Comment on "The burden and quality of life of caregivers of sickle cell anemia patients taking hydroxyurea versus those not taking hydroxyurea"

José Carlos Souza[1]
Jucimara Zacarias M. Silveira[2]

[1] Universidade Católica Dom Bosco – UCDB, Campo Grande, MS, Brazil
[2] Universidade Anhanguera – Uniderp, Campo Grande, MS, Brazil

The article "The burden and quality of life of caregivers of sickle cell anemia patients taking hydroxyurea versus those not taking hydroxyurea"(1) presents the results of a cross-sectional study using two assessment instruments: the World Health Organization Quality of Life Assessment Bref (WHOQOL-Bref) - used to evaluate the general quality of life – and the Caregiver Burden Scale (CB Scale) – used to evaluate the overload of work - of 37 caregivers of patients with sickle cell anemia taking hydroxyurea versus those not taking the medication.

This is an important study because of the following aspect: the analyzed individuals are caregivers of patients with a chronic disease and the study aims to evaluate how these people perceive their own quality of life as caregivers and the effects of the workload on their lives.

Another important factor in this study is the instrument used. The WHOQOL-Bref is an abbreviated version of the Quality of Life-100 questionnaire consisting of a generic set of questions; this instrument has a good psychometric capacity and as the structure used is similar in several different cultures, it is a transcultural instrument. With the use of this instrument it is possible to achieve the most consistent and complete measurement of the quality of life using domains that analyze physical and psychological aspects, social relationships and environmental factors. The CB Scale is appropriate in this study because it subjectively measures the impact of caring for people with chronic diseases.

Another aspect is that this study is the first in the population of Mato Grosso do Sul, Brazil. It is important to encourage studies that analyze local realities as caregivers are part of a specific cultural context and because cultural adaptation of evaluation instruments generates more reliable data. Although the samples were studied utilizing caregivers of patients with sickle cell anemia, the instruments can be used for caregivers of patients of many types of chronic disease. The use of the term 'quality of life' is very common today, whether in the setting of the everyday life, in institutions that create public policies or in the scientific media. That is also influenced by the fact that in recent years there has been an increase in discussion and research in fields including health, work, ethnicity and spirituality.

The term quality of life is subjective and covers a wide area; it can be evaluated objectively and subjectively improving our knowledge and providing new intervention techniques, affecting the life style of the population in general.

After World War II the United Nations (UN) was concerned about the living conditions of member states and recommended studies on variables that affect the life of their citizens(2). Accordingly, the WHO invested much on this issue and that is why we have access to tools that analyze the quality of life. With the advances in medicine, the search for the cure of diseases and the control of symptoms as well as the increase of life expectancy in a cultural context, it became necessary to evaluate how individuals will live these extra years and how the concept of quality of life would be affected in this scenario. Thus the importance of quality of life related to health increased in the 1970s(3). This research thus highlights how this concept is not only related to the length of life but how caregivers of a diseased patient perceive their own quality of life.

The WHO defines quality of life in a more generic way:

> "[...] the perception of the individual of his own position in life, in the cultural and value systems in which he lives related to his own objectives, expectations, standards and concerns. It is a long ranging concept affected in a complex way by physical health, psychological state, level of independence, personal relationships with others, and their own environment"(4).

Based on this definition it is possible to say that the term 'quality of life' refers to how the individual perceives the intrinsic aspects of his life. Such aspects include: affection, family and social relations, and the environment(5). It is a subjective concept related to cultural, social and environmental contexts(4). It is a greater vision with a probable contribution to sociological studies, without considering dysfunction or injury(6).

Conflict-of-interest disclosure:
The authors declare no competing financial interest

Submitted: 6/12/2012
Accepted: 6/13/2012

Corresponding author:
José Carlos Souza
Universidade Católica Dom Bosco - UCDB
Avenida Tamandaré, 6000 Jardim Seminário
79117-900 Campo Grande, MS, Brazil
Phone: 55 67 3312 3605
josecarlossouza@uol.com.br

www.rbhh.org or www.scielo.br/rbhh

DOI: 10.5581/1516-8484.20120064

For the WHOQOL Group, the study on the quality of life is based on three aspects. Subjectivity considers the individual's own perception(4) about his health condition and the non-medical aspects of his life(6).

The multidimensional aspect of the quality of life covers multiple domains in an individual's life(4); it evaluates all the aspects that compose a person's life(6) and it is vital to consider them all when evaluating the quality of life. Another aspect is bipolarity – the presence of positive and negative conditions, such as pain and mobility(4).

In this study the sample size was small, however the results show that most caregivers are women, mulattos and mothers and are not paid for their work. The study shows that there is a great cultural presence in caregiving, highlighting that women predominate in this activity and that in many cases these people abandon their own professions to take care of others.

According to the quality of life and work overload, it is observed that there is a greater burden on the caregivers of sickle cell anemia patients who do not take hydroxyurea. If quality of life can be understood as the individual's own perception of his life, his welfare, and life conditions related to several aspects and his own experiences, there is probably a significant correlation between quality of life and work overload; according to this study, individuals dedicate an average of 16.08 ± 9.88 years to care for a sick person with 89.2% of the people interviewed stating that care is provided for 24 hours per day with long periods of exposure to stressful factors (exhaustion or negative feelings, anxieties, frequent trips to hospitals and doctor's offices for consultations and exams) which compromises the perception of well-being, satisfaction and conditions of life.

References

1. da Silva LB, Ivo ML, de Souza AS, Pontes ER, Pinto AM, Araujo OM**.** The burden and quality of life of caregivers of sickle cell anemia patients taking hydroxyurea versus those not taking hydroxyurea. Rev Bras Hematol Hemoter. 2012;34(4):270-4.
2. Oliveira JA, Oliveira NL. Qualidade de vida: evolução do conceito. In: Souza JC. Qualidade de vida e saúde. São Paulo: Vetor; 2011. p. 11-35.
3. Fleck MP. Problemas conceituais em qualidade de vida. In: Fleck MP. A avaliação de qualidade de vida: guia para profissionais de saúde. Porto Alegre: Artmed; 2008. p. 19-28.
4. The World Health Organization Quality of Life Assessment (WHOQOL): Position paper from the World Health Organization. Soc Sci Med. 1995;41(10):1403-9.
5. Minayo MC, Hartz ZM, Buss PM. Qualidade de vida e saúde: um debate necessário. Ciênc Saúde Coletiva. 2000 [cited 2012 June 6];5(1):7-18. Available from: http://www.scielo.br/pdf/csc/v5n1/7075.pdf
6. Seidl EM, Zannon CM. Qualidade de vida e saúde: aspectos conceituais e metodológicos. Cad Saúde Pública. 2004 [cited 2012 June 6];20(2):580-8. Available from: http://www.scielo.br/pdf/csp/v20n2/27.pdf

xxx