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

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Chapter 2

Caregiver consequences in the Netherlands and other European countries: The development and use of the Involvement Evaluation Questionnaire (IEQ)

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Caregiver consequences in the Netherlands and other European countries

Introduction

Since the 1950's research has been done on the consequences that severe mental illness like schizophrenia can have for the patients themselves, their families, and others involved (Hatfield & Lefley, 1987; Schene, 1986). Many researchers believed that the impact on families was increased by deinstitutionalisation. Patients who would have been hospitalised in the past were now treated in community-based programs. Their return to the community would impose a greater strain on their families and their surroundings (Biegel, Milligan, Putnam et al., 1994). This belief was supported by the rise of self-help family organisations that in many countries were founded in the early 1970s by relatives of psychiatric patients. On the one hand they felt burdened by the increase in care they had to provide, while on the other hand they felt that professionals neglected their needs. Many also had the impression that they were blamed for being responsible for the patient's mental health problems (Schene & van Wijngaarden, 1995). As a result of this increasing interest in the consequences of mental illness for relatives, family burden became one of the outcome measures in mental health service evaluation (Fenton, Tessier & Struening, 1979; Tessler, Killian & Gubman, 1987).

In The Netherlands, deinstitutionalisation has not occurred on a scale comparable to that in countries such as Great Britain, where the number of inpatient beds decreased from 148,000 in 1954 to 65,000 in 1985 (Thornicroft & Bebbington, 1989), or the United States, where the proportion of residential patients per 100,000 inhabitants dropped from 339 in 1955 to 50 in 1986 (Bachrach, 1986). In contrast to these major reductions in number of beds, in The Netherlands the proportion of residential patients per 100,000 inhabitants only dropped from 262 in 1955 to 147 in 1990. While on one hand a reduction was achieved by discharging psychiatric patients into the community, on the other hand mentally retarded, psychogeriatric, forensic, and chronic psychiatric patients were transferred to facilities more appropriate to their needs, such as psychogeriatric nursing homes, sheltered housing, and partial hospitalisation (Schene & van Wijngaarden, 1995).

Not only was the scale of deinstitutionalisation different in The Netherlands, the process also started several years later. It lasted until the mid-1980s before a need was felt for instruments to assess family burden. The need for family burden research originated from studies comparing traditional inpatient care to day care or outpatient care. In one of these studies, conducted at an academic hospital from 1986 to 1990, psychiatric partial and full-time hospitalisation were compared on changes in psychopathology, interpersonal functioning, social functioning, social network and social support, satisfaction with care, treatment duration, medication consumption, and crises and calamities. It was expected
that the patients in the partial hospitalisation condition would have better outcomes on social functioning, quality of life and sense of mastery (Schene et al., 1993). However, based on the experiences abroad, it was also hypothesised that the presence of the patient at home might have consequences for those sharing a household with the patient, because family members would need to care for their patients (Schene et al., 1993). Therefore, it was decided to assess family burden as one of the outcome measures.

In order to find a suitable instrument for this study a literature search and review was conducted that covered a period of more than forty years, starting in 1946 with the study of Treudley who, as one of the first authors, introduced the concept of burden (Schene, 1986; Schene, Tessler & Gamache, 1994). No suitable research instrument could be found. There were no instruments available in Dutch and instruments in other languages did not fit the researchers' conditions (a self-administered questionnaire, short but covering the concept, with a limited time frame and sensitive to change), or had not yet been validated properly (Schene et al., 1993). It was therefore decided to develop a new instrument for the purpose of this study.

A first version of this instrument was produced in 1987, the Burden on the Family (BOF) scale (Schene, 1987). It was used in several studies and, based on the experiences of these studies, adapted several times. In 1992 these adaptations resulted in the Betrokkene Evaluatie Schaal (BES: Schene & van Wijngaarden, 1992a), followed in the same year by its translation in English, the Involvement Evaluation Questionnaire (IEQ: Schene & van Wijngaarden, 1992b). The IEQ has since been translated in eight other languages and has become one of the most widely used instruments in Europe. In this chapter we will describe the development of the instrument, the concepts on which it is based, its validity and reliability, and its applicability and utility in practical research. Because Europe consists of several countries, each with its own languages and cultural characteristics, differences between countries will be highlighted.

The development of the Involvement Evaluation Questionnaire

Family burden or caregiver consequences

The consequences of mental illness for family members have been described in different ways that have changed over time. Treudley (1946) first used the term ‘burden on the family’. She referred to the consequences for those in close contact with a severely disturbed psychiatric patient. Other descriptions used are ‘burden on the community’ (Grad & Sainsbury, 1962), ‘disturbance caused by the patient’ (Brown & Rutter, 1966), and ‘the presence of problems, difficulties
or adverse events, which affect the lives of psychiatric patients' significant others, e.g., members of the household or the family (Platt, 1985). Subsequently 'caregiving' came to be considered to be a more appropriate term because it lacks the negative connotation of 'burden' or 'disturbance'. It covers all possible consequences of mental disorders for family members, positive as well as negative (Joyce, Lees & Szmukler, 2000; Szmukler, 1996). In this chapter we will use the term 'caregiver consequences'.

Consequences of mental illness: domains

The 1986 literature search revealed a large number of possible consequences resulting from caring for a person with a mental illness. These consequences could be summarised in a series of interconnected domains (Creer, Sturt & Wykes, 1982; Fadden, 1984; Schene, 1986, 1990).

**Symptoms and symptomatic behaviour**

The severity of symptoms and symptomatic behaviours were found to be an important source for caregiver consequences. This is especially true for aggressive and hostile behaviour; self-destructive behaviour (suicide attempts and self-mutilation); negative symptoms; sleep disturbance; addiction to medication, alcohol, or illegal drugs; mood swings and dysphoria; hallucinations; delusions; and paranoia. Also difficulties in terms of role dysfunctioning, such as no social contacts, poor hygiene, and lack of household responsibilities, are also of importance.

**Caring and coping**

When the patient is not able to do what normally could have been expected from him or her, others have to take over these tasks. It was found that carrying these extra tasks can be burdensome. These caregiver consequences were described by Gubman, Tessler & Willis (1987) as the do's and the don'ts. The do's were defined as the extra tasks caregivers had to do, while the don'ts referred to those things they were no longer able to do because of their caregiving tasks.

**Family relations**

Because of the psychological problems, symptoms, disruptive behaviour, and the resulting caring tasks, interpersonal relationships between family members might become strained. Some caregivers described their experience as a sense of loss of the premorbid personality, with all its characteristics and promises, and the loss of hopes, dreams, and expectations (Miller et al., 1990).
Household routine and family functioning

The caregiving tasks in combination with a patient's symptomatic behaviour sometimes results in quarrels and distress that may have a great impact on family and marital relationships. Family systems may break up and marital relationships may end in divorce.

Social relations and stigmatisation

The social networks of families caring for a relative with a chronic disorder often decline. This may result in family members becoming more vulnerable for psychological problems themselves. It are not only the patients who are stigmatised; the caregivers suffer as well.

Leisure time and careers

The same holds for the opportunities for pursuing hobbies, sports, club activities, recreation, and holidays. Some caregivers people have to stop working or have lower career prospects.

Finances

The financial position of the family might deteriorate because caregivers have to quit work in order to care for the ill relative. On the other hand, caregivers often have to face extra expenses; for instance, to get medical or psychiatric care, or in case of financial support for the patient.

Children and siblings

Growing up with a parent or sibling with a mental illness might be a risk factor for the healthy psychological development of a child (Beardslee et al., 1983; Beisser, Glaser & Grant, 1967).

The mental health system of care

Many caregivers reported having burdensome contacts with the mental health system. There was a lack of information on the origin of the disorder and its prognosis, on how to cope, on medication and its side effects, and on the availability of services in times of crisis.

Subjective distress

Caring for a mentally ill relative might lead to feelings of guilt, uncertainty, ambivalence, hate, anger, sympathy, withdrawal, depression, anxiety, hopelessness, chronic sorrow, and bereavement.
Caregiver consequences in the Netherlands and other European countries

**Caregiver’s health**

This subjective distress, together with a disrupted family life and the heavy caregiving tasks, may have consequences for the physical health of caregivers, as well as their mental health. Indeed, new mental health problems may emerge, while those problems that already exist may be exacerbated.

**Positive experiences**

In recent years attention also has been paid to possible positive consequences of caregiving. Caring for a relative with a mental disease could lead to positive personal experiences and good aspects of the relationship, such as discovering one’s own strength and feeling closer to the patient or others, feeling useful, and enjoying the patient’s presence (Joyce, Leese & Szmukler, 2000, Szmukler et al., 1996).

**Objective and subjective consequences**

In the literature a distinction is often made between the objective and subjective aspects of caregiving. 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 and his or her family has to do (helping, supervising, controlling, paying, etc.) or is not allowed to do any longer (hobbies, clubs, career, work) as a consequence of the caregiving task. It applies to ‘the time and effort required for one person to attend to the needs of another’ (Biegel, Sales & Schulz, 1991).

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. Perceived distress and interpersonal strains are examples of short-term reactions. They refer to the stress of everyday caregiving. These short-term reactions may lead to more enduring consequences, such as overall well-being, satisfaction with life, physical and mental health, social isolation, divorce, and family disintegration.

Several models have been formulated to understand the relationship between objective and subjective caregiver consequences and the role of mediating variables (Biegel, Sales & Schulz, 1991; Gallop et al., 1991; Maurin & Barmann Boyd, 1990; Schene, 1990). In these mostly stress-coping-support-appraisal models objective consequences are considered as independent variables, and subjective consequences as dependent variables. These models are completed with a set of mediating variables on an individual, familial, societal, and cultural level (Schene, 1990). Examples of those variables are caregiver’s coping style, social support, mental health care system, and culturally.
dependent ideologies and philosophies about mental illness and caregiving. The formulated models indicate that there will not be a simple straightforward relationship between the objective consequences of caregiving and the resulting subjective consequences. Caregivers who, for instance, are able to cope with their caregiving role, who experience a lot of support from their surroundings, and who feel supported by mental health professionals will probably be less prone to experience long-term and enduring subjective consequences than caregivers who are unable to cope and who feel isolated and misunderstood.

The development of the IEQ

The IEQ was based on the results from the already-mentioned literature search. While the study of caregiver consequences was still new in The Netherlands, it was decided to focus mainly on the more objective consequences of caregiving. The instrument should be suitable for the assessment of what caregiving exactly implies in terms of tasks, costs, time consumption, and frequency. For instance, how often will a caregiver take over tasks normally done by the patient. In addition to the conditions mentioned earlier (self-administered, short, sensitive), it should be an instrument that can be used in cross-sectional research in which we would be able to test theoretic models, compare populations, assess interventions, and compare caregiving with other theoretical constructs.

An item pool was created based on literature and existing instruments (Schene, Tessler & Gamache, 1994, 1996) such as the Family Distress Scale (Pasamanick, Scarpatti & Dinitz, 1967), the Family Evaluation Form (Spitzer, Gibbon & Endicott, 1971), the Family Burden Scale (Test & Stein, 1980), and the Family Distress Scale for Depression (Jacob et al., 1987). This item pool was extended with items emerging from interviews with professionals. A series of draft versions were piloted and adapted if necessary. Since the principal aim was a reliable change-sensitive measure of objectives aspects of caregiving, items relating to stigma, guilt, social network loss were dropped, along with events that either happen rarely or are change insensitive, such as patient suicide attempts.

It was considered important that the relative should be someone who lived in the same house as the patient. Items were formulated accordingly, speaking of 'the ill member of your household' instead of 'your ill relative'. This made the questionnaire also suitable for those who shared households with the patient but who were not relatives. As the main objective was to assess the objective aspects of caregiving, the questions were formulated in such a way that they referred to how often a particular event occurred (for instance, a quarrel between the relative and the patient), and not how burdensome this event was for the relative.
After testing the first version of the questionnaire in a sample of relatives of patients and of friends and relations of the researchers, a final version of the questionnaire was made. It was named the Burden On the Family scale \(\text{BOF}^5\) (Schene, 1987), and it comprised of fifty items grouped in seven categories: (1) everyday activities, such as help with personal hygiene; (2) household atmosphere, such as quarrels and conflicts; (3) caregivers' health, such as somatic complaints; (4) social contacts; (5) financial consequences, such as loss of income; (6) leisure activities, such as hobbies and sports; and (7) consequences for children, such as bad school ratings.

The BOF was tested in four Dutch studies conducted between 1987 and 1990: (1) the already-mentioned comparative study of day treatment versus inpatient treatment; (2) a study among caregivers of patients who recently attempted suicide; (3) a study at the psychiatric department of a general hospital; and (4) a study among caregivers of acute psychiatric patients in a community mental health centre. These tests revealed that the instrument's focus on household members restricted the use of the BOF. Since many patients lived alone, information could only be gathered in a sub-sample of caregivers. It was decided to widen the scope of the instrument and to include all caregivers.

The BOF research resulted in a series of adaptations. Major changes concerned the wording of items, the deletion of 'bad' items, and the addition of items that emerged from an updated review of literature in 1991, in particular with regard to depression and caregiving. For example a series of items concerning caregiver's worrying were added along with a set of demographic variables and items regarding the relationship between relative and patient, household composition, and duration of illness. The adaptation of the BOF finally resulted in the instrument that is now known as the Involvement Evaluation Questionnaire (Schene & van Wijngaarden, 1992b).

**Structure and item content of the IEQ**

The IEQ consists of seven distinct sections. It has a modular structure, which means that each section can be used separately. The core module is a thirty-one-item questionnaire to be completed by the caregiver. The items refer to all kinds of encouragement and care the caregiver has to provide to the patient, supervision on patient's dangerous behaviours, interpersonal problems between patient and caregiver, caregiver's worrying, and caregiver's coping and subjective burden. All items are scored on a five-point Likert scale \(0 = \text{never}, 1 = \text{sometimes}, 2 = \text{regularly}, 3 = \text{often}, 4 = \text{always}\). Most items \((n=28)\) refer to the four weeks prior to assessment ("How often during the past four weeks have you helped ..........."), and three items do not have a specified time-frame (items 29-31). The IEQ can be completed by any caregiver. This not necessarily has to be a relative, but can be a friend or a neighbour. To complete
all IEQ items it is necessary that caregiver and patient have had at least one hour per week contact in person or by telephone during the previous four weeks. Caregivers with less than one hour contact per week must skip the items that refer to actual help and encouragement.

In addition to the core module, the IEQ can be extended by the following extra modules:

**Demographics.** Socio-demographic and contact variables, such as age, sex, household composition, and number of hours of contact between patient and caregiver (fifteen items).

**Extra expenses.** Extra financial expenses incurred on behalf of the patient; for instance, for professional help, to pay for damage caused by patient’s behaviour, or for financial support in case of unemployment (eight items).

**Caregivers needs for professional help.** Caregiver’s use of professional help due to somatic complaints (three items).

**Consequences for children.** Consequences for patient’s children under sixteen years of age, such as loss of appetite, sleeplessness, and behavioural problems (eleven items).

**Comments.** One open question for caregiver’s comments and additions.

**Psychological distress.** Between 1992 and 1997 this module consisted of an eight-item scale with items referring to somatic complaints such as sleeplessness, irritability, and feeling depressed. Since 1997 this scale has been replaced by the twelve-item General Health Questionnaire (GHQ-12: Goldberg & Williams, 1988) as a measure of caregiver distress.

**Translations**

Since 1992 several translations of the IEQ have been made. We ourselves produced an English translation in 1992, which was followed by translations in Finnish, French, German, Portuguese and Swedish. In 1996 the IEQ was chosen to be one of the core instruments in the EPSILON study (European Psychiatric Services: Inputs Linked to Outcomes and Needs), a collaborative study of five European countries (Great Britain, Denmark, The Netherlands, Italy, and Spain). One of the aims of this study was to produce a standardised version of the IEQ in order to obtain a cross-culturally valid and reliable instrument (Becker et al., 1999, 2000).

The translation of the IEQ into the other languages largely followed the protocol described in Knudsen and colleagues (2000). This protocol included (1) a translation into the four target languages by professional translators who were informed on the content of the IEQ; (2) a discussion of this translation by the translator and the research group, leading to a revision and a list of disputed items; (3) a back translation in Dutch by a native speaker, who also gave his or her comments on the first translation and the disputed items; (4) a comparison
of the back translation with the original IEQ, discussed by the first translator and the researchers, leading to a second revision and list of disputed items; (5) a discussion of this revision in focus groups, (6) a discussion of the focus group result by the researchers and one of the translators, followed by a third revision leading to the final version.

The focus group method is an arranged communication session among a selected group of persons who represent various parties involved. In case of the IEQ they were representatives of patients, relatives, professionals, and researchers. In the IEQ focus groups the translation and content of the instrument was discussed, with special emphasis to linguistic problems, applicability and relevance of items, redundancy, and missing items. It was concluded that the instrument covered the domain of caregiver consequences (Knudsen et al., 2000). This procedure resulted in standardised translations of the IEQ in English, Danish, Spanish and Italian (van Wijngaarden & Schene, 1997).

Scale structure

The scale structure of the 1992 version of the IEQ was tested in two Dutch studies, one among 680 members of an organisation of relatives of patients with psychotic disorders (Schene & van Wijngaarden 1993, 1995), and one among 260 relatives of patients with affective disorders (van Wijngaarden, Schene & Koeter, 1996). Separate Principal Component Analyses on both samples lead to very comparable factor solutions, and in both samples the items loaded on the same factors. This finding indicated one common underlying factor structure, which was confirmed in a Simultaneous Components Analysis (SCA; Kiers, 1990). This meant that the IEQ adequately covered the major domains of caregiver consequences of both relatives of psychotic patients and caregivers of depressed patients (van Wijngaarden, Schene & Koeter, 1996). This conclusion lead to the decision to find a scale structure that would fit both samples best.

A factor analysis on the core module items of the combined sample (N=940) was executed. The analysis resulted in a four-factor solution, which accounted for 59.6% of the total variance. Of the twenty-eight items that were entered in this analysis, twenty-five loaded greater than 0.40 on one of the factors. Items 14 (patient disturbed caregiver’s sleep) and 28 (caregiver felt burdened) loaded greater than 0.40 on two factors. Only item 21 (able to pursue own activities) had loadings lower than 0.40. The results of the factor analysis are presented in Table 2.1.
Table 2.1  Factor analysis on IEQ core items. Combined samples of relatives of patients with psychotic disorders (N=680) and caregivers of patients with affective disorders (N=260). Explained variance is 59.6%.

<table>
<thead>
<tr>
<th>#</th>
<th>Item</th>
<th>Tension</th>
<th>Worrying</th>
<th>Urging</th>
<th>Supervision</th>
</tr>
</thead>
<tbody>
<tr>
<td>15</td>
<td>Strained atmosphere</td>
<td>75</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Quarrels</td>
<td>75</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Annoyed by behaviour</td>
<td>72</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>20</td>
<td>Thought of moving out</td>
<td>67</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Felt threatened</td>
<td>57</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>Felt burdened</td>
<td>55</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Others were annoyed</td>
<td>49</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27</td>
<td>Worried about own future</td>
<td>42</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Disturbed sleep</td>
<td>41</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>Worried about patient’s future</td>
<td>73</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>22</td>
<td>Worried about safety</td>
<td>68</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>23</td>
<td>Worried about help/treatment</td>
<td>67</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>24</td>
<td>Worried about general health</td>
<td>65</td>
<td></td>
<td></td>
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<tr>
<td>25</td>
<td>Worried about finances</td>
<td>65</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>Felt burdened*</td>
<td>.49</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Encouraged activities</td>
<td>72</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Encouraged proper care</td>
<td>68</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Accompanied on outside activity</td>
<td>62</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Taken over tasks</td>
<td>60</td>
<td></td>
<td></td>
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<tr>
<td>13</td>
<td>Encouraged to get up in morning</td>
<td>57</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2</td>
<td>Helped with proper care</td>
<td>51</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>6</td>
<td>Ensured medication intake</td>
<td>50</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Encouraged to eat enough</td>
<td>44</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>8</td>
<td>Guarded from self-inflicted harm</td>
<td>.66</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Guarded from dangerous acts</td>
<td>.64</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>9</td>
<td>Ensured sufficient sleep</td>
<td>.60</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>11</td>
<td>Guarded from drug abuse</td>
<td>.54</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Disturbed sleep*</td>
<td>.52</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>10</td>
<td>Guarded from alcohol abuse</td>
<td>.49</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>Able to pursue own activities **</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Items loading greater than 0.40 on two factors
** Item loading less than 0.40 on any factor

The first factor, named tension, referred to the strained interpersonal atmosphere between patient and caregivers and relatives. The second factor, worrying, covered painful interpersonal cognitions, such as concern about the patient’s safety and future, general health, and health care. The third factor, urging, referred to activation and motivation, such as stimulating the patient to take care of himself, to eat enough, and to undertake activities. The fourth factor, supervision, referred to the caregiver’s tasks of guarding the patient’s medicine intake, sleep, and dangerous behaviour. Because of the clarity of the factor solution, these factors could be used as IEQ sub-scales, together with a 27-item overall consequences score. The IEQ sub-scales and core items are presented in Appendix III.
Applicability, validity and reliability of the IEQ

Applicability

The IEQ is a structured, easy to understand, and not time-consuming instrument. The entire set takes about twenty to thirty minutes to complete, and the IEQ core module alone about ten minutes. The IEQ can also be administered as a structured (telephone) interview. The good applicability is demonstrated by the high response rates and the high quality of the data. In the Dutch study among members of an organisation for relatives of psychotic patients, 1,000 persons received the questionnaire by mail. Response was 70.2 percent after two reminders, and of the 702 returned questionnaires only twenty-two were incomplete (Schee & van Wijngaarden, 1993). In our other study among caregivers of depressed patients, response was even higher, 81 percent, and only 2 out of 262 questionnaires could not be used due to missing data (van Wijngaarden, Schee & Koeter, 1996). The response rates in the EPSILON study are not exactly known. On average, in 70 percent of cases an IEQ was completed and returned. The actual response from the caregivers was higher because in some cases patients were not able to indicate a caregiver or they refused to name one. Also in the EPSILON study, only few questionnaires could not be used due to missing data, nine out of 288 (van Wijngaarden et al, 2000).

Validity

The Dutch samples

The validity of the IEQ was studied in the two samples that were also used in the factor analysis. The content validity proved to be satisfactory. The IEQ was based on two exhaustive literature and instrument reviews that delivered the domains and items needed to construct the instrument. After that the first versions of the instrument were tested several times en adapted accordingly. The content validity of the 1992 version of the IEQ was confirmed by a qualitative analysis of the open question, item 81, in which respondents were asked to add any issue that bothered, stressed or satisfied them in their relationship to the patient and was not covered by the IEQ. Although many caregivers used this question to express their experiences, the analysis of 680 questionnaires did not reveal missing domains or variables (Schee & Van Wijngaarden, 1993). In addition, the fact that separate analyses on the data of relatives of psychotic and depressed patients revealed factor structures that were very comparable.
to that of the combined sample, also can be considered as an indicator for content validity.

Construct validity could not be assessed properly because there were no other Dutch instrument on caregiver consequences that could be used as an external criterion. However, circumstantial evidence for satisfactory construct validity was found. The conceptual models presented in this chapter predicted a major role for patient's symptoms and symptom behaviour as independent variables, and variables such as caregiver's coping style, social support, and mental health-care system characteristics as mediators (Biegel, Sales & Schulz, 1991; Gallop et al., 1991; Maurin & Barmann Boyd, 1990; Schene, 1990; Szmukler et al., 1996). In both Dutch studies proofs for these models were found. First, in accordance with the models, in the sample of relatives of psychotic patients high IEQ scores could be predicted from the severity of patient's symptoms, 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. Also, a rather high correlation of 0.50 was found between the IEQ and caregiver's distress scores (Schene & van Wijngaarden, 1993).

Second, in the sample of caregivers of depressed patients comparable correlations were found. High IEQ scores could be predicted by a high level of patient's symptomatology, inadequate coping strategies, a lack of social support, and more time spent with the patient. Moreover caregivers of patients whose depression still was florid had higher IEQ scores than caregivers whose patients already were in treatment and were stabilised on medication. Although correlations were not as strong as in the other sample (explained variances ranged from 0.20 to 0.42), these findings matched the results from the first study (van Wijngaarden, Schene & Koeter, 1996).

Third, in a path-analysis on the first data set it was found that the caregiver consequences measured with the IEQ explained a substantial part of the relation between caregiver's distress and the patient, caregiver, and relationship characteristics (Schene, van Wijngaarden & Koeter, 1998). This finding is in concordance with the distinction made between objective and subjective caregiver consequences. As we also saw in the other analyses the 'objective' IEQ scores reflect the things a caregiver has to do as a result of the patient's illness. The path-analysis showed this caregiving is a precursor of subjective consequences (namely, caregiver's distress), which emphasises the conceptual relevance of the IEQ.
The European samples

The validity of the translations of the IEQ was studied in the EPSILON samples. In this study, 288 caregiver’s of patients with an ICD-10 (International Classification of Diseases) diagnosis of schizophrenia (World Health Organisation, 1992) completed an IEQ: 36 in Amsterdam, 30 in Copenhagen, 75 in London, 78 in Santander, and 69 in Verona. For further details on the EPSILON project see Becker and colleagues (1999, 2000) and van Wijngaarden and colleagues (2000).

The content validity of the IEQ translations proved to be good. The uniform, standardised, and well documented protocol, following World Health Organisation (WHO) regulations, ensured high-quality translations. In all focus group meetings it was concluded that the items of the IEQ were clear, that they covered the relevant domains of caregiver consequences, and that no important issues were missing (Knudsen et al., 2000).

The concept validity of the European IEQ versions also proved to be good. First, validity was tested by comparing the patterns of the mean IEQ item scores between the five countries. These patterns were almost identical, and they also matched the patterns found in the original Dutch studies. This means that in all countries, worrying about the patient’s health, future, safety, and financial position were the most frequently mentioned caregiver consequences, followed by the necessity to urge the patient to do something. Also in all countries, the need for supervision and interpersonal tension were mentioned least.

Second, concept validity was tested by means of a Simultaneous Components Analysis (Kiers, 1990). The SCA is a factor analysis that finds the best factor solution for more than one data set simultaneously, where the joint factor solution reflects the optimum fit for each of these data sets. The SCA factor solution proved to be very comparable to the original Dutch factors. This means that the underlying structure of the IEQ is stable in all sites (van Wijngaarden et al., 2003).

Reliability

The reliability of the IEQ proved to be satisfactory in the Dutch samples. The internal consistency (Cronbach’s alpha) ranged from 0.74 to 0.85 for the four sub-scales to 0.90 for the overall consequences score. Test-retest effects were not found, and the IEQ proved to be sensitive to change (van Wijngaarden, Schene & Koeter, 1996; Stam & Cuijpers, 2001).
In the EPSILON project reliability testing was one of the main objectives (Becker et al., 1999, 2000). Reliability was tested in two ways:

1. **Internal consistency.** Cronbach’s alphas were computed for each site separately and inter-site differences were tested.

2. **Test-retest reliability.** Intraclass Correlation Coefficients (ICCs) were computed and inter-site differences were tested.

Benchmarks were set to 0.70 for substantial reliability and 0.80 for high reliability. For more details on the reliability methodology see Schene and colleagues (2000).

Cronbach’s alphas and ICCs are presented in Table 2.2. The shaded areas represent reliability values that did not reach one or both benchmarks. The alpha values ranged 0.68 to 0.91. In twenty out of thirty cases (67%), reliability was high. However, in two cases, supervision in London and urging in Santander, the benchmark for substantial reliability was just not reached, both having a value of 0.68. Alpha testing between sites revealed that differences were significant only on the sub-scale urging. The alpha in Santander was lowest (0.68), that in London highest (0.86).

In all but one case (worrying in Verona, 0.69) test-retest reliability was substantial to high with a range of 0.70 to 0.99. The ICCs proved to be highest in Amsterdam, Copenhagen, and London, demonstrating good reliability. Although all reliabilities are substantial, in Santander the ICCs for supervision, worrying, and urging are somewhat lower compared to the sometimes very high values in the other sites. In none of the cases were both internal consistency and test-reliability below benchmarks.

Overall it can be concluded that the IEQ scales have a moderate to high reliability in all sites (van Wijngaarden et al., 2000). Combined with the good applicability and the satisfactory to good validity, the IEQ proves to be a useful instrument for the assessment of caregiver consequences in at least five European countries.
Caregiver consequences in the Netherlands and other European countries

Table 2.2 Internal consistency (α) and test-retest reliability (ICC) of the IEQ in the pooled sample and by site

<table>
<thead>
<tr>
<th>Sub-scale</th>
<th>Pooled</th>
<th>Amsterdam</th>
<th>Copenhagen</th>
<th>London</th>
<th>Santander</th>
<th>Verona</th>
<th>alpha equality test</th>
<th>ICC equality test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=335</td>
<td>N=88</td>
<td>N=30</td>
<td>N=75</td>
<td>N=78</td>
<td>N=64</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tension</td>
<td>α ICC</td>
<td>α ICC</td>
<td>α ICC</td>
<td>α ICC</td>
<td>α ICC</td>
<td>α ICC</td>
<td>p</td>
<td>p</td>
</tr>
<tr>
<td></td>
<td>.81</td>
<td>.78</td>
<td>.75</td>
<td>.80</td>
<td>.80</td>
<td>.84</td>
<td>.58</td>
<td>&lt;.01</td>
</tr>
<tr>
<td></td>
<td>.89</td>
<td>.92</td>
<td>.95</td>
<td>.97</td>
<td>.82</td>
<td>.88</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worthing</td>
<td>.84</td>
<td>.86</td>
<td>.84</td>
<td>.77</td>
<td>.83</td>
<td>.82</td>
<td>.55</td>
<td>&lt;.01</td>
</tr>
<tr>
<td></td>
<td>.84</td>
<td>.87</td>
<td>.93</td>
<td>.98</td>
<td>.78</td>
<td>.69</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urging</td>
<td>.79</td>
<td>.82</td>
<td>.71</td>
<td>.86</td>
<td>.68</td>
<td>.81</td>
<td>.03</td>
<td>&lt;.01</td>
</tr>
<tr>
<td></td>
<td>.89</td>
<td>.93</td>
<td>.80</td>
<td>.98</td>
<td>.73</td>
<td>.90</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supervision</td>
<td>.77</td>
<td>.80</td>
<td>.73</td>
<td>.68</td>
<td>.75</td>
<td>.82</td>
<td>.47</td>
<td>&lt;.01</td>
</tr>
<tr>
<td></td>
<td>.83</td>
<td>.87</td>
<td>.98</td>
<td>.97</td>
<td>.70</td>
<td>.82</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall score</td>
<td>.90</td>
<td>.91</td>
<td>.87</td>
<td>.89</td>
<td>.87</td>
<td>.91</td>
<td>.45</td>
<td>&lt;.01</td>
</tr>
<tr>
<td></td>
<td>.90</td>
<td>.94</td>
<td>.93</td>
<td>.99</td>
<td>.81</td>
<td>.86</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Differences were found between Amsterdam and Santander p<.001; London and Santander p<.001; London and Copenhagen p<.05; Santander and Verona p<.05

Caregiver consequences assessed with the IEQ

When and how to use the IEQ

The IEQ can be used in several ways, both as a research and a clinical instrument. Because of its modular composition, users can decide for themselves what information they want to collect. However, the core IEQ module should always be included in full in order to compute scales scores. The scope of the IEQ is rather wide. As a research instrument the IEQ can be used in large samples of caregivers to study the relations between caregiver consequences and population and community characteristics. As a clinical instrument the IEQ can be used for the evaluation of the effects of clinical interventions on the caregiver consequences.

In The Netherlands at this time (2001) the IEQ is used in several studies. One of these studies is an evaluation of the care for people with schizophrenia who are outpatients. In this study the caregiver consequences are compared to patient's needs for care and satisfaction with services. Another example is a study among young patients with schizophrenia who were admitted for the first time to a psychiatric hospital. The IEQ is used to evaluate the effects of family...
interventions. In a third study caregiver consequences are compared to measures of expressed emotion.

Depending on the objectives of the study, the IEQ can be scored in two different ways. For factor analysis and correlation studies with other instruments the five-point Likert scale is recommended. For other research purposes and in clinical use item scores are dichotomised to 'no consequences' (categories 'never' or 'sometimes' on the Likert scale), and 'real consequences' (categories 'regularly', 'often', or 'always' on the Likert scale). By doing this the sub-scale scores reflect the number of consequences that are experienced in that domain. Major changes in consequences can easily be detected when an item score changes from 'no consequences' to 'real consequences', or reverse. Collected data may also be interpreted on the item level, for instance, if specific consequences need to be monitored over time.

Consequences for caregivers of patients with a psychotic or affective disorder

As an example of an IEQ assessment, some data collected in the two main Dutch studies will be presented. Caregivers of patients with a psychotic (N=680) or an affective disorder (N=260) most often mentioned worrying as a consequence of caregiving, followed by urging and tension. In both samples supervision was scored least. Especially worrying about the patient's future were mentioned by more than 60% of the caregivers. Also, almost half regularly felt burdened. On the other hand, some consequences were rather rare. For instance, less than 3 percent regularly felt being threatened by the patient, and also less than 5 percent had thought of moving out or had to guard the patient from self-inflicted harm. However, this does not mean these consequences can be neglected. It means that in our samples twenty-nine caregivers at least regularly felt threatened by the patient, most probably a rather burdensing event for these individual persons (van Wijngaarden, Schene & Koeter, in press).

Although the pattern of scores was comparable in the two samples, many differences were found. All significant differences in core module items are presented in Table 2.3.
### Table 2.3 Consequences for caregivers of patients with psychotic disorders and affective disorders compared on dichotomised item scores and average scale scores

<table>
<thead>
<tr>
<th>Item</th>
<th>Percentage that a consequence occurs at least regularly (real consequences)</th>
<th>Psychosis sample (N=680)</th>
<th>Depression sample (N=260)</th>
<th>chi² test</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Encouraged proper care</td>
<td></td>
<td>29.6</td>
<td>7.5</td>
<td></td>
</tr>
<tr>
<td>2. Helped with proper care</td>
<td></td>
<td>6.0</td>
<td>2.0</td>
<td></td>
</tr>
<tr>
<td>4. Encouraged activities</td>
<td></td>
<td>44.4</td>
<td>35.3</td>
<td></td>
</tr>
<tr>
<td>7. Guarded from dangerous acts</td>
<td></td>
<td>9.4</td>
<td>4.0</td>
<td></td>
</tr>
<tr>
<td>9. Ensured sufficient sleep</td>
<td></td>
<td>10.6</td>
<td>16.3</td>
<td></td>
</tr>
<tr>
<td>11. Guarded from drug abuse</td>
<td></td>
<td>5.2</td>
<td>0.8</td>
<td></td>
</tr>
<tr>
<td>12. Taken over tasks</td>
<td></td>
<td>38.5</td>
<td>26.2</td>
<td></td>
</tr>
<tr>
<td>13. Encouraged to get up</td>
<td></td>
<td>19.6</td>
<td>12.3</td>
<td></td>
</tr>
<tr>
<td>17. Annoyed by behaviour</td>
<td></td>
<td>36.9</td>
<td>22.6</td>
<td></td>
</tr>
<tr>
<td>18. Others were annoyed</td>
<td></td>
<td>16.0</td>
<td>3.2</td>
<td></td>
</tr>
<tr>
<td>22. Worried about safety</td>
<td></td>
<td>40.0</td>
<td>25.0</td>
<td></td>
</tr>
<tr>
<td>23. Worried about help/treatment</td>
<td></td>
<td>44.1</td>
<td>26.5</td>
<td></td>
</tr>
<tr>
<td>25. Worried about finances</td>
<td></td>
<td>42.6</td>
<td>13.1</td>
<td></td>
</tr>
<tr>
<td>26. Worried about patient's future</td>
<td></td>
<td>76.9</td>
<td>43.5</td>
<td></td>
</tr>
<tr>
<td>28. Felt burdened</td>
<td></td>
<td>58.1</td>
<td>35.0</td>
<td></td>
</tr>
</tbody>
</table>

**sub-scales**

<table>
<thead>
<tr>
<th>average scale score</th>
<th>t-test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tension</td>
<td>8.0</td>
</tr>
<tr>
<td>Worrying</td>
<td>10.6</td>
</tr>
<tr>
<td>Urging</td>
<td>6.8</td>
</tr>
<tr>
<td>Supervision</td>
<td>2.2</td>
</tr>
<tr>
<td>Overall score</td>
<td>25.7</td>
</tr>
</tbody>
</table>

Significant differences were found on 15 core module EQ items. In all but one case caregivers in the psychosis sample had higher scores. Only in case of ensuring that the patient received sufficient sleep the caregivers in depression...
sample have a higher score. In some cases differences were quite large, especially on the worry items. In the case of psychosis, caregivers worried up to three times as often as caregivers of depressed patients. More than three-quarters reported that they had regularly worried about the patient's future. They and others in their neighbourhood were also more often annoyed by the patient's behaviour, and they far more often had to encourage the patient to take proper care of himself or herself. With these differences in mind, it is not a surprise that they almost twice as much felt burdened at least regularly. This was reported by more than half of the caregivers (van Wijngaarden, Schene & Koeter, in press).

As the caregiving models indicate, caregiver consequences are directly related to patient's symptoms and symptom behaviour. It was possible to distinguish four groups of patients in the depression sample: (1) recently hospitalised patients, (2) outpatients in treatment for less than three months, (3) outpatients in treatment for three to twelve months, and (4) outpatients in treatment for more than twelve months. It was expected that while the recently hospitalised patients and new outpatients had more severe symptoms than the other groups, caregivers from these groups would experience more consequences. This proved to be true, especially for the hospitalised group. Their IEQ item scores were at least equal and sometimes even higher than those found in the study among relatives of patients with a psychotic disorder (van Wijngaarden, Schene & Koeter, in press). They reported higher levels on strained atmosphere, quarrels, feeling annoyed, encouraging to eat and to undertake activities, accompanying the patient outside, take over tasks, and worrying about their own future. This finding was also reflected in the scale scores, where caregivers from the depression sample had higher scores on tension an urging, reflecting the situation of having to deal with a depressed person who lacks the energy to undertake activities.

Caregiving in Europe

In the EPSILON study inter-site differences in IEQ sub-scale and sum scores were found. The highest scores were generally found in Verona, and the lowest in Amsterdam and Copenhagen. In all cases the Verona scores were about twice as high as the Amsterdam and Copenhagen scores. Santander and London held an intermediate position. In Santander especially the worrying score was high, while in London a relatively high level of urging was reported. As the sites differed in percentages ethnic minorities, caregiver's coping, and living situation, an analysis of covariance was executed. However, after this correction differences between sites still existed (van Wijngaarden et al., 2003).
The differences in IEQ scores could not be explained from the available data, although all variables that were known to predict IEQ scores were entered in the analysis of covariance. It is possible that inter-site differences could be caused in part by unknown variables, but that probably is not enough to explain these differences. An explanation might lie in cultural differences. Cross-ethnic research on families of people with psychiatric disabilities in the United States showed that racial and ethnic differences were found on issues like causal attribution, prognostic expectations, kinship roles, and perceived family burden. In all studies it appeared that caregiver consequences were less in African American families when compared to white American families (Lefley, 1998). Although these differences in several cases were attributed to larger social networks and mutual aid systems, other researchers found just the opposite. Also, coping, self-esteem, and expectations regarding the patient's psychiatric disability were mentioned as predictors, but no clear explanations could be formulated. The only finding that remained stable was the lower scores in black families. In addition, almost all studies found that patients' behavioural problems, worrying, patients' dependency, and family disruption were significant predictors of burden both in black and in white families (Lefley, 1998). These findings are comparable to our results. While the caregiving concept was stable across cultures, differences could not be explained, even by the fact that ethnic minorities comprised up to 50 percent of the Amsterdam and London samples. Magliano and colleagues (1998) reported a certain north-south axis, which could be interpreted as the differences between the 'warm-blooded' Mediterraneans and the 'cold-blooded' Northerners, but no evidence on this has been found.

Conclusion

The role of caregivers in mental health provision has become increasingly important over the past decades. Deinstitutionalisation has brought many patients back to their original social network, which has led to an increase in caregiving provided by family members, partners, friends, or others involved. In case of affective disorders, caregivers mainly are partners (van Wijngaarden, Schene & Koeter, 1996). In cases of psychosis, caregivers mainly are mothers of young male patients who have a long history of illness. At the very least, it were those mothers who in many countries became members of family organisations that brought the consequences of caregiving under the attention of policy makers and society at large (Schene & van Wijngaarden, 1995).

With the increased interest in families of patients with a psychiatric illness, the need arose to assess caregiver consequences in order to be able to evaluate family interventions aimed at the reduction of negative and burdensome
consequences. The Involvement Evaluation Questionnaire was one of the instruments that were developed for these assessments. Not only in The Netherlands but all over Europe the need for a valid and reliable instrument was felt. And although the IEQ was originally developed in a relatively small country and worded in a language spoken by only about 20 million people, it has become one of the wider-used instruments in European research.

As was pointed out in this chapter, the IEQ is a sufficiently valid and reliable instrument for the assessment of caregiver consequences, it is sensitive to change, and it has the ability to discriminate between relatives of various patient groups. It is easy to administer and can be used both in research and for monitoring purposes. Also, the applicability is good, the response is very high compared to mailed surveys in general, and caregivers appreciate the fact that their situation is taken serious.

The four IEQ translations that were tested on their instrumental properties proved to be as good as the original Dutch version. This means that we have the disposal of an instrument with which we can compare caregiver consequences in countries with different mental health provisions, different rates of deinstitutionalisation, and different social security systems. However, as is also the case with many other instruments, IEQ ratings probably are influenced by cultural factors, and comparisons have to be made against the background of these factors. This means that local norm groups will have to be formed that will serve as culturally unbiased standards. This is not yet the case, and more international studies will be necessary. The availability of eleven different language versions will help to achieve this task.
References


Brown, G.W. & Rutter, M. 1966: The measurement of family activities and relationships. Human relations, 19, 239-263.


Kiers, H.A.L. 1990: SCA A program for Simultaneous Components Analysis of variables measured in two or more populations. Groningen: lect ProGAMMA.


Schene, A.H. & van Wijngaarden, B. (1993). Family members of people with a psychotic disorder, a study among members of Ypsilon [Familieleden van mensen met een psychotische stoornis: een onderzoek onder Ypsilonleden]. Amsterdam: Department of Psychiatry, University of Amsterdam.


Caregiver consequences in the Netherlands and other European countries


