In our research, it was shown that nurses believe that there is enough protective material and means to work.

Analysis of our research data shows that due to insufficient experience in working with SARS-CoV-2 suspected/positive patients, more time is needed to complete tasks. The COVID-19 pandemic requires the flexibility and resilience of healthcare professionals. They had to prepare for the epidemic and form isolation wards and intensive care units for SARS-CoV-2 positive patients. This required education on the new way of working, as well as the redistribution of nurses within the health system. However, many nurses had no prior training and were assigned to isolation wards without proper preparation. Due to the reorganization of work and numerous self-isolations due to the spread of the disease among health workers, the intensity of work in the isolation wards has increased, with which most respondents agree.

Since the beginning of the COVID-19 pandemic, health workers have been under a heavy workload. Working in 12/24-hour shift is physically and mentally difficult for most respondents. Shifts in the isolation ward due to demanding work tasks can contribute to fatigue and burnout of nurses. Therefore, to minimize the risk of burnout, healthcare facilities should employ additional staff to relieve the burden on nurses and reduce the overload of 12-hour and 24-hour shifts.

Most respondents in our study believe that working with SARS-CoV-2 positive patients has changed their private lives. Seven studies have shown that nurses are extremely concerned about their families and the safety of their families because of SARS-CoV-2 positive patients (10). Nurses are afraid of transmitting the virus to their families even though they wear personal protective equipment while working. Several studies have shown that nurses are concerned about not being able to fulfill their family roles and spend enough time with their children and family members (11).

The majority of respondents could not assess the extent to which working with SARS-CoV-2 suspected/positive patients affected their physical health. On the other hand, most respondents generally believe that there has been a negative impact on their mental health. Nurses feel responsible for caring for patients, but there is a fear of infection. Several studies have shown that nurses experience feelings of anxiety, fear, or depression. Zhang and co-workers observed psychological changes in nurses at Wuhan Hospital in China, the epicenter of the COVID-19 epidemic, from February 9 to March 15, 2020. Using deliberate sampling, they interviewed 23 nurses. In the early stages of the pandemic, nurses deployed to the COVID-19 isolation ward felt fear and nervousness, and some even fear of death (12). After several weeks in the isolation unit, the nurses expressed anxiety, depression, and irritation. The study found that the younger group of nurses were more emotionally exhausted (12).

Several studies have evaluated mental health outcomes among healthcare professionals treating patients exposed to SARS-CoV-2 infection. A systematic review and meta-analysis aimed at synthesizing and analyzing evidence on the prevalence of anxiety, depression, and insomnia among health professionals during COVID-19 was conducted in April 2020 at PubMed, Google Scholar, Cochrane Library, Embase. Meta-analysis of articles determined the prevalence of anxiety 23.2%, depression 22.8% and insomnia 38.9%. Furthermore, according to the same review, there is growing evidence that SARS-CoV-2 infection may even be an independent risk factor for stress in healthcare professionals (13).

Nurses work in teams which is considered an important strategy to improve patient treatment outcomes. Some teams have effective collaboration, while some have difficulties. Using an inductive approach, Laura Petri (14) has systematically analyzed a review of the literature to clarify the current use of interdisciplinary collaboration in health care. Within an effective interdisciplinary approach to patient care, Petri described in the article "Concept Analysis of Interdisciplinary Collaboration" that cooperation can simply be defined as an act of working together, but for it to be effective it must take place in an atmosphere of mutual trust and respect (14).

Our research has shown that working in COVID isolation wards does not create frequent conflicts in the team, moreover, nurses feel that their sense of work is strengthened and that they work in a team with dedicated colleagues. During crisis situations, such as epidemics, nurses work in interdependent but stressful environments, but put collegial relationships first to ensure that the care provided is always of the highest quality. Similar results were shown by a multidimensional study of hospital staff working in two Finnish specialized medical care centers, which showed that in stressful situations caused by the COVID-19 pandemic, nurses cared for and helped each other and, to some extent, felt collective empowerment (15).

Research limitations and implications for future research

The limitations of this research are mostly in its coverage of respondents, that is, in the sample of respondents in the Clinical Hospital "Sveti Duh", which may be a problem in the generalization of research in relation to other sites with isolation wards.

Research has obtained results that show that health facilities must be actively involved in providing support to nurses during and after a pandemic. It is vital that nurses receive clear, concise, and up-to-date information on best patient care and infection control practices, as well as sufficient access to appropriate personal protective equipment to optimize their safety. Experienced and well-trained staff is needed to provide adequate patient care. The physical and psychological impact of work on nurses in the isolation ward needs to be recognized in a timely manner. Proper protection against the poor psychophysical condition of staff will certainly lead to greater ability to perform their tasks.

The results of this research can contribute to the organization and planning of ways of working that would improve long-term working ability and working conditions in this crisis. First, it is important to enable the already mentioned adequate communication as well as the availability of updated and accurate information. Using tools such as strengthening safety procedures, providing systematic support, and monitoring stress levels would greatly help develop a safe environment for staff and patients in every way. Rotation of staff from sites more affected by stressful events to those less affected, pairing less experienced workers with those more experienced, encouraging staff to provide social support to each other, as well as providing and directing staff to places of psychosocial support. Preserving the psychophysical health of nurses can lead to successful coping with everyday stressful situations, which will ultimately result in maximum work productivity and contribution to the community.

Conclusion

The results of the research showed the complexity and effort in working in protective clothing in the COVID isolation ward/emergency department (74%) which is why more time is spent at work than planned (72%) and there is no time for proper exchanges between work in protective clothing and rest (70%). In addition, the respondents stated that working in 12/24-hour shift in the COVID isolation ward/emergency department is extremely mentally and physically difficult (82%).

Furthermore, the intensity of work in the COVID isolation ward/emergency department was increased due to the lack of nurses (88%), and the absence of team members in the COVID isolation ward/emergency department due to reorganization of work and illness complicates the work process (76%). Additionally, it takes more time to complete the task with new staff in the COVID isolation ward/emergency department due to lack of shared work experience (80%) and working in extraordinary circumstances in the COVID isolation ward/emergency department revealed certain shortcomings in the service organization (80%) %), however, there are sufficient protective materials and means for work.

In assessing the impact of work in the isolation ward on personal, family and business life, the research showed that working in extraordinary circumstances strengthened the sense of teamwork in a significant number of respondents (66%) and that working in extraordinary circumstances created additional security and self-confidence. in everyday work and provided experience and knowledge in working with highly contagious patients in isolation conditions (64%).

However, working with SARS-CoV-2 suspected/positive patients negatively affected job satisfaction (46%) and frequent isolation from family (58%). In addition, most respondents (74%) stated that working with SARS-CoV-2 suspected/positive patients changed their private lives.

Furthermore, working with SARS-CoV-2 suspected/positive patients negatively affected the physical health of the majority (78%) of respondents as well as their mental health (70%).

Research has shown that the SARS-CoV-2 pandemic has significantly affected the work of nurses. The situation required rapid adaptation to new working conditions, which affected the psychophysical condition and professional and private lives of nurses who were actively involved in the care of patients with suspected or confirmed SARS-CoV-2 infection.

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IMPLIKACIJE RADA NA IZOLACIJSKOM COVID ODJELU I SREDIŠNJEM HITNOM PRIJAMU NA ŽIVOT I RAD MEDICINSKIH SESTARA/TEHNIČARA

Sažetak

Medicinske sestre / medicinski tehničari, kao najveća skupina zdravstvenih radnika, nalaze se na prvom mjestu odgovora zdravstvenog sustava na pandemiju. U svrhu kontrole širenja infekcije bolesnika sa suspektnom ili potvrđenom infekcijom, naglašava se potreba za formiranjem izolacijskih COVID odjela. Situacija je zahtijevala brzu prilagodbu na nove radne uvjete, što je utjecalo na psihofizičko stanje te profesionalni i privatni život medicinskih sestara/tehničara koji su bili aktivno uključeni u skrb za bolesnike sa suspektnom ili potvrđenom infekcijom virusom SARS-CoV-2. Cilj rada bio je utvrditi najčešće probleme s kojima se suočavaju medicinske sestre koje rade na izolacijskim COVID odjelima i središnjem hitnom prijamu. Na temelju dobivenih rezultata pokazalo se da su najveći problemi u radu sa SARS-CoV-2 pozitivnim bolesnicima, suspektnim ili oboljelim bolesnicima rad u 12/24-satnom dežurstvu (82 %), rad u zaštitnoj odjeći (74 %) i manjak medicinskih sestara (88 %). Također, problematika je prisutna zbog česte reorganizacije rada i bolesti uslijed koje dolazi do odsutnosti članova već iskusnog tima (76 %). Rad sa SARS-CoV-2 suspektnim/pozitivnim bolesnicima negativno je utjecao na zadovoljstvo poslom (46 %), kao i čestu izoliranost od obitelji (58 %). Istraživanje je pokazalo da je rad sa SARS-CoV-2 suspektnim/pozitivnim bolesnicima promijenio privatni život medicinskih sestara/tehničara (74 %) te da je negativno utjecao na fizičko zdravlje (78 %), kao i na mentalno zdravlje (70 %) ispitanika. Unatoč otežanim uvjetima rada, pokazalo se zadovoljstvo dobivenim znanjem i iskustvom u radu s visokokontagioznim bolesnicima u izolacijskim uvjetima (64 %), osnaženim osjećajem za timski rad (66 %) te upoznavanjem članova tima koji su iznimno požrtvovni i dobri kolege (72 %).

Ključne riječi: COVID-19, izolacijski odjel, medicinske sestre / medicinski tehničari

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Needs and Difficulties of Parents with Children Suffering from Malignant Diseases

[1] Jelena Slijepčević

[1] University Hospital Centre Zagreb, Department of Anesthesiology, Intensive Care and Intensive Care And Pain Therapy, Zagreb, Croatia

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Author for correspondence:
Jelena Slijepčević
University Hospital Centre Zagreb, Department of Anesthesiology, Intensive Care and Pain Therapy
Kišpatićeva 12, 10000 Zagreb, Croatia
E-mail: jelena.slijepcevic.kbc@gmail.com

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Abstract

Malignant diseases are one of the leading causes of death in children in developed countries, although constant progress in therapy is continuously decreasing mortality. The diagnosis of malignant disease is a significant stressor in the life of a child and its family, significantly affecting the quality of life for the entire family. It constitutes the prototype of a stressful situation and a disease with a potentially devastating effect on the child and its family. This paper discusses 50 professional and scientific papers published between 1993 and 2022 that explore the needs and difficulties of parents of children with malignant diseases. To provide adequate help and care, a correct evaluation of the problem and parents' needs is required. For the parents, the diagnosis of a malignant disease for their child constitutes a psychological and existential challenge. To meet the parents' needs, as well as to ease their problems, further research – in most cases also supported by the parents themselves – is needed to help them cope with this extremely stressful and hard part of their lives.

Introduction

According to the Croatian Institute of Public Health, in 2019 in the Republic of Croatia, a total of 149 children and young people under the age of 19 fell ill with some form of malignant disease (1). Malignant diseases are one of the leading causes of death in children in highly developed countries, although improved therapy for children with cancer has led to a significant increase in survival rates (2). The resulting stress of the parents of a child with malignant disease is extremely high and significantly affects the quality of life of the whole family (3,4). Previous research has shown a variety of parental reactions, and higher levels of anxiety than in the patients themselves (5). In addition, long-term treatment of a child with a malignant disease causes a state of chronic stress in the parents during this period (6,7). Apprehension, anxiety, depression, and other psychological symptoms are most intense during the active phase of a child's treatment, but over several years they slowly decline and become comparable to levels in the community sample (8).

On the other hand, parental reactions to a child's illness such as symptoms associated with traumatic stress, feelings of helplessness, insecurity, and low self-control were noted many years after the child's treatment was completed (9-12). Some studies show that a child's malignant disease leads to intensive participation within the health system, which requires adjustment and provision of information and can lead to emotional exhaustion of parents, disturbed relationships between family members, stigmatization and alienation, as well as significant changes in the daily life of the family (3,13,14). Most research to date shows that parents express feelings of guilt, anger (15), feelings of insecurity, loneliness, loss of control (16), financial difficulties (17), mental exhaustion manifested as fatigue and increased sensitivity to stress, symptoms of post-traumatic stress disorder (5,10), and sleep problems (16). However, the ability of parents to manage their psychological changes during a child's cancer treatment process is vital, not only for their solace, but also for the impact on the child's well-being (18) and long-term social adjustment (19,20). The parents of a child with malignant disease react in different ways. Most of them go through five basic stages: denial, anger, negotiation, depression, and acceptance according to the Kubler-Ross model (21). Being familiar with these reactions, taking into account the time at which each reaction occurs and their duration, we can find out what really saddens parents, what problems they face and what their needs are during and after the treatment process of their child. In addition to the difficulties mentioned so far, a recent study by Anna Lewandowska from 2022 speaks of the very pronounced need of parents for psychological help, emotional support and the provision of information. In her research conducted over five years, she found that the health care system does not currently meet the needs of parents of sick children, so it is necessary to explore mechanisms by which health care providers can identify and meet the needs of parents (22).

The aim of this paper is to determine the needs and difficulties faced by parents of children with malignant diseases during and after hospital treatment, based on available research. In addition to identifying the needs and difficulties of parents, the paper will discuss an ethical dilemma about the involvement of parents of children with malignant diseases in research.

Methods

A review of the literature related to the needs and difficulties faced by parents of children with malignant diseases was made. Emphasis was placed on the period during the child's hospitalization and the period after treatment. Medline, PubMed and CINAHL databases were searched using the key words: pediatric cancer, parent satisfaction, parent needs, issues, hospitalization, and ethics. 50 professional and scientific papers were reviewed. Only papers with the entire available text were taken into account. The search was limited to the period between 1993 and 2022.

The ways parents cope with their child's diagnosis of malignant disease

In order to better identify the needs and difficulties of parents of children with malignant diseases, we need to know what are the normal, expected reactions of parents, and what are acceptable coping styles after learning about a child's malignant disease. Most parents are not ready for their child to be diagnosed with a malignant disease (23). The life-threatening nature of the disease and its intensive treatment cause many psychological, practical and emotional difficulties for parents. Coping with fear becomes an inseparable part of life. Fear of death, fear of the unknown, and thinking about one's own capabilities and limitations arise. Being faced with a diagnosis of a child's malignant disease causes a variety of emotional reactions. Reactions change simultaneously with different stages of the sick child's treatment (24).

In the first days and weeks after diagnosis, parents describe the reactions they experienced as if they were caught in an emotional whirlpool or a nightmare. Most parents who go through this period share similar feelings, but the ways parents are willing to voice or express those feelings vary. The way they deal with their emotions is marked by their own life experiences, cultural differences and their personal coping styles. According to distinguished authors in the world of research on human emotions and reactions such as Dr. Kubler Ross, five basic phases that a person goes through during a certain traumatic situation (and that we consider acceptable) were identified. The phases, popularly known as DABDA, include the following:

1. Denial
2. Anger
3. Bargain
4. Depression
5. Acceptance

Some researchers are trying to disprove Dr. Kubler Ross' model, such as George Bonanno in his book "The Other Side of Sadness: What the New Science of Bereavement Tells Us About Life After a Loss" in which he states that most people do not grieve and that the lack of grief and other phases is a good outcome after a traumatic event. Literature research done for the purposes of writing this paper does not confirm George Bonanno's assertion. Some parents experience certain emotions for a longer time, some remain in a certain phase for years, while others skip phases. That parents are indeed in a state of chronic stress is confirmed by research on neuroendocrinological measurements in parents of children with malignant diseases (7,25).

After hearing the child's diagnosis, parents are often shocked and confused, they stop listening, do not remember what was said and are not able to think clearly. Healthcare professionals and others involved in the information process need to be aware of possible reactions from parents, to help them in their state of shock. Some parents cannot cope with bad news and can react very aggressively and even physically attack medical staff (26). It has been found that the way healthcare staff respond to parents' feelings and their behavior can affect the parents' ability to absorb the initial shock and begin to adapt to the child's illness. The range of emotions that occur in parents is wide (and includes feelings such as fear, guilt, anger, dullness, hopelessness, and sadness), whereas coping styles in parents differ. After the initial shock, parents can quickly turn to positive thoughts, preoccupy themselves with certain details of illness or treatment, seek support from relatives and friends, find hope in religious beliefs, etc. (26).

Research to date has shown that the way bad news is presented to parents is the most important part of the process of treating their child. For this reason, several recommendations and protocols have been drawn up for medical staff on how to communicate with parents of severely ill children (26-28). The summary of this chapter is that all the reactions and coping styles expressed by parents after hearing a child's diagnosis can be acceptable and expected. They are mainly determined by the time period and various phases that can be identified based on their behavior. Proper recognition and acceptance of parental reactions and coping techniques, without condemnation, are imperative for medical staff.

Needs of parents whose children are suffering from malignant diseases

Previous research conducted with parents of hospitalized children recognized that there is no systematic approach to parental contribution to a child's recovery. There are parents who are maximally involved in the care of their child, as well as those who are less involved, because it is too stressful for them (29). After recognizing the positive impact of room-in, i.e., allowing a parent to be with their child during a hospital stay, a survey was conducted in Iceland in the 1990s on self-assessment of parents' satisfaction with their needs being met. One of the most important self-assessed needs of parents was the possibility of staying with the child 24 hours a day and this need was fully met in all respondents (30). The shortcoming of this research is the small number of respondents (32), making the result unsatisfactory in a wider sense because there are parents who were not included in the research and who were not able to be with their child. Parents are nowadays considered to be partners in the care of their child during hospitalization. It is necessary to determine clear boundaries of parental partnership and set boundaries for their participation in the process of caring for a sick child. The needs of parents whose children have a malignant disease differ from the needs of parents whose children are not seriously ill and depend on the emotional state of the parents at a given time. Research conducted by a nursing professor Linda Shields highlights 9 basic needs that parents listed as most important and which are not impacted by demographic diversity. The research was conducted in Sweden, England, Indonesia and Australia and was compared with the opinion of medical staff on the needs of parents. These are the statements about the needs that parents and medical staff have singled out as very important:

> "We want to be sure that, even though we are not present, our children will receive the best possible care."
>
> "We want to get advice on our child's care before discharge from the hospital."
>
> "We want to be informed about all the procedures that will be performed on our children."
>
> "We would like to be capable to take part in caring for our child."
>
> "We want to be able to stay with our child for 24 hours a day if we want to."
>
> "We want to be sure that, even though we are not present, our children receive the best medical care."
>
> "We would like nurses to recognize and understand parents' feelings."
>
> "We want to feel that we are important in contributing to the well-being of the child."
>
> "We want to get accurate information about our child's condition" (31)."

Parents of children with malignant diseases often have greater needs for emotional support, understanding, and information (31- 34). Parents' needs are met when they are satisfied with the overall care for the child, but also themselves during and after treatment. In addition to the needs of the parents, it is important to highlight the needs of children, especially adolescents whose needs may be different from the needs of their parents (35). To ensure parent satisfaction, it is necessary to continuously evaluate care, meet needs and constantly adjust relationships with parents, which is possible only through continuous research and the application of research results, and should not be limited to uniform approaches aimed at meeting the needs of all parents. There are precisely prescribed programs and interventions (according to research results), on how to help parents, and how to guide them through the process of their child's treatment. One of these programs was created in Philadelphia in 2004 and is based on 4 basic principles:

1. Establishing trust with parents and understanding and accepting their views.
2. Facilitating interaction and communication between parents, medical staff and the sick child.
3. Helping parents alleviate feelings of loneliness and understanding other feelings that parents encounter.
4. Focusing on the family's strengths reflects the perspective that parents and families are competent, able to adapt to adverse circumstances, and to continue growing and developing as a family despite their child's illness (36).

In addition to parents' needs related to the health system, there is also a need for better understanding between partners. In certain phases of the child's treatment, i.e., often during the initial period of diagnosis, partners and family are close-knit (37). But with the passage of time and increasing demands for treatment, relationships between partners and families become strained: 6 to 41 months after diagnosis families of children suffering from the malignant disease can fall into very different and rigid patterns of behavior compared to members of other families (13). Research conducted with both parents speaks in favor of a greater need for psycho-emotional help to mothers than to fathers, although fathers also state a great need for help (38). Precisely because of the child's life-threatening condition, the immediate focus for medical staff is the child's survival, while special supportive procedures by psychologists, social workers, psychiatrists, nutritionists, occupational therapists and others are delayed until problems arise. This is unfortunate because the timely inclusion of all necessary professions in the care of children and parents would have a positive effect on further coping with malignant disease (39).

Croatian hospitals, especially those treating children with malignant diseases, provide organized care by psychologists, social workers, social pedagogues, physicians, nurses and special-needs educators. How accessible they are to parents and children, and how successful they are in their interventions is difficult to assess due to a lack of feedback from parents. There is very little research or papers in Croatian that would contain feedback from parents on the satisfaction of caring for their child and meeting their needs. In Croatia, children receive the best possible treatment – the only difference being that in Europe and the world there is a better support system for children and parents. These systems are more sensitive to parents' needs, they continuously cooperate with them and ask them about their opinions. They rearrange departments according to the real needs of children, build palliative children's centers and invest a lot in the satisfaction of children and parents. They are more advanced in this segment of help because they know exactly what the needs of parents are, and they know that because they conduct research with the parents' help.

Difficulties faced by parents of children with the malignant disease during and after the child's treatment

Few studies deal with difficulties faced by parents of children with malignant diseases. Research has mainly focused on emotional stress and post-traumatic stress disorder (PTSD) in parents, and generally on parents' satisfaction with hospital care (3). In 2004 in Croatia at the University Hospital Osijek, a study was conducted about parent satisfaction with hospital care. From this study, we can single out the following remarks and difficulties: dissatisfaction with communication between physicians and nurses, lack of physician's time, lack of kindness and sufficient care, dissatisfaction with cleanliness, food and beds, and dissatisfaction with long waits for diagnosis (40). There is no targeted research on the difficulties that parents face in Croatia. At the 2012 session of the Croatian Parliament, the parents of children with malignant diseases presented the difficulties they face in front of the working group of the Coordination of Associations for Children, which monitors the implementation of children's rights in the health system. They pointed out the following:

- The right of the child not to be separated from its parent (a comfortable chair beside the child's bed would suffice).
- The right to respect personal dignity (the child is spoken about as if it were not present).
- The child's right to privacy is not respected (examinations are performed in the presence of persons unknown to the child).
- Information about the child's health condition is denied, or given to the child in an incomprehensible way, or given to the parents in an extremely inappropriate way.
- Children are denied the right to freely express their feelings (sadness, fear, anger, loneliness).
- The child is deprived of a safe place (painful examinations and minor procedures are also performed in its hospital bed).
- Children are not prepared for examinations, or medical procedures.
- There are not enough staff to take care of the children's psycho-emotional well-being and to provide professional support.
- Emotional support is also lacking when a child is forbidden to wear its clothes during hospitalization, to have things around it that are important to it, and when peer visits are forbidden.
- The support for families whose children are seriously, chronically, or life-threateningly ill is insufficient in the health care system.

In 2012 in Belgrade a study was conducted about difficulties faced by parents of children with malignant diseases. The aim of the study was to gain insight into the difficulties that parents faced through different phases of treatment – after learning the diagnosis, during hospital treatment and after the end of hospital treatment. Parents describe being informed about the diagnosis as a strong shock (13). In the initial period, some even had suicidal thoughts. Their biggest concern was how to communicate the diagnosis to the child. During the hospital treatment, their mental and physical health was impaired (changes in eating habits, depression, emotional and physical exhaustion). They describe the child's physical changes as the most disturbing experience. Some parents blame themselves for the child's disease and that is an additional burden for them. They express concern for a child experiencing behavioral changes (e.g., refusing to communicate). Hospital treatment is followed by a phase accompanied by fear, insecurity and a feeling of incompetence in caring for the child. Parents are wondering if they will be able to take responsibility for their child after completing hospital treatment. They cite fear of relapse, or of follow-up examinations, and not being able to adjust to a "past" lifestyle (13). In an extensive study by Patterson et al. (2004), several difficulties faced by parents were found, which they divided into four important segments:

1. Difficulties related to treatment (side effects caused by chemotherapy or radiation, infections, hair loss, impaired concentration, loss of limbs, periodic surgery...).
2. Difficulties related to the child (feeling of fear, nervousness, loss of daily routine and activities, concern about the cost of treatment).
3. Difficulties related to the family (during diagnosis and treatment - feeling of being overwhelmed, helplessness and loss of control, fear that the child will die, guilt due to the child's pain, self-blame due to the child's illness).
4. Difficulties related to the community (insensitivity of family friends, lack of support groups, non-cooperation of the school, lack of competence of health professionals – which did not apply to oncologists, however) (41).

Large systems can be sluggish, difficult to change, and insensitive to the individual and further create difficulties for parents who are already in a difficult situation. To avoid a child's prolonged stay in the hospital and the possibility of increasing the chances of difficulties, for some or even most of the hospitalized children, day hospitals may be the solution. This would be a more considerate way of treating children and would reduce the psychological trauma for the child and family brought about by classical hospitalization. Family participation in treatment as well as the child's overnight stay at home contribute to a faster recovery (42). The difficulties that parents of a child with a malignant disease face are usually very individual. They depend on the diagnosis, emotional maturity and age of the parents, and other family members. They vary significantly from hospital to hospital. They depend greatly on the medical staff and the parents' perception of the health care system. It is necessary to purposefully investigate the difficulties that parents face and enable them to express themselves without restraint and hesitation about the problems at hand. The research done on this topic was mostly initiated by nurses. The degree of parents' satisfaction with medical care largely depends on them and they recognize this. Involving the parent as a partner in the care for the child and finding a common level of communication results in a higher degree of parental satisfaction and fewer difficulties (43).

Parental strengths – coping and adaptation

In everyday life, coping, adaptation, and adjustment mean the same thing: how well a person copes with certain aspects of his/her environment. Adaptation in a broader sense means accommodation to environmental requirements, such as school, work, marriage, peers, or a serious illness (28). The most frequently cited theory of coping is that of Lazarus (1991), which defines coping as cognitive and behavioral efforts to manage specific external or internal demands (and conflicts between them) that are assessed as exceeding a person's resources. Coping is a process that leads to adaptation in three domains: functioning at work and social life, life satisfaction and mental health. In research, parents of children with malignant diseases were most often asked what strategies they used to cope with their child's illness or how they dealt with day-to-day problems and stress in the child's treatment process (11). Coping strategies are categorized in several ways: emotion-focused strategies versus problem-oriented strategies; avoidance strategies versus access strategies; strategies of repression versus sensitization; engagement strategies versus distancing (11).

From the literature, we single out another set of strategies which includes seven strategic clusters: focusing on the current problem; palliative response pattern; avoiding; passive behavior, expression of emotions, comforting cognition, and seeking social support (44). The best-described, consistent strategies were adopted by Sloper in 2000. She describes five types of coping strategies: problem-solving; self-directed strategies; support seeking; wishful thinking and distancing (45). Coping using the strategy of "wishful thinking" is somewhat vague. According to Patterson et al. (2004), parents most often use 3 strategies for coping with a child's illness.

- Appraisal-focused coping behaviors; refers to the way a person thinks about stressors or circumstances that have befallen them. Parents tried to be optimistic and maintain hope during the child's illness, to believe in God, they were more focused on the present than on thinking about the uncertain future, denying the illness, looking for the positive in the experience of the child's illness.
- Problem-focused coping behaviors; making decisions important for the course of treatment, seeking information about the tumor, trying to maintain a normal family life, organization of family members, one parent quitting his/her job to be with the child.
- Emotion-focused coping behaviors; humor, fun, celebrating little success in treatment, seeking and receiving support from friends, relatives, religious communities, hiding feelings from family members as a way of coping, "parents pretending" to be stronger than they are to support other family members, diary writing (41).

The mental state of the child has a high impact on parents' coping strategies. In addition, a good coping strategy is influenced by a lower level of stress, financial security, family support and previous effective ways of coping. Useful coping strategies also include open communication, focusing on positive aspects, seeking information, seeking social support, and living life "day by day". According to the results of a study (41), the most common resources that helped parents during the diagnosis, treatment and recovery of the child are: resources from the child (maturity in coping with and accepting illness, the child's courage); family resources (support of family members, quality partnership, religiosity, the cohesiveness of family members, flexibility and open communication); community-based resources (support from friends, peers, church believers, parents of other sick children, schools, doctors, nurses, and social workers) (41).

Early identification of parents at risk is important, in order to involve the entire support and assistance team, so as to prevent parents' psychological problems in a timely manner and help them successfully cope and adapt to the child's illness. By approaching the parent holistically, taking into account his/her behavior, speech, movements, desires, environmental conditions, level of education, gender, defense mechanisms and perception, we can work together to make a very good plan of coping with and adapting to the child's illness, as well as coping with it during and after treatment.

Ethical dilemmas related to the involvement of parents of children with malignant diseases in research

Due to the small number of studies involving parents of children with malignant diseases, the question arises why this is so. Is the reason in our perception of them, do we think it is better not to intrude on their intimacy or are we afraid of their reaction? What would be the optimal moment to research such a vulnerable group? Several studies have been conducted that refer to parental participation in research (46,47). A study conducted in Boston in 2012 cites a positive opinion of parents regarding research. Among 276 parents, 194 agreed to participate. 62% of parents said that their participation in the research was not disturbing at all, and 69% thought that the questionnaire was useful. The question still remains about the 30% of parents who did not participate and whether taking part in a study caused them discomfort, stress, and anger, or it was some other reason (46).

According to a retrospective study of the attitudes of parents of a child with Ewing's sarcoma after the primary interview, we can determine that parents want to participate in research more than we think. Most participants experienced the first study as a positive experience (as many as 97.5%) and they believed that their involvement in the study was beneficial to others, although some parts of the interview were painful to them. From this study, it is evident that time is a very important factor. Parents whose interval between 2 interviews was more than a year, remembered the interview as less painful. An important reason for involving parents in research is altruism, i.e., helping other parents in a similar situation (47).

Research conducted on grieving parents of children who have died also has a positive view of the need for research on them. In one such 2006 study through in-depth interviews, parents stated that a period of 6 months after the child's death was appropriate for conducting the study, while several parents stated that a period of two years after death would be more appropriate. They stressed that the skills and compassion of the interviewer are very important to them. They considered empathy and understanding as skills. Some parents described participation in the study as a kind of therapy (47).

Recent research speaks in favor of traumatic growth, which implies positive consequences after surviving trauma. It does not develop immediately after trauma, but later, and has a long-term effect (48). Demographic characteristics such as a child's diagnosis, gender, age, income, and education do not have a significant impact on a parent's decision to participate in studies. Parental beliefs, values, and perceptions play a larger role in decisions to participate (49). According to the studied literature, we can observe that qualitative research on parents of children with malignant diseases in English speaking countries is the subject of constant interest (50), while in Balkan countries this is not the case.

The conclusion of this chapter is that parents of children with malignant diseases should be included in studies, not protected from them, because ultimately the results of studies can be an important resource for health professionals and others involved in generating new and improving existing forms of psychological care, and support to parents and families as a whole. We can rule out the ethical question of whether parents should participate in studies or not and turn to the ethical approach, timing and manner of conducting studies with such a group of parents. Parents of sick children in different stages of the disease may react differently, so it is necessary to determine the right time for research so as not to further traumatize the parents. By increasing the transparency of research with expert guidance, and a holistic and individual approach to parents, we can argue that we will get the answers that parents keep to themselves.

Conclusion

Malignant diseases in children have a special sociomedical dimension. They cause difficulties in adapting to a new life situation. They particularly affect parents, so it is extremely important to help the parents in overcoming and coping with the daily difficulties they face. Parents of children suffering from malignant diseases are faced with a difficult and stressful situation that leaves indelible consequences on them and accompanies them throughout their lives to a greater or lesser extent. These consequences can be negative, such as feelings of sadness, guilt and emptiness that accompany them through life, or positive, such as understanding life as a gift from God and rejoicing in everyday "little" things.

Various professional support programs for parents of seriously ill children in health care institutions across Europe and the world have proven to be a good practice. Some hospitals, e.g., in the United States, have specifically designed interventions and specially trained health professionals of all profiles who can be made available to parents in 24 hours. Based on various studies of parents whose children have had malignant diseases, they have developed good methods of communication, approaches to parents and children, techniques for communicating bad news and skills to support parents. Going through the various phases – from getting the diagnosis, through treatment to the end of treatment, parents encounter various difficulties in which the medical staff can greatly help them. Proper access to communication can facilitate, and in some cases prevent, the difficulties that parents typically face.

In addition to the health care system, the educational and social care systems, as well as the legal system, also have their shortcomings, which they should work on in order to be supportive of parents, and not be an obstacle and an additional burden. Unless we have experienced a particular trauma, we cannot imagine all the emotional turbulence and difficulties that parents go through, but that is why we can be their support and partners in the process of treating a child, which is very important to them. It means a lot to them to feel that they are not alone and abandoned in health care and other systems.

Given the literature studied, we can conclude that we should not be afraid of parental reactions during the treatment of their child, nor should we be afraid to ask them about their condition, needs and difficulties. The vast majority of parents need psychological help and support, advice and guidance, and the opportunity to express their difficulties to health care professionals. Only continuous research on the needs and problems of parents can make life's difficult moments easier for parents.

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POTREBE I POTEŠKOĆE RODITELJA DJECE OBOLJELE OD MALIGNIH BOLESTI

Sažetak

Maligne bolesti jedan su od vodećih uzroka smrti djece u razvijenim zemljama, iako konstantan napredak u liječenju kontinuirano umanje smrtnost. Dijagnoza maligne bolesti znatan je stresor u životu djeteta i njegove obitelji te bitno mijenja kvalitetu života cijele obitelji. Predstavlja prototip stresne situacije i bolesti s potencijalno razarajućim efektima na dijete i njegovu obitelj. U ovom radu obrađeno je 50 stručnih i znanstvenih radova koji istražuju potrebe i poteškoće roditelja djece oboljele od malignih bolesti objavljenih u razdoblju između 1993. i 2022. Pravilna procjena problema i potreba s kojima se susreću roditelji djece oboljele od malignih bolesti presudna je za pružanje prikladne pomoći i skrbi. Za roditelje dijagnoza maligne bolesti njihova djeteta predstavlja psihološki i egzistencijalni izazov. Da bi potrebe roditelja bile zadovoljene, a njihove poteškoće olakšane, potrebno je nastaviti istraživanja koja uglavnom podupiru i sami roditelji kako bi im se u budućnosti olakšao taj iznimno stresan i težak dio života.

Ključne riječi: maligne bolesti djece, zadovoljstvo roditelja, potrebe roditelja, poteškoće, hospitalizacija, etika

Author Guidelines

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