

PERSONS WITH INTELLECTUAL DISABILITY: SEXUAL BEHAVIOUR, KNOWLEDGE AND ASSERTIVENESS

OSEBE Z INTELEKTUALNO OVIRO: SPOLNO VEDENJE, ZNANJE O SPOLNOSTI IN SPOLNA ASERTIVNOST

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ABSTRACT

Keywords:

sexuality, intellectual disability, knowledge of sexuality, sexual assertiveness

Background: Persons with ID most often have incomplete, contradictory and imprecise knowledge of sexuality and sexual intercourse itself. They are not provided with sufficient information on their own body and sexuality, and are often discouraged from and sanctioned for trying to sexually express themselves. Sexual abuse due to low sexual assertiveness is also common.

Aim: The principal aim of this study was to establish the presence or absence of sexual activity in adults with ID residing in institutional housing, as well as the level and structure of their knowledge of sexuality, their sexual assertiveness and preparedness to react in a sexually dangerous situation.

Methods: The sample consisted of 100 participants with ID residing in institutional housing. The instruments used included the General Sexual Knowledge Questionnaire, What-if test and Hulbert index of sexual assertiveness. Comparative statistics included coefficient of linear correlation and multiple regression analysis.

Results: The results showed that 82% of the participants are sexually active. Most participants admitted to sometimes having sexual intercourse against their wishes as well as to having difficulty asserting themselves. Their knowledge of pregnancy, contraception and sexually transmitted diseases was very low. Female participants and those that reported having sexual intercourse had more sexual knowledge and were also more sexually assertive.

Conclusion: Knowledge of sexuality and sexual assertiveness of persons with ID residing in institutional housing is very low. Additional information on sexuality is necessary, as well as support in learning to express their own desires and to deal with unwanted sexual activity.

IZVLEČEK

Ključne besede:

spolnost, intelektualna ovira, znanje o spolnosti, spolna asertivnost

Podlaga: Osebe z intelektualno oviro imajo najpogosteje nepopolno, protislovno in netočno znanje o spolnosti in spolnem odnosu. Ne prejmejo dovolj informacij o lastnem telesu in spolnosti ter jih pogosto odvrta od spolnega izražanja in jih kaznujejo, če se poskušajo spolno izražati. Pogoste so spolne zlorabe zaradi nizke spolne asertivnosti.

Cilj: Glavni cilj te študije je bil ugotoviti obstoj ali neobstoj spolne dejavnosti pri odraslih z intelektualno oviro, ki prebivajo v institucionalnih ustanovah, ter raven in strukturo njihovega znanja o spolnosti, njihovo spolno asertivnost in pripravljenost na odzivanje v nevarnem položaju, povezanem s spolnostjo.

Metode: Vzorec je bil sestavljen iz 100 udeležencev z intelektualno oviro, ki prebivajo v institucionalnih ustanovah. Uporabljeni so bili naslednji instrumenti: vprašalnik o splošnem znanju o spolnosti, test »kaj če« in Hurlbertov indeks spolne asertivnosti. Primerjalna statistika je vključevala koeficient linearne korelacije in multiplo regresijsko analizo.

Rezultati: Rezultati te študije so pokazali, da je 82 % udeležencev spolno aktivnih. Večina udeležencev je priznala, da imajo včasih spolne odnose proti svoji volji in da imajo težave z asertivnostjo. Njihova raven znanja o nosečnosti, kontracepciji in spolno prenosljivih boleznih je bila zelo nizka. Udeleženke in tisti udeleženci, ki so navedli, da imajo spolne odnose, so imeli višjo raven znanja in so bili tudi spolno asertivnejši.

Zaključek: Osebe z intelektualno oviro, ki prebivajo v institucionalnih ustanovah, imajo zelo nizko raven znanja o spolnosti in spolni asertivnosti. Treba je zagotoviti dodatne informacije o spolnosti ter podporo pri učenju, kako izraziti svoje želje in se spopasti z neželeno spolno dejavnostjo.

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1 INTRODUCTION

1.1 Sexuality of persons with ID

Persons with ID experience difficulties in understanding the subtle and complex thoughts and emotions of others, and are consequently unable to express their own thoughts and emotions (1). Regardless of the difficulties in understanding their own sexuality and how to express it appropriately, studies show that persons with ID do have sexual needs and engage in various sexual contacts (2, 3). Significant limitations of persons with ID in intellectual functioning and adaptive behaviour are manifested in poor conceptual, social and practical adaptive skills, and consequently in sexual behaviours (4). Slower memory processes, unstable and fluctuating attention, lower level of speech development, poorer deduction and generalization capabilities all stem from the aforementioned limitations, and further lead to difficulties in the implementation of learned information, in managing novel situations, in self-care, communication and social skills (5). These characteristics make engaging in sexual interactions more challenging for persons with ID (6).

Pedersen and Harakopos conducted a study that investigated the specificities of sexual behaviour in persons with ID residing in institutional housing, and their results showed sexual expression was present in 80% of the participants (7). Stereotypes and prejudices concerning this segment of the population still persist in the wider community, as well as among professionals and parents of persons with ID, especially when it comes to expressing sexuality (8). Another problem is the lack of information provided to persons with ID concerning their bodies and sexuality (9), their frequent discouragement and even punishment for trying to express themselves sexually (10), as well as sexual victimization (11).

1.2 Knowledge of sexuality in persons with ID

Persons with ID most often have inadequate, contradictory and imprecise knowledge of sexuality and sexual intercourse itself, and find it hard to identify body parts, especially genitals (12). Some studies indicate that persons with ID differentiate male and female genitalia, and can tell a person's gender and gender differences, while others speak to the contrary (13, 14).

Persons residing in institutional housing were shown to be better informed on sexual intercourse, appropriate behaviour on a date, contraception and birth control compared to persons living in families, who on their part had more knowledge of sexually transmitted diseases, risky sexual behaviour and intimacy (15).

Frawly and Wilson concluded that young people with ID often know the most facts about sexuality but do not know how to behave in actual situations (16). Insufficient knowledge of sexuality leads to subsequent problems in sexual behaviour (17, 18).

Persons with ID also have difficulty understanding sexual relationships and making free-will decisions on starting and maintaining them (19). Persons with ID are not well informed on sexuality, although their interest in sexual life is high. Moreover, the sources of information used by members of the typical population are mostly inadequate for persons with ID, and this all leads to the development of socially unacceptable sexual behaviour, susceptibility to sexual abuse and other risks, such as sexually transmitted diseases or unwanted pregnancy (20).

The results of a study in Serbia showed the negative attitudes and low level of knowledge in the general population with regard to the sexuality of persons with disabilities, and point to the need for educating parents and professionals on this subject (8). Although there are programs of sexual education in Serbia which contribute to the improvement of knowledge of sexuality in the general population (21), these programs are not adapted to persons with ID.

1.3 Sexual abuse of persons with ID

Persons with ID are often victims of covert psychological violence, and may seemingly voluntarily consent to sexual intercourse after being lured into it various promises. Studies have also found multiple factors that determine the sexuality of persons with ID, namely: lack of information on sexuality; cognitive limitations that influence the expression of sexual needs; insufficient social and communication skills, low self-respect and lack of positive sexual experiences and models. Furthermore, the sexuality of persons with ID is also determined by an inability to distinguish between consenting and nonconsenting partners, by difficulties in establishing personal and physical boundaries, difficulties in separating private from public, and safe from risky behaviors as well as appropriate from inappropriate sexual encounters (22). Along with being constantly dependent on others and unable to stand up for themselves, the above-mentioned factors contribute to higher levels of victimization of persons with ID where sexual abuse is concerned. In addition to individual factors of increased risk for sexual abuse, factors associated with the perception of the risk of sexual abuse and those that concern the possibility of reporting on the actual abuse, are also significant (2).

Studies show concerning results that point to sexual abuse of people with ID (23), indicating that most are victims of sexual assault at least once in their lives, with the perpetrators most often being persons that are close to them (24). Wissink and associates found a three- to four-fold greater likelihood that a person with ID will fall victim to abuse compared to the typical population (25).

As mentioned above, various factors make persons with ID more susceptible to sexual abuse, with studies emphasizing poor self-defence due to physical/motor limitations, inability to assess potentially dangerous situations due to

cognitive impairment, lack of knowledge of sexuality and interpersonal relationships, lack of education on abuse and on adequate self-defence strategies, and a lack of sexual assertiveness (26).

1.4 Sexual assertiveness

Sexual assertiveness can be defined as a person's capability to develop assertive behaviour in a sexual context (27). Morokoff offered a more comprehensive definition by which sexual assertiveness represents an ability to initiate sexual intercourse and to decline unwanted sexual contact, and a capability to protect oneself from unwanted pregnancy and sexually transmitted diseases (28). Santos-Iglesias and Sierra conducted a study that confirmed the link between the sexual assertiveness and sexual life of a person (29). Hulbert included initiating a sexual act and talking to one's partner about potential sexual problems in the notion of sexual assertiveness (30). Sexual assertiveness is also associated with the use of birth control, especially condoms. Insisting on the use of condoms is directly associated with higher levels of sexual assertiveness (31). Studies on sexual assertiveness in persons with ID are rare, and in this context assertiveness is only used with the purpose of protection against sexual violence, so that a person could defend themselves against unwanted sexual intercourse (32).

1.5 The present study

This study has two aims. The first is to assess the sexual activity of persons with ID residing in institutional housing, as well as their level and structure of knowledge with regard to sexuality, sexual assertiveness and preparedness to react in sexually dangerous situations. The second aim is to assess the role of certain demographic variables in the prediction of sexual knowledge and sexual assertiveness.

2 METHOD

The study was conducted in the residential facility "Otthon" in Stara Moravica, Serbia. Currently 299 persons with moderate and severe ID reside in this facility.

Questionnaires were completed individually, in the form of interviews: the examiner asked questions and wrote down the participants' answers. If necessary, the examiner provided additional explanations to the participant.

2.1 Sample

The study only included participants who signed a written consent or had a written consent signed by their guardians. Apart from that, the inclusion criteria encompassed: a diagnosis of moderate intellectual disability (information on this was obtained by reviewing the personal files of each potential participant) and good command of the Serbian language. These criteria were met by 100 of the

299 residents. Data were collected in the period of May/June 2018.

The sample consisted of 100 participants with ID, 54% female and 46% male. The age range was 23 to 63 years. The average age for the entire sample was 47.64 years ($SD=9.66$). When observed by age category the majority of participants belonged to the over 50 years of age category. When answering the question where they lived prior to moving into this residential facility, the majority stated that they came from their family of origin (80%), while the remaining participants came from other residential facilities or foster families. As to their marital status, 81% of participants stated that they had never been married; 46% of participants indicated that they currently have a partner. Of the entire sample, 24% stated they had children, with most having only one child. Out of the total of 100 participants, 82% reported being sexually active.

2.2 Instruments

- For the purpose of this study information on the degree of intellectual impairment was obtained by access to the participants' files.
- For assessment of knowledge of sexuality, we used the General Sexual Knowledge Questionnaire (33) which was linguistically and grammatically adjusted to the Serbian language. This general questionnaire is divided into six sections, with 63 questions in total. The questionnaire allows sexual knowledge to be scored in total as well as by specific section. It assesses the following areas of sexual knowledge: Physiology (33 items), Sexual intercourse (10 items), Pregnancy (8 items), Contraception (5 items), Sexually transmitted diseases (8 items) and Sexual orientation and gender identity (3 items). In our study this instrument was shown to have good test-retest reliability ($r=0.86$) and good internal consistency (Cronbach alpha >0.80). Factor analysis yielded six factors along with the possibility to calculate the total result.
- The next instrument used for study purposes was the What-if-situations-test that consists of 29 questions (33). The test was developed with the aim of preventing sexual abuse and assesses participants' behaviour in risky situations. Eleven questions are created in a way that the participant is asked to differentiate between acceptable and unacceptable situations. Seventeen further questions refer to actions that should be taken in particular situations, and one question pertains to naming intimate body parts. The internal consistency coefficient on our sample (Cronbach alpha) was good $\alpha=0.843$.
- To assess sexual assertiveness, we used the 25-item Hulbert index of sexual assertiveness (30, 31). The items are based on self-assessment of cognitive, emotional

and behavioural aspects of expressing sexual needs. Answers are given on a Likert-type scale, with 13 items scored from 0 to 4, with 0 having the highest value and 4 the lowest, while the remaining 12 items are reverse-scored (from 4 to 0). This questionnaire had excellent reliability on our sample $\alpha=0.953$.

2.3 Data analysis

Data entry and analysis was performed using the program package SPSS 20.0. We used descriptive statistics to analyse the obtained results and show the sample structure on relevant variables.

The Pearson coefficient of linear correlation and multiple regression analysis were used as methods of comparative statistics. In all the tests we performed the threshold of risk probability was at a significance level of 95% ($p<0.05$) (the difference in statistical parameters is significant) or 99% ($p<0.01$) (the difference in statistical parameters is highly significant).

3 RESULTS

Table 1 shows the average scores on scales used in this study. The performed analysis indicates that the distribution of results on all three questionnaires corresponds to the normal distribution (for total scores). The results show an extremely low level of knowledge of sexuality, both when the total score is observed and the scores on individual sections. Participants obtained very low scores on the test of sexual assertiveness and on the What-if test as well.

In order to establish if there is a connection between the scores on tests of sexual knowledge (General Sexual Knowledge Questionnaire and What-if test) and scores on sexual assertiveness (Hulbert index of sexual assertiveness) we applied the Pearson coefficient of linear correlation

(Table 2). With regard to the correlations among these phenomena, we found only one statistically significant correlation, between the score obtained on the What-if test and score on the General Sexual Knowledge Questionnaire. The correlation was of moderate intensity and in the positive direction ($r=0.360$; $p<0.01$). The higher the level of knowledge of sexuality a person has, the better they are able to deal with "problem" situations regarding sexuality. None of the remaining correlations between the variables we investigated reached statistical significance; this result indicates that sexual assertiveness is a skill independent of knowledge and formal education with regard to sexuality and reproductive health.

Table 2. Correlation coefficients between the three tests and significance levels.

	General Sexual Knowledge Questionnaire	What-if test	Hulbert index of sexual assertiveness
General Sexual Knowledge Questionnaire	1	.360**	.187
What-if test	.360**	1	-.191
Hulbert index of sexual assertiveness	.187	-.191	1

*** $p<.001$, ** $p<.01$, * $p<.05$;

In order to determine the proportion of variance of sexual knowledge (General Sexual Knowledge Questionnaire and What-if test) that can be explained by the variance of different socio-demographic variables and other significant variables, we performed a series of multiple regression analyses. The set of predictors included the following variables - gender, age, time spent in the institution and sexual activity. Criterion variables were total scores on the following tests: General Sexual Knowledge Questionnaire,

Table 1. Average scores and basic characteristics of the distribution.

Domains	No of studies					
	min	max	AS	SD	Sk	Ku
General sexual knowledge questionnaire	14	74	33.63	13.63	.986	.226
Physiology pictures	10	16	5.88	4.68	-.725	-.488
Physiology questions	0	17	3.92	1.72	.930	-.389
Sexual Intercourse/Sex/Masturbation	1	9	4.70	2.50	.286	-.415
Pregnancy	1	16	2.19	2.95	1.29	1.43
Contraception	0	10	1.72	2.58	1.14	-.026
Sexually transmitted diseases	0	12	0.94	0.28	1.36	1.50
Sexuality	0	2	5.88	4.68	-1.45	1.20
What-if test	7	37	19.88	5.54	.474	.875
Hulbert index of sexual assertiveness	33	64	48.80	5.82	.014	-.032

What-if test and Hulbert index of sexual assertiveness. Preliminary analyses were conducted to check for significant deviations from the expected normal distribution, linearity, multicollinearity and homoscedascity.

The first model tested the predictive value of gender, age, time spent in the institution and sexual activity for general knowledge of sexuality. The model was statistically significant $F(4, 95)=6.842, p=0.000$. The multiple correlation coefficient was $R=0.473$. The percentage of variance on the General Sexual Knowledge Questionnaire explained by the predictor variables was 22.4%. The variables Gender and Are you having sexual intercourses? had significant individual contributions to the prediction (Table 3). Both correlations were positive, but the variable pertaining to having sexual intercourses had a slightly higher individual contribution to the prediction (B coefficient). Females and those having sexual intercourses scored higher on the General Sexual Knowledge Questionnaire.

The model was statistically significant in the prediction of success on the What-if test $F(4, 95)=4.832, p=0.001$. The multiple correlation coefficient was $R=0.411$. The percentage of variance on the What-if test explained by the set of predictor variables was 16.9%. The variables Gender and Age (Table 3) had significant individual contributions to the prediction. Both correlations were positive, but the variable Age had a slightly higher individual contribution to the prediction (B coefficient). Females and persons of older age scored higher on the What-if test.

The predictive model of sexual assertiveness was also statistically significant $F(4, 95)=3.765, p=0.007$. The multiple correlation coefficient was $R=0.370$. The percentage of variance of the Hulbert index of sexual assertiveness explained by the predictor variables was 13.7%. Only the variable/question Are you having sexual intercourse? (Table 3) had a significant individual contribution to the prediction. The correlation was negative and of moderate intensity ($\beta=-0.317$). Therefore, individuals who actively practiced sex had a lower total score on the Hulbert index of sexual assertiveness.

4 DISCUSSION

The results indicate that most persons with ID who participated in the study were sexually active. At the time the study was conducted 54% of participants claimed to have a sexual partner, while 46% reported the contrary. A total of 82% of participants reported having sexual experiences, while 18% had never been involved in sexual activity. These findings confirm that persons with ID have sexual needs and the capacity to engage in sexual behaviour. Gil-Liario and colleagues (2) obtained similar results, and their study showed that 84% of participants had previously had sexual intercourse with another person, with a greater proportion of women in this category (2).

The General Sexual Knowledge Questionnaire consists of six sections on which our participants had rather heterogeneous results. The best results were obtained in the section of Physiology, which examines the respondents' knowledge of body parts. Our participants had no difficulty identifying and naming external body parts; there was, however, a problem with identifying internal organs, such as the ovaries, uterus and testicles.

In their own study, Isler and colleagues also obtained results that indicate that respondents with ID had difficulty in identifying internal reproductive organs (34). In Kijak's study, 90% of participants answered questions on female and male bodies accurately (1). In our study all participants (100%) answered questions that asked them to identify external body parts (head, arm, leg, stomach, and chest) correctly, but had poorer results when it came to identifying internal body parts (testicles, ovaries, and vagina). It was our hypothesis that educational programs dealing with internal body parts and elements of sexual health, which require a certain level of abstraction in order to be fully understood, need to be better adapted to persons with ID.

Persons with ID often request education and support from peers, supervisors and other professionals in the domain of sexuality (35). In our study the participants scored low in the domain of knowledge of sexual intercourse, which should be especially addressed in educational programs. In a study conducted by Edmondson, respondents answered 70% of questions on body parts and sexual intercourse

Table 3. Partial contributions to the prediction of sexual knowledge and assertiveness.

Beta (B)	General Sexual Knowledge Questionnaire	What-if test	Index of sexual assertiveness
Gender	.348**	.261**	-.076
Age	.070	.360**	.050
Time spent in the institution	.006	-.165	.112
Are you having sexual intercourses?	.243**	.008	-.317**

correctly (36). However, in more recent studies (34, 37) participants scored much lower on questions concerning Sexual intercourse.

Our participants displayed rather poor knowledge of Pregnancy, Contraception and Sexually transmitted diseases. Lockhart also reached a conclusion that persons with ID have substantial knowledge of body parts and on intimate behaviour (holding hands or kissing), while their knowledge of pregnancy and childbirth is very poor (38). Poor education and, to a significant degree, isolation of persons with ID in institutional housing can cause a lack of information and skill in the domain of sexuality, but with appropriate education and good social support, people with ID are capable of improving both their sexual knowledge and behaviour.

Eastegate and colleagues (39) found their study participants' knowledge of sexuality varied from extremely basic, without understanding the concept of sexual intercourse, to rather complex, including understanding the process of egg fertilization. Younger participants identified school as their primary source of information, while older ones stated that they did not even realize you could talk about these issues at school. Other sources of information listed by persons with ID included books, talking to their mothers or professionals. The participants confirmed having difficulty behaving assertively in relationships and being mostly unable to protect themselves from unwanted sexual experiences. In our study, most participants admitted to sometimes having sexual intercourse against their wishes and having difficulty asserting themselves, which is in line with results obtained by Eastegate and colleagues (39). We can look for causes for this behaviour in the domain of individual characteristics, factors associated with the perception of the risk of SA and factors linked to the possibility of reporting on the abuse actually taking place (2, 22). It is also important to consider housing conditions and the lack of independence of persons in institutional housing. This subject requires further investigation.

The What-if test was created with the purpose of preventing sexual abuse. Our participants were shown to be mostly aware of basic risk situations and that they could ask for help if they ever found themselves in them. However, their strategies for dealing with potentially dangerous situations were far from adequate. We presume that the support and education offered to persons with ID do not include role-playing situations, and that the information the participants acquire in such education is not applicable to real-life situations. The results of the study conducted by Lee and Tang indicate that persons with ID are able to differentiate between appropriate and inappropriate situations, but they are far less successful when it comes to reporting the latter and asking for help (40), which is in accordance with the results of our study.

We tried to ascertain which groups of participants, with regard to sexual activity and socio-demographic parameters, have lower knowledge of sexuality, low sexual assertiveness and are the least prepared to prevent sexual abuse. We found female participants and those having sexual intercourse to score higher on the General Sexual Knowledge Questionnaire. Within our sample group there were women who had carried one or more pregnancies to term. During their pregnancies they had experiences and communication with health-care workers and other professionals which allowed them to widen their knowledge of sexuality. Moreover, women who reside in institutions are educated on self-care in the context of menstruation and contraception, which can all be predictors of the observed gender differences. Other studies (14) show no influence of gender and age on knowledge of sexuality (40), while the effect of age was found by other research (42). However, age did not turn out to be a significant predictor in our own study.

The literature available to us does not explain if the previous sexual experience of persons with ID correlates with their level of knowledge of sexuality. Michie and colleagues (43) conducted a study which showed that individuals with ID who had committed a sex-related crime knew more on sexuality compared to non-offenders. We can hypothesize that the reason for this lies in the fact that sexual perpetrators have had more specific experiences which are not available to other persons with ID (43). Lambrick and Glaser (44) reported numerous examples of people with ID who, despite their impairment, have highly developed social skills and are completely able to understand problems associated with sexuality. Presumably these persons obtain their information via television shows or by talking to family and friends (44). The results of our study show sexual activity to be predictive of higher levels of knowledge of sexuality, i.e. study participants who are sexually active have more knowledge about sexuality compared to those without sexual experiences. Moreover, the sexually active participants score higher on the Hulbert index of sexual assertiveness, whereas no socio-demographic variable makes any difference in the sexual assertiveness of persons with ID in the current study. When we observe the results obtained from the What-if test that are indicative of how prepared persons with ID are to prevent sexual abuse, we can see that older women are the most prepared.

Taking into account the results of these earlier studies as well as our own, we can create an educational program that would involve learning specific self-protection skills and ways to apply them in specific risk situations, as other authors have done (45). All the authors in the literature we examined agree that there are many potential adverse consequences of poor knowledge about sexuality among persons with ID. Incomplete or inadequate knowledge can increase the risk of sexual abuse, sexually transmitted

diseases and unwanted pregnancy (46). Most participants in our study demonstrated a low level of knowledge of sexuality and similar issues, which is very important for future practice since most of the participants are currently involved in the process of deinstitutionalization, which will bring new challenges in the years to come.

Several limitations of the present study need to be acknowledged. First, the participants were recruited from a single housing institution for adults with ID, which limits the generalizability of results. Second, the sample included only participants with moderate ID. The participants were also assisted by examiners in answering the questions, which is a possible confounding factor we attempted to control as much as possible. However, we must consider the possibility of the difficulties the participants experienced in understanding questions and verbalizing answers, and this may have impacted the results.

5 CONCLUSION

With adequate support persons with ID can learn how to react in order to prevent high risk situations that involve sexuality. It is thus crucial to teach them to recognize potential abuse, give them information on how to react in such situations and who to report them to. All the results of this study are very important to us, especially information regarding the groups of participants that have the least knowledge and assertiveness, so that these individuals can be included in future programs that will be created for persons with ID. Adequate sexual education can only be efficient if what is learned can be applied to the actual situations and experiences of individuals with ID. Such programs are highly relevant for the process of (re) habilitation, as well as for encouraging the independence and social participation of people with ID.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest in relation to this work.

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ETHICAL APPROVAL

All the procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and national research committee. The ethical approval number of the Faculty of Medicine at the University of Novi Sad for the current study is 01-39/59/1.

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