Quality of life in patients with acute stroke: comparison between the Short Form 36 and the Stroke- Specific Quality of Life Scale (SSQOL)

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#### Abstract

Rationale, aims, and objectives: The study was to compare the Turkish version of the (Stroke Specific Quality of Life Scales) SSQOL and the SF-36 scales used to determine The Health-Related Quality of Life (HRQOL) of stroke patients, to evaluate the effectiveness of both scales and to determine whether these two scales differ according to sociodemographic characteristics in stroke patients. HRQOL measurements, are commonly used to quantify disease burden, to evaluate treatment method, and to facilitate benchmarking. Descriptive and methodological design. Method: This study was conducted with 205 patients who were hospitalized with the diagnosis of stroke, and followed up for at least 48 hours in a neurology department of a hospital in Istanbul. The data of the study were collected using a form including 18 questions related to sociodemographic characteristics of the patients and the disease, SF-36 and SSQOL Scales. In the analysis of data; in addition to descriptive statistical methods, Kruskal- Wallis test, Mann Whitney U test, Sperman's correlation analysis were used. Significance was evaluated at p < 0.05. Approval of the institutional ethics committee was obtained. Results: The mean age of the study group was  $65.23 \pm 13.64$ years, and consisted of primary school graduates (46.6%), married (75%), and unemployed (84.9%) patients. It was observed that mean scores of SF-36 and SSQOL subdimensions - apart from mental health-mood subdimensions- were higher than those of SSQOL, and both scales have higher internal consiistencies ranging between: 0.74- 0.97 for SSQOL, and 0.59-0.95 for SF-36. Besides, there was a positive, and statistically significant correlation between dimensions of the scales (p < 0.05), while, moderate correlation existed between similar subdimensions (r= 0.042-0.59). Conclusions: Both scales can be used to evaluate the quality of life of acute stroke patients. However, SSQOL is recommended as a priority for acute stroke patients.

# 1. INTRODUCTION

Stroke is a major public health problem that affects both short- and long-term quality of life of the patients, and is one of the top ranked diseases leading to serious mortality and morbidity<sup>1</sup>.

In 2012 World Health Organization defined stroke as "a clinical syndrome consisting of rapidly developing clinical signs of focal (or global in case of coma) disturbance of cerebral functions lasting more than 24 hours or leading to death with no apparent cause other than a vascular origin."

According to WHO 2012 data, every year 15 million people suffer a stroke which cause a permanent damage in 5 million of them. It is the third leading cause of death worldwide after coronary heart disease and cancer<sup>1, 2</sup>. Irrespective of heart diseases, it ranks 5th among causes of death<sup>3</sup>. It has been reported that the incidence of stroke in Turkey is 175 per 100 thousand people<sup>4</sup> and it is among the top 10 causes of death seen in all age groups, while cerebrovascular diseases take the second place with an incidence of 15 percent<sup>5</sup>.

Acute stroke has devastating effects on both the patient and his/her family. It exerts many negative effects

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on patients including physical dysfunction, cognitive disorders and inability to perform activities of daily life<sup>6</sup>. It is the leading cause of motor handicap, second prominent cause of dementia and the third foremost cause of death<sup>7</sup>.

Stroke patients are faced with many physical, mental, social and economic handicaps during their life time<sup>8</sup>. Patients experience restrictions in their functional independence and social relationships and are forced to make changes in their personal, social and professional goals in order to deal with the symptoms of the disease, to maintain self-care and to adapt to changes in their body images. As a result, these handicaps impose an adverse effect on quality of life (QOL) of these patients<sup>9</sup>. Health-Related Quality of Life (HRQOL) focuses on the impact of an individual's perceived health status<sup>10, 11</sup>.

# 1.1 Background

Health-related quality of life (HRQOL) is considered as an important outcome measure and aims to measure how the individual's functions are affected by the disease and changes in their functions. These subdimensions usually determine whether there is a lack of physical, psychological or social functions<sup>8</sup>.

It is useful to determine health-related quality of life in order to specify health care and treatment strategies, to make patient -specific planning, and to evaluate the effectiveness of health care and treatment <sup>12</sup>. Many bodily functions of stroke patients are affected adversely, and therefore evaluation of the quality of life of stroke patients carries utmost importance.

The concept of quality of life (QOL) is defined as a multidimensional concept that includes physical, psychological / spiritual and socio-economic well-being<sup>13</sup>. QOL is a complex concept involving highly subjective parameters and there is no common measurement tool. Although there are approximately 5000 disease-specific generic scales, a universal scale for quality of life assessment is lacking<sup>7</sup>. Health-related quality of life instruments are widely used to measure disease burden, to assess treatment modality, and to facilitate comparative evaluations<sup>14</sup>. Subjective effects of stroke cannot be evaluated by objective measurement tools. For this reason, the health-related quality of life of stroke patients is evaluated using many measurement tools that assess subjective well-being which are quite widely employed in evaluations of health state of the patients in recent years<sup>8, 15, 16</sup>.

Generic or specifically standardized scales are being used to evaluate objective quality of life in stroke. The most common generic quality of life scales used in stroke are Nottingham Health Profile (NHP) and Short form-36. However, disease-specific scales developed in recent years have been frequently used in studies to assess the quality of life of these patients<sup>17</sup>.

In studies where stroke-related quality of life has been evaluated, frequently disease-specific SSQOL scale has been used $^{9, 19-21}$ .

It has been reported that assessments made with disease-specific scales measure the patient's physical functions and well-being better than the generic scales. Because they have been prepared considering the symptoms of the disease so as to obtain more specific measurement results<sup>17,22</sup>. SF-36 and SSQOL scales were used together in validity studies<sup>9</sup> and in patients suffering from aneurysmal subarachnoid hemorrhage for the purpose of comparative evaluation<sup>14</sup>. However, we haven't encountered any study that compared the SSQOL with other similar scales in stroke patients. This study was performed to compare the Turkish version of the SSQOL with the less frequently used SF- 36 scales to determine HRQOL in stroke patients, to evaluate the effectiveness of both scales and to assess whether these two scales differ according to sociodemographic characteristics of stroke patients.

## 2. METHODS

#### 2.1 The aim of the study

A descriptive and cross-sectional study was performed in order to evaluate the health-related quality of life (HRQOL) of stroke patients, to compare SF-36 which is one of the globally used QOL scales with stroke-specific quality of life (SSQOL), to investigate the relationship between them, and inquire whether they differ

according to sociodemographic characteristics of the patients. For the purposes of this study, definition of stroke proposed by World Health Organization was used.

# 2.2 Hypothesis

We have assumed that SF-36 and SSQOL would show similar sensitivities on the basis of similar subdimensions. These subdimensions are Physical Functioning, Social Functionality, Vitality, Mental Health; for SF-36, and Physical Activities, Social and Family Roles, Energy, and Mood for SSQOL.

## 2.3 Study population

The study population consisted of all patients admitted to the neurology department of a training and research hospital in Istanbul between July 2014 and December 2015. During the study period 514 patients were admitted to the neurology service with the diagnosis of stroke. Of these patients, 12 died, 53 were transferred to other wards, and 85 refused to participate in the study. Among 364 patients who were followed up in the ward and agreed to participate in the study, 205 cases who met the study criteria were included in the study. Literate patients older than 18 years of age without mental retardation who were being followed up for at least 48 hours and agreed to participate in the survey consisted the study population.

Aphasic patients, cases with visual and hearing impairments with whom exchange of information is impossible, and patients with musculoskeletal and nervous system disorders other than stroke (developmental hip dysplasia, advanced osteoarthritis, rheumatoid arthritis, ankylosing spondylitis, amputation, myasthenia gravis, Parkinson's disease) were not included in the study.

## 2.4 Data collection instruments

The study was approved by the Ethics Committee of Ümraniye Training and Research Hospital was acquired (protocol #:: B.10.10TKH.4.34.H.GP.0.01 / 43) and the purpose of the study was explained to the participants before their informed written consent was obtained. The Helsinki Declaration of Human Rights was followed.

The data of the study were collected using a, SF-36 scale comprising 18 questions related to sociodemographic characteristics of the patients and the Stroke Specific Quality of Life Scale (SSQOL) via face-to-face interviews with the patients performed by a qualified nurse.

Sociodemographic and disease-specific characteristics of the patients including, gender, educational status, marital status and working status were questioned. Among the characteristics of the disease, the presence of post-stroke sequalae and additional disease(s) were inquired.

2.4.1 Short Form-36 (SF-36)

SF-36 is the best-known and the most widely used health-related quality of life scale in health care researches. It has been reported that it can be used to evaluate QOL in patients with physical illness<sup>23, 24</sup>.

The scale was developed by Ware et al. in 1987 to assess the overall quality of life in healthy and ill individuals<sup>25</sup>. The validity and reliability of its Turkish version was made by Pmar in 1995<sup>26</sup>. The scale, consists of 36 items, two main (physical and mental), and eight subdimensions. The subdimensions of the scale were: (1) physical functioning (PF), (2) role limitation due to physical problems (PR), (3) social functioning (SF), (4) role limitation due to emotional problems (RE), (5) mental health (MH), (6) vitality (VT), (7) bodily pain (BP) and<sup>8</sup> general health perception (GH). In total and subdimensions, the scale score ranges from 0 to 100, and the increase in the score of each health subdimension indicates a positive increase in health-related quality of life. In the study of Pmar (1995), the test-re test value of SF-36 was found to be 0.94 and the Cronbach's alpha value of internal consistency was 0.91. In our study, Cronbach's alpha values of the subdimensions ranged from 0.59 to 0.97 (PF = 0.95; PR = 0.92; BP 0.88; GH 0.71; VT = 0.65; SF = 0.60, RE 0.65; MH = 0.59).

2.4.2 Stroke Specific Quality of Life Scale (SSQOL)

This is a stroke-specific quality of life scale developed by Williams, Weinberger, Clark, Haris and Biller in 1999. SSQOL consists of 49 items and 12 subdimensions (mobility, vitality, upper extremity functioning, work / productivity, mood, self-care, social roles, family roles, language (L), vision (V), thinking (T) and personality (P)) which are rated using 5-point Likert type scale (1 = I totally agree, 2 = I partially agree, 3 = I neither agree nor disagree, 4 = I partially disagree, 5 = I disagree) taking the previous week for consideration<sup>21</sup>. The scale was adapted into Turkish by Khorshid<sup>27</sup> in the year 2009. In its Turkish version in the factor analysis, different from the original version, 49 items were composed of 8 subdimensions (Activities, Social And Family Roles, Language, Vision, Vitality, Mood, Personality, Thinking)<sup>27</sup>. In the evaluation, total score, and score of each subdimension are obtained. The higher the score, the better is the quality of life of stroke patients. The total Cronbach's alpha value of the Turkish version of the scale was 0.97. In our study, Cronbach's alpha values for the subdimensions, ranged between 0.73 (Personality / Thinking) and 0.96 (Energy).

## 2.5 Statistical analysis

When evaluating the findings obtained in this study, IBM SPSS Statistics 22 for statistical analysis (SPSS IBM, Turkey) software program was used. SSQOL scale scores were converted to percentile scores so as to compare with SF-36 scores. The prevalence of the lowest ("floor" effect) and highest ("ceiling" effect) possible quality of life scores in SSQOL and SF-36 were also calculated. The difference between the distributions of ceiling and floor scores was examined by chi- square test. The conformity of the data to the normal distribution was evaluated with the Shapiro- Wilks test. In addition to the descriptive statistical methods (mean, standard deviation, frequency), Kruskal -Wallis test was used for the comparison of quantitative data, and Mann- Whitney U test was used for the comparison of the two groups. Spearman's correlation analysis was employed to examine the relationships between the parameters. Significance was evaluated at p <0.05.

## 3. RESULTS

The mean age of the study group was  $65.23 \pm 13.64$  years, and consisted of primary school graduates (46.6%), married (75%) and unemployed (84.9%) patients, and 64.4% of the participants were from middle income families (Table 1).

Insert Table 1 about here

## 3.1 Total and subscale scores of similar subdimensions of Sf-36 and SSQOL Scales

Mean scores of PF, SF, VT, MH subdimensions of the SF-36 scale were;  $42.37 \pm 34.37$ ,  $52.07 \pm 31.02$ ,  $45.24 \pm 22.50$ , and  $62.30 \pm 19.41$ , respectively. The mean scores of the subdimensions of SSQOL, including PA, SFR, E and M, were  $62.25 \pm 24.81$ ,  $56.08 \pm 26.20$ ,  $53.66 \pm 27.33$ , and  $61.85 \pm 26.25$ , respectively. When the similar subdimensions of the scales were examined, it was seen that the mean scores SF-36 subdimensions were lower relative to the SSQOL mean scores except for the subdimensions of MH-M. Mean MH-M scores of both scales  $(62.30 + 19.41 \ vs \ 61.85, 26.26)$  were very close to each other.

# 3.2 Cronbach's alpha coefficients of the SSQOL and the SF-36 Scales

Cronbach's alpha coefficients for SSQOL and SF-36 scales ranged from 0.74 to 0.97, and from 0.59 to 0.95, respectively, which supports the presence of a robust internal consistency. When the similar subdimensions of the scales were examined, it was seen that the Cronbach's alpha coefficient of SF-36 was lower than that of SSQOL (SF <SFR, VT<E, MH< M). Cronbach's alpha coefficient of SF-36 was found to be 0.70 in three subdimensions (VT, SF, MH). However, the Cronbach's alpha coefficient of the SSQOL scale was > 0.74 in all subscales (Table 2).

#### 3.3 Floor effects and ceiling effects for the SSQOL and the SF-36 scales

Table 2 and Chart 1 show the distributions of floor effect rates of both scales. When the lowest scores of both scales were compared, any significant difference was not observed between distribution in dimensions of PF-PA (20% -2.9%; P = 0.096), VT-E (1.5%, 15.1%; p = 0.39) subdimensions (p> 0.05), while the floor

effect rates of SF-SFR (; 9.8% -12.2%; p=0.000 respectively), MH-M (0- 7.5%; p=0.005) were found to be statistically significantly different. When ceiling effect rates of scales were compared PF-PA (5.4%-5.9%; p=0.02), SF-SFR (13.2% -8.8%; p=0.004), VT-E (2.4%, 13.7%; p=0.019, respectively), any statistically significant difference was not found between the distributions of MH-M (2.0% -13.2%; p=0.437, respectively).

Insert Table 2 about here

Insert Chart 1 about here

The relationship between the subdimensions of the scales is shown in Table 3. A statistically significant correlation was found between SF-36 and all dimensions of SSQOF scale (0.21[?] r [?] 0.59; p < 0.01). A moderate correlation was detected between similar subdimensions (r = 0.428-0.59). The strongest, and the weakest correlations were detected between subdimensions of PF-PA (r = 0.59 p < 0.05) and MH-M (r = 0.042, p < 0.05), respectively. The comparison of the SSQOL and the SF-36 subdimensions according to sociodemographic characteristics.

Insert Table 3 about here

The four subdimensions of SF-36 and SSQOL scales (SF-36:PF, VT, MH, SF; SSQOL: Activities, Energy, Mood, Social and Family Roles) were compared in terms of demographic and disease-related data. A statistically significant difference was found between indicated subdimensions as for age (PF / PA, VT / E,), gender (PF / PA), educational levels (PF / PA), working status (MH / M) of the patients, and post-stroke sequelae (PF / PA, VT / E, MH/M, SF / SFR). Relatively higher quality of life scores were detected in younger patients in the subdimensions of physical activity, and energy, in male patients, and lycée graduates (P < 0.05) (Table 4).

Insert Table 4 about here

Both scales showed significant differences in different sub-dimensions according to demographic characteristics. When compared with SSQL, statistically significant differences were seen in indicated subdimensions of SF-36 regarding age (SF), educational level (VT), and working status (PF, VT, and SF). SSQOL differed statistically significantly from SF-36 with respect to educational status (E) included in socio-demographic characteristics (P < 0.05) (Table 4).

When the overall quality of life was evaluated with SF-36, it was seen that quality of life scores were better in young people and men regarding social functioning, college graduates demonstrated higher scores in energy, and employees in domains of physical and social functioning. When quality of life was evaluated using SSQOL scale, it was seen that lycée graduates received more favourable scores in energy subdimension.

## 4. DISCUSSION

The aim of this study was to compare the SFQ-36, which was developed specifically for stroke in patients with acute stroke and to compare the sociodemographic characteristics of stroke patients with similar subdimensions. It was concluded that both instruments were useful in determining the QOL in acute stroke patients. Both scales have been utilized for evaluating HRQOL in different populations. There are numerous studies where the two scales have been used for evaluating HRQOL<sup>7, 13, 14, 16, 17</sup>.

Some validity and reliability studies have used two scales in combination<sup>9</sup>. However, as far as we know, this is the first study comparing both scales in acute stroke patients.

## 4.1 Assessment of floor and ceiling scores of scales

Lower percentages of floor and ceiling scores and high reliability criteria indicate that the measurement was performed well<sup>28,29</sup>. A percentage greater than 20% indicates a significant floor / ceiling effect<sup>22,30</sup>. Considering the effects of floor and ceiling scores of both scales, SSQOL ceiling score percentages were higher in our study, but floor score rates were higher in three subdimensions of SF-36 other than PF / PA. These findings may be due to the fact that though similar, these subdimensions do not evaluate the same structure, and that SF-36 evaluates both the positive and negative aspects of health. However, SSQOL

assesses these post-stroke functions in more detail<sup>12</sup>. In the Turkish version of SSQOL, the PA subdimension assesses upper extremity functions, work / productivity, mobility, and physical status during self-care<sup>27</sup>. SF-36, on the other hand, evaluates the constraints in severe physical activities due to health problems in the PF subdimension. However, the fact that there were significant positive relationships in the four dimensions of the two scales and that their internal consistencies were close to each other, showed that both scales generally evaluated a similar structural characteristics.

### 4.2 Cronbach's alpha coefficients of the SSQOL and the SF-36

One of the criteria showing that a measurement is made appropriately is its high reliability coefficient<sup>28</sup>. In our study, Cronbach's alpha values ranged between 0.59-0.95 in SF-36 and 0.74-0.97 in SSQOL. These values are consistent with the literature and indicate a high level of internal consistency<sup>12, 22</sup>.

In a study comparing the World Health Organization Quality of Life BREF (WHOQOL-BREF) scales of SSQOL, Cronbach's alpha values of SSQOL were found to range between 0.61-0.82 which were consistent with our study findings<sup>31</sup>. However, in our study, Cronbach's alpha values of SSQOL were relatively higher than SF-36. In one study, it was reported that SF-36 was not suitable for the assessment of stroke patients and should be used for comparison between large groups. Reliability was found to be low especially when the items were responded by the patient's relative(s)<sup>32</sup>. However, it has been reported that SSQOL is moderately susceptible to changes in the first three months after stroke, but further research is needed regarding this issue<sup>21</sup>. The fact that the internal consistency of the two scales was similar in the four similar dimensions shows that both scales evaluated the similar structural characteristics.

#### 4.3 Correlation values of both scales

The highest correlation was found between similar subdimensions of the scales namely between SF-36 Physical Functioning and SSQOL Physical Activities. This result shows that both subdimensions physically evaluate HRQOL in stroke patients using the same criteria. The weakest correlation between SF-36 Mental Health and SSQOL-Mood subdimensions may be related to the expressions of happiness-unhappiness included in the Mental Health dimension. In contrast to the findings in our study, in a study where WHOQOL-BREF and SSQOL were compared, a significant relationship was reported between Psychological Health (PSH) domain of WHOQOL-BREF and the Thinking subdimension of SSQOL<sup>31</sup>. Similarly, in a study comparing SF-36 with another stroke-specific scale (Stroke Impact Scale: SIS), in contrast to our study, it was reported that SIS assessed physical, and social functioning better than SF-36, and use of the items that measures these parameters in SF-36 was not appropriate for stroke patients<sup>17</sup>.

A moderate positive correlation found between the total score of the SSQOL scale and all subdimensions of SF-36, indicates that both scales could be used to assess quality of life in stroke. However, in general, the average scores of the SSQOL scale were higher relative to SF-36 scale, which could be interpreted as SSQOL being more appropriate for these patients. In addition, since the items of the disease-specific scales better describe the disease in question, use of disease-specific scales has been recommended in these studies<sup>17</sup>.

# 4.4 The comparison of the SSQOL and the SF-36 according to sociodemographic characteristics

When HRQOL was examined in stroke patients according to demographic characteristics, some differences in some domains were noted between these two scales. A statistically significant difference was detected in Energy subdimension relative to Educational Status subdimension of socio-demographic characteristics in SF-36 scale in contrast to SSQOL scale. (P < 0.05) (Table 4). When the general quality of life was evaluated with SF-36, it was seen that the youth and men were better as for social activities, and high school graduates received higher scores in Energy subdimension, and employees fared better in physical energy, and social functioning. When the quality of life was evaluated with SSQOL, it was seen that the energy of lycee graduates was at a higher level.

The distributions of subdimension and total scores of both scales according to demographic characteristics were comparable. In other words, the parameter had a high average score in both SSQOL and SF-36 scales. The differences in the different subdimensions of the two scales according to demographic characteristics may

be due to the fact that SF-36 provides an overall assessment of QOL. However SSQOL is disease-specific, and it rather focuses on the effect of the disease on the activity, energy, mental status and social status of stroke patients<sup>17</sup>. The mean scores of relatively younger patients in all age groups were higher in all similar dimensions of both scales than the other age groups. This result can be interpreted as that the adaptation of the young people to the disease is better and that the state of being more active in their daily lives physically, psychologically and socially continues throughout the disease process. However, in contrast to our study, in a study it was reported that the average scores of patients aged 70 years and over in terms of self-care, mobility, upper extremity functioning, family role and social role increased with increasing age<sup>31</sup>. SF-36 scores were lower in all similar subdimensions compared to SSQOL. This decrease was mostly seen between PF, and PA which may be due to the fact that the activities discussed in the PF dimension of SF-36 are mostly out-of-home activities and that patients with stroke have difficulty performing these activities. However, SSQOL-PA dimension mostly evaluates self-care and in-home activities.

#### 4.5 Limitations and future research

There are some limitations of this study. Firstly, the research data were confined to the stroke patients hospitalized in the neurology service of a training and research hospital. Therefore, the study results can be generalized only to this patient group. Secondly, the periods after the acute phase of the disease were not included in the study. Finally severity of stroke was not graded

#### 5.CONCLUSION

In conclusion, SSQOL and SF-36 scales are reliable measurement tools that can be used to evaluate the quality of life of acute stroke patients However, when similar subdimensions were examined; It was concluded that SSQOL generally had higher mean scores, higher internal consistencies, and also a moderate correlation existed between similar subdimensions of both scales. Besides, celling and floor values of both scales were similar except for PF and A subdimensions. In line with these results; use of disease-specific SSQOL scale is priorly recommended for the evaluation of the quality of life of acute stroke patients. It is also recommended that this study be performed in different groups of stroke patients, one month or longer after a stroke attack.

# Clinical practice

SF-36 scale is being used to assess the quality of life of stroke patients in Turkey (Topcu and Pınar, 2012). The results of this study showed that the use of the SSQOL scale may be more appropriate, especially in acute stroke patients. In addition, stroke -specific QOL scale (SSQOL) will provide nurses more objective information when evaluating especially the physical activity of the patients, when compared with SF-36.

#### What does this paper contribute to the wider global clinical community

- Stroke -specific QOL scale (SSQOL) will provide nurses more objective information when evaluating especially the physical activity of the patients, when compared with SF-36.
- In future studies, the use of SSQUL may be recommended for quality of life assessment of stroke patients.

Nurses can plan patient care based on more objective results.

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### Conflict of Interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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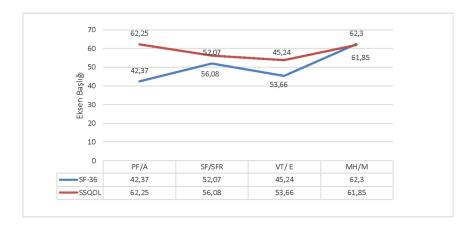


FIGURE 1 Floor effects and ceiling effects for the SSQOL and the SF-36 scales

## **TABLES**

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tables (1).docx available at https://authorea.com/users/290742/articles/417646-quality-of-life-in-patients-with-acute-stroke-comparison-between-the-short-form-36-and-the-stroke-specific-quality-of-life-scale-ssgol