

**Background:** The precise psychosocial impact of the disease varies according to age but general themes persist: fear of what the disease can provoke and fear of chronic pain; denial; anger and frustration; depression or lack of motivation.

**Aim:** Analysis of the emotional satisfaction of the people with Haemophilia according to the demographic characteristics and different social - demographic variables.

**Material and methods:** 30 people with Haemophilia, registered in the National Haemophilia Registry in the Center for Haemophilia, Institute of Transfusion Medicine of RM, have been questioned. A block of nine questions has been applied with six degrees of the Likert-type scales of possible answers. The data collected from the investigation were filed in a specially designed data base, and the statistical analysis was made by using appropriate statistical software (Statistica for Windows 7.0 and SPSS 17.0).

**Results and discussion:** 21 (70%) of investigated people with Haemophilia are of Macedonian ethnicity and 7 (23%) are of Albanian ethnicity. 16 of them were married (46.7%), and as far as the education is concerned, most of them were with university education 14 (46.7%), and 12 (40%) of them were with high school education. The analysis according to the work status shows that most of the people were employed, i.e. 17 (56.7%), and 10 were unemployed (33.3%). The average age of the people with Haemophilia was  $34.57 \pm 10.51$ . For the explanation of the higher reported quality of life in some studies, 'disability paradox', a phrase is used, to describe the interesting correlation between poor quality health and the development of adaptive coping strategies, which leads to good quality of life being reported. The least emotional satisfaction the people with haemophilia showed for the question "Did you feel exhausted?" with average score from  $1.9 \pm 0.99$  (all the time/ most of the time). In 50% of the people with haemophilia, the score for this question is under 2 Median (IQR)=2 (1-2). The score for the largest emotional satisfaction was for the question "Did you feel so bad that nothing could cheer you up?", with average score  $5.33 \pm 1.35$  and Median (IQR)=6 (5-6) - which points out to small or no part of the time. The average score of emotional satisfaction of the whole group of people with haemophilia is  $40.63 \pm 6.1$ . The need to make a contribution to society by working is essential for adult individuals with haemophilia and has a hugely positive impact on their self-esteem. The level of emotional satisfaction with regards to the different social - demographic characteristics of the people with Haemophilia is investigated. The analysis pointed out that according to the average value from the scoring, the higher level of the emotional satisfaction is associated with other ethnicity, university education and younger age. The statistical analysis for  $p > 0.05$  shows no significant statistical relation with the analyzed social - demographic variables.

**Conclusion:** Next activities of the team from Center for Haemophilia related to Psychosocial support of people with Haemophilia will be focused on the field of Professional orientation

**Background:** Hemophilia is an X-linked congenital bleeding disorder caused by a deficiency of coagulation factor VIII (FVIII) (in hemophilia A) or factor IX (FIX) (in hemophilia B). Self-perception of health in people with haemophilia is important segment and indicator of evaluation of their quality of life.

**Aim:** Evaluation of self-perception of health in people with haemophilia using method of self-evaluation of health.

**Material and methods:** Cross sectional study is done in the period avg-sep. 2014. 30 people with haemophilia which represent 10% of registered adults with haemophilia in Centre for haemophilia in Skopje, are evaluated by E-mail. SF - 36 is very well known standardized questionnaire for evaluation of quality of life. This instrument evaluates eight dimensions of life for evaluation of its quality. First three questions represent self-evaluation of health and because of that are separated in Questionnaire for health. Data analysis is performed with statistical software Statistica 7.1 for Windows.

**Results and discussion:** 46,7 % investigated persons evaluated own health as good, and only 13,3% evaluated as great. Much better health in comparance with previous year had 23,3% of investigators. There is moderate strong significant negative correlation ( $p < 0,05$ ) between grade of health and activities like walking around one block (determined territory in populated area). For all other activities like running, lifting heavy objects, participating in difficult sports, climbing up few stairs, walking around many blocks there is strong significant negative correlation ( $p < 0,05$ ) between grade of health and analysed activities.

**Conclusion:** There is partly unreal self - perception for own health in people with haemophilia using method of self-evaluation of health. It is necessary to implement interview as additional method due to perform much more adequate analysis of quality of life in people with hemophilia.

**Key words:** Haemophilia, self-perception of health, SF-36, quality of life