QUALITY OF LIFE ASSESMENT IN PACIENTS WITH CHRONICAL DISEASES

Mirela Pârvu, MD (1), Marcela Sigmirean, MD, PhD (1), Ancuţa Sigmirean, PhD Candidate; 1 – University of Medicine and Pharmacy, Tîrgu-Mureș, 2 – Technical University of Cluj-Napoca

Abstract: Quality of life assessment has become an element of the current research on chronic disease. For clinicians, to assess the quality of life in patients with immune-inflammatory diseases is to assess the effects of therapy on symptoms and identify the negative impact of the disease on daily activities. Questionnaire, descriptive tool, is assessing a subjective manner a wide range of effects of the disease, which subsequently summarize in a final score. Health Assessment Questionnaire (HAQ) and Enhanced Quality of Life Questionnaire (EQoL) specific tools are used to assess the quality of life of patients with immune-inflammatory diseases. Since it is useful to combine the means of assessing the quality of life questionnaire specific to the generic can be attached to a better evaluation of the patient with chronic rheumatology diseases. Using the instrument of evaluation of quality of life, by clinicians, complete other methods of investigation of the patient, therapeutic conduct further being able to improve the quality of life of these patients.

Keywords: quality of life, health questionnaire, specific tools, chronic diseases, immune-inflammatory diseases,

Introduction

Quality of life a vast concept, incorporating a multitude of factors: personal, social, financial, is closely related to health. So, a certain medical condition, as is the case of rheumatoid arthritis, has an important impact on the quality of life of the persons concerned, but also to those families (1,2).

Rheumatoid arthritis (RA), a distinct entity within the chronic rheumatic diseases, through the joint destruction and the consequences of systemic inflammation of internal organs and the psychological burden of early disability and social instability has an important socioeconomic impact (3,4).

The relationship between quality of life and health in rheumatoid arthritis

Quality of life in relation to health is a consequence of the disease and treatment of the RA patient's perception of his ability to have a full and useful life (5,6,7). By its nature, the quality of life has a multidimensional and subjective interpretation, based on the patient's experience (8). Quality of life in relation to health includes many areas, such as: symptoms, physical function, and the role of social interactions, functional, psychological status and treatment side effects. New concepts include among these areas and the financial costs of the disease. Each of these areas in turn includes a number of other components such as *1.symptoms:* pain, stiffness, fatigue, sleep disorders, *2.physical function:* self-care, mobility, *3.functional role:* domestic activities, occupation, school, *4.social interaction:* family, friends, colleagues, community, leisure time, *5.mental wellbeing, emotional status:* depression, anxiety, response mechanisms with disease treatment, *6.side effects:* disorders involving internal organs, *7.financial costs:* direct and indirect (6,8,9,10,19).

Why should evaluate the quality of life in rheumatoid arthritis

Worldwide, the incidence of the disease is about 0,5/1000 in women and 0.2/1000 in men, and the prevalence is about 1.7% for women and to 0.7% for men. The average age at which this occurs is between 30 and 50 years of age, but it can affect people of any age (11,12). Under the conditions of our country we can appreciate as rheumatoid arthritis in about 1% of the general population, such as the total number of people suffering is estimated to rise to 180,000 (13). RA is a chronic, potentially debilitating disorder with an unpredictable disease course, radiological evidence of joints erosion can occur as early as the first 2 years of diseases (14).

RA is considered to have a physical impact and sever pathology disorders, and redefining the criteria of functional status in 1992, has highlighted the large populations of patients with active forms and severe poliarticular impairment (14,15). Based on the classifications of functional capacity, developed by Steinbroker, functional status in RA is classified into four classes by American College of Rheumatology, depending on the patient's ability to perform usual activities, family, professional, and recreational activities (15).

The severity of the disease result from the fact that over 50% of patients will workday lost or cease professional activity in the first 5 years of the disease, and in 10% of cases there presented serious disability in the first 2 years of evolution, as has been shown in epidemiological studies. The consequences of RA on the quality of life can be devastating, and socioeconomic consequences of functional disability are severe (14).

Over time there a lot of articles have been written about the epidemiology and impact of the RA in society, Kvien (2004) conclusion that RA can lead to a premature death (shortening of the average life span of 5-10 years) due to an increased risk of developing cardiovascular disease (such as myocardial infarction or stroke), gastrointestinal diseases and respiratory diseases (16) Pincus (1984) shows that, in patients with RA, quality of life is lower than those with migraines, hypertension, chronic obstructive pulmonary disease and diabetes mellitus (17).

Quality of life and health status are two different concepts. Smith et al. considers that the concept of quality of life as being linked to more than mental health, while health status refers to the physical function (18).

The classic algorithm of the functional assessment of the impact of PR has been extrapolated, the insertion of the evaluation of the quality of life, which is a useful tool, was imposed in the current medical practice (15). Analysis of quality of life, clinical and laboratory balance outperforms, filling a new dimensions: the impact of physical and social function. A detailed analysis of the degree of disability and the impact on quality of life in patients with RA is important in assessing, monitoring short-and long-term disease and to quantify treatment response(1).

RA has serious consequences, both on the physical health of those affected, as well as a negative impact on patient's quality of life. Functional status reflects the ability to perform daily activities-physical, social and emotional, while health-related quality of life refers to the subjective aspects of the impact of the health status of the individual quality of life (19).

Quality of life assessment has become an element of the current research on RA, to assess the quality of life related to health, consisting in quantification in a standardized and objective

manner, the impact of the disease on the daily activities of the patient, on the health and well being (1,20).

Tools for assessing the health status/quality of life

Questionnaire is a descriptive tool, which assesses in a subjective manner a wide range of effects of the disease, which he summarizes in a final score. Tools for assessing the health status of the patient's perspective and the tools for evaluation of quality of life are different, generic and specific (14,21,22).

- Specific assess the severity of symptoms
- •Generic-evaluates the status of general, social relationships, and emotional skills to carry on enjoyable activities by the patient

Psychometric properties of the instruments of assessment:

- Fidelity or reproducibility: the ability of an instrument to get the same results from different tests, when applied in similar conditions to the same population
- Validity: verifying whether measures what instrumental aims-
- Sensitivity (responsiveness to change): how a tool can be distinguished from the minor modifications of the health assessment

Properties of questionnaires

- Distinctness: means the ability to distinguish levels of impairment of health between patients
- Evaluative capacity represents the main to detect changes related to illness or treatment evolution

Outcomes Measures in Rheumatology (OMERACT) is an international, informally organized network initiated in 1992 that aims to improve outcome measurement in rheumatology. OMERACT strives to improve end point outcome measurement through a data-driven, iterative consensus process. Agreement regarding the use of standardized end points in randomized controlled trials and longitudinal observational studies is extremely important (22). Their use facilitates comparisons of outcomes across studies to provide the best estimates of benefit and safety for therapeutic interventions across differing patient populations. A measure is considered "applicable" when it passes the OMERACT filter in its intended setting (23). The OMERACT filter can easily be summarized in only 3 words: truth, discrimination, and feasibility. Each word represents a question to be answered of the measure, in each of its intended setting (1,24).

The Short Form 36 – Health Survey

The SF-36 is the most widely used generic measure of health status. The SF-36 can be self administered or with the use of an interviewer. It can be completed in 5-10 minutes and has been applied to large populations in a number of countries and to patients with a variety of illnesses of all age groups. There are 36 questions in the SF-36, these items are grouped into 8 scales; physical functioning (PF), role-physical (RP), body pain (BP), general health (GH), vitality (VT), social functioning (SF), role emotional (RE) and mental health (MH). There are 2 summary measures which aggregate the 8 scales; Physical Health (PF, RP, BP, and GH) and Mental Health (VT, SF, RE, MH). All but one of the 36 items is used to score the 8 SF-36 scales. Each item is used in scoring only one scale. These 8 scales were selected from the 40 used in the Medical Outcomes Study, those chosen were felt to represent the most

frequently measured concepts in widely-used health surveys and those most affected by disease and treatments. It is a practical tool for use in patients with RA (19,25).

Health Assessment Questionnaire Disability Index -HAQ DI

HAQ DI original, or HAQ, was developed to assess functional status in adults with arthritis, but is now commonly used among many disciplines (9).

Originally developed for use in patients with RA and osteoarthritis, the HAQ has had application now in both adults and children within a wider range of rheumatologic conditions. Physical function is only one of several domains determining health-related quality of life, its importance in RA, as well as its prevalence of use, has led to HAQ scores being used to estimate health utilities with a variety of derivations (26). HAQ contents eight categories, reviewing a total of 20 specific functions evaluate patient difficulty with activities of daily living over the past week. Categories include dressing and grooming, arising, eating, walking, hygiene, reaching, gripping, and errands and chores. Also identified are specific aids or devices utilized for assistance, as well as help needed from another person (aids/help). There are 41 total items: 20 4-point Likert-scale questions assessing specific activities of daily living, 13 additional questions assessing use of assistive devices, and 8 additional questions assessing help received from another. Computation of an Alternative Disability Index (or Alternative HAQ score) is made possible by not taking into account questions regarding the use of aids/help (27).

There are 3 steps to scoring the HAQ (with aids/help): 1) identify the highest subcategory score from each of the 8 categories. Adjust for use of aids/help by increasing the category score from 0 or 1 to a 2 if use of aids/help for that category (utilize table of companion aids/help for HAQ categories). If the category score is already a 2 or 3, no adjustment is made; 2) sum the category scores; and 3) divide the final sum by the number of categories answered to obtain the final HAQ score rounded to the nearest value evenly divisible by 0.125. Requires a minimum of 6 categories answered; if less, do not score. Total score is between 0–3.0, in 0.125 increments. Increasing scores indicate worse functioning with 0 indicating no functional impairment and 3 indicating complete impairment. It is easy to complete, time to complete is 5-6 minute and time to score is 2 minute, it can be self administrated or complete by interviewer (27). In patients with RA, the predominant determinants of HAQ disability are disease activity, pain, and psychosocial factors. It has been shown to be the most important predictor of mortality, compared to other patient measures including radiographs, joint counts, and laboratory values (28). The HAQ has been shown to have high sensitivity, but is limited in the normal function range (5).

Enhanced Quality of life questionare -EUQol

By applying this tool to obtain an index that can be used in the evaluation of the health status of both clinically and economically. EUQol have five domains evaluation: portability, self care, current activities (work, study, household activities, and recreational activities), pain/discomfort, and anxiety/depression. Each domains evaluation has 3 levels (degree of impairment).

The possible combinations of the five dimensions with three levels of health status shows 243 (an individual who completes the questionnaire can be put in one of theses status).

Also, this tool has a "Visual range" with which the individual self appreciate his health. The scale has values between 0 and 100, 0 meaning very bad condition, and 100-perfect condition of health. This tool can be used concurrently with the SF 36, HAQ, etc. EUQoL questionnaire is easy to apply, self administrated, and it is necessary 2 minute to complete. It is useful in epidemiological studies, assessment of drug safety and psychometric properties have all necessary for an instrument rating (29,30,31,32).

Rheumatoid arthritis quality of life questionare -RAQol

RAQol-rheumatoid arthritis quality of life, is a specific tool for measuring the quality of life in patients with PR, assessing the quality of life and functional joint degree in performing daily activities. Includes 30 questions with *Yes* or *No* answers, converting the response not exceed 30 scores, which can be assimilated with reduced a quality of life. RAQol in clinical trials has been correlated with DAS and HAQ, being used mainly in clinical trial assessing efficacy of the drugs. Completing the questionnaire takes between 2-4 minutes, can be self-administrate, the validity and reliability of being good, but low sensitivity (23,29,32).

Conclusion

Correlation of indices characterizing the health of the population, with the complex factors of the environment, the degree of development of the health service and the effectiveness and efficiency of their work provide knowledge and correct interpretation of the health status of the patient with RA and establish the measure and solutions that should be adopted by the public health insurance system.

This expanded base of knowledge could help develop context-specific values to monitor changes in patient health and evaluate the level of severity of disease.

Quality of life becomes an important goal in patients with RA, which requires a comprehensive approach to implement health programs for screening, prevention, treatment and management, leading to lower direct and indirect costs.

REFERENCES:

Tugwell P, Idzerda L, Wells GA. Generic Quality-of-life assessment in rheumatoid arthritis. Am J Manag Care. 2007; 13:S224-S236

Dinesh K, Tsevat J. Health related Quality of life - an introductions Am J Manag Care. 2007; 13: S218-S223

Lempp H, Scott D, Kingsley G. The personal impact of rheumatoid arthritis on patients identity: a qulitative study. Chronic Illness 2006; 2 (2): 109-120

Chorus AMJ, Miedema HS, Boonem A, van der Linden SJ. Quality of life and work in patients with rheumatoid arthritis and ankylosing spondylitis of working age. Ann Rheum Dis 2003; 62:1178-1184

Maska L, Anderson J, Michaud K. Measure of functional status and quality of life in rheumatoid arthritis. Arthritis Care Res; 2011; 63 S11:S4-S13

Ware JE Jr, Dewey J. Health status and outcome assessment tools. Int Electronic J Health Education.2003; 3:138-148

http://publications.nice.org.uk/quality-standard-for-rheumatoid-arthritis

Iaquinta ML, Larabee JH. Phenomenological lived experience of patients with rheumatoid arthritis. J nurs Care Qual 2004; 19(3):280-289

Haroon N, Aggarval A, Lawerence A, Agarwal V, Misra R. Impact of rheumatoid arthritis on quality of life. Modern Rheumatology;17(4):290-295

Rheumatoid arthritis – Living with. www.Nhs.uk. Accesat mai 2014

Alaire S, Lavalley MP. Contemporary prevalence and incidence of work disability associated with rheumatoid arthritis in US, American College of Rheumatology, Arthritis & Rheumatism.2008:59; 4,

Fontaine K. Arthritis and Health related quality of life. John Hopkins Artrhitis Center. http://www.hopkinsarthritis.org/updates 2011, accesat mai 2014

Ionescu R. Esentialul in reumatologie, (Balanescu Andra, Cap. Poliartrita reumatoida), ed. Medicala Amaltea,2006:214-251

Guillemin F. Functional disability and quality-of-life assessment in clinical practice. Rheumatology 2000:39 S1:17-23

Hochberg MC, Chang RW, Dwosh I, Lindsey S, Pincus T, Wolfe F. The American College of Rheumatology 1991 revised criteria for the classification of global functional status in rheumatoid arthritis. Arthritis and Rheumatism 1992;36(5):498-502

Kvien TK. Epidemiology and Burden of Illness of Rheumatoid Arthritis, Pharmacoeconomics 2004; 22 S1: 1-12

Pincus T., Callahn LF. Severe functional declines, work disability and increased mortality, in rheumatoid arthritis patients Arthritis and Rheumatism1984:27(8),:864-872

Smith KV, Avis NE, Assmann SF. Distinguishing between quality of life and health status in quality of life research: a metaanalysis Qual Life Res, 1999;8(5):447-459

Pollard L,Choy EH, Scott DL. The consequences of rheumatoid arthritis: Quality of life measures in the individual patient. Clin Exp Rheumatol 2005; 23 (39:S43-S52

Harrison MJ, Davies LM, Bansback NJ, Ingram M, Anis AH, Symmons DP. The validity and responsive of generic utility measure in rheumatoid arthritis: a review Rheumatol 2008;35(4):592-602

Burckhardt C, Anderson K. The quality of life scale (QOLS): reability, validity and utilization Health and Quality of life outcomes 2003;1:60

Proceedings of the OMERACT 7 International Consensus Conference on Outcome Measures in Rheumatology Clinical Trials; 8 – 12 May 2004; Asilomar, California, USA. J Rheumatol 2005, 32(12):2447–95.

Boers M, Brooks P, Strand V, Tugwell P: The OMERACT Filter for outcome measures in rheumatology. J Rheumatol 1998; 25: 198–199.

Saag K: OMERACT 6 brings new perspectives to rheumatology measurement research. J Rheumatol 2003; 30: 639–641

Bruce B, Fries JF. The Stanford Health Assessment Questionnaire: dimensions and practical applications. Health Qual Life Outcomes 2003;1:20

Fries JF, et al. The Arthritis, Rheumatism, and Aging Medical Information System. Aramis: HAQ. URL: http://aramis.stanford.edu/ HAQ.html.

Wolfe F, Michaud K, Pincus T. Development and validation of the health assessment questionnaire II: a revised version of the health assessment questionnaire. Arthritis Rheum 2004; 50:3296–3305.

Wolfe F, Michaud K, Gefeller O, Choi HK. Predicting mortality in patients with rheumatoid arthritis. Arthritis Rheum 2003; 48:1530–42.

Linde L, Sorensen J, Ostergaard M, Horslev-Petersen K, Hetland ML.Health-related quality of life: validity, reliability, and responsiveness of SF-36, 15D, EQ-5D (corrected) RAQoL, and HAQ in patients with rheumatoid arthritis. J Rheumatol 2008; 35:1528–37

Petrou S,Hockley C. An investigational into empirical validity of EQ-5D and SF-36 based on hypotethetical preference in a general population. Health Econ 2005;14(11):1169-1189

Salafi F, Carotti M, Ciapetti A, Gasparini S, Grassi W. A compararison of utility measurement using EQ-5D and SF-36 preference-based generic instruments in patients with rheumatoid arthritis Clin Exp Rheumatol 2011;29(4):661-671

Lillegraven S, Kvien TK. Measuring disability and quality of life in estabilished rheumatoid arthritis Best Pract Res Clin Rheumatol 2007;21(5):827-840