Comparing the consequences of caregiving across countries for a person with a serious mental illness needs to take into account not only different languages, but also different cultures, quality of mental health services and standards of living. So far, one questionnaire has shown the most validity and become the exemplar in cross-national research; yet it is still not free from possible cultural bias or criticism from its creators who acknowledge that much more research needs to be done.

Psychiatric research in Europe has always been hindered by the multitude of countries, each with their own language, their own mental health care system and their own cultural traditions. For instance, the European Union (EU) consists of 15 countries, in which 11 official languages are spoken. In the course of 2004, 10 new countries, most from Eastern Europe, will join the EU, adding another seven languages. It is not only this diversity in languages, but also the differences in mental health care systems, standards of living and locally developed research instruments that are often used that make it difficult to compare data between EU countries.

In order to improve scientific quality, the European Network for Mental Health Service Evaluation (ENMESH) was established in 1991 to promote the development and dissemination of study designs, research instruments, mental health outcome indicators and relevant forms of statistical indicators. At the first ENMESH conference in Amsterdam, the Netherlands, in 1994, it was decided to initially focus on five topics that were considered to be important in evaluating psychiatric care for patients suffering from severe mental illness: quality of life, need for care, client satisfaction, costs of services and consequences for patient's caregivers.

In 1996, this initiative led to the EPSILON project (European Psychiatric Services: Inputs Linked to Outcomes and Needs) in England, Denmark, the Netherlands, Italy and Spain, in which research instruments for these five topics were translated and tested in a population of mostly outpatients (Becker et al., 2000). The Involvement Evaluation Questionnaire (IEQ) (Schene and van Wijngaarden, 1992) was chosen as the instrument to assess caregiver consequences. The IEQ was translated according to World Health Organization regulations and tested in focus groups, and it proved to be sufficiently valid and reliable in all sites (van Wijngaarden et al., 2000). In this report, special attention will be given to the applicability of the IEQ in cross-national research.

The IEQ is an 81-item questionnaire to be completed by the caregiver, covering events from the prior four weeks. The IEQ consists of seven sections, which take about 20 to 30 minutes to complete. The core section contains 31 items on caregiver consequences. They can be summarized into four scales (Table 1). In addition, a 27-item total score can be computed. The other six sections of the IEQ are: sociodemographic data of patient and caregiver (15 items), a cost section (eight items), the 12-item General Health Questionnaire (GHQ) (Goldberg and Williams, 1988), caregiver’s use of professional help (three items), consequences for patient's children (11 items), and one open question for comments and additions.

Possibility of Cultural Bias

The cross-cultural applicability of the IEQ translation was checked and adapted in local focus groups meetings (Knudsen et al., 2000), and its conceptual validity was checked with Simultaneous Component Analysis (Kiers, 1990). These analyses proved that the IEQ assesses caregiver consequences in all countries in the same way (van Wijngaarden et al., 2003). The introduction, which explains the scoring system, was checked on cultural validity in each translation and focus group process. Despite this good validity, nothing was known of a possible cultural bias. Caregiver consequences might be affected by cultural factors. Cross-ethnic research on families of people with psychiatric disabilities in the United States found racial and ethnic differences on perceived family burden (Lefley, 1998), indicating the existence of culturally induced response tendencies. In order to study possible cultural bias, the EPSILON data were re-analyzed.

Method and Results

The five EPSILON samples consisted of 288 caregivers of patients with a diagnosis meeting ICD-10 schizophrenia criteria (F20-F25). The samples were compared on patient characteristics (e.g., age, sex, education, psychiatric symptoms and disabilities), caregiver characteristics (e.g., age, sex and...
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net income), characteristics of patient-caregiver contact (e.g., number of days lived together) and site differences. These sample characteristics were used as covariates to calculate adjusted IEQ means scores.

In Table 2, the mean sub-scale scores are presented (unadjusted scores). Analysis of variance showed that the five sites differed significantly on all scales. In all, the London, Santander, Spain, and especially the Verona, Italy, respondents reported higher levels of caregiver consequences, and respondents in Amsterdam and Copenhagen, Denmark, reported the lowest.

The sample analysis revealed considerable differences between sites pertaining to patient's age, ethnic minority, caregiver's coping and living situation. Amsterdam and London have the largest percentages of minorities, and in London the patients are older and have a longer psychiatric history. In Verona, caregivers are less able to cope with the mental disease. In Northern Europe (London, Amsterdam and Copenhagen), many patients live on their own and have less contact with their caregivers. In the Mediterranean sites (Verona and Santander), most patients live with their relatives and therefore have more contact with caregivers.

The sites also differed in some general sociodemographic characteristics, such as percentages of married people, unemployment, single-parent families and service provisions, such as number of psychiatric hospital beds (Becker et al., 2002, 2000).

The IEQ scores are known to be correlated with several patient and caregiver characteristics and with characteristics of their relationship (Schene et al., 1998). To correct for these characteristics, adjusted IEQ scores were computed (Table 2). The differences in adjusted mean IEQ scores between sites were somewhat smaller than the unadjusted means, but the overall picture remains the same.

Cultural Applicability
The IEQ has a high validity and reliability in all language versions (van Wijngaarden et al., 2003, 2000). The underlying structure of the IEQ is stable in all sites and is identical to the original Dutch IEQ. In all, the IEQ can be considered to be a valid instrument to assess caregiver consequences in all countries, and the possibility of an instrument bias seems to be unlikely.

It was expected that sample characteristics could explain the level of IEQ scores across sites. However, adjusting for these variables only marginally affected the IEQ scores. A possible explanation for the still existing differences could be that the IEQ scores were influenced by variables that were not assessed, such as social support, coping, personality and stigma. However, since the sites still differed considerably after correction, it is questionable whether these variables would completely explain these differences.

A second explanation could be differences in the quality of local mental health care provisions. In case of low-quality services, caregivers might be forced to do more for the patient. However, although the quality was not assessed, the known differences in mental health care provisions could not explain the differences between sites.

This leaves the possibility of culturally induced response tendencies. The relationship between cultural background and caregiver consequences in our study, however, was not apparent. The up to 50% ethnic minorities in Amsterdam and London, opposed to almost 0% elsewhere, could not explain site differences. This means the presence of cultural bias is still unknown and should be studied further.

Alternative Instruments
Schene et al. (2001) identified 19 other family burden instruments and analyzed them on content, coverage of important domains, and psychometric properties. Because two instruments were developed for depression research, the remaining 17 are presented in Table 3. This table shows the year of origin, type, number of items, time to complete, main domains, applicability, the availability of reliability and validity data (+, =/- and -), and the number of translations. Finally, in a MEDLINE literature update in February, we checked whether there were publications in which these instruments were used. The table shows that some instruments focus on special domains, such as grief, that on several there have not been recent publications, and that others are insufficiently validated. When those are eliminated from consideration, the six alternative instruments in the shaded areas remain. Researchers should choose an instrument according to their personal research preferences (type, length, domains).

For international research, three instruments are available. The Family Problems Questionnaire was used in a European project similar to the EPSILON study (Magliano et al., 1998). The original Italian questionnaire was translated into German, English, Greek and Portuguese. Although this instrument was well validated in Italy, to our knowledge no cross-national validation data were published. Recently, the Perceived Family Burden Scale was translated into Chinese and Spanish, and the Family Burden Scale in Spanish (Mat'as-Carrelo et al., 2003; Tsang, 2001). The psychometric properties of the translated versions have yet to be ascertained.
Therefore, although alternatives for the IEQ are available, only the IEQ has been fully validated in all language versions in cross-national research. However, researchers should be careful in their interpretation of their findings across countries, since cultural bias cannot be ruled out.

References: References
10. Schene AH, van Wijngaarden B (1992), The Involvement Evaluation Questionnaire. Amsterdam, the Netherlands: Department of Psychiatry, University of Amsterdam.

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