Quality of life and needs for care of patients with schizophrenia
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Summary
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Schizophrenia is a chronic psychiatric illness that often causes severe limitations in everyday functioning. In spite of ongoing improvements in the pharmacological treatment of the disorder, many patients suffering from this illness experience life long consequences on their daily living that extend to many different life domains. In this thesis we study the consequences of schizophrenia on the lives of patients suffering from schizophrenia and their caregivers. Our main aim was to provide more clarity about the conceptualisation of quality of life and needs for care in schizophrenia, to study the interrelatedness of these concepts as well as their relationship with illness severity and other patient characteristics.

The results of the study provide valuable information with regard to:
1. The Quality of life (QoL) and needs for care of patients with schizophrenia in two regions in The Netherlands, an urban and a more suburban region.
2. The identification of mental health care aspects that should be improved in order to reduce the unmet needs of patients with schizophrenia and to improve their quality of life.
3. The stability of QoL and needs for care within an 18-month period.
4. Feasibility, validity and reliability of several instruments developed to measure these concepts within the context of mental health service evaluation.
5. Understanding the relationship of these concepts with illness consequences and other patient- and external factors.

In chapter 1, the introduction of this thesis, we address the effect of schizophrenia on patient’s functioning and provide an overview of developments in health care for patients with schizophrenia during the last decennia. Further, we introduce the EPSILON multicenter study on schizophrenia, a study that preceded and partly overlaps the present study. The aims of this multicenter study were: 1. To produce standardised versions of four key research instruments measuring the concepts needs for care, consequences for informal carers, service satisfaction and QoL; 2. To compare the characteristics of people with schizophrenia and their carers in these five countries; 3. To investigate relationships between the four concepts mentioned; and 4. To compare results from this study in the five participating countries.

Instrument description as well as the study results are summarised in chapter 1.

The Dutch part of the EPSILON study comprised of 61 patients from Amsterdam. The Dutch extended study, which is the basis of the remainder of this thesis, had four additional aims: 1. To compare an urban and a more suburban area; 2. To assess the longitudinal stability of needs, QoL and relationships between these concepts over time; 3. To compare different operationalizations of QoL; and 4. To investigate in more detail relationships between the above described concepts (needs for care, QoL and caregiver consequences) and their respective relationships with patient- and illness characteristics.

To do so a sample of patients from a more suburban catchment area (West Friesland) was added to the urban Amsterdam sample of the EPSILON study. Both the Amsterdam sample and the new sample were assessed twice within an 18-month time interval. Finally, another QoL instrument (the MOS Short Form-36) was added to the instruments covered in the EPSILON study.

We included in both regions a total of 143 patients that fulfilled the following criteria: patients were aged between 18 and 65, inclusive; had an ICD-10 F20 diagnosis (schizophrenia),
and had been in contact with mental health services during the 3-month period preceding the start of the study. Exclusion criteria were patients residing in prison, secure residential services or hostels for long-term patients; co-existing learning disability (mental retardation); primary dementia or other severe organic disorder and extended in-patient treatment episodes longer than one year.

Results from the EPSILON study on schizophrenia confirmed the adequate psychometric properties and the validity of a set of instruments covering the concepts Quality of Life (QoL), Needs for Care, Caregiver Consequences and Service Satisfaction in the five participating countries. With regard to the comparison of the two Dutch sites, overall we concluded that illness severity in the suburban West Friesland sample was slightly higher compared to the urban Amsterdam site. West Friesland patients also reported more (unmet) needs for care and a worse health related QoL on three of the eight domains. Since the differences between the populations of the urban and the suburban site were relatively small, we decided to pool the data to gain power for the analyses described in the next chapters.

In chapter 2 we investigate and compare two QoL instruments stemming from different traditions and theoretical frameworks, the extended Dutch version of the Lancashire Quality of Life Profile (LQoLP) and the MOS Short Form-36 (SF-36), on reliability, feasibility and conceptual overlap in a group of schizophrenic outpatients. The LQoLP, an interview, measures general subjective QoL (life satisfaction) as well as objective QoL indicators on different life domains. The SF-36, a questionnaire, is a generic QoL instrument that focuses on health related QoL. Feasibility and reliability for both instruments were satisfactory. A second order factor analysis on the ten LQoLP and eight SF-36 scales resulted in three factors: a health related QoL factor and two general QoL factors (an 'internal' factor and a factor reflecting more 'external' (circumstantial) aspects of QoL). The study showed that the LQoLP and SF-36 can both be reliably used in a sample of (ambulatory treated) patients with schizophrenia. However, the choice for a particular instrument may have serious implications for outcome, as the two instruments appear to reflect in part different underlying QoL constructs.

In chapter 3 we elaborate further on the conceptualisation of QoL and predictors of QoL in patients with schizophrenia. We assess which patient- and illness characteristics best predict the general QoL of patients and to what extent this relationship is mediated by patient's health related QoL. Lower general QoL was predicted mainly by a higher level of anxiety and/or depression and by lower self esteem. Social integration variables predicted only a relatively small proportion of the variance in general QoL. Health related QoL proved to be an important mediator of the relationship between both symptomatology and self esteem versus patient's general QoL. The results of this study improve our understanding of the relationship between both conceptualisations of QoL. In addition this study provides information to clinicians with regard to determinants of the QoL of their patients, which might help them focus their interventions (for example by paying attention to their patient's mood and self esteem).

Another concept that has gained an important place in mental health service evaluation is patient's needs for care. Contemporary community mental health care services for people with long term mental disorders try to cover their patient's needs for care on a broad area of life domains. Our assumption was that the number of (perceived) needs for care of a patient in combination with the extent to which these needs are met by professional caregivers is related in some way to a patient's perceived QoL. In chapter 4 we study changes in (un-
needs of our patient group over an 18-month time interval and investigate whether patient’s needs for care are related to their subjective QoL. The Camberwell Assessment of Need (CAN) was used to measure needs for care; QoL was measured by the Lancashire Quality of Life Profile (LQoLP).

Patients reported most unmet needs on the domains ‘social needs’ and ‘health needs’. The overall proportion of unmet needs decreased on the majority of the CAN domains after an 18-month time interval. Information about individual dynamics in unmet needs revealed important additional information with regard to the ratio of persistent and transient unmet needs for the domains of the CAN. QoL was related to the total number of unmet needs, to the ratio of unmet / total needs, and to unmet needs on several individual domains. All associations were in the expected direction. However, associations between changes in needs and changes in QoL were non-significant. This study reveals that dynamics in needs for care at an individual level can be far more diverse than appears from a comparison of prevalence ratings at two different time points. The fact that (persistent) unmet needs tended to be associated with a worse subjective QoL suggest them to be important potential targets for intervention. However this conclusion is somewhat tempered by our finding that the relation between changes in needs for care and changes in QoL was not statistically significant. Larger studies are needed to give more detailed information about dynamics in longitudinal relationships between QoL and needs for care.

In chapter 5 we studied the effect of needs for care on consequences experienced by the informal caregivers of the patients. Where schizophrenia often has far reaching consequences for the lives of the patients, taking care of a family member or friend with this illness often also has an impact on the lives of these caregivers. We investigate whether needs for care of patients with schizophrenia were related to (negative) consequences for their informal caregivers. All patients and informal caregivers who participated in the EPSILON study of schizophrenia in five European countries were included, 285 in total. Caregiver consequences were measured by the Involvement Evaluation Questionnaire (IEQ) and needs for care by the Camberwell Assessment of Need (CAN). Higher levels of patient needs were associated with higher levels of caregiver consequences and some types of patient needs like ‘health needs’, ‘basic needs’ and ‘functioning needs’ were better predictors of caregiver consequences then others (‘social needs’ and ‘services needs’). The distinction between met and unmet needs did not have much influence in this respect. Of the four caregiving domains studied, ‘worrying’ and ‘urging’ were more related to the level of (met and/or unmet) needs than the domains ‘tension’ and ‘supervision’. Finally this study showed that the amount of informal care patients mentioned to receive from their informal carers is modestly related to the caregiver consequences mentioned by the informal carers. All relationships found, although statistically significant, were only weak in terms of explained variance. This indicates that differences in patient needs only explain a limited fraction of differences in caregiver consequences as assessed with the IEQ.

Chapter 6 focuses on the psychopathological heterogeneity of our sample of outpatients with schizophrenia and on associations of symptoms with patient- and service variables as well as needs for care and QoL. We explore the existence of clinically meaningful patient groups within our representative sample of outpatients who had been in regular contact with mental health services and who were generally considered to be in a stabilised phase of their illness. We used two different methods to construct subgroups of patients based on similarity in symptom patterns: an empirical method (cluster analysis) and a method based on a-priori defined criteria. The relative homogeneity of our patient group in terms
of symptomatology and the modest variance limited the interpretability of patient groups resulting from cluster analysis: differences in average subscale scores between the clusters were, although statistically significant, marginal. Furthermore the patient clusters were not mutually exclusive in terms of discriminating characteristics. The second method used a-priori defined criteria with regard to symptom scores. We constructed four patient groups based on clinically relevant symptoms (at least one BPRS item score of ≥ 4, indicating moderate to severe pathology): a group with no clinically relevant symptoms, one with only negative symptoms, a group with only positive symptoms and a group with both positive and negative symptoms. Because the a-priori patient group allocation offered the most straightforward clinical interpretation, we decided to continue only with the 4 a-priori groups. These groups were subsequently described in terms of overall functioning, QoL, service use and needs for care as well as socio-demographic characteristics. We expected patient groups with more severe symptomatology to show lower average levels of functioning, worse QoL and more (unmet) needs for care. With regard to general and health related QoL our results were generally in the expected direction: patients without clinically relevant positive and/or negative symptoms reported more favourable QoL compared to the other groups, whereas QoL with regard to general health, mental health and social functioning was lowest for the group with both positive and negative symptoms. Differences between the four groups with regard to the total level of subjective needs for care were in line with scores on functioning and QoL. Patients with low overall symptomatology reported the lowest overall number of needs for care. Patients with both positive and negative symptoms reported most unmet needs. The latter group reported a substantial number of unmet needs on the domain ‘physical health care’ suggesting that their mental as well as their physical health may be more impaired. Treatment of psychotic symptoms as well as overall psychological wellbeing was regarded as insufficient by a majority of the patients with clinically relevant positive symptoms. We found that patients with negative symptoms seem to be in need of more help with self care and personal hygiene compared to the other groups. No significant group differences were found for other basic need domains (such as accommodation, food etc.), daytime activities and social contacts.

In the final chapter we reflect on the results from the 5 studies described in this thesis. We elaborate on the concepts QoL and needs for care, their different theoretical and conceptual backgrounds as well as their history in psychiatry research. We also discuss several methodological issues such as the level of score aggregation, the influence of adaptational processes and response shift on subjective constructs as QoL and needs and we give some recommendations with regard to the choice of a particular QOL instrument. Further we reflect on strengths and weaknesses of the study and on clinical implications with respect to improvements in mental health care for patients with schizophrenia. We conclude by providing several suggestions for future research.