Consequences for caregivers of patients with severe mental illness: the development of the involvement evaluation questionnaire
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Chapter 7

Conclusion and discussion:
The psychometric qualities and applicability of the IEQ summarised
Introduction

The aims of this thesis was to describe the development of the Involvement Evaluation Questionnaire (IEQ) and to assess its psychometric qualities and applicability. The IEQ was developed for measuring the consequences for caregivers of patients who suffer from severe mental illness. Our aim was to cover the most important domains of caregiving in psychiatry. In Chapter 2 these domains, such as the effects of patient’s symptoms, family relations, social relations, social support and coping, finances, and caregiver’s distress, were described. In an early phase it was decided to focus on what was called the ‘objective’ aspects of caregiving, in terms of tasks, costs, time consumption, and frequency. The ‘subjective’ consequences were covered by measuring caregiver distress, the (psychosomatic complaints of caregivers, such as being quickly tempered, headache, sleeplessness, and extreme tiredness.

Developing, testing and revising the Involvement Evaluation Questionnaire has been an ongoing activity in the last seventeen years. Between 1986 and 1997 several versions and revisions of the IEQ were made, to make it an instrument applicable for a broad spectrum of mental diseases and a large range of caregivers. The scope of the instrument has widened from only household members to anybody who is involved with someone who has a psychiatric illness, and from caregivers of patients with mixed psychiatric disorders, in particular psychosis (BOF), to caregivers of patients with major psychiatric illnesses, such as schizophrenia and mood disorders (the present version of the IEQ). In addition the potential research population became much larger by the translation of the IEQ into ten languages. To date almost all European countries have the possibility to apply the IEQ in their research programs and patient care.

The IEQ was tested in several studies. In the preceding chapters we focused on the studies on the validity and reliability assessments since 1997. A comparison with earlier work on the IEQ and its predecessor the BOF is hindered by the fact that besides changes in scope and applicability there also have been changes in sub-scale contents and in scoring rules. These changes were based on the results of psychometric tests, which resulted in changes in the kind and number of items in the IEQ, and widening the scope of the instrument (see Chapter 1). Because of these changes data of earlier IEQ versions can not fully be compared to data collected more recently. However, for the description of the development of the IEQ and the evaluation of the psychometric qualities, these data, and data from studies on the IEQ carried out by others (van den Berg, 1

1 The first version of the instrument was called the 'Burden on the Family Scale', but for reasons of uniformity all versions will be named IEQ in this chapter.
Evaluating the psychometric properties of the IEQ: sensibility, validity, reliability, and applicability

An essential element in scale development is the assessment of validity and reliability, of which validation assessment is the more difficult part. Validation can only occur within a system of hypothesised relations between the construct of interest and other constructs (Spector, 1992). In natural sciences instruments can be validated by comparing outcome with a golden standard (the standard meter stored in Paris), by comparing two constructs (Celsius versus Fahrenheit), or in predicting outcome (laboratory tests). The validity of instruments therefor refers to quantitative validity measures such as construct validity, concurrent validity, and predictive validity. However, in social sciences many constructs are theoretical abstractions, and therefor cannot directly be validated (Carmines & Zeller, 1979; Spector, 1992). There are no golden standards, outcome can not be predicted, and also concurrent validity is hard to established since constructs in social sciences are frequently not sharply defined. In social science the typical scale-validation strategy involves testing the scale against a set of hypothesised relations with other constructs. While the validity cannot be proven, as much as possible (circumstantial) evidence is collected to support or refute the validity of a construct. When a sufficient amount of data supporting validity is obtained, the instrument will be declared valid, at least for the time being (Spector, 1992).

In this accumulation process of collecting evidence the emphasis often still lies on quantitative techniques, such as factor analysis and correlational techniques. More qualitative theory-oriented strategies of validation are often considered problematic, or of less value (Carmines & Zeller, 1979). This position is challenged by others, for instance Feinstein (1987), who states that the qualitative attributes of an instrument, such as face validity, content validly, and common sense are of equal value or perhaps even more valuable in case of clinical instruments, because these attributes are the things that clinicians...
evaluate as ‘sensibility’. This sensibility, or ‘enlightened common sense’, is a mixture of ordinary common sense, added with clinical experience and clinical reality, and the applicability of an instrument. Feinstein (1989) therefore introduces a third category in the testing of the psychometric properties of an instrument, the sensibility of the instrument.

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?

To make instruments sensible they must be based in reality, and reflect this reality, they must be appealing to those who are the intended users, they must be build on already existing knowledge, they must have a clear goal. Maybe even before the first item of an instrument is formulated, and before the format and lay-out of the instrument are designed, the sensibility of the instrument must be made clear.

These qualitative aspects of the development of instruments have also been a major issue in the development of the IEQ. Therefore, aside from reliability and validity, it was decided to assess its sensibility. The evaluation of the IEQ will start with a description of the steps that were taken to make the instrument as sensible as possible. This description then will be followed by the evaluation of the validity and reliability of the IEQ.

The sensibility of the IEQ

**Purpose and framework**

In the mid-1980s in The Netherlands the first experiments with partial psychiatric hospitalisation, or day treatment, had started, and although it was expected that this would lead to better outcomes on social functioning, quality of life, and sense of mastery, compared to fully hospitalised patients (Schene et al., 1993), there also were worries about the consequences partial hospitalisation would have for those sharing a household with the patient. In comparison to full-time hospitalisation family members probably would have to continue caring for their ill relatives, and the question was to what extent these
caregiver consequences would adverse the expected positive effects of partial hospitalisation (Schene et al., 1993). In countries such as the United Kingdom and the United States, this issue of caregiver consequences had been recognised even before the start of deinstitutionalisation in the 1950s. Already in the mid-1940s terms like 'family burden' or 'disturbance caused by the patient' emerged, and Treudley (1946) was the first to state that in families where one of the members had a psychiatric disease only limited attention was given to the other family members who had to live with a mentally ill person (Treudley, 1946). In the 1950s the first descriptive studies on burden were carried out, and from the 1970s on also epidemiological studies and randomised clinical trials were conducted (Schene, 1986; Schene et al., 1998). For these studies research instruments had been developed, but none were available in Dutch.

The need for an instrument to assess the caregiver consequences in research projects on partial hospitalisation in The Netherlands led to the development of the IEQ. It was initially designed as a research instrument to be used in a 2x3 research design, that is to assess the consequences for caregivers of two groups of patients, either in full-time hospitalisation or in day treatment, and to assess these consequences over time. Assessment would be made at admission, at the end of treatment, and at a six-month follow-up (Schene, 1992). Therefor the instrument should be able to detect differences between study conditions, and detect changes over time. It was also decided to develop a self-administered questionnaire, short but covering the concept, with a limited time frame and sensitive to change.

The purpose of the IEQ has changed over time. In the first version the target group was caregivers who belonged to the household of the patient, a spouse, a parent, a sibling, or a child. In later versions the IEQ was made suitable for all those who were in one way or another involved with a patient. The minimum requirement in the latest version is that the full IEQ can be administered when caregiver and patient have had at least one hour per week personal or telephone contact.

The first version of the IEQ consisted of items that were derived from the at that time available literature on the consequences for carers. This literature was almost solely focused on caregivers of patients with psychoses. As a consequence this first version of the IEQ focused on psychosis, although it was used in a research project that included patients with a variety of diagnoses.

2 Throughout this thesis the term 'caregiver consequences' is used. This definition is preferred over 'burden on the family' because of the connotation that all consequences for caregivers by definition would be adverse. Although the IEQ also mainly assesses negative consequences, it is known that caring for a close one with a psychiatric illness can be rewarding (Szmukler, 1996).
such as schizophrenia, mood disorders, anxiety disorders, drug and alcohol related disorders, and eating disorders (Schene, 1992). In later versions items referring to other psychiatric diseases (especially depression and bipolar disorder) were added, making the IEQ applicable for caregivers of patients with a wide range of psychiatric disorders.

When the IEQ was designed, one of the aims was to be able to conduct factor analysis in order to obtain sub-scales. Therefore a five-point Likert response scale was chosen, to score the frequency with which an event happened, ranging from 'never' to 'always'. Mean sub-scale scores were used to correlate the IEQ with other instruments. In later years it became apparent that the use of mean scores had disadvantages. Mean sub-scale scores were difficult to interpret, and did not give any clinical insight in the details of the situation. A caregiver with a high score on one or two items and low scores on the other items could get the same average sub-scale score as a caregiver with moderate scores on all items. The need arose to use cut-off points and discriminate between 'real consequences' and 'no consequences' (see Chapter 6), or 'caseness' and 'non-caseness', a division often made in clinical practice (e.g. clinical diagnosis, survival analysis, decision rules). It was decided to define 'real consequences' as events that happened at least regularly. Sub-scale scores then could be interpreted as the number or percentage of real consequences.

To illustrate the differences between mean scores and dichotomised scores, Table 7.1 contains the scores of eight carers who all had exactly a mean score of 1.5 on the sub-scale urging (8 items). This means that their mean score was exactly in between the categories 'sometimes' and 'regular'.

Table 7.1  Score distribution on sub-scale urging (8 items) if mean IEQ scale scores are 1.5 (sometimes-regular)

<table>
<thead>
<tr>
<th>Number of real consequences</th>
<th>N</th>
<th>% Real consequences on sub-scale urging</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>1</td>
<td>25.0</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
<td>37.5</td>
</tr>
<tr>
<td>4</td>
<td>3</td>
<td>50.0</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>62.5</td>
</tr>
</tbody>
</table>

The number of real consequences ranges from two to five, or from 25.0 to 62.5% of the possible maximum score. This means that there can be large differences in caregiver consequences between carers who have exactly the same mean sub-scale scores. Considering the fact that if an event happens regular means that a caregiver’s life is clearly affected, the variety of
consequences was considered to be more important than a single event happening very often. For this reason, this way of scoring the IEQ was preferred over Likert scores. It gives a clearer view on the situation and can be used to assess meaningful changes from 'real consequences' to 'no consequences', for example as a result of clinical intervention.

As described in Chapter 2, a distinction is often made between objective and subjective aspects of caregiving. Objective aspects comprise caregiving tasks and consequences directly connected to the patient's symptoms, symptomatic behaviour, and social functioning. Subjective consequences of caregiving refer to caregivers' short- and long-term reactions to these caregiving tasks, and to the symptomatology and behaviour of the patient. The IEQ was developed to assess the more objective consequences of caregiving in terms of tasks, costs, time consumption, and frequency. This focus is reflected in the item wording and category scores that are used. All items start with 'How often ...', and the response categories are 'never - sometimes - regular - often - always'.

In summary, over the years the purpose and framework of the IEQ has changed from a research instrument for those living with a patient with schizophrenia, to a research and clinical instrument, applicable for all people involved with someone who has a serious mental disease. With respect to purpose and framework, the 1997 version of the IEQ can therefore be considered as a highly sensible instrument with a broad scope.

**Content validity**

The development of the IEQ was in 1986 preceded by an elaborate literature search in which all relevant domains and existing instruments were collected (Schene, 1986). Later, in 1990, an additional literature search, especially focusing on depression, was carried out. These searches were the source of the original item pool for the IEQ, which was extended with additional items emerging from interviews with professionals. Items for the IEQ were selected from the item pool in such a way that all relevant domains were covered. In three studies carried out in later years (Schene, Tessler & Gamache, 1994, 1996b, Schene et al., 2001), an overview of all burden instruments was given. These studies were not restricted to published papers, but researchers were personally contacted about their work in progress. Literature, personal contacts and databases of researcher's networks were used to identify family burden researchers. They received an 80-item Family Burden Researchers Questionnaire in which information was asked about the characteristics of the instrument, the way it was developed, the domains, the foundation on earlier instruments or theoretical frameworks, and psychometric properties (Schene, Tessler & Gamache, 1994). This study resulted in an overview of 21 instruments. The overview revealed that the IEQ indeed covered most domains, sixteen out of the twenty dimensions that were distinguished. Some of the items had to be
dropped during development to make the IEQ change-sensitive. Items that were dropped referred to more subjective consequences of caregiving, such as guilt, shame or stigma, to rather change-insensitive aspects of caregiving, such as network loss, or to events that only happen rarely, such as patient suicide attempts. As a consequence the dimensions shame, guilt and stigmatisation were not covered by the IEQ.

In the overview studies of Schene and colleagues (1994, 1996b, 2001) all present instruments also were evaluated on the theoretical foundations underlying their measures. Of the twenty instruments described in the latest overview (Schene et al., 2001), the IEQ appeared to be based most on earlier work in this field. It covered ten out of fourteen major studies conducted between 1958 and 1987. This means that of all instruments the IEQ was best embedded in the tradition of ‘family burden’ research.

During the ongoing development of the IEQ the item content and the coverage of domains were checked on several occasions. First, the draft versions of the IEQ have been reviewed by colleagues and missing items were added. Second, in a study on a large sample (N=680) of members of a Dutch organisation for relatives of patients with psychotic disorders, respondents were asked to make comments on the IEQ. Although almost three-quarters of them utilised the opportunity to write down their own special experiences, varying from a few words to eighteen typed sheets, only a few comments were on the instrument itself. In most cases comments concerned the time frame of the IEQ, the four weeks prior to the assessment. These relatives found it difficult to separate their life-time experiences from what happened in such a short period. Or they explained that at the moment times were better, but that there had been periods in which their caregiving tasks had been very difficult. None of the comments, however, indicated that domains of caregiving or items were missing, meaning that in the eyes of these respondents all relevant domains were covered (Schene & van Wijngaarden, 1993a).

A third check on content validity was done in 1992, when the IEQ was adapted for caregivers of patients with mood disorder. Sixteen caregivers of depressed patients who were in outpatient care at a university hospital were interviewed on the caregiver consequences they experienced. These interviews were carried out according to the format and items of the IEQ. After finishing the interview the caregivers were asked to evaluate the IEQ items, and to indicate what items or domains they felt were missing. The caregivers rated the items on tension, quarrels and disturbed behaviour to be very relevant, and also the items on worrying. Some of these last items had been added after the depression literature search, so this addition was considered to be meaningful. The coverage of the more objective consequences was not criticised, but the caregivers missed items referring to the subjective consequences of caregiving, such as grief, fear, loss of control, items intentionally not included in the IEQ.

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They also missed items on coping and social support, and the support they received from professionals (van den Berg, 1994), concepts that are considered to be associated with caregiver consequences (Birchwood & Cochrane, 1990, Perlick et al., 1999; Biegel et al., 1994). Because coping and support are different concepts than caregiver consequences, it was decided not to add items covering these concepts to the IEQ. Researchers were advised to use existing instruments. In one of our own studies an abbreviated version of the Ways of Coping Checklist (Folkman & Lazarus, 1980) and a Dutch social support questionnaire (Inventarisatielijst Sociale Betrokkenheid: van Dam-Baggen, Huiskes & Kraaimaat, 1986) were added to the IEQ.

The fourth content validity check was done in the EPSILON study, conducted in Great Britain, Denmark, The Netherlands, Italy, and Spain (Becker et al., 1999, 2000). The translation of the IEQ into the other languages followed the WHO-protocol by Sartorious & Kuyken (1994). The translation process described in this protocol has aimed at maintaining the semantic, the conceptual, and the technical equivalence between the source and target languages. Semantic equivalence refers to words with a similar meaning in both languages, conceptual equivalence refers to the need to get an identical meaning of concepts that may have different cultural understandings, and technical equivalence refers to the complexity of the language, the question length, and the level of abstraction. This means that translators have to be highly qualified. They need to have a good technical knowledge of both source as target language, a good knowledge of the emotional aspects of these languages, and a good knowledge of cultural differences related to concepts and terms used in the instrument (Knudsen et al., 2000).

The translation process, however accurate, will not necessarily guarantee that the concepts and constructs in the translated version are fully applicable. To check these concepts and constructs focus group interviews were carried out in five countries. The focus group interview is a highly structured group interview, in which a moderator discusses a set of previously formulated questions with a group of six to ten carefully selected participants. The moderator has to guarantee that all participants get the opportunity to give their opinion, and to facilitate effective group functioning. The interview takes about three hours and is audio- or videotaped. All issues discussed are presented in a focus group report (Knudsen et al., 2000).

The focus group interviews on the IEQ were conducted with representatives of patients, relatives, professionals, and researchers. Groups varied between seven to nine participants. The issues discussed were: (1) the overall impression of the quality of the translation, (2) missing domains or items in the instrument, (3) the applicability and relevance of domains or items, and (4) the translation, contents, comprehensibility, and categories of each individual item.
In general, the IEQ proved to cover all domains of caregiver consequences in all countries. In Italy it was suggested to add a domain on the help or support received from community psychiatric services, and an item on the effect of patient's illness on caregiver's life choices. In the United Kingdom no extra domains were needed, but the focus group would like to add some items. These were: (1) extending the items on the effects on children with items referring to siblings and other household members, (2) items on the effort put into encouraging the patient to be independent, (3) an item whether the carer had become the legal appointee of the patient, (4) an item on the need to check the house to prevent that medication is stock-piled, and (5) an extra caregiver's distress item on digestive problems. In Spain also no domains were missing, but the focus group would like to have more items on the need to encourage the patient, and an item on the possibility for the patient to get a job. In Denmark a social support domain was missing. Also some extra items were suggested: (1) whether the caregiver had to take sick leave in order to care, (2) extra caregiver's distress items on alcohol abuse, lack of concentration and anxiety, (3) an item on the caregiver's effort to get support, and items on the (lack of) collaboration between relatives an mental health institutes.

In the list of missing domains and items two topics were mentioned in more than one focus group: social support and caregiver's distress. Social support was not included, because the developers of the IEQ considered this not to be a caregiver consequences domain. Although support is an important mediator in the experience of caregiving, it should be assessed separately with a local validated instrument. The extra items desired on caregiver's distress were not added, since it was decided to incorporate the GHQ-12, a well-known and in many countries validated instrument. In all other cases it was decided not to add extra items, in some cases because these items were difficult to incorporate in one of the existing domains, in other cases because it would change the existing sub-scale structure. By not adding new items the international versions would have the same sub-scale structure as the Dutch one.

The IEQ was judged to be a suitable instrument to assess caregiver consequences in all countries, although there were some cultural differences on individual items. For instance the question whether the caregiver had to guard the patient from excessive intake of illegal drugs had to be changed, because in Italy, Spain and Denmark all illegal drug use was considered to be excessive. All other remarks were on the technical aspects of the translations, and on the wording of response categories. The translations were revised according these remarks.

Factor analyses on data collected with the IEQ showed that the instrument indeed covers a broad concept of caregiver consequences. Factor solutions were very similar across diagnostic groups and across European countries.
Wijngaarden et al., 1996, 2003). In all samples four distinct and good interpretable scales were found. These scales represent four major domains of caregiver consequences. **Tension** stands for the interpersonal conflicts between patient and caregiver, caused by behavioural problems, annoyance, quarrels and sometimes aggression. **Urging** stands for all those things a caregiver has to do to encourage the patient into activity, to counteract inertia and negative symptoms. **Supervision** stands for the necessity to (sometimes) prevent accidents or suicide attempts, or to look over medication intake, and to prevent alcohol or drug abuse. Finally, **worrying**, stands for the uncertainties on the course of patient’s disease, and on what the future will bring. And, as the results show, these four domains are equally important in all samples that were studied. These domains form the core of caregiver consequences.

In summary, the effort put in developing an instrument that covers the consequences for caregivers of patients with a broad spectrum of diagnoses and of caregivers living in different countries, has led to a high level of content validity.

**Face validity**

The aspects of face validity of the IEQ have for a part already been discussed in the previous paragraph. In the focus groups also the face validity was discussed. For instance the logic of the order of the items was judged. Also the way the items reflected the daily experiences of caregivers, and the question if items should be deleted, were discussed. An example of the latter was that in England and Denmark the item on education level of the caregiver in the socio-demographic section was judged to be possibly provocative. The focus group participants questioned what education level had to do with caregiver consequences. Another example was the neutral term ‘person’ that was used in the original version of the IEQ. Many found this term too impersonal, and advised to use terms like ‘patient’ or ‘relative/friend’. Alterations were made accordingly.

A proof of good face validity can be found in the response rates and the remarks from respondents. In studies done with the IEQ response rates vary from 70 to 89% (Magne-Ingvar & Öjehagen, 2002; Schene & van Wijngaarden, 1993a; Tennakoon et al., 2000, van Wijngaarden et al., 1996, 2000, Wolthaus et al., 2002). This is a very high number compared to the response rates normally achieved in studies that use mailed questionnaires (about 40-50%). Probably the caregivers who receive an IEQ feel appealed by it and are willing to cooperate. This is confirmed by the answers the 680 members of the family organisation gave on our request to evaluate the IEQ. Many respondents indicated that they were pleased that attention was paid to the problems they had in caring for their loved one, and they wished the researchers success with their study. Several respondents wrote that they hoped they did their best, so
their answers would be useful for the project. Others indicated that they had been moved by the items of the questionnaire (Schene & van Wijngaarden, 1993a).

In summary, one can state that the face validity of the IEQ is good. Respondents recognise themselves and their caregiving in the instrument, they recognise the importance of co-operation and, as a result, response rates are high.

**Overt format**

The IEQ has a very structured format. All questions have the same structure and start with the phrase: “How often during the past four week have you ……….”. Also the terms used in the questions were kept the same, such as “…….. have you encouraged your relative/friend ……….”, or “…….. have you worried about ……….”. Finally, all questions had the same response categories: never - sometimes - regular - often - always. The items can be summarised in four sub-scales scores and in an overall consequences score. The overall format also is comprehensible. This can be concluded from the only 0.8 to 3.1 percent of questionnaires that could not be used in analysis due to missing data, (Schene & van Wijngaarden, 1993a; van Wijngaarden et al., 1996, 2000).

**Ease of usage**

The IEQ is an easy to understand, and not time-consuming instrument. The IEQ core module (31 items) takes about ten minutes to complete. The entire set, which includes the GHQ-12 and the other additional modules (31 items) takes about twenty minutes. The IEQ can also be administered as a structured (telephone) interview.

All in all 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 validity of the IEQ**

In the previous paragraphs the content and face validity were discussed in the context of the sensibility of the IEQ. The construct validity of the IEQ could not be assessed properly because of the lack of a golden standard. However, an indication of construct validity was found in a study conducted in the United Kingdom among 40 caregivers of patients with first-episode psychosis (Tennakoon et al., 2000). In this study caregivers were interviewed about their experiences of caregiving, coping strategies and distress, using the IEQ and the
Experience of Caregiving Inventory (ECI; Szmukler et al., 1996). The ECI measures caregivers’ appraisal of the caregiving experience. The way the ECI was developed resembles that of the IEQ. It is also based on a stress-coping-appraisal model, items and domains were generated in interviews with members of two major British family organisations, scales were constructed by means of factor analysis, and the time frame was set to one month. The 66 items are phrased as: “During the last month, how often have you thought about ……….” The ECI comprises of 10 sub-scales that cover negative as well as positive aspects of caregiving. Negative aspects that are distressing for caregivers are: (1) difficult behaviour, such as being irritable or suspicious, (2) negative symptoms, such as withdrawal, (3) stigma, such as how to explain the illness to others, (4) problems with services, such as difficulty getting information, (5) effects on the family, such as family break-up, (6) need to backup, such as financial support, (7) dependency, such as helping with daily activities, and (8) loss, such as suicide risks, or loss of opportunities. The two sub-scales measuring positive aspects of caregiving are positive personal experiences (e.g. learnt more about myself, or became closer to friends), and good aspects of relationship (e.g. contributed to the well-being of the patient). The validity of the eight negative sub-scales was good, the validity of the positive scales bad (Szmukler et al., 1996).

The IEQ sub-scales worrying, tension and supervision correlated significantly with one or more of the ECI sub-scales difficult behaviour, negative symptoms, need to backup, effects on family, and loss. Worrying correlated with all five ECI sub-scales, supervision with difficult behaviour, need to backup, and loss, and tension with loss. Strongest correlations were found between thinking about patient’s difficult behaviour, and worrying (R = 0.55) and supervision (R = 0.52). Thinking about loss was the only ECI sub-scale that correlated with all three IEQ sub-scales (Tennakoon et al., 2000).

Although the IEQ and ECI measure different aspects of caregiving, thinking about aspects of caregiving versus the actual consequences of this caregiving, these results are an indication of good convergent validity. First, the higher correlations between thoughts about difficult behaviour, and actual worrying and supervision, is in concordance with other studies where positive symptoms were the main predictors of caregiver consequences in first-episode psychosis (Wolthaus, 2002). Second, in case of first-episode psychosis feelings of loss and uncertainty about what is to come, will be prominent, and this is reflected in the correlations between caregivers’ thoughts about loss and the consequences they reported on worrying, tension, and supervision. Third, caregivers’ thoughts about patient’s difficult behaviour, need to back up, and loss is connected to the actual supervision of the patient. The caregivers actual need to supervise are reflected in their thoughts about the patient who needs support, because of his or her behaviour and loss of control.
Conclusion and discussion

Also divergent validity seems to be satisfactory. No correlations were found between IEQ sub-scales and the other IEC sub-scales. The IEQ does not measure positive aspects of caregiving, stigmatisation, and problems with services, as four of the IEC sub-scales do. The absence of significant correlations indicates that these concepts are indeed not covered by the IEQ. One may have doubts on the IEC sub-scale dependency, because it contains some items also covered by the IEQ urging sub-scale. Here correlations could have been expected.

Until the mid-1990s the IEQ was the only validated instrument of its kind in The Netherlands. A test of convergent validity became possible when at that time a new instrument came available, the Burden on the Family Interview (BFI: Kramer, 1998). The BFI is a structured interview consisting of 141 items covering a broad range of caregiver consequences. Its lay-out and focus is quite different from the IEQ. Where the IEQ has a fixed time frame (previous four weeks), the BFI has a variable time frame (present moment, past year, ever), and where the IEQ has a fixed set of ‘objective’ response categories (never - always), the BFI has a varying set of objective and subjective response categories (e.g. never - always, no burden - heavy burden, not distressing - very distressing). Despite these differences BFI and IEQ items scores that were considered to be equivalent were correlated. These correlations ranged from 0.33 to 0.56. The author who had expected correlations of at least 0.60 concluded that a satisfying convergent validity could not be established (Kramer, 1998).

More evidence for a satisfactory convergent validity was found. First, in the Dutch studies caregiver consequences assessed with the IEQ could be predicted from mediating variables that were proposed in several mostly stress-coping-support-appraisal models (Biegel et al., 1991; Gallop et al., 1991; Maurin & Barmann Boyd, 1990; Schene, 1990). In Figure 7.1 an adapted version of the theoretical framework proposed by Schene (1990) is presented.

In this model patient’s symptoms and functioning have consequences for the caregivers. For instance tasks normally done by the patient have to be taken over by the caregivers, the interpersonal relationship between patient and caregiver changes, or patient’s children have to move to family or friends because the patient is not able to practice his or her parental role. Loss in patient’s role performance, tasks added to the caregivers’ normal workload, and changes in family and social relations lead to strains that can become chronic. The patient’s symptoms and (disturbing) behaviour can also directly lead to chronic strain. This chronic strain itself can lead to feelings of distress and mental health problems of the caregivers.
There are, however, mediating variables, not only on an individual and familial level, but also on a societal, and communal/cultural level (Schene, 1990). Examples of those mediating variables are caregiver’s coping style, social support, mental healthcare system, and culturally dependent ideologies and philosophies about mental illness and caregiving. In other words, there won’t be a simple straightforward relationship between patient’s symptoms and functioning, and the objective and (resulting) subjective consequences. For example, on an individual level, caregivers who are able to cope with their caregiving role and the consequences resulting from it, probably will feel less distressed than those who can’t cope properly. On a familial level, caregivers who receive social and practical support from their family or friends might experience less strain. Finally, on a community or cultural level, both objective as subjective consequences could be less, if the caregiver can rely on a high-quality and supporting mental health care system, that is not hindered by labelling or stigmatisation. That is why already in the 1950s Clausen and Yarrow (1955) stressed the importance of informing the civilian population on the origin and treatment possibilities of mental illnesses, in order to adjust popular beliefs in the community.
Proof for the validity of this model was found in a sample of 680 members of a Dutch family organisation, who were the relatives of patients suffering from schizophrenia. High IEQ sub-scale scores could be predicted from the severity of patient’s symptoms on agitation, apathy, psychosis and affect, a deterioration of the illness since onset, less caregiver’s coping ability, more caregiver’s contacts with mental health professionals, and more time spent with the patient. Explained variances ranged from 21 percent in case of urging to 55 percent in case of tension, and 46 percent in case of the overall caregiver consequences score. These findings suggested that the objective consequences indeed are influenced by patient and caregiver characteristics, and that the IEQ is able to detect these influences, at least for a part (Schene & van Wijngaarden, 1993a).

A rather high correlation of 0.50 was found between the IEQ overall consequences scores and caregiver’s distress score. This distress score could also be predicted from patient and caregiver characteristics. To study the relation between objective and subjective caregiver consequences, and patient and caregiver characteristics, these variables were incorporated in the proposed model. Since not all variables mentioned in the model had been measured (for instance no social support, and no community or culture characteristics) further analyses were conducted on a simplified model (Figure 7.2).

Figure 7.2 Prediction of IEQ and distress scores: explained variances (multiple regression analysis)

(Adapted from Schene, van Wijngaarden & Koeter, 1998)
Multiple regression analyses were carried out with the IEQ overall score and distress score as dependent variables. Patient, caregiver, and relationship characteristics were entered one by one as an entire set in the regression equation (Schene et al., 1998). The IEQ overall consequences score was best predicted by patient characteristics (age, sex, symptom levels, clinical status, duration of disorder, and course over time), followed by caregiver characteristics (age, sex, in contact with mental health professionals, and coping ability), and relationship characteristics (living with the patient, number of hours contact with the patient). Especially symptom levels, coping, and number of contact hours were predictors. A similar result was seen in the multiple regression analysis on the distress scores, with patient characteristics explaining most variance, followed by caregiver and relationship characteristics. In both analyses the three sets of variables accounted for unique parts of the variance (Schene et al., 1998). A subsequent path-analysis (Wright, 1985) revealed that the objective consequences (IEQ overall score) explained a substantial part of the relation between caregivers’ distress and the patient, caregiver and relationship characteristics. This was especially true for the relationship characteristics, 75% of the correlation with distress was explained by the IEQ overall score. In the other cases that was 64% (patient characteristics) and 45% (caregiver characteristics) respective (Schene et al., 1998). The strongest paths are indicated with bold lines in Figure 7.2.

These analyses showed that the caregiver consequences measured with the IEQ fit in the model as was expected. It is a mediator between on the one hand patient’s characteristics (symptoms), and on the other hand mediating variables as contact hours and caregiver’s coping. As was indicated in the model in Figure 7.1, chronic strain, and the resulting subjective consequences, are caused partly by a direct response on patient’s symptoms and partly by an indirect response via the caregiver consequences. The fact that this indirect response is bigger than the direct response shows the importance of caregiver consequences as a concept. The fact that this importance can be demonstrated with IEQ scores, emphasises the conceptual relevance of the IEQ.

In case of caregiver consequences of depression, IEQ scores could also be predicted from background characteristics. Best predictors were coping, a changed relationship with the patient, the presence of social support, and the presence of acute depressive symptoms, with predicted percentages ranging from 13% in case or urging to 52% in case of tension, and a 44% predicted percentage of the IEQ overall consequences score. Caregiver consequences will be more prominent in case of a disrupted (marital) relationship with a patient who is in an acute phase, lack of social support, and an inability to cope with the situation (van Wijngaarden, Schene & Koeter, in press). While these results are similar to what was found with respect to the caregiver consequences of schizophrenia, and also supportive of the caregiving model, the differences
between the 'contents' of caregiver consequences in schizophrenia and depression samples are evidence for the construct validity of the IEQ.

The context in which caregiving takes place in depression is in general different to that of schizophrenia. In depression caregiving in many cases is provided by partners of patients. The change in (sexual) relationship, the change in perspective on the future, leads to interpersonal strains, especially in the cases where the caregiver cannot rely on others and/or cannot cope with the situation. In case of schizophrenia the caregiver mainly is an elderly mother still caring for her child, far beyond the patient's infancy. These differences in context are visible in the IEQ scores. In depression especially the interpersonal strain is prominent, in schizophrenia caring tasks and the mothers’ worries about the future (Schene & van Wijngaarden, 1995, van Wijngaarden et al., Chapter 6).

Other indications for good construct validity were obtained in a study on the effect of psycho-educational support groups on 164 caregivers of patients with severe mental illness (47% psychosis, 18% major depression, 12% bipolar disorder, and 23% other/unknown). Analysis revealed that interventions aimed at the reduction of caregiver consequences, such as training of coping skills and providing support to the caregiver led to a reduction in caregiver consequences measured with the IEQ, as was expected by the model (Stam & Cuijpers, 2001). Also the relationship between objective (IEQ) and subjective caregiver consequences was studied. IEQ sub-scale scores were used to predict the scores on three measures for subjective caregiver consequences\(^3\): (1) the IEQ distress score, (2) an adapted version of the Maslach Burnout Inventory (MBI: Maslach & Jackson, 1986; Schaufeli & van Dierendonck, 1995), and (3) the caregiver's general feeling of burden. A multiple regression analysis revealed that the MBI burnout score and the general feeling of burden were predicted by worrying, strain on the relationship, supervision, the caregiver's ability to cope, and the kind of relationship between caregiver and patient (explained variances 53 and 56% respective). The IEQ distress score was explained by worrying, ability to cope, type of disorder, caregiver's sex and kind of relationship between caregiver and patient (41% explained variance). Burnout and general feeling of burden increased if the caregiver was the patient's partner, worried much, had to supervise more, reported more interpersonal strains, and was less able to cope (Cuijpers & Stam, 2000). These results are in agreement with models presented in Figures 7.1 and 7.2. IEQ sub-scale scores are the best predictors of the overall feeling of burden and burnout. In case of schizophrenia, the IEQ distress score seems to be directly

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\(^3\) Cuijpers & Stam did not use the IEQ tension sub-scale but only the items that refer to strain on the relationship. The tension sub-scale item on feeling threatened by the patient was used as a separate predictor.
related to the caregiver's characteristics, a phenomenon that also was apparent in the path analysis in Figure 7.2.

The relationship between psychiatric symptoms and caregiver consequences was confirmed by Wolthaus and colleagues (2002). They studied the correlation between IEQ scores and patient's symptoms and personality traits. Patients (N=138) were in a first or second psychotic episode, and met criteria for the DSM-IV diagnosis of schizophrenia (75%) or spectrum disorders (25%). Symptoms were measured with the Positive and Negative Syndrome Scale (PANSS: Kay, Fiszbein & Opler, 1987), rated by trained researchers. Personality traits were assessed with two self-report questionnaires, the Schizotypal Personality Questionnaire (SPQ: Raine, 1991), and the NEO Five Factor Inventory (NEO-FFI: Costa & McCrae, 1989). These instruments were completed after clinical stabilisation on antipsychotic medication. Multiple regression analysis revealed that three of the IEQ sub-scale scores (tension, urging, and supervision), the overall caregiver consequences score, and the IEQ distress score were predicted by one component of the PANSS, the disorganisation component (explained variances ranging from 30 to 46%). Sub-scale worrying was predicted by the agitation-excitement component of the PANNS and the schizotypical trait disorganisation of the SPQ (44% explained variance). The authors conclude that, as patients with early-onset schizophrenia tend to have more disorganisation than older and more chronic patients, these positive symptoms contribute significantly to caregiver consequences in the early phase of schizophrenia. This in contrast to chronic patients where negative symptoms seem to be of more importance (Wolthaus et al., 2002).

Finally, a proof for the construct validity of the IEQ was found in the matching of the patterns of the mean IEQ score in the European samples. These patterns were almost identical, which means that in all countries, worrying about the patient's health, future, safety and financial position were the most frequently mentioned caregiver consequences, and the need for supervision and interpersonal tension least (van Wijngaarden et al., 2003).

**Conclusion**

Although the construct validity of the IEQ could not be assessed properly, a considerable number of research results indicate that the validity of the IEQ is quite satisfactory. Several studies confirmed (parts of) the proposed stress-coping-support-appraisal model. Findings were very similar. Caregiver consequences can be predicted from a set of background and intermediating variables, especially patient's symptoms, caregiver's coping ability, and social support. Also caregiver consequences are strongly related to various concepts of subjective consequences, such as caregiver's distress, burnout and appraisal.
Conclusions and discussion

The reliability of the IEQ

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.

**Internal consistency**

The internal consistency of the sub-scales and overall caregiver consequences score were computed in all samples (Cronbach’s alpha). Because of the fact that in 1997 the content of IEQ sub-scales has changed, the internal consistency analyses that were reported over the years (Schene & van Wijngaarden, 1993a; van Wijngaarden, Schene & Koeter, 1996, 2002; van Wijngaarden et al., 2000) are not fully comparable. For this chapter an additional analysis was done on the sub-scales that are used since 1997. Analyses were done on the three main samples described in this thesis: (1) members of an organisation for relatives of patients with schizophrenia in The Netherlands, (2) caregivers of patients with depression in The Netherlands, and (3) caregivers of patients with schizophrenia in five European countries. In Table 7.2 the Cronbach’s alpha scores are presented.

**Table 7.2 Internal consistency of the IEQ (Cronbach’s alpha)**

<table>
<thead>
<tr>
<th>Sub-scale</th>
<th>Family organisation sample (N=680)</th>
<th>Depressive sample (N=252)</th>
<th>European sample (N=335)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tension</td>
<td>0.84</td>
<td>0.82</td>
<td>0.81</td>
</tr>
<tr>
<td>Supervision</td>
<td>0.78</td>
<td>0.64</td>
<td>0.77</td>
</tr>
<tr>
<td>Worrying</td>
<td>0.82</td>
<td>0.81</td>
<td>0.84</td>
</tr>
<tr>
<td>Urging</td>
<td>0.77</td>
<td>0.80</td>
<td>0.79</td>
</tr>
<tr>
<td>Overall score</td>
<td>0.89</td>
<td>0.90</td>
<td>0.90</td>
</tr>
</tbody>
</table>

Cronbach’s alpha benchmarks for good reliability are dependent on the type of study. For a psychological test, such as a verbal intelligence test the standard used for good reliability often is α ≥ 0.80. In case of instruments like the IEQ this standard seems somewhat unrealistic. The constructs that are covered are more diffuse, and the boundaries between constructs are less clear. This means that by definition the items that constitute sub-scales are more diverse and less closely related than items in a psychological (one-dimensional) test. Based on benchmarks found in literature in the EPSILON study alpha values of 0.50 to 0.70 were considered as ‘moderate’ and values over 0.70 as ‘substantial’ (Schene et al., 2000).
In all but one case the alpha values were about 0.80 for the sub-scales, and about 0.90 for the overall scores, which means that in general the benchmark for substantial reliability was reached. In the depression sample the alpha value of sub-scale supervision only could be considered as moderate. In Chapter 2 further details on the internal consistency of IEQ scales in the European sub-samples were presented (see Table 2.2). The figures showed that in general all alpha values were above 0.70, and that only in case of urging (Santander) and supervision (London) this benchmark just was not reached. The internal consistencies also did not differ between sites on three sub-scales and the overall score. Only on urging differences were found, mainly caused by a lower alpha score in Santander. As was pointed out by Schene and colleagues (2000), differences in alpha scores should be carefully interpreted, since these scores are dependent on sample variances. Indeed further analysis revealed that the differences in alpha scores probably were caused as much by differences in sample variance as by differences in true reliability. All in all, the internal consistency of the IEQ was considered to be satisfactory in all sites (van Wijngaarden et al., 2000).

Internal consistency was also determined in a study on the German translation of the IEQ. In this study (N = 138) alpha values ranged from 0.71 to 0.88 (Bernert et al., 2001).

**Test-retest reliability**

In the depression sample retests that were conducted on average 3.3 weeks after the first assessment resulted in lower scores on the IEQ in case of caregivers of patients who had recently started outpatient treatment, or patients who had received more than two months outpatient treatment (on average 1.3 years). In case of stabilised patients receiving long-term outpatient treatment (on average 4.7 years) test-retest scores were about equal. The differences in test-retest results between samples could not be accounted for. It was hypothesised that these results might have been caused by the fact that in the first two samples real changes had occurred as a result of treatment. However, this treatment effect only would be expected in case of the patients who recently started treatment, not in case of other patients. Patients in the latter sample should be stabilised (on medication) and changes in the consequences for their caregivers were not expected to occur in such a short time interval. On the other hand the stable scores in the long-term outpatient sample was considered as an indication of test-retest reliability (van Wijngaarden, Schene & Koeter, 1996).

As was described in detail in Chapter 2 (see Table 2.2) a test-retest validity analysis was also done in the EPSILON study. The test-retest time interval was set on one to two weeks, and the actual average time interval ranged from 6 days (Santander) to 22 days (Verona). Intraclass correlations (ICC) in the pooled
sample were high, ranging from 0.83 (supervision) to 0.90 (overall score). All individual sites had ICC scores above benchmark (0.70). Santander and Verona had somewhat lower ICCs that the other sites. These differences could not be attributed to different time intervals between test and retest (van Wijngaarden et al., 2000). In all, it was concluded that although all ICCs were above benchmark values, the test-retest reliability of the IEQ still remains unclear and should be studied further.

The test-retest reliability in the study on the German version of the IEQ was somewhat different from the Epsilon study. Three sub-scales and the overall score had ICCs between 0.79 and 0.94. However, the tension ICC score was only 0.39. No explanation for this divergent finding could be given (Bernet et al., 2001).

Sensitivity to change

Stam & Cuijpers (2001) studied the effect of family interventions on the caregiver consequences of severe mental illness using a quasi-experimental design. Caregivers in the experimental group attended 6 to 10 sessions of a support groups aimed at reducing caregiver consequences, caregivers in the control group attended only one informal meeting. At retest after one year the IEQ scores of the control group had not changed, in contrast to the experimental group where IEQ scores dropped significantly. Multiple regression analysis was used to test whether differences in experimental and control groups were due to the intervention or not. This analysis revealed a significant effect on worrying and urging, and an almost significant effect on tensions and the overall consequences score. Although the authors consider their study to be a pilot-project because of limitations (Stam & Cuijpers, 2001), these results indicate that the IEQ is sensible enough to measure changes.

Additional proof for the IEQ's sensitivity to change was found in two studies in small samples of caregivers of patients with severe mental illness who were admitted to inpatient treatment. In the first sample (N=19) caregivers completed the IEQ twice, at admission and after three months. In the second sample (N=36) the time interval was 8 weeks. In both samples IEQ scores dropped significantly on the overall consequences score and three out of four sub-scales. Although scores on the urging sub-scale also dropped, these changes were not significant (Dekker, 1996; van Wijk & Haverman, 1992; van Wijngaarden, Schene & Koeter, 1996).

In conclusion, 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. Although above benchmark, test-retest validity scores
varied between countries and in other studies some contradicting results were found. Test-retest reliability therefore should be further investigated in the future.

The applicability of the IEQ

Throughout this thesis several studies on the IEQ were presented. One of the recurred conclusions was that the scale structure was stable across patients samples, and across countries. This was also true for the patterns of consequences. This stability in results is exactly what should be expected of an instrument that claims to cover almost all important domains of caregiver consequences. Caregiving itself is universal, independent of diagnosis or culture. Situations that requires spouses, parents, siblings, or friends to care for their loved ones, will lead to similar activities and similar consequences. Carers will have to take over tasks, have to face the consequences that the mental illness has for the patient him/herself, have to cope with symptom behaviour, or have less time to spend for their own. And all these caregiving tasks and experiences will have consequences for the carers. There will only be differences in which consequences will have the most impact in which situation. The studies presented in Chapters 5 and 6 showed that caregivers of patients with depression experience consequences that are quite similar to those experienced by caregivers of patients with schizophrenia or another type of psychosis. But it also showed that the kinds of consequences were related to the context of caregiving. In depression interpersonal tension between spouses was experienced most in a context of changed relationships, and changed expectations. In schizophrenia, where caregivers are mostly mothers, the consequences of ongoing care for adult children was most prominent.

Together with the high level of sensibility discussed earlier in this chapter, 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 (Bernert et al., 2001; Magne-Ingvar & Öjehagen, 2002; Pereira & de Almeida, 1999; Tennakoon et al., 2000). It even has led to utilisation in settings outside the psychiatry domain, such as geriatrics (demented versus depressive patients: Leinonen et al., 2001), and obstetrics (high-risk pregnancies: Birnie et al., 1998).
Limitations

The IEQ has been developed to measure the objective consequences for caregivers. The things caregivers have to do, the frequency with which a caregiving task has to be carried out, the number or times a caregiver worries, or has to supervise. The question is whether this claim of measuring objective, measurable consequences is accomplished. First there lies some danger in the choice of response categories. In earlier versions of the IEQ exact figures were assessed when asking how many times during the past four weeks an event had happened. Tests evaluating this way of asking, however, revealed that it was very difficult for caregivers to answer. They did not keep a diary in which they recorded all consequences, and the felt obligation to produce exact figures made them uneasy. These findings led to the decision to apply response categories used in other, well-known and tested, instruments such as the SCL-90 (Derogatis, 1977). Instead of figures the response categories consisted of global frequency identifiers: never, sometimes, regular, often, and always. An objection to these response categories may be that by doing so subjectivity has entered the objective caregiver consequences scores. If a caregiver reports that an event happened ‘often’, how often did it actually happen: once, four times, daily? The ‘often’ of one caregiver might be something different than the ‘often’ of another caregiver.

Some of the results indeed indicate a certain subjectivity. For instance, the analyses of research data showed that the IEQ sub-scales were correlated, coefficients ranging from 0.32 to 0.50 (Schene & van Wijngaarden, 1993), and the Homals analysis in Chapter 6 showed that reporting many consequences on one sub-scale was combined with reporting many consequences on the other three sub-scales. Szmukler and colleagues (1996) found similar relations. In their study two type of response categories were tested, one in which caregivers were asked how often they had thought about a certain issue (objective), and one in which they were asked how much they had been upset by the same issue (subjective). Correlations between answers were greater than 0.90 in all cases. These findings indicate that the correlation between IEQ scores and measures of subjective consequences should be studied more closely.

Another criticism on the IEQ might be the in general low number of real consequences reported on several items, especially items on supervision and urging. Does this mean that the IEQ is insensitive for these kind of caregiver consequences? Probably not, regarding all the evidence that was found on its validity and reliability, and on its stability across samples and situations. It might reflect the fact that these caregiver consequences are relatively rare, a hypothesis that, however, is not in agreement with the often voiced caregivers'
statements that they experience a lot of consequences from caregiving. Are caregivers just naggers who complain without an actual reason? To understand the apparent paradox between rather low IEO scores and the caregivers' experiences, one must look at caregiving from a point of view of role functioning. In case of little children caring is one of the essential parts of the parental role. Parents spend a lot of time, energy and emotion into caring, and many parents will recognise the suddenly changed situation, in which night and day rhythms are determined by the sleeping and eating habits of the baby, and in which visiting friends or going to the cinema or theatre is not as obvious as it was before. Although this caring sometimes can be very burdensome, most parents will know that this is the 'price one has to pay' for having a baby. And they are rewarded in the form of the first smile and the first word. Also, parents will realise that their caring is time-limited. Someday, when their child has grown up, they do not have to care anymore.

In case of caring for an adult person with a severe mental illness a different situation exists. In adult role functioning people should be able to care for themselves, and undertake their own activities. When mental illness keeps them dependent on their parents, like in schizophrenia, or become dependent on their partners, like in depression, these caring tasks are experienced by carers as additional. Even if it may not appear much at first glance, providing more care than would normally be appropriate in a reciprocal relationship, may be very disrupting (Schene, van Wijngaarden & Koeter, 1998). The awareness that this caregiving may not end, and the fact that in many cases rewards are absent or only few, will only strengthen this feelings of disruption.

Caregivers' distress scores were rather high. Caregivers of patients with depression scored on average on four out of eight distress items, and 23% of caregivers of patients with schizophrenia scored above the cut off point (3) for psychiatric caseness on the GHQ-12. Also rather high correlations were found between distress and caregiver consequences. Does this prove that more consequences lead to more distress or are both scores biased? There could be a possibility that high distress scores are caused by the fact that these caregivers, independent of caregiver consequences, already experienced more distress than the average citizen. This finding is supported by the results of a study on the occurrence of infectious diseases in relation to schizophrenia. Infectious illness episodes could be predicted by more severe patient positive symptoms and less satisfaction with social support (Dyck, Short & Vitaliano, 1999).

Other studies have shown that in case of depression there is evidence of assortative mating, the tendency for persons to marry someone with a similar phenotype (Mathews & Reus, 2001). This means that the partner of a patient with depression has an increased chance to have depressive complaints her/himself. In case of schizophrenia there is a genetic component (Harrison &
Conclusions and discussion

Owen, 2003). Schizophrenia has a heritability of around 80%, so it is possible that caregivers, who are mainly relatives, could have higher levels of distress of their own. However, since the exact impact of these relations are not known, conclusions cannot be drawn so far.

Future research

The studies described in this thesis and elsewhere have shown that the ongoing development and testing of the IEQ has resulted in an instrument with good validity and reliability, and high sensibility and applicability. This, however, does not mean not further work has to be done. In order to keep improving the IEQ further research is necessary, especially considering the fact that the IEQ is used in several countries, all with their own language and cultural peculiarities. For instance the test-retest validity assessment did not yet lead to unambiguous results. There might be a cultural component involved that should be cleared up. This means that researchers outside The Netherlands should be encouraged to do local tests on the psychometric qualities of the IEQ. These and other studies should be collected in a national database, in order to be able to construct national norm groups.

The IEQ should be tested against concepts that fit in the stress-coping-support-appraisal model presented in Figure 1, such as social support and coping. Also other concepts should be incorporated in this model, for instance Expressed Emotion. In a recent study on EE it was found that the usual idea that high EE causes symptom exacerbation and relapse might be only one side of the story. The results suggested that more severe negative symptoms of the patient in their turn may increase EE in caregivers (King, 2000). Therefor the inclusion of EE in the model may lead to new insights in the consequences of caregiving and in the mutual influences of these consequences and patient functioning.

Finally, more research is needed on the effects of psychiatric treatment, family support and family education on caregiver consequences, in order to search for the most effective interventions. This research should focus on caregivers of all patient groups. Caregiver consequences are not only an issue in schizophrenia but probably in all mental illnesses.
References


Berg, R., van den (1994) "Belasting van betrokkenen van depressieve patiënten." Amsterdam: University of Amsterdam, Academic Medical Center, Department of Psychiatry.


Derogatis, L.R. (1977) SCL-90: Administration, scoring, and procedures manual for the Revised Version Baltimore: John Hopkins University School of Medicine, Clinical Psychometrics Research Unit.


Conclusion and discussion


Schaufeli, W.B. & van Dierendonck, D.J. (1995). Dutch version of the Maslach Burnout Inventory. *Maslach Burnout Inventory, Nederlandse versie (MBI-NL).* Utrecht: University of Utrecht.


