

QUALITY OF LIFE
(oral presentations)

THE USE OF CONCEPT MAPPING TO EXPLORE THE QUALITY OF LIFE CONCEPT OF THE CHRONICALLY MENTALLY ILL BOTTOM-UP. W.A. Boevink, J.R.L.M. Wolf, Ch. van Nieuwenhuizen, A.H. Schene, The Netherlands Institute of Mental Health, P.O. Box 5103, 3502 JC Utrecht, The Netherlands.

The Netherlands Institute of Mental Health, in cooperation with the Department of Psychiatry of the University of Amsterdam, has used the method of concept mapping to explore the concept of 'quality of life' with regard to chronically mentally ill patients bottom-up. Concept mapping is a structured method which offers the participants in the mental health care system, i.e. patients, significant others and professionals, the opportunity to specify their ideas about what constitutes the quality of life of chronically mentally ill patients.

In the presentation we will outline the concept mapping procedure. Furthermore, the results of the concept mapping activities are presented. On the basis of 79 statements a concept of quality of life is constructed, containing nine domains and four dimensions. These components are put in order of relevance. The perspectives of the patients, the family and professionals are being compared. Finally, the results will be related to the current state of the art in the quality of life research.

QUALITY OF LIFE MEASUREMENT.

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A research group at the Institute for Social Medicine made an independent evaluation of the first two years of community mental health service in Copenhagen. It was studied whether treatment in Community mental health centres could influence quality of life in a group of long-term users of psychiatric services. The study was a part of the Copenhagen Community Psychiatric Project (CCPP).

Quality of Life Scale, developed by Anton Aggernæs, were used to measure quality of life. The scale consists of 12 questions covering four areas of life:

1. Elementary biological needs (sleep, food, sex, health, physical fitness).
2. Need for warm contact with others (frequency of seeing people, spending a cosy time with somebody or confiding in somebody)
3. Need for variation in daily life (exciting experiences or important events during the last year, something to look forward to)
4. Need for meaningful activities (helping somebody or doing something necessary or important in one's own estimation)

The validity of the scale was analyzed using loglineat test for itembias.

Results will be presented.

ASSESSMENT OF QUALITY OF LIFE OF THE CHRONICALLY MENTALLY ILL: A COMPARISON BETWEEN CAREGIVERS AND THEIR PATIENTS. Chijs van Nieuwenhuizen & Aart Schene, Dept. of Psychiatry, Academic Medical Centre, Tafelbergweg 25, 1105 BC Amsterdam, The Netherlands.

Introduction

Quality of life is a popular concept in current-day research. The concept first appeared in the 1950s, was introduced into general medicine in the 1960s, and has recently gained much attention in the field of psychiatry. There has been a rapid growth in the number of studies in which quality of life (QOL) has been one of the outcome measures, in the last four or five years. The focus on QOL in psychiatry is primarily directed to that group of patients with long-term and disabling disorders. During the last two decades, the focus of assessment has gradually changed from the measurement of distinct and in themselves complex concepts such as psychopathology, social functioning, social support, and social networks to a comprehensive measure as QOL. What has emerged is a tremendous increase in the development of QOL scales in psychiatric research. Although the prospect of measuring the QOL of the severe and chronically mentally ill is an attractive one, research has shown that patients may disagree on the issue of QOL with their caregivers. The aims of this study, therefore, is to evaluate whether there is a discrepancy between the experienced QOL of caregivers and their patients.

Method

In order to evaluate any discrepancies, a selection of subjective questions of the Lancashire Quality of Life Profile (LQOLP) was made. The LQOLP assesses 9 domains of quality of life: work and education, leisure and participation, religion, finances, living situation, legal and safety, family relations, social relations, and health. Twenty patients were interviewed with the LQOLP, and 20 caregivers filled in the Lancashire Quality of Life Profile-Caregivers version (LQOLP-C) for these patients.

Results

The results from a comparison between the LQOLP-C and the original LQOLP will be presented and the most salient differences will be discussed.

THE DEVELOPMENT OF THE WORLD HEALTH
ORGANIZATION QUALITY OF LIFE INSTRUMENT:
THE WHOQOL

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The World Health Organization (WHO) is developing an international Quality of Life assessment instrument: the WHOQOL. It will allow an enquiry into the perception of individuals of their own position in life, in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns.

The WHOQOL is to measure quality of life related to health and health care. It is being developed in the framework of a collaborative project, involving numerous centres in different countries. In addition, it will have proven psychometric properties of validity, reliability and responsiveness to change, and will be sensitive to the cultural setting in which it is applied (while maintaining comparability of scores across cultural settings).

The methodology for the international development of the instrument will be outlined (domains, facets, questions, response scales, modules) and some translation issues will be stressed.

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THE USE OF QUALITY OF LIFE MEASURES IN THE EVALUATION OF 'NEW LOOK' COMMUNITY MENTAL HEALTH SERVICES. Joseph P.J. Oliver, Department of Psychiatry, University of Manchester, Oxford Road, Manchester M13, UK.

Members of the University of Manchester, with colleagues in local and regional government have been involved in the development, implementation and evaluation of 'new look' community services, designed to meet the needs of community care in a post-institutional era. This paper reports on the results of nine years of research and development into one form of new social care service for the long-term mentally ill. The new services, called community mental health support teams (CMHSTs), are designed to meet individual needs by providing a variety of domiciliary, day, respite and other support services with the objective of enabling individuals to remain living in their own homes wherever this is possible. Within the county of Lancashire, England, a sustained effort by local government managers, politicians and professionals has seen the number of these teams gradually increase to the present level of 13, with each team supporting between 10 and 40 clients. The **Lancashire Quality of Life Profile**, developed by the speaker, has been employed to monitor and evaluate these new services since their inception. This presentation describes the structure and function of these teams, the diagnosis of their client group and provides a comparison between CMHST clients and those supported by other forms of social care. A detailed longitudinal analysis of changes in quality of life for a substantial number of individuals highlights the relationship between service intent and outcome. Lessons are drawn from this experience concerning the use of these outcome measures in routine service evaluation.

DIFFERENCES IN QUALITY OF LIFE BETWEEN
SCHIZOPHRENIC LONGSTAY AND OUT-PATIENTS. Wolfgang
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One of the (unexpected and indirect) consequences of German unification and that of the before divided city of Berlin is the closure of 1.500 psychiatric hospital beds within the next years. The 'Berlin Deinstitutionalization Study' (Cooperation of Nervenlinik Spandau and Department of Social Psychiatry) examines and evaluates the process of discharge of longstay patients and their referring to community care in three districts of (former: West-) Berlin. One of the measures of the study is the 'Berliner Lebensqualitätenprofil', which is a German version of J.P.J. Oliver's 'Lancashire Quality of Life Profile' (translated and modified by S. Priebe and C. Hoffmann). Results of the baseline examination of the longstay patients are compared to an examination of chronic schizophrenic outpatients, who are treated by the outpatient-clinic of the same state hospital and who have been discharged 5 years or more before. The characteristics of the quality of life of chronic longstay schizophrenics in (since the reform of West-German psychiatry in the seventies and eighties) modernized psychiatric hospitals and in a type of community care, which was till now only partly confronted with these patients are discussed.

A PILOT STUDY ON QUALITY OF LIFE IN PSYCHOTIC PATIENTS. Marek Jarema and Anna Jakubiak.
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Evaluation of Quality of Life in psychotic patients is gaining importance among psychiatrists. Not anymore solely the decrease of psychotic symptoms is an indication of clinical improvement. It has to be accompanied by the improvement of many various factors, among them "Health" plays an important role. Other factors, such as "Family life", "Work", "Recreation", "Finance" and other should be considered as important as physical and mental health. There are different ways how this problem can be approached. We tried to evaluate the Quality of Life in our patients who were under pharmacological treatment because of various psychoses. As there is no tradition in evaluation of QoL in our country, we adapted the standard tools, such as SF-36 to our needs in order to have the instrument comparable to this used elsewhere. Patients filled-in the questionnaire before the start of the therapy and after four weeks of treatment. The psychotic symptomatology was evaluated with the use of standardized rating scales. All patients gave their informed consent to participate in the study. In this pilot study we present and discuss first results of our research project and we try to evaluate the usefulness of the instrument used. Some theoretical as well as practical considerations are made. The need for further studies and the utility of QoL evaluation in everyday practice are discussed.

Measuring Social Functioning by Self-Report: the Development of the Groningen Questionnaire about Social Behaviour (GQSB)

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Quality of Life of psychiatric patients pertains to the consequences of their illness in daily life. Social disabilities are part of these consequences. Over the last three decades the interest in their assessment has substantially increased in psychiatric and epidemiologic research. The development of the Groningen Social Disabilities Schedule (GSDS; Wiersma et al., 1990), an interview schedule to assess disabilities in social role functioning, can be considered as a result of this interest.

The subject of this paper, the development of the Groningen Questionnaire about Social Behaviour (GQSB; de Jong and van der Lubbe, 1993), can be seen as the next step in this line of activities and seemed necessary for two reasons. Firstly, the application of an interview schedule like the GSDS requires much time and manpower. Secondly, the interview cannot readily be used as a diagnostic tool since it was primarily developed as an instrument for research.

Both the GQSB and the GSDS were included in a study aiming at establishing the reliability and validity of the GQSB as an instrument to assess disabilities in social role functioning. Data on 200 psychiatric out-patients (age 18-65) were collected.

The average time to complete the questionnaire was 23 minutes. This means a reduction of more than 40 minutes, in comparison with the interview. Furthermore, nearly all patients were able to complete the questionnaire without any assistance, except for two of them who were not able to read because of bad eye-sight.

The results show satisfying reliabilities (Cronbach alpha, ranging from .73 to .89) for all subscales of the GQSB. The associations between sociodemographic variables and the interview schedule could be replicated with the questionnaire. The overall concurrent validity of the GQSB is sufficient (most correlations with the interview > .60). The disabilities recognized with the GSDS are to the same extent found again with the GQSB.

This study shows that the GQSB can be considered as a useful, reliable and valid self-report questionnaire to assess social disabilities of psychiatric patient.

**QUALITY OF LIFE
(poster presentations)**

ASSESSING QUALITY OF LIFE IN SMI PATIENTS
SUBJECT TO INTENSIVE CASE MANAGEMENT.

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The Department of Health in the UK has funded a multicentre trial of intensive case management for severely ill patients in the community. The trial is based at Manchester and at two sites in London. Each site aims to recruit 100 patients to both the intensive case management or control service. St George's has established a parallel and very similar study of 200 patients and will collect the same core data set with a view to possible meta-analysis.

At present we are exploring the choice of a suitable measure of quality of life. The Lancashire Quality of Life Scale has been selected for the study. We have begun admitting patients and will report early impressions of its applicability to this group.

QUALITY OF LIFE IN CANCER PATIENTS DURING
RADIOTHERAPY. Alina Jarema* and Marek Jarema#. *Department of Radiotherapy, Medical Academy
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Psychological situation of cancer patients is difficult. This is caused not only by physical sufferance but also by the uncertainty about the possibilities of cure and the threat for life. Thus this delicate situation of such patients should be the subject of careful evaluation. The more information about their psychological and physical state we will be able to collect the better will be the understanding of our patients. This was the aim of the study was to present our preliminary results. We tried to collect the data which would regard not only patients physical conditions but data which would allow to explore patients' situation in their environment, how they are able to cope with everyday life and to what extend they are able to experience the satisfactor which life brings. We used the Quality of Life questionnaire SF-36, which was the subject of translation and linguistic validation into Polish, to evaluate the QoL in cancer patients before and during radiotherapy. We try to compare our first results with the clinical evaluation of radiotherapy effectiveness. We believe that this comparisor will be helpful for further studies on QoL in cancer patients.

QUALITY OF LIFE MEASURES IN LONG-TERM MENTALLY ILL GROUP HOME RESIDENTS. METHODOLOGICAL CONSIDERATIONS. Thomas Middelboe, Dept. of Psychiatry, Community Mental Health Centre, Bispebjerg Hospital, DK-2400 Copenhagen NV, Denmark.

In a combined prospective and cross-sectional study of long-term mentally ill living in group homes, quality of life (QL) was measured along with psychopathology, social functioning, satisfaction with services as well as various demographic measures. Three measures of QL were applied: A) A semistructured interview developed in Denmark, based on general subjective QL and need-specified QL. B) A 22-item self-report scale measuring health-related QL status. C) A 16-item self-report scale measuring changes in health-related QL during past ½-1 year.

The following methodological and psychometric issues were regarded as crucial: 1) The concurrent validity between a need-specified QL-interview and the health-related, life-domain oriented self-report scales. 2) The predictive validity of QL status in relation to measures of community tenure, psychopathology and satisfaction with services. 3) The ability of these instruments to reflect changes in the respondents QL. 4) The agreement between residents, relatives and case-managers concerning change in QL, assessed by instrument C.

The instruments and preliminary results will be presented, and methodological problems discussed.

THE QUALITY OF PSYCHIATRIC CARE AS ONE OF THE ASPECTS OF MENTALLY ILL PATIENTS' QUALITY OF LIFE. Tatiana A. Solokhina and Ella Rectick, Mental Health Care Dept., National Mental Health Research Center, Moscow, Russia

The improvement of psychiatric care quality is the present-day task for our country. Financing of the service and patterns of diagnostic and treatment connected with it play an important role among various factors, influencing quality of care. It is necessary to note that the psychiatric hospitals in our country never had a satisfactory financing and never provided patients with medical care they needed. Based on fixed budget system of financing of the mental health facilities did not provide improvement of quality and efficiency of medical care. The transition to financing psychiatric hospitals per a treated patient that has taken place in a new socio-economic situation enables to relate the volume of financing with the volume of provided services. We have developed our own version of the diagnosis-related groups (DRG) for the more adequate financing in terms of this system. It is important to note that in USA DRG were created for the stabilization and restriction of the hospital charges, in some other countries it is used for planning or forecasting of charges. In our country the application of DRG promotes the increasing of the psychiatric hospitals financing due to the corresponding to every group medical standards of diagnostic and treatment, based on patients' needs in medical aid. During the DRG creation we have also studied the influence of some personal, clinical and socio-demographic factors on length and cost of hospital stay in mental health hospitals. Based on these results the system of 28 DRGs, differed in clinical diagnosis, the most important psychopathological syndrome and age was developed. The mathematical analysis has shown that the inclusion of mentioned factors in DRG system increases the accuracy of individual prediction of length and cost of hospital stay. In several DRGs the prediction can be carried out to 34% accurately, that exceeds the similar parameters of foreign DRG-versions. As it has been marked for each DRG the standards of treatment, diagnostic procedures and time parameters have been developed. These standards and length of the hospital stay can be used as the criteria of quality of medical care, its completeness and adequateness. All the parameters entering the discussed DRG-version reflect the level of care in the urban psychiatric hospitals.

MEASURING QUALITY OF LIFE IN PEOPLE WITH PSYCHOSIS

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Quality of life has emerged as an important outcome measure in attempts to evaluate the provision of mental health services. This paper will present data on quality of life from the ongoing PRISM study of psychotic patients. This study has used case identification techniques within a defined geographical area of 38,538 population in an inner city area of London to identify all patients with a psychotic disorder. A random sample of these patients are being interviewed for a long term follow-up study and the Lancashire Quality of Life Profile¹ has provided information on leisure, finances, religion, living situation, legal and safety issues, family relations, social relations, physical health, self esteem and general wellbeing. Results will be presented on 150 patients particularly examining the relationships between diagnosis and severity of psychopathology, and quality of life scores. The implications of findings for the use of such measures in this group of patients will be discussed.

J.P.J. OLIVER (1991) The Social Care Directive: Development of a Quality of Life Profile for use in Community Services for the Mentally Ill. *Social Work & Social Sciences Review* 3 (1)pp.5-54.