



Original Research Article

Challenges in Accessing Sexual and Reproductive Health Services among People with Physical Disabilities in Macedonia

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ABSTRACT

Introduction: Although people with physical disabilities (PWPD) have the same sexual needs and requests to sexual and reproductive health (SRH) services as anybody else, it is widely known that PWPD have significantly unmet SRH needs. Due to the fact that they have limited mobility, PWPD could have even greater needs to access SRH services, education and information, than people without disabilities.

Objectives: the main objective of this study is to define challenges that people with physical disabilities in Macedonia are facing while accessing sexual and reproductive health services.

Material and Methods: The survey is a quantitative KAP-study that was conducted with 510 persons with physical disabilities, represented in accordance with the proportional population structure in all regions in Macedonia, at the age of 15-49 years. The data was collected from the target population by using pre-designed and pre-tested structured questionnaire. Data was presented as mean \pm standard deviation by using SPSS software version 17.0. Differences between mean of continuous variables were analyzed using the independent samples t-test, $p < 0.05$ being considered as statistically significant difference.

Results: The study findings show statistical significance in relationship between the degree of disability and age of respondents with physical disabilities, as well as with their employment status. Approximately 4 to 5 years difference is noted at the first sexual intercourse between PWPD and those without disabilities. 85% of respondents knew about HIV, while 15% did not have such knowledge. Lack of information about SRH, physical inaccessibility, inadequate services according their needs, insufficient education and low professional skills from health workers regarding SRH to PWPD have been appointed as one of challenges that PWPD faced.

Conclusions: Persons with physical disabilities face social, educational and health challenges when trying to access SRH services. These findings call for immediate action from all relevant institutions and organizations in order to reach and meet the respective SRH needs of PWPD.

Keywords: Persons with physical disabilities, sexual and reproductive health, HIV, AIDS, STI.

INTRODUCTION

More than one billion people in the world live with some form of disability, of

which nearly 200 million have significant difficulties in functioning. ^[1] One of the achievements of the UN Convention on the

Rights of Persons with Disabilities is the recognition that human rights play an essential role in terms of sexual and reproductive health (SRH) among persons with disabilities. Towards the European integration process the Republic of Macedonia is placed in front of a serious challenge for promotion of the rights of persons with disabilities in the country - the right to healthcare, and in that context also the right to SRH.

Although there is little information in this area, it is widely known that people with disabilities have significant unmet SRH needs. They have the same sexual needs and needs for the same services as everyone else.^[2] In that respect and due to the fact that they are more vulnerable to abuse,^[3] people with disabilities could have even greater needs for SRH education and information than people without disabilities. Challenges for SRH and rights are not always related to the disability of the person. They usually reflect stigma and discrimination, lack of social care, legal protection, access to services, understanding and support.^[4]

Sexual and reproductive health issues are among the most sensitive and controversial issues in international laws on human rights, but they are also among the most important. Their sensitivity and importance are reflected in the Millennium Development Goals (MDGs), which comes from the Millennium Declaration. SRH is a prerequisite of all MDGs, in particular with those related to gender and health. Monitoring process has been performed through achievement of targets and their indicators for monitoring under MDG 5.^[5]

MATERIALS AND METHODS

The survey is designed as prospective quantitative study of 510 persons with physical disabilities (PWPD), diagnosed as such by the relevant institutions in Macedonia. Only PWPD at

the age of 15-49 years were included in this survey, i.e. age when they are sexually active and they are in the reproductive period, as defined by WHO.^[1]

The sample is calculated by using statistical software PEPI 4.04, with the confidence interval of 95%, the proportion of physically disabled persons of 0.07% and a maximum acceptable error of 0.05. The study excluded people who did not use any services, who are not categorized as persons with physical disability (according to the opinions of relevant commission for defining the type and degree of disability), persons who are under 15 or over 49 years of age, and those who do not wanted to participate in the survey.

The research was conducted with the help of pre designed and pretested questionnaire. The preparation of the questionnaire, given its specificity was made in consultation and with the help of professionals who were trained to work with persons with disabilities (special education teachers, pediatricians, psychologists, social workers, etc.). The questionnaire consists of 58 questions, divided in several areas:

- I. Demographic characteristics
- II. Level of disability
- III. Sexual behavior
- IV. Knowledge and awareness of HIV /AIDS
- V. Sexually transmitted infections (STIs)
- VI. Family planning
- VII. Sexual and reproductive health

Data was presented as mean \pm standard deviation by using SPSS software version 17.0. Differences between mean of continuous variables were analyzed using the independent samples t-test, $p < 0.05$ being considered as statistically significant difference.

The study relies on ethical principles. The questionnaire is filled out using outreach approach in community services through direct contact with persons with

physical disabilities, with the help of various associations of physically disabled people, represented by the National Council for Physically Disabled Persons of Macedonia. [2] Written consent by participants was obtained before starting the interview. The participants were explained that all the information entered in the questionnaire will be strictly anonymous and will be treated as such.

RESULTS

Socio-demographic characteristics:

The study population included 15-49 years age group persons with physical disabilities from 16 cities in the country, represented in accordance with the proportional population structure, where the representation of respondents is from 3.7% in Debar to 11.2% in Skopje, with the proportional representation in other cities is in the range of 5.3% to 7.4%. The study is represented by 65.3% males and 34.7% females, of which 75.9% respondents are Macedonians, 14.5% are Albanians, Turks and Roma are represented by 3.1%, 1.4% Serbs, Vlachs by 1.2% and by 0.9% Bosnians.

The percentage of respondents who have completed secondary education is 66.3%, primary education - 14.9%, 11.8% have a university degree, and 2.2% have no education at all. Recipients were more likely to be unemployed (33.9%), while some of them are welfare recipients (13.9%) and 1.4% are redundant. Employed are 36.3% and 17.6% are volunteers or on contract basis.

Level of disability

According to the opinion of the Expert Commission for "categorization" in the first instance, 71.4% of respondents were registered with a moderate physical disability, 18.4% with severe physical disability, and 8.2% with profound physical

disability. 2.0% of respondents did not comment on the degree of disability.

Table 1: Socio-demographic characteristics of the sample

Gender	No	%
Males	333	65,3
Females	177	34,7
Age	No	%
15 - 19	5	1,0
20 - 24	18	3,5
25 - 29	78	15,3
30 - 34	78	15,3
35 - 39	99	19,4
40 - 44	107	21,0
45 - 50	125	24,5
Nationality	бpoj	%
Macedonians	387	75,9
Albanians	74	14,5
Roma	16	3,1
Turkish	16	3,1
Vlachs	6	1,2
Serbs	7	1,4
Bosnians	4	0,9
Education	No	%
Without any education	11	2,2
Low education	2	0,4
Completed primary education	76	14,9
Completed secondary education	338	66,3
Completed college	23	4,5
Completed high education	60	11,8
Working status	No	%
Unemployed	173	33,9
Volunteer or on contract basis	90	17,6
Employed	185	36,3
Student	7	1,4
Redundant	7	1,4
User of social support	71	13,9
Pensioner	1	0,2

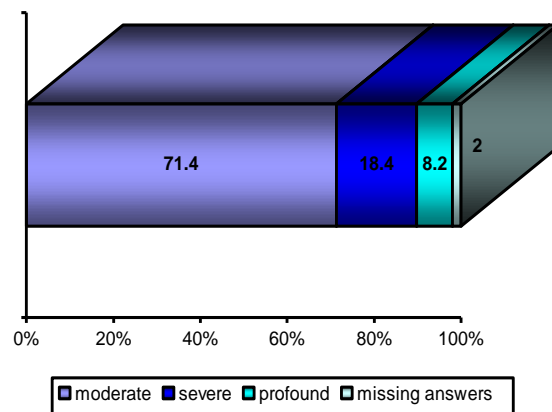


Figure 1: Level of disability of respondents

27.2% of persons with moderate physical disability were aged 45 to 50 years, 21.2%

were aged 35 to 39 years, followed by 19.2% of persons aged 40 to 44 years and etc.

Sexual behavior

The majority of respondents (90% of them) had sexual relationship. Higher percentage - 94.3% of male respondents with physical disabilities had sex and 83.0% of females. The percentage difference of having sexual intercourse between male and female is statistically significant for $p=0.0000$.

There is no registered statistically significance between nationality and having sex of respondents - Pearson Chi-square: 10.8397, $p=0.093471$.

The average age of PWPD at their first sexual intercourse was 19.3 ± 3.3 yrs., min at 13 years and max at 32 years, while average age of PWPD' first sexual partner was 21.0 ± 4.9 yrs., min 14 years and maximum 43 years.

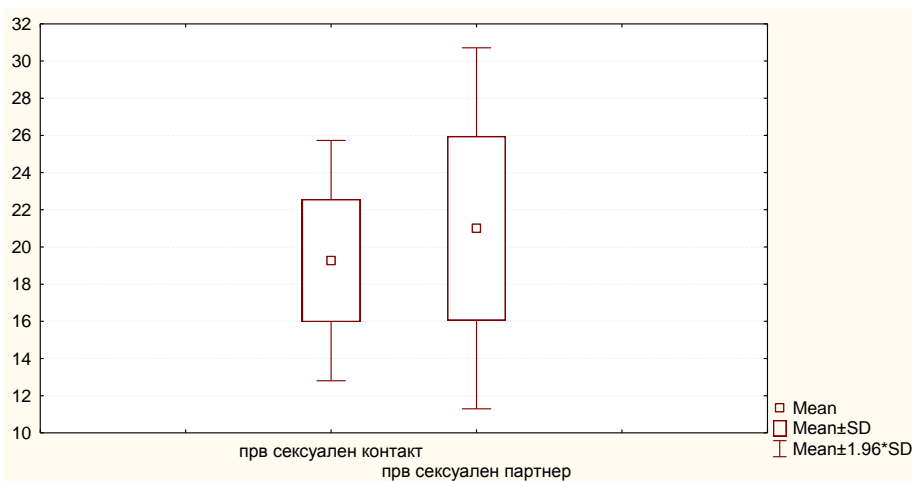


Figure 2: Average age of PWPD at first sex and average age of their first sexual partner

64.1% of PWPD had one partner in the past 12 months, 13.7% between two to five partners, 2.4% over five and 7.8% did not know.

The difference between respondents who use condoms and those who did not is statistical significant. 51.6% of respondents with physical disabilities did not use a condom last time when they had sex with their partner, 32.0% has used, and 4.7% do not know.

Knowledge and awareness of HIV/AIDS

One of the main objectives of this survey was to access the knowledge and awareness of HIV/AIDS among PWPD. From the table 2 below it can be seen that almost 85% of PWPD responded that they

know about HIV, while 15% responded that they had not.

Table 2: Knowledge of HIV

Do you know what is HIV?	No	%
Yes	433	84.9
No	77	15.1
Вкупно	510	100.0

Although the majority of respondents said that they know about HIV, when they were asked further to clarify the ways of HIV transmission, they could not identify them all. Only 81.2% of respondents knew that HIV is transmitted through sex without using a condom, 4.9% said that it is transmitted through sexual intercourse using a condom, 19.2% responded that HIV can be transmitted by sharing a toothbrush, 3.9%

through bite of mosquito or insect, 48.4 through blood transfusion, 3.9% over the care of persons with HIV/AIDS, 3.5% by sharing the food.

However, when it comes to specific modalities of transmission, the majority of respondents 69.4% know that the virus can be transmitted from an infected mother to her child, apart from 2.0% who said that could not be transferred, 8.6% did not know and 16.5% did not answer.

Table 3: Knowledge of AIDS

Do you know what is AIDS?	No	%
Yes	451	88.4
No	47	9.2
Missing answers	12	2.4
Total	510	100.0

The majority of participants knew what is AIDS – 88.4%, 9.2% did not know, and 2.4% did not respond. With regards to the meaning of AIDS, only 51.2% of respondents said that AIDS is spread through sex, 36.1% believe that AIDS is a disease that is not curable, 18.4% said that the cause of AIDS is HIV, 7.5% believe that it is a disease that is spread through vaginal fluids. 12 respondents answered another meaning, 4 of which consider that AIDS is a disease that is spread through blood and body fluids for which there is no cure or vaccine, 4 that represents loss of immunity, and 4 did not specify.

Sexually transmitted infections (STIs)

The study findings show that 70.6% of respondents are familiar with diseases that are sexually transmitted, other than

HIV/AIDS, and 29.4% answered that are not. Statistically significance has been registered between the knowledge of STIs, and respondents’ age and gender. For instance, 59.4% (214) of those who knew about sexually transmitted diseases were males, and 40.6% (146) were females.

In terms of STI symptoms, 41.1% of respondents answered feel of “burning” during urinating, 35.3% - small red sores on genitals, 20.8% white-yellowish-greenish discharge from genitals, 13.7% has appointed blood in urine, 10.8% - abdominal pain, 8.8% - weight reduction, 11.8% of respondents did not know what symptoms can have a person with STI, and 33.9% did not answer. In total 337 participants answered about the STI symptoms, of whom 60, i.e. 17.8% did not know any of the symptoms, and 82.2% of participants gave more than one answer.

Family planning

34.5% of respondents have never been married, and 62.4% were. The youngest married persons with physical disabilities are from Roma and Turkish nationality at the age of 24.6 and 24.4 years, and oldest married respondents are from Macedonian nationality of 26.7 years. Moreover, according to the table 4 below, in comparison with the educational level, data shows that the youngest married PWP without educational attainment has 22.8 years, and the older married respondent is with senior level education at the age of 26.2years.

Table 4: Analysis of Variance-test (ANOVA)

	SS	df	MS	SS	df	MS	F	p
Marriage	449.1009	4	112.275	4765.14	231	20.628	5.44276	0.000332

In most cases, in the majority of persons with physical disabilities (82.6%) the first child has been planned, 10.6% did not, and 6.8% do not know.

Sexual and reproductive health services

With regard to the problems that PWP are facing concerning SRH services, response has been provided by 152 participants (29.8% of the total), and 358 (70.2% of the total) did not give respond. Of

those who responded, the highest percentage of 34.9% did not specify problems, 17.8% have no problems, and 13.0% indicated problems as lack of information, a little information on SRH services, limited availability, inadequate services according to their needs, little education and low skills of health professionals. 10.5% indicated problems as architectural barriers (lack of ramps, elevators in all public health institutions etc.). 5.9% of respondents as problems indicate lack of SRH services. 4.6% has specified insufficient information about the places where to address the issue, 3.9% indicates problems as the inexistence or insufficient communication between PWPD and healthcare providers at every level of life (from adolescence, to adulthood). Other problems cited were below 2.0%.

DISCUSSION

Demographic characteristics showed statistical significance in relationship between the degree of disability and age of respondents with physical disabilities, as well as with their employment status, where 33.9 of participants were unemployed, 36.3 employed and 13.9 used some social support, while from persons with moderate disabilities only 33.2% were employed, 28.0% were unemployed, 14.9% are under contract or volunteers, etc. This reciprocity is based on physical barriers that PWPD are facing, as transportation to educational institutions or work in most cases is not fully acceptable for persons with physical disabilities. Due to this reason, in other countries as well, PWPD have not been fully included into the labor market [6] or they are employed in the informal sector, where work is unstable. [7] In many countries, labor regulations are very limited and inadequate for this group of population, as they do not have defined legislation to promote and

protect the workers with disabilities' rights. [7]

Moreover, the study shows that statistical significance is registered between the status of having sex and gender of respondents. In 2011, a study named as "The influence of psychosocial determinants on sexual and reproductive health in the Republic of Macedonia" has been published. [8] According to its findings, from the total proportion of sexually active respondents (31.1%) significant majority were males (76.4%), while 23.6% were female.

With regard to sexual behavior, the difference in the average age at the first sexual intercourse between the gender of PWPD is statistically significant, where the average age of PWPD at first sexual intercourse among males is $19.1 \pm 3.4g.$, and females at 19.8 ± 7.6 . The other similar study in Macedonia for the general population [8] shows that the average age of the persons without disabilities at their first sexual intercourse is at lower ages. For instance, for male are 14.9 years and 15.5 years for females. Approximately 4 to 5 years difference is noted at the first sexual intercourse between persons with physical disabilities and those without disabilities, which might be due to the disability status and their limited ability for physical movements.

Although PWPD experience sex in their later ages, some other surveys for general population showed decreasing trend of the age of initiation of sexual activity and their first sexual activity before entering into marriage. For instance, the study in Macedonia done in the municipality of Shtip [9] among women without disability showed that the average age of their first sexual intercourse was 17.8 years, and only 6.5% of respondents had first sexual intercourse after entry into marriage. At the age of 15-19 years 64.2% of respondents had first sexual intercourse, at the age of 24 years already

100% of the respondents had their first sexual experience. Statistically significant difference have been obtained from the analysis of age, level of education, ethnicity, employment status and place of residence, as well as the lack of knowledge of any STDs and their symptoms.

With regard to the HIV/AIDS knowledge, 85% of respondents knew about HIV, while 15% did not have such knowledge. The percentage difference registered between knowledge and acknowledge about HIV is statistically significant.

95% of people with physical disabilities under 29 years had knowledge about HIV, apart from 86.1% who were over 35 years. The percentage difference is statistically significant for $p = 0.0157$, which shows that the elderly population has less knowledge of HIV than youngest PWPDP.

Also, statistical significance difference was registered between the age of respondents and knowledge of HIV - Pearson Chi-square: 34.3800, $p = 0.000006$, as well as between the nationality of respondents and knowledge of HIV - Pearson Chi-square: 21.0303, $p = 0.001813$, and between the level of education of respondents and knowledge of HIV - Pearson Chi-square: 71.4549, $p = 0.000000$. Similar results were obtained from the research conducted among disabled people in Malawi in 2004, ^[10] where 87% of disabled people have heard about HIV, deferent than 13% who responded negatively, of whom bigger part belongs to persons with physical disabilities, which is often connected with their inability to speak and listen. Apart from it, still it has been noted that although some persons with disabilities had hearing or speech impairments, a major part of them knew about HIV.

Unlike HIV knowledge, the survey showed that respondents knew more about

AIDS and its ways of transmissions. Even 88.4% of them knew about AIDS, they had quite less knowledge in comparison with the respondents from Malawi' survey, where almost 95% had heard about it. With regard to the meaning of AIDS in both surveys is mentioned that the cause of AIDS is HIV. The lower level of PWPDP' knowledge to HIV/AIDS may be due to the reason that, in general, persons with disabilities often face exclusion from HIV/AIDS public health campaigns, HIV programs, outreach approach, as well as lack attention from HIV/AIDS supporting groups and organizations. ^[11,12] There are even studies that show that persons with physical or/and intellectual disabilities were not given substantial attention before 2004, and consequently a considerable proportion were infected with HIV. ^[13] It is often widely believed that PWPDP do not belong at the risk group of HIV/AIDS due to their sexual inactivity and their limited mobility of having sexual contact in comparison to non-disabled people.

Nevertheless, the reality of the issue is that persons with physical disabilities are at bigger risk for each risk factor for HIV/AIDS. ^[14]

In terms of STI knowledge, the results shows that respondents had less knowledge about STI than about HIV/AIDS, while male persons with physical disabilities have more knowledge about STIs, in comparison with female PWPDP. Similar results were obtained from the other survey in Macedonia ^[14] conducted among younger population, of whom 26% did not know any STI. This could be defined as a very risky knowledge if we have in mind that the last WHO report estimates that on daily basis more than 1 million people are sexually infected. Approximately 60% of these infections occur in less than 25 years old people and the other 30% were younger than 20 years. Between 14 and 19 years STDs are

more common in girls than boys with a scale of 2:1. This number equates to 20 years of age. In 2008 appeared about 498.9 million new cases of syphilis, Neisseria gonorrhoea, Chlamydia trachomatis and Trichomonas vaginalis. [15]

When it comes to the family planning, as can be seen from the results, the youngest PWP who were married are without educational qualifications from Roma and Turkish nationality, and the oldest married PWP were Macedonians who had high level of education. According to ANOVA test developed by R.A.Fisher [16] the difference between the average ages according to the level of education is statistically significant for $p=0.000332$. Furthermore, there is a large selection of so-called "*post hoc*" tests performed after ANOVA test when statistically significant results were provided. They are called tests for multiple comparisons. They all aim to reveal the differences that lead to overall statistically significant result. In that respect, the post hoc Tukey HSD test that was used in the study, shows that the difference was statistically significant between the high levels of education versus other levels of education.

In addition, the results showed that the majority of PWP had planned their first child apart from 10.6% of respondents who did not, and 6.8% who did not know whether their child has been planned or not.

Although the majority of respondents did not give answer about the problems that they are facing with regards to SRH services, still those who had answered mostly indicated insufficient information about SRH, physical inaccessibility, inadequate services according their needs, little education and low professional skills from health workers regarding SRH to PWP etc. Regarding limited physical accessibility, the study among PWP in Kampala founded out that one of the most

common barriers that they faced were inappropriate physical health facilities, such as missing accessible ramps, hospital beds with hydraulics, limited number (or absence) of wheel chairs and disability friendly sanitation facilities in public health institutions. These barriers have been marked by WHO and UNFPA as one of the major constrains that PWP face while accessing SRH services. [17] These findings correspond with those of Gipson [18] who argues that accessibility of persons with physical disabilities to sexual and reproductive health services is predisposed by the by architectural and transportation concerns among others. Nteere [19] in a report on sexual and reproductive rights among disabled persons in Kenya distinguished that PWP are not included in any governmental strategies, programs and action plans for obtaining SRH services. Apart from the situation in Kenya, the Government of the Republic of Macedonia in 2009 has adopted the National Strategy for Sexual and Reproductive Health 2010-2020, [20] which purpose is to ensure better quality of life of Macedonian citizens, through improving the sexual and reproductive health of men and women, with special focus on adolescents towards effective and appropriate health programs. For the first time, persons with disabilities are included in this strategy as a special group of population, even though concrete measures regarding their SRH needs are still missing.

Additional barriers to SRH services that respondents indicated are insufficient communication between PWP and healthcare providers and insufficient geographical distribution of health services. Usually health professionals use language that consists a lot of medical terms, which are not understandable for persons with disabilities, and in their education prevail medical approach, which does not cover

social aspects of PWP. ^[21] The general impression is that education and counseling for SRH are insufficiently practiced by professional services for preventive health care in Macedonia, and from distributional system of contraceptives are excluded most of health facilities that provide services for SRH. ^[22] Besides that, the lack of gynecological units in rural and distant areas in the country makes difficult or limited access of women to gynecological health services, ^[23] in particular to women with physical disabilities.

CONCLUSIONS

The survey describes the persons with physical disabilities' knowledge, attitudes and practice about sexual and reproductive health services. Unlike the rest of population, persons with physical disabilities have increased limited access to social, educational and health services, due to physical barriers that PWP are facing, such as transportation to educational, social or health institutions. The first sexual intercourse of PWP has been experienced at their later ages than persons without disability, which might be due to their disability status and limited functionality for performing certain physical movements. Although the majority of participants said that they have heard about HIV/AIDS, the study found that the comprehensive knowledge on HIV/AIDS is poor. The level of knowledge about STI is even lower, which might be categorized as risky knowledge.

Persons with physical disabilities face multiple challenges while trying to access SRH services, such as: physical inaccessibility at health facilities, insufficient information about SRH, inadequate services in accordance to their needs, lack of health professional knowledge about SRH services for PWP etc.

Therefore, a lot of major steps should be taken in order to improve the PWP's access to SRH services. In this respect, the improvement of physical accessibility to SRH services for PWP by tackling transportation needs and infrastructure of health institutions is needed. Additional training for healthcare providers should be conducted in order to better meet the PWP's needs, as well as education and information to PWP about SRH services. Appropriate information strategies about SRH services should be implemented as well. In general, all existing policies should be reevaluated and stretched accordingly in order to reach and meet the respective SRH needs of PWP.

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