Consequences for caregivers of patients with severe mental illness: the development of the involvement evaluation questionnaire
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Chapter 1

The development of the IEQ: A historical overview
A historical overview

Introduction

This thesis describes the development and psychometric testing of the Involvement Evaluation Questionnaire (IEQ), an instrument to assess the consequences of severe mental illness for the caregivers, mostly family members, of patients suffering from these illnesses. The development of the IEQ started in 1986 when an instrument measuring caregiver consequences was needed for a study in which full-time psychiatric hospitalisation was compared with psychiatric day treatment (Schene, 1992). It concerned one of the first Dutch experiments with partial hospitalisation in psychiatry.

This chapter contains an outline of the deinstitutionalisation process and the growing emancipation of caregivers, the emergence of family organisations in psychiatry, new visions on the roles caregivers play in relation to their relatives, and the need to study the caregiver consequences of psychiatric illnesses, which led to the development of the IEQ. Due to the fact that the IEQ has had several versions and adaptations over time, a brief historical overview of this development will be given, starting in 1987 with the construction of the first Dutch instrument to assess caregiver consequences, and ending in 2000 with the last adaptations on the final IEQ European Version.

A growing interest in caregivers

Since the early 1970s, in many Western countries there has been a growing interest in the role of caregivers of psychiatric patients. This was partly due to the start of the deinstitutionalisation of psychiatric care. Relatives of patients claimed that deinstitutionalisation caused disproportionately heavy burdens for them, since they (in many cases again) had to care for their ill loved ones (Schene & van Wijngaarden, 1995a). This deinstitutionalisation movement coincided with a number of other societal developments. One of those were the many emancipation and individualisation processes that started in the 1960s. Several (minority) groups began to draw attention to their position in society. Women were claiming equal rights, a youth subculture was emerging with its own rules, music, and dress codes, and coloured people and homosexuals were opposing discrimination. Also in psychiatry an emancipation movement among patients and their caregivers emerged (Wennink, 1998). This combination of deinstitutionalisation and emancipation led in many countries to the foundation of family self-help organisations, some already in the 1960s, such as France's Unité Nationale des Amies et des Familles des Malades Mentaux, some in the 1970s, such as the National Schizophrenia Fellowship in
Great Britain and the National Alliance for the Mentally Ill in the United States, and others in the 1980s, such as the Bundesverband der Angehörigen Psychisch Kranker in Germany (Schene & van Wijngaarden, 1995a). In 1997 at least 35 countries had one or more family organisations (Johnson, 1997).

The first family organisation in The Netherlands was founded in 1984. It started with a feminist meeting in a Rotterdam public library, where women were invited to talk about important issues in their lives. It appeared that a number of these women were dealing with children who suffered from psychiatric illness, and wanted to talk about the problems they met in caring for them. This observation led to the foundation of a self-help group for mothers of psychiatric patients. Later also the fathers joined in, and the family organisation Ypsilon was founded (Dercksen & van ’t Hof, 1996). The organisation was named Ypsilon, because the letter ‘Y’ (ypsilon in Greek) plays a marginal role in the Dutch language, just like the marginal role patients with psychosis play in society. The first members were very dissatisfied about the treatment patients received, and the way parents were blamed for causing their child’s illness. These relatives demanded good care for their children and rehabilitation for themselves. Over the years, Ypsilon’s aims have not changed much. The organisation brings relatives in contact with each other, offers them the possibility to exchange experiences, gives them support and information, and helps them to cope with their problems, their feelings of guilt, and stigma (Dercksen & van ’t Hof, 1996; Schene & van Wijngaarden, 1993a, 1995a).

Although the position of patients, relatives and other caregivers has improved over the years, Ypsilon is still growing, from 2,700 members in 1991 to 4,000 in 1993, and 7,000 in 2003. The issue of caregiving in case of physical diseases, addiction and psychiatry is also still a point of discussion, at least in The Netherlands. The ongoing deinstitutionalisation process, cutbacks in the funding of medical care, and shortages of trained nurses and other professionals have led to a further substitution from professional care into informal care, and policy makers and health insurance companies are looking for ways to support these informal caregivers. Two recently published reports stress the societal and political importance of informal caregiving. One report, written for the Dutch Health Care Insurance Board, focuses on the recent developments in caregiving and the effects of caregiving on the treatment of patients suffering from psychiatric illness or addiction (Geelen, 2003). The other report, written for the Dutch Social and Cultural Planning Office, focuses on all informal carers in The Netherlands, including those of patients with somatic diseases, and deals with the cost of informal care, the effects of informal care on the take-up of professional health services, and the need to provide support among the providers of informal care (Timmermans, 2003).

The emancipation process of psychiatric patients and their carers has been accompanied by a new perception of the roles of relatives and others involved.
In stead of solely being considered as the instigators of psychiatric illness, especially schizophrenia, caregivers were considered to play a set of mutually connected roles. The first role is that of the caregiver, someone who cares for a loved one, who gives support and protection, and who wants the best professional help for their relative. The second role is that of the 'victim', someone who has to cope with the consequences resulting from caregiving, such as feelings of guilt, stigma, fears and worries, household disruptions as a result of patient's behaviour, or being cut off from own social contacts and activities (Schene & van Wijngaarden, 1995b). These two roles are the ones that family organisations mainly focus on.

A third role refers to the effects the emotional attitudes of caregivers themselves can have on the functioning of the patients, and on the course of psychiatric illnesses. A well-known construct in this context is Expressed Emotion, which can be defined as a set of family behaviours directed towards the patient. This set consists of criticism, hostility, emotional overinvolvement, warmth, and positive attitudes. Studies showed that in high EE families, where one or more of the first three attitudes dominate, there is a more than three time higher chance on relapse than in low EE families, and in fact EE turns out to be a better predictor of relapse than any other disease or environmental characteristics (Kavanagh, 1992; Linszen et al., 1996, 1997; Parker & Hadzi-Pavlovic, 1990). These and other similar findings led to the development of psycho-education programs and family interventions in order to assist caregivers in obtaining a better understanding of the illness, and to help them to cope better with the (stress) of the disease. The goals of these interventions are informing caregivers on the incomprehensible and frightening aspects of psychiatric illnesses, lowering family EE in order to prevent relapse, and learning new strategies to cope with psychiatric illness (Falloon et al., 1985; Goldstein et al., 1978; Leff et al., 1982; Linszen, 1993; Tarrier et al., 1988).

The need for an instrument

In response to deinstitutionalisation and emancipation processes in society, professionals also on a scientific level began to stress the importance of the social environment of patients with severe mental illness, and the consequences caregiving could have for patients' relatives (Schene, 1986). To study these consequences several instruments have been developed since the 1960s, most of them in the United States and Great Britain. The need for a Dutch instrument to assess caregiver consequences arose when, in 1986, a study was prepared in which full-time psychiatric hospitalisation was to be compared with day treatment or partial hospitalisation. Although it was expected that the latter, compared with full-time hospitalisation, would lead to better outcomes
on social functioning, quality of life, and sense of mastery (Schene et al., 1993), there also were concerns about the fact that family members or other caregivers would have to continue caring for their ill relatives. Patients would spend their evenings and weekends at home, and the question was to what extent caregivers would experience consequences that could counteract the expected positive effects of partial hospitalisation (Schene et al., 1993). Since none of the instruments developed elsewhere were translated in Dutch, and also no original Dutch research instrument was available, it was decided to develop one.

This scientific interest in studying caregiver consequences paralleled the growth (and growing influence) of the family movement in The Netherlands, and the development of the instrument was done in the context of these developments in society. It was decided not just to focus on a suitable instrument but to also give a broad description of the concept of caregiver consequences (or family burden). An extensive literature search done in 1986 was published in a book with the objective to inform scientists, as well as policy makers, professional and patient’s relatives (Schene, 1986).

The instrument developed for the study on partial hospitalisation, which was named the Burden on the Family Scale (BOF; Schene, 1987), was based on the literature search, and covered a broad range of caregiver consequences in a target group of patients with mixed psychiatric disorders, in particular psychosis. It focused solely on relatives or other caregivers who shared a household with the patient. The results of the study showed that the emphasis on only household members limited the applicability of the BOF. In The Netherlands, patients frequently live on their own in their own houses (van Wijngaarden et al., 2003), but they often still spend a considerable amount of time with their relatives. In these cases where also (a lot of) caregiving takes place, the consequences of caregiving could not be assessed.

This limitation and the other results from the partial hospitalisation study led to a series of adapted versions of the instrument. First, psychometric less optimal items were deleted, and other items were rephrased in such a way that they covered the caregiver consequences resulting from severe mental illness for caregivers who had at least one hour per week contact with the patient. This made the instrument applicable for use in a broad range of situations. To further broaden the scope, based on a new literature search, additional items were added in order to make the instrument also applicable for use in samples of caregivers of patients with depression. These adaptations finally resulted in an instrument, which was named the Involvement Evaluation Questionnaire (IEQ; Schene & van Wijngaarden, 1992). This IEQ was tested in a study among 1000 members of the family organisation Ypsilon. Factor analysis on the data from this study resulted in four sub-scales: tension, urging, worrying, and
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supervision (Schene & van Wijngaarden, 1993a). In Appendix I the 1992 version of the IEQ is presented.

Since 1992 there have been several adaptations of the IEQ (see Figure 1.1). The major adaptations concern: (1) a new scale structure (1996), based on a combined sample of caregivers of patients with psychosis or depression, (2) the European (EU) IEQ versions of 1997, in which the original caregiver’s distress items were substituted by the 12-item General Health Questionnaire (GHQ-12: Goldberg & Williams, 1988), and the structure and lay-out of the questionnaire changed (see Appendix II for the final 1997 IEQ-EU version), and (3) a new scoring method was devised (2000). This means that papers and reports that were published throughout the years are based on different versions of the IEQ. Although the adaptations did not lead to large differences in results, reported data will vary across the papers that are referred to in this thesis.

This thesis does not cover all versions of the IEQ. Studies on earlier versions, and studies that used the old scale structure were published elsewhere, (Schene, 1992; Schene & van Wijngaarden, 1993a, 1993b, 1994, 1995a; Schene, van Wijngaarden & Koeter, 1998; van Wijngaarden, Schene & Koeter, 1996). This thesis mainly describes the research and developments since 1996.
Figure 1.1 Development of the IEQ

1987

**Burden On the Family scale (BOF):** only applicable for caregivers sharing the same household.

- **Domains:** daily activities, domestic strains, caregivers distress, disruption of social contacts, additional expenses, work and leisure time, effects on children.
- **Diagnostic target groups:** mixed psychiatric disorders, in particular psychosis.

1992

**Involvement Evaluation Questionnaire (IEQ) Dutch version:** applicable for all who are in contact with the patient at least one hour per week, adapted for use in depression samples.

- **Domains:** items on worrying added, social contact items deleted.
- **Scaling:** four sub-scales (tension, urging, worrying, supervision) based on factor analysis on a sample of relatives of patients with psychosis (mainly schizophrenia).
- **Diagnostic target groups:** psychosis and mood disorders.

1993

**Involvement Evaluation Questionnaire (IEQ) English version:** authors' translation based on the Dutch version, no changes in domains or items. (See Appendix I).

1996

**New scale structure:** based on a combined sample of caregivers of patients with psychosis and mood disorder. The four sub-scales remain, but with different item content.

1997

**Translations in English, Danish, Italian and Spanish (IEQ-EN versions):** translations following the WHO protocol (translation and backtranslation, focus groups).

- **Adaptations:** changes in order of items, changes in wording of items, adaptations in instructions, caregivers' distress items substituted by GHQ-12.
  (See Appendix II).

2000

**Changes in scoring:** sub-scale scores are no longer computed using the original 5-point Likert scale (1 = never, 2 = sometimes, 3 = regular, 4 = often, 5 = always), but dichotomised scores (0 = never or sometimes, 1 = regular, often or always).
  (See Chapter 7).
Content of this thesis

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

Chapter 2 was written on request as an overview of the development and testing of the IEQ. It describes the concept and domains of caregiver burden, and summarises the bulk of research that has been conducted between 1986 and 2000. Some data presented in this chapter are discussed in detail in the other chapters of this thesis.

In Chapter 3 the results of the reliability testing of the IEQ are presented. This study was done in five European countries (UK, Denmark, Italy, Spain, and The Netherlands) using the 1997 EU-versions of the IEQ (Becker et al., 1999). This study focused on the caregivers of patients (mainly outpatients) with an ICD-10 diagnosis of schizophrenia.

In the European study substantial inter-country variability in IEQ scores was found. In Chapter 4 these differences between countries will be studied in detail, with the objective to assess the validity, and especially the cultural validity, of the five IEQ-EU language versions.

Chapter 5 focuses on the consequences for caregivers of patients with depression, and the validity of the IEQ as an instrument to measure the caregiver consequences of depression. The analyses are based on a study conducted in 1994 in a sample of caregivers of mainly outpatients with depression. This study was published in 1996 (van Wijngaarden, Schene & Koeter, 1996). For this chapter the data were re-analysed using the 1996 scale structure and 2000 scoring method.

In Chapter 6 the results of the depression study are compared with the results of the European study on outpatients with schizophrenia. The main question posed in Chapter 6 is in what sense the caregiver consequences of depression differ from caregiver consequences of schizophrenia.

In Chapter 7 all available data on the validity, reliability and applicability of the IEQ are discussed in detail. The results from the studies that were presented in the other chapters of this thesis will be completed with the findings published in all other papers and reports on the IEQ. Special attention will be given to the
content validity, the way concepts were translated into items that cover the caregiving domains, and the way the instrument was constructed. The chapter will conclude with a discussion of the applicability of the IEQ, its limitations, and recommendations for further development and research.
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