# Assessment of Quality of Life in Migraine Migrende Yasam Kalitesinin Değerlendirilmesi

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#### Abstract

Quality of life is the perception of an individual's position in life associated with his objectives, expectations, interests, and standard's of life. Health-related quality of life, on the other hand, includes satisfaction with his health and emotional reaction to his state of health. Primary headaches are encountered commonly in adults during their most productive years like end of puberty and at the beginning of 50's. Migraine alone is responsible for 1.3% of years with disability in the world, all headaches together being responsible for twice of this load. Headaches both worsen quality of life of individuals and place a significant burden on the society. This review will focus on the effects of primary headaches, especially migraine, on quality of life and tools used to evaluate these effects. (Archives of Neuropsychiatry 2013; 50 Supplement 1: S60-S64)

Key words: Headache, migraine, quality of life

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#### Özet

Yaşam kalitesi, kişinin kültür ve değerler sistemi içinde amaç, beklenti, ilgi alanı ve standartları ile ilişki olarak yaşamda bulunduğu yeri algılama şeklidir. Sağlıkla ilişkili yaşam kalitesi ise kişinin sağlık durumundan memnuniyetini ve sağlık durumuna verdiği duygusal yanıtı içerir. Primer başağrıları, erişkinlerin en üretken olduğu ergenlik sonu ve 50'li yaşların başı arasında sıkça karşılaşılan durumlardır. Tüm dünyada özürlülükle geçen yılların %1.3'ünden tek başına migren, bu yükün yaklaşık iki katından da tüm BA hastalıkları hep beraber sorumludur. Başağrısı hem kişinin yaşam kalitesini bozmakta hem de topluma ciddi maddi yük getirmektedir. Bu derlemede, hastalık yükünün primer başağrısının, özellikle migrenin, kişinin yaşam kalitesi üzerine etkisi ve bunun değerlendirilmesinde kullanılan ölçütler gözden geçirilecektir. (Nöropsikiyatri Arşivi 2013; 50 Özel Sayı 1: S60-S64)

Anahtar kelimeler: Başağrısı, migren, yaşam kalitesi

Çıkar çatışması: Yazarlar bu makale ile ilgili olarak herhangi bir çıkar çatışması bildirmemişlerdir.

### Introduction

The definition of health was made not only as "absence of disease or disability" but also "a complete physical, mental and social well-being" by the World Health Organization (WHO) in 1948 (1). The WHO has the objective that each person is healthy, productive socially, economically and psychologically and has a better quality of life.

Quality is the perfection level which is whished to be reached. Quality of life and health-related quality of life are two different concepts. Quality of life has a considerably wide scope. It covers individual evaluation of both positive and negative aspects of life (2). The definition of this term which means something for everybody may vary according to each academic discipline, person or group. Quality of life is the way of perception of an individual in relation with

his/her objectives, expectations, areas of interest and standards within his/her culture and fundemental values. The determinants of quality of life include the health, occupation, shelter, education and environment of the individual. The complex effect of culture, values and beliefs on the quality of life makes its measurement difficult. Investigators have developed tools to help us understand and measure these different areas and their relations with each other.

Health-related quality of life constitutes only one part of quality of life. It includes the individual's satisfaction with his/her health status and emotional response he/she gives to his/her health status. It has been developing since 1960s such as to cover all determinants (physical and mental) which have been shown to affect the health status (3, 4, 5, 6, 7).

Healt related quality of life includes individual physical and mental healt concept and relations (conditions which jeopardize health, functional status, social support, socioeconomical status) as well as a community's perception of health and sources, conditions, politics and applications affecting its functional status. Measurement of health status and determination of the efficiency of healthcare service should not only include the changes in the frequency and severity of morbidities, but also show the improvement in healt related quality of life. Standardized criteria related with health-related quality of life help to evaluate the developments in reaching public health objectives, health-related incompatibilities in different groups of the population and the efficiency of addressing age-related diseases (8,9,10,11).

Almost half of the adult population in the world complain one or more types of headache (HA)at least for one time for a life time. Although it shows variance according to different areas of the world, migraine, tension HA and medication overuse HA are among the most common diseases of the human being. Prevalance studies show that -3/4 of the adult population between the ages of 18 and 65 years have experienced HA in the last one year. Migraine is observed in 11% of the adults worldwide and affects women 3 fold more frequently compared to men. 1.7-4% of the adult population experience HA for 15 days a month or more frequently. Based on the figures related with migraine prevalence and the incidence of attacks, it is calculated that 3000 migraine attacks are experienced each day per one million of the generalpopulation. The study entitled "Global Disease Burden" updated by the WHO in 2004 showed that migraine was responsible alone of 1.3% of the years with disability and the remaining HAs were responsible of a similar burden all together (12, 13, 14).

The complete burden of headache in terms of public health is not known. Despite this, a great portion of the patients can not receive efficient medical treatment because of limited resources allocated by countries to HA. The WHO who colloborated with a campaign which was related w,th eliminating the burden ("Lifting the Burden") and was conducted in the whole world published the HA atlas in 2011 (15, 16, 17). The information included here was obtained by way of a questionnaire applied to neurologists, general practitioners and patients representing 101 countries between November 2006 and March 2009. In only 18% of the countries included in these surveys, information about the social burden due to HA could be reached. IN 12% of the countries included in the surveys, HA was used in in the yearly health reporting system and in only 7% HA was used in calculation of the gross national product (14).

Primary headaches are observed frequently in the period between the end of adolescence and the begining of mid-fifties during which adults have the maximum productivity. Neurological diseases are responsible of 3% of the years with disability in the whole world and migraine is responsible of 1/3 of this (18). Recurrent HA attacks and frequently persistent fear and concern about the next attack disrupt the individual's familial, occupational and social life. The individual cancels his/her social activities and confronts with labeling as an "unreliable-not to be working together" person by his/her friends and employers beacuse of not being able to finish a work due to an unexpected attack or not being able to show the expected performance at a very significant time. This decreases the possbility of advancing in the career and reduces his/her expectation about career and financial future. In addition to the burden on the individual who experiences HA, his/her employers, co-workers, family and friends in his/her private life take their share from the individuals lost working hours and reduced productivity.

Although there is no mortality related with primary HAs, the experience of pain of the patient with HA, both disrupts the quality

of life and puts a severe financial burden on the community. In this review, the effect of primary HA diseases on the quality of life of the individual will be reviewed, but not the disease burden on the community.

A screening in medline by giving the key words "migraine" and "quality of life" will show how the interest on this issue has increased since 1990s. In 2001, Andresik, stated that he detected 63 subscales which did not intersect with each other to measure the effect of migraine on the quality of life and recommended to determine the areas which relate these subscales with each other instead of developing more scales (19). There are 70 articles published between 2010 and 2012 which adressed health-related quality of life and /or disability as primary and secondary end points in adult patients with primary HA. Analysis of 12 of these showed that health-related quality of life and disability as well as HA frequency were afffected positivley by treatment approaches, similar results were obtained in two observational studies and SF-36 was sensitive in displaying the temporal change in quality of life and functions in HA patients similar to disease-specific tools (20).

The methods to be used in measurement of health-related quality of life have been defined for many morbidities (21).

I. Criteris assessing the general health status: General quality of life questionnaires include Brief Form-36 and its shortened forms (22, 23, 24, 25, 26, 27, 28, 29), European Quality of Life Scale (30), Disease Impact Profile (31) and its shortened form); Health Utilities Index (HUI) (33), Well-Being Scale (34, 35), Notthingham Health Profile (NHP) (36, 37, 38, 39), Patient Generated Index (40), Quality of Life Assessment Tool -100 (WHOQOL-100) (41) and WHO Quality of Life Assessment Tool Brief Form (WHOQOLBREF) (42), Quality of Life Index (43), Life Satisfaction Index (44), (World Health Organization Disability Assessment Schedule, second version, WHO-DAS II) (45).

These questionnaires provide comparison between different diseases; they are not specific for accompanying diseases. Their most important limitation is the fact that they are very long. However, brief forms have been developed for some questionnaires later and their use in large researches and clinical studies has been facilitated.

**SF-36:** It is most commonly used in medicine. 8 subscales containing 36 items provide assessemtn of the individual in terms of physical and cognitive status. Its adaptation for the Turkish population was performed (23). Its disadvantages include inability to assess the areas including sleep, cognitive function, sexual function, communication and recreation, insensivity to the cognitive dimension of subjective well-being while being sensitive to the emotional dimension and presence of ceiling and floor effect (25).

Short form 36 (SF-36) is a questionnaire which assesses the effect of disease in 8 dimensions of health (physical function, rol limitation related with physical problems, body pain, general health perception, vitality, social function, role loss due to emotional problems and mental health). For each subscale a score of 0-100 is obtained. A higher score shows a better quality of life (24). When it was developed initially, a change of 5 points in the general health scale was stated to be minimal clinically important difference (MCID) (24). However, the studies conducted later showed that changes of 3-5 points could be significant, but it should be carefully examined if the differences were significant or not (25, 26, 27, 28, 29)

European Quality of Life-5 Dimensions(EQ-5D) scale was developed by the EuroQolgroup (WestEurope Quality of Life Research Association) in 1987. It was translated to more than 60 languages

including Turkish. It is composed of five dimensions(movement, self-care, ordinary activities, pain/discomfort, anxiety/depression) where the individual reports his/her own status himself/herself (30, 46, 47, 48, 49, 50). For each dimension one answer is given among three options (no problem, some problems are present and major problem). With this scale 243 possible different health results are defined. The index score ranging between -0.59 and 1 from the 5 dimensions of the scale is calculated by using the coefficients produced by Dolan et al.. A value of 0 indicates mortality and a value of 1 indicates perfect health, while negative values indicate conditions including loss of consciousness and bed-ridden status. Instant healt states of individuals are measured by marking one of the values between 0 and 100 on the visual analog scale (VAS); a score of 100 represents the best status. It is used in assessing the effect of different morbidities including psychiatric diseases, other medical conditions and surgical operations on quality of life (30, 46, 47, 48, 49).

Disease Impact Profile assesses the health status in 12 areas (ambulation, mobility, body care and movement, communication, attention, emotional status, social integration, sleep and rest, nutrition, house-related activities, occupational status, hobbies and recreation) with 136 items. The whole scale may be used or its parts may be used seperately. SIP68 is a short form containing 68 items. Its disadvantages include its lenght and absence of an area of pain (31, 32).

**Notthingham Health Profile:** This is a scale which aims to assess the physical, emotional and social health status perceived by the individual himself/herself. It has a Turkish version (36, 37, 38, 39). It is composed of two parts: The frequently used part is the first part composed of 38 items and assesses quality of life in 6 areas (sleep status, energy level, emotional status, social isolation status, physical mobility and pain). The second part is applied in appropriate patients and assesses the areas including gainful occupation, Works related with house, social life, sexual life, hobbies and areas of interest and vacation life.

An inter-cultural validity study of the WHO Disability Assessement Schedule was performed in 17 countries including Turkey to understand the differences in the language and concepts used while describing disability and the community's response to this (37). This tool is a semi-structured interview scale composed of 36 items. It tries to determine how much difficulty the individual has experienced while performing certain activities in the last one month. The titles of 6 activities are as follows: 1) Understanding and communication, 2) Movement and going from one place to another, 3) Self-care, 4) Human relations, 5) Life activities, 6) Participation in the cial life. The answers given to all these areas as none, some, moderate, much, excessively/never are scored between 1 and 5. WHO-DAS-II has been prepared to assess individuals above the age of 18 years who are different in terms of education level, cultural properties and cognitive abilities. The patient needs not to be literate. For a standard interview, the interviewers who will as the questions and record the data should be educated. The interviewer should ensure that the patient has understood the questions and give the necessary explanations, when the patient does not understand or misunderstand the questions. The application last for approximately 20 minutes (45).

II. Disease-specific criteria: Disease-specific quality of life scales developed for migraine include MIDAS (Migraine disability Assessment Scale) (50, 51), 24 h MQoLQ (24-hour Migraine Quality of Life Scale) (52), Migraine-Specific Quality of Life Questionnaire-MSQ (53, 54, 55, 56, 57, 58) and Headache Requirement Assessement Scale (59). The reliability and validity of the first two scales for the

Turkish population was examined. The others are migraine-specific health quality scales, but their reliability and validity for the Turkish population have not been studied yet.

Since disease-specific questionnaires are more sensitive compared to general quality of life questionnaires, they do not overlook differences or changes which are significant in terms of that disease

(1) Migraine-specific Quality of Life questionnaire version 2.1 (MSYK v2.1)

MSYK v2.1 is composed of 14 questions which assess the limitations in daily performance because of migraine (54). It is composed of three areas including restrictive role, preventive role and emotional function. The first two areas reach the data related with decrease in and prevention of daily social and occupational activities, while the last area assesses the emotions related with migraine. The scores corresponding to the answer given to each question are summed and a value is obtained. Higher scores indicate a better health-related quality of life.

When we examine the studies in the literature related with both general and migraine-specific quality of life scales, the following picture is confronted:

It was shown that EYK-5D scores became worse compared to the period without attack, when frequent attacks were experienced in patients with migraine (64). When the service utility values of EQ-5D scores of 106 patients with migraine were evaluated, it was found that utility was significantly low in all migraine pain degrees, as the severity of migraine increased, utility decreased, severe migraine pain was described as "worse than death" and these results could be used in utility cost models in which the economical values related with migrain treatment are examined (65).

SF-36 has been used frequently in painful states as well as in studies conducted with patients with migraine (60, 61, 64, 65). The studies in which both SF36 and its short form SF12 have been used have showed that the quality of life is worse in patients with migraine compared to both the general population and patients with otherchronic diseases. The greatest reductions in scores in patients with migraine were observed in the areas related with role limitation, social function and body pain (61). In addition, the reduction in scores in patients with chronic migraine is extensive including more subscales. Improvement in pain and psychological well-being scales are the most beneficial scores to predict improvement in SF-36. Another study which aimed to elucidate the effects of pain and depression on the quality of life in migraine showed that the risk of experiencing extensive chronic pain in women with migraine increased depending on the frequency of HA and both depressive symptoms and chronic migraine could predict the quality of life independent of other factors (62). These results indicate the importance of diagnosis and treatment of comorbid psychiatric diseases during treatment of HA.

Studies have shown that migraine affected the individual's daily life and quality of life negatively, the frequency, severity, accompanying symptoms including nausea, phonophobia and photophobia of migraine and comorbid conditions including mood disorders contributed to this negativity and pain was sufficient to disrupt the quality of life by itself independent of accompanying factors (63, 64, 65, 66, 67, 68).

While the difference in quality of life between patients with migraine and other episodic HAs has been assessed using SF-36 in many studies, fewer studies have used SF-36 in chronic daily HA. It was found that the scores of the patients with chronic daily HA were lower in most areas of SF-36 compared to healthy controls and this was especially more prominent in the areas of physical

role and body pain. It was observed the scores of the patients with chronic daily HA were worse in most areas of SF-36 compared to the patients with episodic HA and this was especially more prominent in the areas of general health, vitality and emotional role. In all the studies except for one study, SF-36 quality of life scores were found to be lower in patients with chronic daily headache carrying migraine-like characteristics compared to patients with chronic daily headache who do not carry migraine-like characteristics. Again, in most studies, SF-36 quality of life scores in patients with chronic daily headache with medication overuse were found to be lower compared to patients with chronic daily headache without medication overuse. According to MIDAS assessments, it was found that disability and productivity were affected with a higher rate in patients with chronic daily headache compared to patients with episodic headache (69).

In studies performed in Spain and France, it was shown that the quality of life was worse in patients with chronic daily headache compared to patients with episodic migraine. Similar SF scores were found in patients in HA clinics (61). Two studies performed in Taiwan and USA (60,70) showed that the quality of life was worse in patients with transformed HA who presented to HA clinics compared to patients with episodic migraine.

Another area in which the assessment of quality of life is used includes studies aimed to display drug efficiency. It was shown that improvement occured in health-related quality of life measured using both general and disease-specific scales in patients treated with sumatriptan (71, 72, 73). According to the results of the 24-hour migraine-specific quality of life questionnaire, the quality of life of the patients who used 10 mg rizatriptan was better compared to the placebo group (74). In a study in which the effect of acute migraine attack treatment on migraine-specific quality of life in the short-term was examined, complete and persistent pain control after treatment and achievement of normal function in the second hour of treatment caused to a better short-term health-related quality of life (75).

When determining the effect of migraine on health-related quality of life, it was a problem not being able to show the counterpart (77) in the perspective of the "International Classification of Functioning, Disability and Health" (ICF) (76). In a study performed in Italy to demonstrate the relation between health-related quality of life and disability in the biopsychosocial model defined in ICF, a general new tool was used (World Health Organization Disability Assessment Schedule, second version WHO-DAS II) (45). In this study, the relation between MIDAS and WHO-DAS II was also examined. At the end of the study, it was reported that health-related quality of life and WHO-DAS II examined different psychosocial aspects of migraine, researchers should use both in their studies, because migraine affects the individual's functionality to a great extent apart from its economical burden (78).

In the last 20 years, the importance of disease burden and awareness of the effect of treatment options on the health status of patients have increased. It is observed that these are measured using objective criteria in clinical studies. These criteria provide significant information in the preferance of treatment options and in development of optimal treatment algorithms. Development of these criteria in the area of migraine and demonstration of their reliability have provided perception of migraine by the patient's eye. The data related with the quality of life of patients with HA who are confronted widely will be beneficial in development of better treatment approaches and management methods by providing treatment satisfaction and determination of individual requirements.

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