Consequences for caregivers of patients with severe mental illness: the development of the involvement evaluation questionnaire
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Summary

Since the 1940s professionals and researchers have studied the effects of severe mental illness on the relatives or other caregivers of the patients. The first studies on these caregiver consequences, or family burden, were descriptive but from the 1970s on also epidemiological studies and randomised clinical trials were conducted, mainly in the United States and Great Britain. In The Netherlands it lasted until the mid 1980s until caregiver consequences became an issue. When in 1986 a study was prepared in which full-time psychiatric hospitalisation was compared with day treatment, one of the first Dutch experiments with partial hospitalisation in psychiatry, the researchers recognised the importance of assessing caregiver consequences. Although it was expected that day treatment, compared with full-time hospitalisation, would lead to better outcomes on social functioning, quality of life, and sense of mastery, there also were concerns about the fact that family members or other caregivers would have to continue caring for their ill relatives. Patients would spend their evenings and weekends at home, and the question was to what extent caregivers would experience consequences that could counteract the expected positive effects of partial hospitalisation. Since none of the instruments developed elsewhere were translated in Dutch, and also no original Dutch research instrument was available, it was decided to develop one. This thesis describes the development and psychometric testing of this instrument, the Involvement Evaluation Questionnaire (IEQ).

Developing instruments is a process of ongoing testing, adapting, and learning over the years. This process is reflected in the chapters of this thesis, that all but one are written as individual journal papers or book chapters. This means that besides a certain redundancy in information, results sometimes are presented in different ways. In the concluding chapter, however, all results are reviewed, and discussed in a uniform format.

Chapter 1 contains a concise outline of the changed roles of relatives and other caregivers in the treatment of severe mental illness. It describes the influence of deinstitutionalisation in psychiatry, the growing emancipation of caregivers, the emergence of family organisations in psychiatry, new visions on the roles caregivers play in relation to their relatives, and the need to study the caregiver consequences of psychiatric illnesses. Also a brief historical overview of the development of the IEQ is given, starting in 1987 with the construction of the first Dutch instrument to assess caregiver consequences, and ending in 2000 with the last adaptations on the final IEQ European Version.

Chapter 2 was written on request as a chapter in a book on international perspectives in family interventions in mental illness, edited by Harriet Lefley
and Dale Johnson. It contains the theoretical background of caregiver consequences that served as the foundation of the IEQ. The most important domains of caregiver consequences are discussed: (1) the patient's symptoms and symptomatic behaviour, (2) the caregiver's caring and coping, (3) family relations, (4) household routine and family functioning, (5) social relations and stigmatisation, (6) caregivers' leisure time and working career, (7) caregiver's and patient's financial situation, (8) children and siblings, (9) contacts with the mental health care system, and (10) caregiver's health. These domains can be subsumed in stress-coping-support-appraisal models, formulated to understand their mutual relationship. In these models a distinction is made between objective and subjective consequences, where objective consequences are considered as independent, and subjective consequences as dependent variables. The objective aspects comprise the caregiving tasks that are directly connected to the patient's symptoms, symptomatic behaviour, and social functioning. They cover those things that the caregiver has to do (help, supervision, etc.), or can not do any longer (hobbies, work) as a consequence of the caregiving task. The subjective consequences of caregiving refers to caregivers' short- and long-term reactions to the symptomatology and behavioural characteristics of the patient and the caregiving tasks resulting from it.

In the second half of this chapter the development of the IEQ, based on the stress-coping-support-appraisal model, is described. It is explained why it was chosen to develop an instrument that focuses mainly on the objective consequences of caregiving, and why the chosen domains and items were included. To describe the psychometric properties of the IEQ, the bulk of research on the instrument, conducted between 1986 and 2000, is summarised. This summary includes the studies done in samples of caregivers of patients with mixed psychiatric illness, schizophrenia or depression in The Netherlands, Great Britain, Denmark, Spain and Italy. The item content, the factor analysis based scale structure, the applicability, and the validity and reliability are discussed. Most analyses on the psychometric properties are described and discussed in more detail in the chapters to follow.

In Chapter 3 special emphasis is put on the reliability assessment of the IEQ. This was done in the EPSILON study that was conducted in five European sites (UK: London, Denmark: Copenhagen, Italy: Verona, Spain: Santander, and The Netherlands: Amsterdam), and that focused on the caregivers of mainly outpatients with an ICD-10 diagnosis of schizophrenia. This study was conducted to develop internationally standardised measures for multi-country research in schizophrenia. One of these measures was the IEQ, which for this purpose was translated in English, Danish, Spanish and Italian, following the World Health Organisation guidelines. Simultaneous Component Analysis showed very similar factors in all sites, indicating that the IEQ scales sufficiently cover caregiver consequences in all five countries. However, significant
differences in IEQ scores between sites were found. In Verona and Santander IEQ scores were generally higher.

The IEQ was administered twice with an interval of one to two weeks. Test sample sizes ranged from 30 to 90 across sites and retest sample sizes ranged from 21 to 77. The internal consistency of the IEQ was assessed with Cronbach’s alpha and the Standard Error of Measurement (SE_M). The test-retest reliability was assessed with Intraclass Correlation Coefficients (ICC) and SE_M.

Cronbach’s alphas ranged from 0.68 to 0.86 for the sub-scales and from 0.87 to 0.91 for the overall score. Alpha testing between sites showed differences on the sub-scale ‘urging’, Santander having lower scores than Amsterdam, London and Verona. The SE_M scores suggested that differences in alpha values between sites are caused as much by differences in sample variance as by differences in true reliability. The test-retest reliability values were high in Amsterdam, Copenhagen and London (ICC = 0.87-0.99). Although high enough, the Verona and Santander scores are significantly lower (ICC = 0.70-0.90). The SE_M values indicate that this lower reliability of the IEQ in Verona and Santander can be attributed, at least partly, to higher measurement error. Retest values were generally slightly lower than test values, indicating a certain test-retest effect. The absolute differences, however, were rather small, and were no higher in one site compared to another.

It was concluded that the internal consistencies and the test-retest reliability estimates of the IEQ scales were satisfactory. However, these estimates differed between sites. These differences could not be explained by sampling or test effects. There was no direct connection between the test-retest interval and reliability. The differences in IEQ scores between sites could also not be explained. The fact that in Verona and Santander the IEQ was administered regularly as an interview or completed under the supervision of a research assistant might yield a possible explanation. But also cultural influences could not be ruled out.

The possibility of cultural influences on the IEQ scores is further elaborated in Chapter 4. The central question in this chapter is whether social and cultural factors on caregiver consequences might lead to biased assessments. When differences in caregiver consequences between cultures or nations are found, these might be caused by: (1) ‘real’ differences; factors not accounted for cause more burden in one country than in another, such as mental health care provisions, (2) differences in sample characteristics; such as sex, or living conditions, (3) differences in how persons react to burden, due to differences in personality or personal strength, (4) cultural bias; cultures differ in how people appraise their caregiving, (5) instrument bias; the intercultural validity of the instrument is not sound, or (6) a combination of the above causes.
The study was conducted on the same EPSILON sample as was used in Chapter 3. In addition to the IEQ measures, socio-demographic characteristics, the Brief Psychiatric Rating Scale (BPRS-24) and the Global Assessment of Functioning Scale (GAF) were used.

To study sample differences the five sites were compared on: (1) patient characteristics, such as age, sex and education, psychiatric symptoms and disabilities; (2) caregiver characteristics, such as age, sex and net income, and (3) characteristics of patient-caregiver contact, such as number of days lived together and type of relationship. These sample characteristics were used in an analysis of covariance as covariates to calculate and test adjusted IEQ means scores.

Sample differences were found. These differences pertain to patient's age, ethnic minority, caregiver's coping, and living situation. Amsterdam and London have the largest percentages of minorities and in London the patients belong to a somewhat elder group with a longer psychiatric history. In Verona caregivers are less able to cope with the mental disease. The way patients live, splits the sites into two distinct groups. The north-European sites (London, Amsterdam and Copenhagen) where many patients live on their own, and where they have less contact with their caregivers, and the Mediterranean sites (Verona and Santander) where most patient live with their relatives and have more contact with their caregivers. Aside from these sample differences the sites also differed in some general socio-demographic characteristics, such as percentages married people, unemployment, single-parent families and residential psychiatric hospital places.

In order to correct for these differences in site, patient, caregiver and relational characteristics, adjusted IEQ scores were computed. This resulted in somewhat smaller differences, but the overall picture remains the same. In general the Verona and Santander scores were still higher than the Amsterdam and Copenhagen scores.

Although the five IEQ versions in this study cover the same caregiving domains, and measures were adjusted for sample characteristics, sites still differ on IEQ scores. This could be due to sample or site differences that were not measured, such as social support, coping, personality, public information on psychiatric diseases, and stigmatisation. Another explanation for differences between sites might be that there are real differences in caregiver consequences between the five sites, for instance in the quality of local mental health provisions. The third explanation might be cultural bias, as some cross-ethnic research has shown. As long as cultural bias can not be ruled out, nations are advised to compose their own national norm groups and use these as a local standard.
Caregiver consequences usually are studied in schizophrenia samples. Mood disorders do not attract much attention. However, the limited amount of studies on caregiver consequences in depression suggest that these can be serious. Since all studies had one or more methodological drawbacks we focus in Chapter 5 on the consequences for caregivers of patients with depression, assessed with the IEQ. The Dutch version of the IEQ has been validated in studies among caregivers of patients with schizophrenia and patients with mood disorders.

Research questions were: (1) what are the consequences for caregivers of sharing daily life with depressed patients?, (2) are these consequences related to diagnosis (major depression vs. dysthymia), illness phase, duration and severity of the illness, and patient or caregivers’ (socio)demographic characteristics?, and (3) are these consequences related to caregivers’ feelings of distress and to which extent do they lead to use of (mental) health care?

The study was conducted amongst caregivers of patients fulfilling the clinical DSM-IV criteria of major depressive disorder (single episode or recurrent), dysthymic disorder, or other depressive disorders. The total patient group comprised three sub-samples: (1) inpatients (N=20), patients recently admitted, (2) acute outpatients (N=110), patients who recently started outpatient care, and (3) non-acute outpatients (N=203), patients longer than 2 months in outpatient care.

In addition to the IEQ we used an abbreviated 15-item version of the Ways of Coping Checklist (WCC), the 20-item Dutch ISB social support questionnaire, and the Zung Selfrating Depression Scale (SDS). The IEQ and other instruments were send by mail to 333 caregivers. The response rate was 78% (N=260).

The non-acute outpatients scored lower on the Zung SDS sumscore and the inpatients had a shorter psychiatric history. The inpatients were oldest and acute outpatients were youngest. Caregivers of inpatients were on average oldest. The majority of caregivers (72.3%) was the partner of the patient, and in 85.3% of the cases caregiver and patient shared households. Caregivers of inpatients had less hours contact with the patient.

The IEQ scores showed that almost half of the caregivers had been worried about the patient’s general health and/or future at least regularly. In a quarter to one third of cases caregivers had to encourage patients to undertake an activity, felt burdened by the patient’s mental health problems, had been worried over their own future, about the patient receiving the proper treatment, or the patient’s safety, had to take over tasks normally done by the patient, or reported that the atmosphere between themselves and the patient had been strained.
Differences were found between the three samples. Caregivers of inpatients reported most consequences. The caregivers of the non-acute outpatient reported least consequences, with the exception of consequences for children under the age of 16. These children in general experienced most consequences, especially on sleeplessness, lesser play with friends, less attentiveness at school, and not attending school.

More than a third of all caregivers reported that they had got used to the patient's mental health problems and that they were able to cope with these problems. On the other hand, also a third reported that they were not used to these problems, and were not able to cope. About 80% of caregivers reported distress, on average 3.8 out of eight distress items. About a quarter of these caregivers received some kind of treatment and/or used prescribed medication for these complaints. Caregivers of inpatients sample reported most distress and most treatment. The caregivers of non-acute outpatients had the lowest scores.

Caregiver consequences in depression can be predicted by a set of four variables: coping, a changing relationship, social support, and acute depressive symptoms. More consequences will be reported when the relationship with the patient has changed over time, when the caregiver gets no support from other people, uses daydreaming as coping mechanism, feels not able to cope, and/or one has to care for an acute outpatient. Disruption of the (marital) relationship and family life, together with the acuteness of the depression, seem to be the key predictors of caregiver consequences.

In conclusion, our study has shown a frequent occurrence of caregiver consequences in depression, and distress in caregivers. In acute phases these levels of occurrence can be quite high, meaning that in clinical practice attention should be paid to caregivers of patients with florid symptoms. The effects in the long run, however, also should not be neglected. Especially the consequences on children's behaviours should be taken very seriously.

In Chapter 6 caregiver consequences in depression are compared with caregiver consequences in schizophrenia. The research questions are: (1) what are the differences in caregiver consequences between caregivers of patients suffering from depression and caregivers of patients with schizophrenia?, (2) is it possible to specify distinct groups of caregivers, based on their levels of caregiver consequences?, and (3) what are the clinical implications of the impact of caring for someone with depression?

The depression sample was the same as was used in Chapter 5. The schizophrenia sample originated from the EPSILON study. Since we have shown in Chapter 4 that the Northern and Southern European sites differed on IEQ scores, only the Northern European cases were included (N = 151).
For the comparison of both samples, item scores were dichotomised into ‘no consequence’ [never, sometimes] and ‘real consequence’ (regularly, often or always). Each IEQ sub-scale score was recoded into three categories: (1) no consequences, no real consequences were reported on this sub-scale, (2) few consequences, sub-scale score belongs to the lower 50% of all scores, and (3) many consequences, the sub-scale score belongs to the upper 50% of all scores. Sub-scale patterns were analysed with Homals, and the depression and schizophrenia patterns were compared.

Caregiver consequences in the depression and schizophrenia samples are quite similar. The caregivers in the schizophrenia sample worried more about the patient’s future and especially about his financial situation, and more often had to encourage the patient to get up in the morning, and encourage and help him to take proper care. On the other hand in the case of depression the caregivers more often experienced a strained atmosphere. Sub-scale scores show the same pattern. Caregivers of patients with schizophrenia had to urge more, caregivers of patients with depression experienced more tension.

The pattern analysis showed a wide variation in the number of consequences reported by caregivers. Some reported many real consequences, others none. This was true for caregivers in both samples. Distinct patterns were found. Having a ‘many consequences’ score on one sub-scale, implied a high probability on a ‘many consequences’ score on the other sub-scales. Based on this finding caregivers in both samples could be divided into three subgroups: (1) a low level subgroup, no consequences on at least three out of four sub-scales, (2) a medium level subgroup, few consequences on at least two sub-scales, and (3) a high level subgroup, many consequences on at least two sub-scales.

In the depression sample the caregivers in the high level subgroup more often are female, the patients more often are male, and almost all caregivers and patients live in the same household. Approximately 60% of the patients belong to the acute subgroup. They have most symptoms, and the shortest psychiatric history. The caregivers also report most distress, more often feel burdened, and more often state that their relationship with the patient has changed over time. They feel less supported by relatives and friends, and have more problems in coping with the situation. More than the other caregivers they use evasive coping strategies (like daydreaming and fantasising that all will be well in the future), or blame themselves for the illness of their loved one. They also report the highest additional expenses on behalf of the patients.

High level subgroup caregivers in the schizophrenia sample also more often live in the same household as the patient, and/or spend more time together. They also have to spend most extra money on behalf of the patients, and feel more distressed than the caregivers in the other subgroups. The BPRS scores
show that patients of caregivers in the high level subgroup have more symptoms.

In conclusion, caregiver consequences in depression are very similar to caregiver consequences in a comparable schizophrenia sample, not only on IEQ scores but also on score patterns. The study has shown that, according to their levels of caregiver consequences, caregivers of depressed patient also need attention from professionals. This is especially true for the high level subgroup, caregivers who have to cope with an acute patient who is their partner and who more recently has become ill. They not only experience most consequences, but they also feel most distressed, are less supported and are less able to cope adequately. Also the caregivers in other groups might benefit from support, especially since long-term effects can not be ruled out.

In Chapter 7 all available data on the psychometric properties of the IEQ are discussed in detail. The results from the studies that were presented in the other chapters of this thesis are completed with the findings published in all other papers and reports on the IEQ. Aside from the more classic assessment of reliability and validity, special attention has been given to the concept of sensibility. The evaluation of sensibility consists of five major topics: (1) purpose and framework; what is it supposed to measure, with what goal, why do we need it, is it applicable for the population it is intended for?; (2) content validity; are all important variables included, are all important domains covered, are there suitable and comprehensible scales?; (3) face validity, does it contain the topics one expects, is the instrument coherent, does it trigger the curiosity of the respondent, does it invite the respondent to co-operate?; (4) overt format is it comprehensible, is it replicable, does it have an adequate scope, does it have a logical pattern of ratings?; (5) ease of usage; is it appealing, not difficult, how long does it take to complete, are there any risks for respondents? All of these topics are discussed in this chapter and it was concluded that the IEQ can be considered as a highly sensible instrument. Its broad scope, its covering of most caregiver consequences domains, its ease of usage, its structured format, its importance in the eyes of caregivers, and its adequacy in research and clinical practice, makes it a very suitable instrument to assess caregiver consequences.

The construct validity of the IEQ could not be assessed properly because of the lack of a golden standard. However, in several studies evidence of construct validity was found, for instance in two studies where the IEQ was compared with other instruments that assess caregiver consequences, and studies in which caregiver consequences are found to be strongly related to various concepts of subjective consequences, such as caregiver's distress, burnout and appraisal. Also evidence for a satisfactory divergent and convergent validity were found in several studies in which IEQ could be predicted from mediating variables from the stress-coping-support-appraisal model. It was concluded
that a considerable number of research results indicate that the validity of the IEQ is quite satisfactory.

The reliability of the IEQ was tested in three ways: (1) the internal consistency of the sub-scales in all studied samples, (2) the test-retest reliability, and (3) the sensitivity to change. It was concluded that the reliability of the IEQ seems to be satisfactory to good. Internal consistencies of sub-scores in general are substantial, and the IEQ is sensitive to change. The results of test-retest validity assessments, however, were somewhat problematic, and therefore should be further investigated in the future.

Finally, the studies presented in this thesis have shown that the IEQ is applicable in many settings, because of its stable scale structure across patient samples, and across countries. Together with the high level of sensibility, the stability of the IEQ in different settings makes it an instrument that can be used in a large variety of situations where caregiving takes place. This high level of applicability has resulted in translations into nine languages (English, Danish, Italian, Spanish, Portuguese, German, French, Swedish and Finnish), and utilisation by researchers throughout Europe.

All in all, the IEQ has proven to have sound psychometric properties and good applicability.