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## Familieleden onder druk. Ontwikkeling en psychometrische beoordeling van het Interview voor de Belasting van de Familie (IBF)

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**Summary**  
**Families under pressure**  
**The development and psychometric evaluation of the**  
**Interview for the Burden on the Family (IBF)**

Since the fifties researchers have studied the 'Burden of mental illness on the family' in very different ways. Brown (1967, p. 53) described it as follows: "The impact of living with a patient on the way of life and health of family members".

Platt (1985, p. 383) defined it as: "The presence of problems, difficulties or adverse events which affect the life (lives) of the psychiatric patients' significant other(s), e.g. members of the household and/or the family". Gubman and Tessler (1987, p. 226) wrote: "The term family burden is used colloquially to characterize the load, carrying capacity, and strain experienced by family members as individuals and as members of a social system".

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The interest in the burden on the family was stimulated by the new mental health movement in the US and in Europe, that of deinstitutionalization. The aim of that movement was returning longstay patients to the community and substituting inpatient care with community care. As a consequence more families had to provide care for the patient, a task for which families were not always equipped. In the course of time, the question arose whether families were at all able to cope with such a situation.

The Substitution Project in the province of Drenthe was a randomised clinical trial in which the feasibility of daytreatment as an alternative to inpatient care was evaluated (Kluiter, e.a., 1992; Wiersma, e.a. 1995). One of the questions addressed was whether daytreatment would burden families more than ordinary inpatient care did. At that time, no suitable interview schedule was available to measure the burden of having a mentally ill member in the family. Therefore, the prototype of the 'Interview for the Burden on the Family' (IBF) was constructed. The IBF is a semistructured interview. Experience with the IBF in the Substitution Project Drenthe was positive, but the psychometric properties of the IBF had to be examined. The aim of the present study was to develop the IBF further and to evaluate its psychometric and practical qualities.

In **chapter two** the literature about the 'Burden on the family' up to 1995 is reviewed. The influence of different kinds of treatment, demographic variables, illness variables, social support and of role expectations on the burden on the family is described. The tentative conclusion of the review is that there is no reason to believe that the alternatives for inpatient care burden the family more than ordinary inpatient care. For example, there are even indications that the transfer of tasks is less in the case of daytreatment: Patients in daytreatment retain (part of) their household tasks, while hospitalised patients do not. In other respects, the burden in case of inpatient care is equal to that with daytreatment.

Certain aspects of the illness of the patient are related to burden. Especially symptom behaviour proves to be an important predictor of subjective burden: More symptom behaviour increases the subjective burden and the distress as it is reported by family members.

The differential effects of the kind of psychiatric illness on burden need further examination. Up to the present, studies compared a few syndromes only, with small numbers of subjects. Because of this the differential effects remain unclear.

The relationship between burden and the duration of illness has been addressed in both cross-sectional and follow-up studies, the latter up to four years. The cross-sectional studies are inconclusive about the effect of the duration of illness. The follow-up studies, however, indicate that family members of schizophrenic patients experience greater burden with the passage of time, especially when the patient has had an episode of illness lasting two years or more.

Sex and age of the patient nor the sex of the family member appear to have any relation to burden. The age of the parent of the patient makes a difference: In cross-sectional studies older parents seem to be less burdened than younger parents, although in one study it was found that older parents were burdened differently but not less than younger parents.

The effect of the relationship with the patient on the burden is confounded by the nature of the illness. For example, parents are more often respondent for patients with schizophrenia, and partners more often for patients with a depression. Because of this, it is difficult to know whether differences in burden are attributable to the nature of the relationship or the nature of the illness. The same can be said of the nature of the relationship and the living arrangement: Those who don't live with the patient often are more distantly related to the patient than those who live with the patient.

Social support appears to be a buffer against negative life events. This also happens with the burden on the family: Social support tailored to the needs of the family has a beneficial influence, i.e. less burden and less distress. There is also evidence that feelings of 'mastery' and 'adequate' coping strategies of the family influence the burden in a positive way. The influence of role expectations on burden has not been thoroughly examined. There is evidence that if expectations are not met partners experience more distress.

So far conclusions are difficult. This can be attributed to confounding of variables, to heterogenous groups of patients and respondents, to questions of design and operationalisation and the many instruments used to measure the burden. There clearly is a lack of a generally accepted valid and reliable instrument to measure the burden.

The use of the IBF in the Substitution Project in Drenthe was promising. In **chapter three** its further development and content are discussed. Some changes were made, based on common sense, advice of mental health professionals, reviews of the literature and the 'Stress-process model' of Lazarus & Folkman (1984). In the version of the IBF that was used in the present study sociodemographic information is gathered first, followed by information about the history of the illness, symptom behaviour and the burden on the family. The burden on the family is addressed in the following sections: inconvenience, efforts, task transferral, impairments in work or education, financial consequences, the atmosphere in the house, social life and leisure time, consequences for children, the relationship with the patient, worrying and overburdening. Information about social support (practical help and emotional support) and satisfaction with professional support is also gathered.

In **chapter four** the design of the study is described. It starts with a description of the family members (the respondents) and the patients involved. Family members of psychiatric patients were selected according to the following criteria:

- The patient has a DSM-III-R axis-I classification. Psychosocial problems, addiction to drugs or alcohol and a personality disorder is not the primary reason for treatment. Patients with Alzheimer disease are excluded from the study.
- The family member lives in the same house as the patient.
- The patient has recently started inpatient care, daytreatment or outpatient treatment.
- Family members are 18 years or older.

Several mental health institutions in Groningen and Drenthe participated in the study. The patients were asked for their permission to interview a family member and also which family member was to be interviewed. A total of 186 family members agreed to have an interview: 54% were men; 73% were partners, 23% were parents and 4% were a child or a sibling of the patient. The mean age was 44 years. The patients were mostly women (57%). The mean age was 38 years and 49% had a depression at the time they were admitted for treatment; the other half had a diversity of illnesses. During the first interview two periods were assessed. The first period concerned the week before the start of their inpatient or daytreatment (the index measurement); the second period covered the two weeks before the day of the interview (the short-term follow-up).

The results are described in **chapter five**. Interrater reliability was evaluated as follows: One hundred and thirteen interviews were also rated by two other assessors, in some cases from audio-tape, in others while attending the interview. Cohen's kappa (Cohen, 1960) was used to evaluate agreement between the raters for both the index measurement and the short-term follow-up. Where possible the 'Squared weighed kappa' was calculated. The algorithm is similar to the Intra Class Correlation coefficient (ICC), and can be interpreted as follows: (1-ICC) is the percentage of variance due to the disagreement among the raters (Bartko, 1976). Compared to the criteria reported and used by Kraaykamp (1991) agreement between raters was very good. For only two variables reliability was too low.

Where possible and relevant, items were combined to form subscales. Data about symptom behaviour of the patients were analysed by means of factor analysis. Four scales were formed: one in which all reliable (based on inter-rater agreement) items were represented (36 items), one for desorganized behaviour (15 items), one for depressed/anxious behaviour (5 items), and one for negative symptom behaviour (8 items). Other subscales were: emotional burden (19 items), efforts (13 items), partner problems (six items), and professional help (five items). Transfer of tasks (except those concerning the care of children) was added in the form of one scale. Some scales included two items. These were: 'negative changes in social life' and 'irritation and estrangement'. Cronbach's alpha was calculated if the scale had more than two items and if the measure made sense for both index measurement and short term follow-up. Cronbach's alpha was 'good' for the total behaviour scale, the scale for desorganised

behaviour, the emotional burden scale and the scale on professional help (Cronbach's alpha equal or greater than .80). Cronbach's alpha was acceptable for the scale on depressive/anxious behaviour, the scale on negative symptom behaviour, the efforts scale and the scale on partner problems (Cronbach's alpha ranged from .69 to .78).

Test-retest reliability was also assessed. Forty three respondents were interviewed within three weeks from the first interview. This measurement was taken as the retest measurement. To check for changes between the two short term follow-up and the retest measurement, the amount of symptom behaviour, the amount of contact and other changes in the situation of the family member and the patient were assessed. All in all, the situation of six respondents had not changed between the measurements, the other 37 respondents had experienced changes that could have influenced the burden. Because of these changes it was hard to assess test-retest reliability. The sections which represented more objective forms of burden, like the transfer of tasks, efforts made for the patients and quarrels in the household, were especially susceptible to perceived changes and had 'low' test-retest correlations. The emotional burden and the relationship between patient and family member were stable despite changes.

To assess sensitivity to change of the IBF, 99 respondents were interviewed again half a year later. This measurement was called the long-term follow-up. The assumption was that starting inpatient care and daypatient treatment would bring about a change in the condition of the patient and therefore in the burden on the family. The data from the index measurement were compared with the long term follow-up data by means of paired t-tests. Symptom behaviour as well as burden had significantly decreased, except for two burden variables: changes in the relationship with the patient since the problems began and the number of tasks transferred to the respondent. Further inspection of the data did show changes in the relationship for individual family members, but these changes leveled each other out for the group as a whole. Therefore, the mean score remained unchanged. The overall conclusion is that the IBF is sensitive to change.

Indications for construct validity were gathered in several ways. First, the internal structure of the IBF was evaluated through the correlations between variables measuring burden. The results showed that there were no excessively high correlations between variables of different domains of burden, therefore the overlap was limited. Furthermore, the relations between the variables were logical and in accordance with expectations. Because of the central role of the emotional burden in the IBF the

relationship between this scale and 10 other burden variables was inspected with linear regression analysis. The results show that ten burden variables explained 54% of the variance in emotional burden. This shows that there is a strong connection between the emotional burden and the other kinds of burden.

In the second part of the construct validation the relationship was examined between the burden on the one hand and several illness variables, sociodemographic variables and the social support on the other. Where possible hypotheses based on former burden research were tested, otherwise a first step was made towards further validation. Correlations and t-tests were used. The results were mostly in agreement with what was expected: The amount of symptom behaviour was positively related to both the practical, objective forms of burden, such as 'efforts' and 'task transfer' and the more subjective kinds of burden, such as the emotional burden and the atmosphere in the household. Sociodemographic variables like sex and age of the patient and age of the family members were not related in any way to the burden. The sex of the respondent, however, did make a difference: Women expressed more emotional burden and more problems in the relationship with the patients than men. These results are not in accordance with the results of other burden studies; but were in accordance with results of studies in which sex differences in emotion were examined and with the ratings of the sexes on the Hopkins Symptom Check List (HSCL, Derogatis e.a., 1974; Luteijn e.a., 1984), with which psychological and somatic wellbeing was measured: Compared with men, women rated higher on the HSCL too.

On basis of the literature it was expected that family members who needed social support would be more heavily burdened than family members who didn't express the need for any kind of support. The results of t-tests show that family members who needed practical help reported significantly more emotional and other 'subjective' kinds of burden as well as more practical, 'objective' kinds of burden than those who did not need any practical help. Family members who expressed the need for emotional support were more heavily burdened emotionally than family members who needed no emotional support.

Convergent validity was assessed by comparing the results of the IBF with those of several self reporting questionnaires. These questionnaires were filled out as soon as possible after the interview and sent back to us. The questionnaires were: the Dutch version of the HSCL, the SSL (Van Sonderen, 1993) and the BES (Schene & Van Wijngaarden, 1992). The HSCL measures psychological and physical wellbeing. The

SSL is an instrument with which social support is measured. The BES is a questionnaire developed to measure the burden on the family.

Ninety three per cent of the questionnaires were returned. The short term follow-up data of the IBF were correlated with comparable scales or items of the questionnaires. The HSCL total scale correlated  $r=.63$  ( $p<.001$ ) with the emotional burden scale in the IBF. This is quite good and supports the validity of the emotional burden scale. The correlations with the BES were between  $r=.33$  and  $r=.55$ , which is rather low for items with similar content. The correlations with the SSL were even lower:  $r=.28$  and  $r=.41$  for the need of practical help and emotional support. This means that the interview and the questionnaires lead to different results. Because there are several explanations for this result and there is no golden standard, it is hard to say anything about the convergent validity of the instruments used.

The content and face validity were a matter of concern in the developmental stage of the instrument. These kinds of validity were assessed by asking family members their opinion about the interview. The questions were part of the questionnaires to be returned by mail. The results show that family members didn't miss topics of importance in the IBF, and in most cases they found the content of the interview good (92%).

According to the interviewers the interview schedule was quite easy to handle, and there were hardly any problems with the rating of the responses in the various categories. The respondents stated that the interview was not at all or only a bit tiring in 92% of cases. The interview took on average approximately one and a half hour, including sociodemographic information, the history of the illness, behaviour of the patient, the burden on the family, social support and satisfaction with the services. This was not too long or a bit too long for 97% of the family members.

In **chapter six** the burden on the family members is described. The burden was heaviest in the week before mental health professionals were called in. The burden had diminished markedly two months later, except for the number of tasks transferred which had actually increased. At that time, the patients were receiving some kind of treatment and spent less time at home. The financial consequences of the illness were quite large for the families involved: An average of Dfl. 4100 per household had been spent during the last year. Half a year later the treatment of the patients had ended or was less intense in most cases. Some patients, however, had been readmitted. The



overall burden had decreased, but nearly 75% of the families reported that their life had changed in a negative way since the psychiatric problems of the patient had begun.

Satisfaction with the support of family members was also discussed in chapter six. Family members were more satisfied with the help mental health professionals gave to the patient than with the support and attention given to themselves: One third of the family members were not very satisfied with the attention the mental health professionals had paid them. Half a year later one fifth of the familie members said that they were not satisfied.

In **chapter seven** it is concluded that the IBF is an instrument with which the burden on the family can be measured in a reliable and valid way. The instrument is sensitive to changes and quite easy to handle. Nevertheless, some notes concerning the study and some recommendations for further research are made. The chapter ends with a discussion of what can be done to reduce the burden on the families to a minimum.

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