

FAMILY OR CAREGIVER BURDEN
(oral presentations)

ASSESSING FAMILY BURDEN 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 family burden. We are particularly concerned to draw on suggestions that caring for an ill relative can have some positive aspects for family members. We will present the scale which we have chosen and discuss its merits and drawbacks.

DEVELOPING SENSITIVE CHANGE MEASURES OF SUBJECTIVE WELL-BEING: 'QUALITY OF LIFE', 'FAMILY/CAREGIVER BURDEN' AND 'SATISFACTION WITH SERVICES'

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The evaluation of mental health services is a problem of both target and design. Assuming that we chose to implement a clinical trial to assess the effectiveness of mental health services, we are confronted with some fundamental methodological problems. What is the expected experimental effect and how many subjects do we have to enroll into the study, to be sure to have enough power to conduct the study validly? Considering the actual experimental effect in chronic mental health assessment instruments, we can easily demonstrate that we need a large number of subjects, especially when our target is to compare two presumably effective settings. To enroll such a large number of subjects we need time, time which makes it very difficult to keep the compared settings standard. The multi-center solution used in pharmacological research is of little use due to the logistics involved in protocolizing and replicating psycho-social interventions over settings. We will propose a multi-stage sampling strategy to develop solutions for this problem related to the number of subjects (Pomerantz, 1994).

Another problem is related to development of sensitive change measures to assess the target of the mental health setting. Of course, the first objective is clinical effectiveness. In the field of chronic psychiatry, where repeated interventions have not resulted in much change over long periods of time, the expected experimental effect is very low. This is not the case for related effect measures of subjective experience, such as the Quality of Life of the patient, the absence of burden in family members and caregivers, and the satisfaction with the services.

At the IPSER institute and the Department of Social Psychiatry we have developed the Experience Sampling Method (ESM), a random time sampling strategy, aimed at the collection of mental state information. We will demonstrate how the prospective collection of samples of subjective experience in the natural environment of subjects, yields reliable and sensitive assessments of the subject's well-being and is a promising instrument for the simultaneous generation of different subjective parameters that can be used in mental health service evaluation: 'Quality of Life', 'Family and Caregiver Burden' and 'Satisfaction with Services'.

UNDERSTANDING CAREGIVING FOR RELATIVES WITH SERIOUS MENTAL ILLNESS: A MEASURE OF THE EXPERIENCE AND ITS RELATIONSHIP TO COPING AND MORBIDITY.

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Background: The aim of this study was to develop a practical, comprehensive, and valid self-report measure of the experience of caring for a relative with a serious mental illness. Caregiving was conceptualised within a 'stress-appraisal-coping' framework.

Method: A final 66-item version of the Experience of Caregiving Inventory (ECI) was derived from analyses of responses from 626 caregivers, and then tested on an independent sample of 63 relatives of patients with schizophrenia recently discharged from acute care. The relationships between the ECI and a range of demographic and illness-related factors were examined, as well as caregivers' 'mastery', social support, positive and negative affect, life events, and coping style. The extent to which the ECI scales predicted psychiatric and physical morbidity was examined.

Results: The ECI produced 10 sub-scales with good internal consistency, 8 negative (difficult behaviours; negative symptoms; stigma; problems with services; effects on the family; need to backup; dependency; loss) and two positive (positive personal experiences; good aspects of the relationship with the patient). A consistent pattern of relationships with the other variables was evident. Coping style accounted for most of the explained variance of the ECI, with small contributions from other variables. Although the ECI could predict substantial variance in GHQ scores, most of this was accounted for by coping style.

Conclusions: The ECI taps important aspects of caregiving which are distinct from, but are linked with, coping and psychological morbidity. It could prove a useful outcome measure for interventions aimed at reducing caregiver 'burden'.

THE NORWEGIAN FAMILY IMPACT QUESTIONNAIRE. Tom Sørensen and Olav Grunnvold. Department group of psychiatry. University of Oslo. Psychiatric Dept. A, Ullevål hospital, 0407 Oslo, Norway. And psychiatric outpatient clinic, Lofoten hospital.

NFIQ is a self-completing questionnaire. It is constructed of seven sections in addition to two general questions about burden of care. Section 1 asks about strain (no -...terrible strain) in different life domains. In section 2 there are sentences describing feelings pertaining to different aspects of the relation to the patient (Yes, agree... no disagree). Section 3 covers areas where the family has to help the patient (Never .. always). Section 4 asks about need for different treatment modalities. Section 5 inquire about the satisfaction with the respect and understanding patients are met with by different treatment agencies (Extr. sat. extr. dissat.). In section 6 there are statements about different elements of psychiatric services (Yes, agree ... no, disagree). Section 7 asks about satisfaction with help and support regarding the patients social functioning (Extr, sat. extr. dissat.). The development of - and first experiences with the instrument are presented.

LIVING WITH THE MENTALLY ILL. Eija Stengård* and Raimo K. R. Salokangas**, *Dept. of Public Health, University of Tampere, Box 607, SF-33101 Tampere, Finland; **Dept. of Psychiatry, University of Turku, 20520 Turku, Finland.

The number of psychiatric hospital beds has decreased very sharply in Finland as well as in many other western countries. This has placed an increasing burden on the relatives of discharged patients. The purpose of the present study is to describe how the patient's mental illness affects his family members and what kind of positive resources the relatives use in coping with the problems of everyday life. Three voluntary association for relatives of mentally ill participated in the study. A questionnaire was mailed to all members and 249 (67 %) of them were returned. In addition, 104 of those who returned their questionnaire were interviewed by three trained interviewers. The members resembled the members of other western family organisations like NAMI and Ypsilon. Most of the members were parents (58 %) or spouses (14 %) with mean age of 54.6 years. Half of the patients (53 %) were males with mean age of 38 years. At the time of the study, half of the relatives experienced constant worrying about the patient. One-quarter to one-fifth reported also problems in their leisure, economy and work. 60 % of the relatives felt that patient's mentally illness had also affected their social relationships. On the other hand, relatives also felt that the mental illness of a family member had changed their values for better direction and that relationships with close people had become more important to them. The interviewed relatives found religion, their personal characteristics and close relationships the most helpful positive resources in coping with difficult situations. The relatives wanted to give two advice for other people living in similar situations: 1) take care of yourself and 2) get help from mental health professionals in crisis situations. Although the relatives were quite satisfied with the psychiatric care, they complained about being deprived of information and advice. The relatives wanted more information about the patient's psychiatric illness, its treatment and more counselling how to handle difficult crisis situations at home. This study implicates that the relatives need more help and support from the psychiatric services in order to cope with the difficulties of every day life.

THE INVOLVEMENT EVALUATION QUESTIONNAIRE;
PSYCHOMETRICS OF AN INSTRUMENT TO MEASURE
CAREGIVER BURDEN. Aart H. Schene and Bob van Wijngaarden.
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The Involvement Evaluation Questionnaire is a questionnaire for the measurement of the consequences of severe mental illness for family members or caregivers. Its item content is based on a thorough review of the literature and on already existing instruments. The first edition (1986) was used to study the family impact of day hospitalization versus inpatient hospitalization. Using data from three other samples, it was subsequently revised to survey a large organization of relatives of patients with psychotic disorders (N=680).

This 77 item instrument takes about 30 minutes to administer, and may be used as a self administered or mail questionnaire. In this paper we show some psychometric properties. Factor analysis identified four factors: tension, supervision, worrying and urging. The instrument also includes a distress scale, and a separate section about children.

With the data of the study among relatives we further investigated the concept 'caregiver burden'. Results with regard to the relationship between patient and caregiver characteristics on the one hand and burden factors and distress on the other will be shown.

We further studied caregiving models. Here we considered the burden factors as direct results of caregiving, and distress as a consequence. Pathanalysis showed a relationship between distress and patient/caregiver characteristics. However, the fraction of the variance of distress that could be explained was largely determined by the height of the burdenscores and less by the direct influence of patient/caregiver characteristics.

FAMILY BURDEN IN COMMUNITY PSYCHIATRY. Fiona M. Keogh & Ian Daly,
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A pilot comprehensive community psychiatric service was established in West Dublin, in 1989 with the aim of reducing hospital stay and providing alternatives to hospital admission. An evaluation of this service commenced in 1990 examining five main outcomes: clinical, family burden, patient & family satisfaction, family doctor satisfaction and economic outcome. A two-groups repeated measures design was used, comparing the pilot service to a neighbouring standard community psychiatric service. The catchment areas of the two services have very similar socio-demographic structure and use the same in-patient facility.

Because concerns are often expressed that community care places more burden on families particular attention was paid to the assessment of family burden. 145 relatives were interviewed twice at 18-month intervals using the Social Behaviour Assessment Schedule (SBAS). The SBAS was found to be a useful tool for assessing family burden. Reliability coefficients (alpha) for the subjective burden scales were .73 for the patient behaviour subscale and .78 for the patient social performance subscale. Alpha was .67 for the objective burden subscale.

The results of the evaluation showed that although burden was reduced in both services only the comprehensive service achieved a significant reduction in burden due to patient behaviour ($p = .03$). The comprehensive service also showed a significant reduction in burden due to social performance but only for the relatives of new patients ($p = .03$). Neither service achieved a significant reduction in objective burden. Examination of diagnostic subgroups showed, as expected, considerable levels of burden reported by relatives of those with schizophrenia. Interestingly relatives of those with an affective disorder also reported considerable burden. However, the affective disorder group showed much greater improvement on all burden scores over 18 months.

Possible modifications to the SBAS and the results of the evaluation will be discussed in this paper.