Epilepsy (continued)

INSTRUMENTS

England

Development of Outcome Measures in an Ambulatory Care Setting

By Keith A. Meadows, Centre For Health Services Research, University of Newcastle, UK.

There is a growing need for the evaluation of effective health care in an ambulatory care setting (general practice and hospital outpatients). To meet this need, a package of outcome measures covering the clinical, functional, psychosocial and domains is currently being developed by the Ambulatory Care Programme at the Centre for Health Services Research, University of Newcastle upon Tyne.

The aim of the Outcome Measures in Ambulatory Care (OMAC) study is to develop condition-specific, patient self-completion measures of outcome for use in the management of diabetes and asthma. Applications would include evaluation of specific interventions or changes in the process of routine care, as well as aiding doctor-patient communication and identifying problem areas for individual patients.

Background research to the project commenced with a Delphi survey of general practitioners to identify priority areas for the development of outcome measures. Results from this study showed that high priority should be given to outcome measures for asthma and diabetes.

As a result of the Delphi survey, discussions with clinicians and patients, and a review of existing measures, relevant areas or domains for the assessment of outcome were identified for inclusion in the OMAC measures. These included control and complications of the disease, activities of daily living, social functioning and psychological well-being.

In developing the OMAC measures, we have taken as our base a number of existing generic and disease specific health status/outcome measures. These are the Functional Limitations Profile (FLP), the Medical Outcomes Study Questionnaire and the St George’s Respiratory Questionnaire.

Seven hundred diabetic and 600 asthmatic patients drawn from both hospital outpatient clinics and general practices have completed combinations of these measures. In addition, information was obtained on comorbidity and severity of illness, symptom frequency, as well as other clinical parameters including disease control and complications.

Currently, analysis is being carried out on these data to examine and evaluate the structure and psychometric properties of the measures. In addition, a conceptual and methodological framework has been developed (based on the work of The Health Care Research Unit, London and the Ambulatory Care Programme at the Centre for Health Services Research, University of Newcastle upon Tyne).

The potential use of the OMAC measures will be evaluated in terms of their validity, reliability, responsiveness and utility. This work will focus on examining how different levels of health status as measured by the OMAC measures relate to clinical factors including disease severity, symptom frequency and disease control. The results from this phase of research are likely to result in further refinement of the OMAC measures before they become generally available for use in early 1994.

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Footnote: This article is an abbreviated version of an essay for which the authors were awarded the Parke-Davis Non-medical Essay Prize (Australia, 1992).

WORK IN PROGRESS

Portugal

Assessment of Functional Status of Asthmatic Children and Adolescents

By Pedro Lopes Ferreira, Ph.D., School of Economics, University of Coimbra, Portugal

The purpose of this study was to assess the functional status and quality of life of children and adolescents visiting the Allergy Department of the Coimbra Pediatric Hospital, the only pediatric hospital of the central region of Portugal. This department is the second largest ambulatory department of this hospital.

The main objectives of this research, funded in part by the EC Biomed Programme, were:

1. To determine the impact of a chronic disease such as asthma on young patients’ relations with their family, friends, and colleagues, at home or at school; 2. To compare parents’ and patients’ evaluations of well-being and QOL; 3. To study the utility and acceptability of the tools used to assess patients’ functional status.

The questionnaire used to assess functional status in this pilot test was the Portuguese version of the Dartmouth COOP System for Assessing Function of Adolescents and Children1, initially designed by the Dartmouth COOP Project, Hanover, NH, USA, and translated and adapted by us.

Various authors have pointed out that using questionnaires with asthmatic children is a difficult task. For that reason, the patients’ physicians and parents played the role of special observers in this research. The parents of 114 children of less than 7 years of age, and of 140 children between 7 and 12 years of age, were asked to fill in the functional status questionnaire. Additionally, the physicians of the 140 children between 7 and 12 years of age were asked to administer the questionnaire to the children. Finally, 58 adolescents were asked to fill in the questionnaire on their own.

The clinical data, including indicators of asthma severity and the type of therapeutic prescribed, were also collected from the questionnaires with a precise input from the physicians.

Statistical analyses are now being performed. Physicians, nurses and social workers are polled about the utility and accessibility of the instruments used. In the future, we plan to assess the patients’ subjective experiences of asthma systematically, and to design other studies to evaluate the burden of this disease both in families and in school.


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Hungary

Measuring Quality of Life of Cancer Patients - Results and Plans

By Peter Csöpe, M.D., Institute of Social Medicine, Semmelweis University of Medicine, Budapest, Hungary.

The very first Hungarian article on quality of life study of cancer patients was published just recently. The QOL of 118 breast cancer patients during adjuvant chemotherapy was measured in a county hospital in 1990 using the Functional Living Index Cancer (FLIC) developed by Schipper. The main objective of this study was to explore the feasibility and impact of the inclusion of QOL assessment into the day-to-day clinical care of breast cancer patients management considering Hungarian characteristics. Our first experiences were favorable: the patients collaborated in filling in the questionnaire with great pleasure, the response rate was almost 100 %. They appreciated our interest in their psychosocial condition. We measured relatively high scores in physical and social functions and low ones in somatic well-being and psychosocial function. The patients considerably trusted the efficacy of treatment. Therefore we can emphasize the important role of communication between doctors and patients.

We are planning a longitudinal QOL study in different groups of cancer patients, e.g. breast, ovary and lymphoma. The instruments of this study will include the Rotterdam Symptom Checklist, the Psychosocial Adjustment to Illness Self Report (PAS-SR) and the ECOG Performance Status2. We will also register the patients’ medical status (tumor size) and the patients’ subjective experiences of medical illness. Psychological Medical 1993;4:635-647.

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