



## Quality of life of people with disabilities in Bosnia and Herzegovina – is there a moderating effect of the health status?

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### ABSTRACT

Quality of life (QOL) is one of the most researched topics in the field of disability in the last 30 years. However, there are few studies that examined the QOL in relation to the type of disability and self-reported health status. The goal of the present study was to examine the QOL in people with disabilities in relation to the type of disability and self-reported health status. The sample for this study consisted of 286 people with disabilities who were interviewed using the Personal Outcomes Scale as a measure of QOL. The results of this study revealed statistically significant differences in the self-reported QOL between people with different types of disabilities. The results also revealed a moderating effect that self-reported health status had on QOL across disability categories. There were no interaction effects of self-reported health status and disability category on the QOL. Generally, people with intellectual disability reported lower QOL than people in other disability categories. Self-reported health status had a significant impact on the QOL across the disability groups. Non-governmental organizations can, through their policies and practices, enhance the person-referenced QOL outcomes.

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### Introduction

Quality of life (QOL) has become one of the most researched topics in the field of disability in the last 30 years. It is currently embraced and studied by several scientific branches including economics, medicine and social sciences (Cummins 2005). This wide interest in QOL concept can be best illustrated by the number of articles published in the last decade that contain in its title 'quality of life'. For example, Pubmed search of articles published in the last 10 years (2006–2015) that contain QOL in its title identified 30,972 such articles. There is almost no health-related issue that was not covered by a study on the QOL of people having the particular medical condition. There are various conceptualizations on what QOL is and how it is defined. It is important to note that there is no consensual definition of QOL, as the QOL means different things to different people. The conceptualization of QOL can change for the same individual over the course of life (Sprangers and Schwartz 1999). However, most authors agree that QOL is a multidimensional social construct consisting of many domains. According to Verdugo et al. (2012), QOL consists of the following domains: personal development, self-determination, interpersonal relations, participation, rights, emotional well-being, physical well-being and material well-being. Another point of consensus among the QOL researchers is that its components are the same for people with disabilities and

people without disabilities (Raphael et al. 1996). World Health Organization (WHO 1995) work group on QOL defined it as *individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and norms*. One critique of this definition is that it strongly emphasizes the subjective dimension of QOL construct without regarding the objective dimension. To grasp the concept of QOL, it is important to regard subjective, as well as objective measures and it needs to capture the dimensions such as life conditions, life satisfaction, and also personal values, aspirations and expectations (Felce and Perry 1995; Verdugo et al. 2012). It has been widely postulated in the literature on the QOL that its indicators need to grasp socio-economic status such as the quantity of material possessions that satisfy individual perceived needs (Milton 2013).

It is difficult to estimate the exact relationship between disability and QOL and in what amount disability does affect the QOL. This relationship is confounded by many social and culturally dependent factors and it probably differs in developed and developing countries. For example, a study by Hosain, Atkinson, and Underwood (2002) in Bangladesh showed that disability had a negative effect on the possibility of education, prospects of marriage and salaries, factors which all affected the emotional well-being of people with disabilities. On the other hand, Amundson (2005) points to the fact that people with disabilities report their QOL only slightly lower than people without disabilities and that their reported QOL is much higher than projected by people without disabilities. Thus, it is important to gain the insight into the individual QOL from the perspectives of people with disabilities themselves, as it provides more objective data than the data provided through the proxies such as family members.

Unlike disability, the effects of health status on QOL have been studied extensively. The QOL construct is strongly related to health. Chronic health problems often lead to diminished QOL and this is especially true in the case of chronic pain (Breivik 2014). The QOL has been mainly studied in specific clinical populations and instruments used for measuring it varied widely. There is a lack of studies directly comparing QOL in different clinical conditions and most of the comparison studies compared the clinical populations with the control (typical) population. Another line of research was focused on comparing the QOL in certain clinical conditions taking into account the severity level of particular disease (or disability). There are ambiguous findings on the impact of severity of disability on QOL. Some studies reported the same level of QOL regardless of the severity, while the others found that the QOL is lower as the severity of disability is higher (Amundson 2010). To date, it is unknown whether the severity of disability has the same effect across the disability categories on QOL and this issue needs further attention. Knowing the QOL in a certain disability category across severity levels could help in creating better programmes for improving QOL in a particular category.

Making the direct comparison of QOL in certain groups of people proved to be very difficult. One way to solve this issue is to use a single instrument across populations of interest. The rationale for conducting this study lies in the fact that QOL in people with disabilities has become an important target and outcome in scientific studies. Thus, we believe it is of great importance to assess the potential differences in the QOL between different disability categories. These findings might help the community in more efficacious allocation of funds for supporting people with disabilities. This study will also contribute to the better understanding of how certain disability type affects the QOL and provide an insight into the relationship between self-reported health status and QOL. All this in turn might help in improving the QOL of people with disabilities.

The goal of the present study is to examine the QOL in people with disabilities in Bosnia and Herzegovina (BiH). Researchers from BiH did not keep up with the trend of examining QOL, especially in relation to disability and there is lack of literature on the subject. So, in order to fill this gap, we set the goal of the current study to investigate the QOL of people with disabilities in BiH. According to the Law on social protection in BiH, disability categories are divided into two ways: 1. In terms of the origin of disability, there are four disability categories: war veterans with disabilities, civilian war victims with disabilities, people with work-related cause of disability and people with disabilities of

different origin (congenital or acquired) that is manifested in childhood. In terms of types of disability, there are five categories: (1) People with disabilities due to visual impairment, (2) People with disabilities due to hearing impairment, (3) People with disabilities due to motor impairments, (4) People with disabilities due to intellectual and psychiatric disorders and (5) People with disabilities due to combined causes. We recruited the participants for this study through the collaboration with Non-governmental organizations (NGOs). People with psychiatric disorders were not included in this study, as we could not find any NGOs that provide support to this category of people, so the process of recruiting them for the study would be very difficult. In this study, we compared the QOL in people with disabilities due to visual, hearing, motor impairment and intellectual disability. These disabilities were manifested prior to 18 years of age. The theoretical framework for the QOL in this study follows Verdugo et al. (2012) QOL domains mentioned above, and was originally formulated by Schalock and Verdugo (2002).

The specific aims of this study were:

1. To compare QOL of people with four different categories of disabilities;
2. To assess the QOL in relation to the self-reported health status in people with disabilities;
3. To investigate whether there is an interaction effect of self-reported health status and disability type on the QOL.

## Methods

### Procedure

Centres for social work and non-governmental disability organizations (NGOs) were contacted to obtain information about people with disabilities, the users of their services. Total of 40 NGOs were contacted throughout BiH and 22 of them accepted to participate in this study. We then contacted the people with disabilities and explained the goal of the study to them. In order to be included in the study, participants had to have an official, *certificate of disability* that was issued by the relevant authorities (Centres for social work). Certificate of disability is an official document based on which people with disabilities achieve their rights, such as right for disability allowance. The participation in the study was voluntary and all the participants gave their informed consent to participate in the study. In the case of people with intellectual disability, the inclusion criteria were that they were verbal and could independently provide answers to the questions in the questionnaire. The data were collected in direct interviews with people with disability. The interviews (Personal Outcomes Scale [POS]) were conducted by the Members of the Association of special education teachers, occupational and speech therapists in Canton Sarajevo, and in some cases, the interviews and questionnaires were conducted by the professional staff (special education teachers, psychologists and social workers) at the NGOs. The interviews with the participants were conducted in the period January 2014–June 2014.

### Participants

The sample for this study consisted of 286 people with disabilities, both sexes, with different types of disability: people with intellectual disability, people with disabilities due to visual impairments, people with disabilities due to hearing impairment and people with motor disabilities. The average age of the participants was 31.6 years (standard deviation 10.7 years). There were no statistically significant differences in the mean age of participants in different disability categories,  $F(3, 282) = 2.5, p = 0.56$ . Also, the age of participants was not significantly correlated with the self-reported QOL (Pearson  $r = .10; p = .07$ ). The participants were from all parts of BiH. All participants had developmental intellectual, motor or sensory disability (manifested before 18 years of age). War veterans and civilian war victims were not included in this study. The reason for not including this large group of

people was that their disability allowances are much higher than those of people with developmental disabilities, and hence this might have been a confounding factor. There were 153 (53.5%) people with intellectual disability, 62 (21.7%) people with hearing impairment, 40 (14%) people with motor disability and 31 (10.8%) people with visual impairment.

In relation to the gender, the sample consisted of 164 males (57.3%) and 122 females (42.7%). There was no significant effect of gender on QOL ( $F = 2.0$ ;  $p = .15$ ). Also, the effect of gender on QOL was the same across disability categories, so the interaction effect of gender\*disability was not statistically significant ( $F = 1.0$ ;  $p = .38$ ).

### Instrument

For this study, we used POS constructed by Van Loon et al. (2008). POS measures QOL based on eight dimensions of QOL validated in numerous cross-cultural studies. That was one of the main reasons we decided to use this instrument for the purposes of this research. The eight dimensions measured on this questionnaire are: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional, physical and material well-being. The instrument is a 3-point Likert-type scale with 48 items. The results on the scale range from 48 to 144 points, higher scores indicating better QOL.

Besides taking the overall score on the QOL measure as a dependent variable, we analysed one item from the POS that regards self-reported QOL. That item was: Are you satisfied with your health? Potential answers are (1) Yes, (2) More or less, (3) No. As there were only 18 people who answered NO, that reply was merged with the reply More or less. So, there were two categories of responses to the question about self-reported health: (1) Yes (2) More or less/not satisfied.

### Statistical analysis

Data were shown descriptively (means and standard deviations). For the testing of the first aim of the study, comparison of QOL in different disability categories, we used analysis of variance (ANOVA, Welch correction) followed by Games–Howell *post hoc* test. For the second aim, examining the QOL in relation to self-reported health status, we used an independent *t*-test and as a measure of an effect size, we used Cohen's *d*. For the third aim, interaction effect of health and disability category on QOL, we used two-way ANOVA (interaction effects). An alpha level of .05 was set for all statistical tests. The data were analysed by using the computer program SPSS v.13 for Windows.

### Results

The first aim of this study was to assess the QOL as measured by POS in people with disabilities. Descriptive data on the mean results on POS are shown in Table 1.

As the sample sizes were not equal across the groups, prior to conducting ANOVA, we performed a Levine's test for the homogeneity of the variances. The test was significant, indicating that the assumption was violated. Thus, we performed Welch ANOVA test, as it is known to handle this violation of homogeneity well. The results indicated significant differences in the mean scores of the groups ( $F(3, 282) = 33.9$ ;  $p < .001$ ). Games–Howell *post hoc* test was performed to examine where the group differences are, as this test is one of the best options when population variances are not equal (Field 2009). The test indicated that only the intellectual disability group differed

**Table 1.** Mean scores on POS in relation to the type of disability.

Disability	Mean	N	SD
Intellectual disability	105.7	153	16.3
Hearing impairment	123.1	62	12.5
Physical disability	117.8	40	15.6
Visual impairment	126.1	31	12.1
Total	113.4	320	17.2

significantly from the other groups, while the motor and sensory disabilities group did not differ significantly between each other.

These results are shown in [Table 2](#).

These results indicate that there are two distinct groups according to the QOL results: the first group consists of people with intellectual disability, who differ from all other groups, meaning they have lower results on the POS. The second group consists of people with hearing impairment, visual impairment and motor disability. They had higher POS results than people with intellectual disability, but did not differ among themselves on the POS.

The second goal of this study was to assess the effect of self-reported health on the QOL.

[Table 3](#) shows the mean results on QOL along with the t-test for the groups who reported good health and the group that reported their health to be more or less good and not good.

We can see that there are considerable differences in the POS scores in relation to the self-reported health status. People who reported good health had also higher POS scores.

Finally, the third aim was to assess if there were any interaction effects of self-reported health status and disability category on the QOL. The results indicated no interaction effect, meaning that the impact of self-reported health status was the same across disability categories (interaction: self-related health status\*disability category,  $F(3,282) = 0.23, p = .88$ ).

## Discussion

This is the first study examining the QOL of people with disabilities in BiH. One of the most important finding of this study was the significant differences among people with different categories of disability in the self-reported QOL. According to the results, there were two distinct, statistically significantly different, categories of people in QOL. The first category consisted of people with intellectual disability (lower QOL). The second category (higher QOL) was composed of people with disabilities due to visual, hearing and motor impairment. People in this category did not differ statistically significantly in their QOL. These findings can have two potential explanations. The first one is that people with intellectual disability really regard their QOL to be lower than those in other disability categories. The second one is the possibility that the differences in cognitive abilities in the groups lead to differently weighted responses in the survey. Similar comments were also made by Matikka (2000) in the study that compared the QOL of people with intellectual disability and people without disabilities. But as the QOL is inherently subjective measure, it is a fact that people view their QOL to be lower than those in other groups. Future studies need to deal with qualitative differences as to why people with intellectual disability view their QOL to be worse than in other groups.

It is important to note that besides collecting quantitative information through the structured questionnaire, we also asked people with disabilities to tell us about the biggest obstacles they face in their everyday lives. The most frequent answer to that was that they were faced with discrimination in trying to find employment and that the state (BiH) is not doing enough in systematic employment of people with disabilities. Also, the frequent answer was that society at large has many unfavourable attitudes and prejudices towards people with disabilities. This situation with underemployment and negative attitudes is present in more developed countries as well (Albrecht and Devlieger 1999; Barnes and Mercer 2005). People with motor disabilities, due to motor

**Table 2.** Comparison of mean group results on the POS.

(I) Disability	(J) Disability	Mean difference (I–J)	Std. error	<i>p</i>
Intellectual disability	Hearing impairment	–17.4	2.1	<.001
	Physical disability	–12.2	2.8	<.001
	Visual impairment	–20.4	2.5	<.001
Hearing impairment	Physical disability	5.3	2.9	.28
	Visual impairment	–2.9	2.7	.69
Physical disability	Visual impairment	–8.2	3.3	.068

**Table 3.** The mean results on the POS in relation to the self-perceived health.

Self-reported health status	<i>M</i>	<i>SD</i>	<i>t</i> -test	Cohen's <i>d</i>
Good health	121.2	12.6	10.8*	1.27
More or less/not good	102.4	16.8		

Note: *N* = 286.

\**p* < .001.

impairment, often stated the problem of inaccessibility of public buildings, shops, toilets, and so on. Again, the problem of accessibility, not just physical, but attitudinal, is prevalent regardless of the culture (Kaye 1997). Other studies have also shown that people with disabilities, in particular people with motor disability, tend to identify societal and environmental barriers for some of the obstacles that they face in their everyday lives and not their impairment (Watson 2002). Obviously, this is not in the spirit of full inclusive society which is based on the premise that it is not the individual who needs to adjust to the environment but the other way around. Unfortunately, many countries around the world have not fully embraced this concept of inclusive society.

Another result of this study was a strong moderating effect of self-reported health status on QOL across disability categories. These findings are in line with existing studies. Earlier studies showed that self-reported health status is dependent on socio-economic status (Choi, Kim, and Park 2015). Memisevic et al. (2016) found that the strongest predictor of QOL in people with intellectual disability was the employment status. Future studies should also examine the effects of socio-economic status as a potential confounder of the link between self-reported health status and QOL. There was no interaction effect of self-reported health status and disability category on QOL, so the effect of health status was virtually the same across disability categories. This finding is useful for creating programmes for improving the QOL in people with disabilities. The better the self-reported health status, the higher the QOL. The significance of health status also points to the greater role that medical staff can play in increasing the QOL of people with disabilities through different education trainings about the benefits of physical activity aimed at this population and their families. Health status can be improved through numerous activities, especially physical activities and this in turn can have a huge positive effect on the QOL. As is the case in more developed countries as well, there is a growth in the older adult population in BiH, and with it increased risk of disablement. Again, the physical activities, such as walking can positively affect the QOL (Motl and McAuley 2010). Thus, given its importance, it would be very beneficial that disability service providers offer more opportunities to people with disabilities for engagement in different kinds of physical activities.

As the people with intellectual disabilities have reported the lowest QOL, let us briefly describe the current situation and trends with regard to them. Although the sample of people with intellectual disability in this study was living in their local communities, there are still many people with intellectual disability who are residing in the large, state-run institutions for lifelong care. Currently, there are around 3000 people with intellectual disability who are placed in four such institutions. Institutionalization of people with intellectual disability is still the leading model of 'social support' in BiH. Actually, some people with intellectual disability from this sample will probably end up in these state-run large institutions when their parents/caretakers die. On the positive side, local NGOs are advocating for deinstitutionalization and community-based living of people with intellectual disability, as it is not just more humane approach, but it is also an obligation of BiH according to the UN Convention on the Rights of Persons with Disabilities, a Convention that BiH signed and ratified. Some small steps have already been made by these NGOs with the programme of community-based living, through which between 20 and 30 people with intellectual disability have been deinstitutionalized and are now living in their own apartments with the professional support. However, the activities of these NGOs are dependent on the donors such as USAID and Open Society Fund, and are still not part of the social care system in BiH. We hope in the near future BiH will fully embrace the spirit of UN Convention and provide full support to community-based living of people with intellectual disability. This, in turn, will significantly contribute to the improvements in their QOL.

The construct of QOL has been suggested as a method to assess service outcomes for people with disabilities (Townsend-White, Pham, and Vassos 2012). Improving the individual's QOL is one of the main goals of support services for people with disabilities (Brown, Hatton, and Emerson 2013). The main providers of support services for people with disabilities in BiH are the above-mentioned NGOs. As is the case in many other countries (Lang 2000), NGOs play a key role in the provision of community-based support services for people with disabilities in BiH and in advocacy for their rights. NGOs are advocating for the full implementation of the UN Convention on the Rights of Persons with Disabilities in all its aspects, from appropriate education to independent living in the community. Fortunately, disability NGOs are now increasingly being recognized by the local authorities as partners in drafting policies, strategies and legislature in the disability field. This will in turn, hopefully, lead to better QOL outcomes for people with disabilities.

Finally, let us mention some of the limitations of the current study. It is recognized as a limitation of this study that some potential variables such as socio-economic status was not investigated as a potential confounder in the relationship between QOL and health. Future studies should take this into consideration. Secondly, although the sample for this study was relatively large, it was not fully random, so caution should be taken in the generalization of these results. As the sample was recruited through the NGOs, it is possible that people with disabilities included in NGOs activities had higher QOL than people with disabilities who are not included. Although requiring a study on its own, we will point out that there are different rates of disability allowances due to the cause of disability (war related or developmental) which represents a kind of discrimination among people with disabilities due to the cause of disability. However, it is important to note that many disability NGOs are advocating for the same disability allowances regardless of the origin of disability and, currently, the BiH government is trying to solve this issue and make disability allowances the same regardless of the origin of disability.

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