



# QUALITY OF LIFE FOR PATIENTS WITH HEMOPHILIA

Gülbahar KESKİN, PhD

Meral MADENOĞLU KIVANÇ, PhD

Istanbul University Faculty of Health Science, İstanbul/Türkiye  
E-mail: [gulbaharkeskin@hotmail.com](mailto:gulbaharkeskin@hotmail.com), [mmkvanc@yahoo.com](mailto:mmkvanc@yahoo.com)



Hemophilia is an important chronic blood disease which emerges at birth and lasts for life, causing frequent bleedings in muscles and joints. Permanent joint impairments occur in children and young people with hemophilia who do not receive sufficient treatment, thus leading to an increase in the population of people with disabilities within the society. In recent years, due to the rapid improvements in the hemophilia care in our country and with the laws legislated, the quality of life and living for patients with hemophilia is upgraded.

Being a life threatening and permanently disabling disease previously, hemophilia is no longer a chronic disease since the early 1970s (1,2). With the use of clotting factor concentrates (CFC) both for primary and secondary prophylaxis and for cure, the life expectancies of the patients with hemophilia have prolonged from under the ages of 30s to above the ages of 60s (1,3).

The way individuals perceive the environment they are living in determines their expectations of life. The level of the expectations met either facilitates or obstructs individuals' adaptations to life. The individuals who succeed in this adaptation process state that they might have an opportunity to maintain a quality of life, even in harder conditions (1,3).

Health related quality of life is a component of the general quality of life, which might be influenced by the health condition defined by the person and the clinical procedures. ICF mentions the components of health or the interaction between the concepts, rather than the causal relationship (2). ICF describes disability involving environmental and personal factors using a biopsychosocial approach (6). These factors are also very important for the patients with hemophilia. The United States Federal Environmental Protection Agency (USEPA) describes the concept of quality of life as "improvement of the qualities of the environment people are living in and the state of well being individuals and groups are in" (7,8).

The state of well-being of a person has two components (1,2). The first component is the capability of performing the daily activities which represent the physical, spiritual and social state of well-being. The second component is the fulfillment of the patient due to the body functioning and the level of control of the hemophilia (9,10). The state of well being is related to the perception of the disease and the functional effects of the treatments by the patients with hemophilia (3).

In 1980, the limitations and the inabilities are published by the World Health Organization (WHO) as the International Classification of Impairment, Disability and Handicap (ICIDH). According to this, impairment reflects the area of the defected organ, disability reflects the area of the personal quality of life and handicap reflects the work and social area (4,5).

Patients' expectations from quality of life is the holistic and subjective perception of the good and fulfilling aspect of life and means that the gap between the expectations of the patient and the things he/she can reach should be as small as possible. Expressing the fulfillment of the person due to his/her life and a general state referred as personal well being as a whole is important. The patient's perception of his/her position in life is also important in terms of the perspective of both the cultural structure and the system of values the person has, and one's own goals, expectations, standards and concerns (11, 12).

As a result, hemophilia patients' life quality related with oral and general health is in worse conditions compared with general population. In order to eliminate the dilemma in the field of health, we should facilitate the hemophiliacs' lives by serving the health care in a multidisciplinary view.

## Resources

1. United State Environmental Protection Agency. <http://www.epa.gov>, Date of access 10.01. 2012.
2. Avcı Pala, K. Uludağ University School of Medicine doctors working and expert evaluation of the quality of life. Uludağ University School of Medicine 2004; 30 (2): 81-85.
3. Aydemir, O. Consultation-liaison psychiatry measurement of quality of life: Short Form-36. 3 P Journal 1999;14-22.
4. Bottomley, A. The Cancer Patient and Quality of Life, The Oncologist 2002; 7:120-125.
5. Mccall S. "Quality of Life", Social Indicators Research 1975; 2: 229-248.
6. Özmete. Emine / Ankara University Faculty of Health Sciences Department of Social Services, Date of access 25.12.2011
7. Osterfeld E. Aristotle on the good life and quality of life. In: Nordenfelt L (ed.), Concepts and Measurement of Quality of Life in Health Care, Amsterdam, Kluwer, 1994; 19-34.
8. Gerharz EW and Emberton M. Quality of life research in urology. World J Urol 1999; 17: 191-192.
9. Muezzinoğlu, T. Yaşam kalitesi. Üroonkoloji Derneği Celal Bayar Üniversitesi Tıp Fakültesi, Üroloji Anabilim Dalı, Manisa (2004)
10. Uluslararası Sosyal Araştırmalar Dergisi The Journal of International Social Research Volume 3 / 11 Spring 2010
11. World Health Organization. Measuring quality of life: the development of the World Health Organization Quality of Life Instrument (whoqol). Geneva: WHO, 1993.
12. Zülfikar B, Hemofili. Türkiye Klinikleri J Pediatr Sci, 2005;1(3):53-68.

