Quality of life

The term “quality of life” was first introduced in 1920 by Pigou, in a book about economics and welfare. In this book, he introduced the concept of governmental support for the lower class, and discussed its impact on their lives as well as on public finance. This concept surfaced more strongly after 1948 as consequence of the acceptance of the World Health Organization’s definition of health that included physical, emotional and social well-being:

Health is a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity. (WHO, 1948)

Over the past ten years, the burden of disease on the individual patient as well as on the community as a whole gained a greater level of attention. Health-related quality of life (HRQoL) surveys have been extensively used in the assessment of a disease’s impact on the patient’s perception of health status (HS) (i.e. well-being) or in the evaluation of a drug’s ability to restore it. Increasing attention has been dedicated during the last quarter of a century to health status measures.

The use of HRQoL tools in headache disorders had a late development, compared to their early application (in the 1980s) in the care of patients with diseases posing a high risk of death. Despite public attention to the prevalence of headache disorders, there has not been an immediate parallel implementation of HRQoL measurement tools, nor has there been a noticeable follow-up of such studies in daily medical practice. A large number of studies of triptans focused on the benefits of pharmacotherapy on HRQoL, but the use of different methodologies failed to create a real body of evidence on that issue. Overall, it may be due to the increase in HRQoL tools that have become available also throughout the recent dramatic increase of scientific headache information on the Web. However we observed a boosting attention of research plans to a global, holistic approach to headache patient. This trend has produced a progressive increase in the number of scientific papers on “Headache and QoL”, from 1 in 1990 to 32 in 2000.

The main Web dedicated to this emerging area of clinical medicine can be divided in three sections:

General outcomes

The World Health Organization (WHO) recently reformulated the International Classification of Functioning, Disability and Health (ICF), presented at http://www3.who.int/icf/icftemplate.cfm. At this address the reader can also order online the newest ICF book or the ICF pocket book and the multilingual CD-ROM. Five different languages are available.

Healthy People 2010 (http://web.health.gov/healthypeople/) is a set of health objectives to be achieved in the USA during the first decade of this century. This is a general program that has established broad health goals and that serves as a basis for the development of local and community plans, including headache.

The National Center for Chronic Disease Prevention and Health Promotion (CDC) (http://www.cdc.gov/nccdphp/hrqol/methods.htm) furnishes an online approach to disability problems using its own HRQoL methods and measures.

HRQoL assessment tools

The Researcher’s Guide to the Choice of Instruments for Quality of Life Assessment in Medicine (http://www.qmed.org/url.htm) provides links to the main organizations and research groups involved in HRQoL. It is also possible to browse a list of Web sites dedicated to the related methodology. The available instruments in measuring HRQoL are reported, including the most popular surveys for headache, such as the headache impact test (HIT) and the migraine disability assessment (MIDAS).

Utilities on HRQoL surveys applied to diseases (including headache disorders) can be reached at www.qmetric.com and www.amlhealthy.com. These sites describe the majority of the surveys on HRQoL, including, SF36, SF12, SF8, HIT and MIDAS (the total number of available surveys is now more than 200). This resource can help the physician to be updated on the use of these health outcomes.

Online scientific journals

Quality of Life Research (http://www.wkap.nl/journalhome.htm/0962-9343) is a leading journal in this area of medicine, and the official journal of the International Society for Quality of Life Research (ISOQOL) (http://www.isoqol.org/main.html). The journal, published by Kluwer Academic, has hosted several studies on QoL in headache disorders.

Qualitative Health Research (http://www.ualberta.ca/~qhr/review.htm), a journal published by Sage, is an additional resource that covers the description and analysis of the illness experience.

Recently, Springer-Verlag has begun publishing a new journal in the area of medicine bridging social and clinical prevention and care. The European Journal of Health Economics (HEPAC) is available at http://www.link.springer.de/link/service/journals/10198/index.htm.

There is a need for new instruments for disease-specific QoL assessment, in particular for headache disorders. The complexity of construction, validation, translation and adaptation, the possible differences among respondents (clinicians, patients, relatives, care givers), and the type of questionnaire (e.g. interview, self-assessment, telephone, mail or email query) make further studies necessary. This is the direction to build new tailored surveys for headache, such as the recent disability-adjusted life years (DALYs) questionnaire.

The ultimate goal of this new approach to disease evaluation and management is to help in building broad coalitions between medical societies and patient associations, to accomplish for them the WHO definition of health.