Quality of life and needs for care of patients with schizophrenia
Meijer, C.J.

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General discussion
7.1 Introduction

In this thesis we studied two concepts that have become an important focus of health and health care evaluation among patients with long-term mental illness: their needs for care resulting from the illness and their experienced quality of life (QoL). These concepts were addressed in a group of patients with schizophrenia, one of the most serious psychiatric illnesses because of its chronic course, its consequences that stretch to a wide variety of life domains, and the enormous impact on patient's overall social and societal functioning.

The aims of QoL and needs measurement in a mental illness as schizophrenia can be various: to inform policy decision making, guide allocation of services, evaluate effects of policy or service program implementations, evaluate mental health interventions, determine QoL differences between groups as well as to evaluate on an individual patient level. Achieving acceptable levels of QoL and wellbeing is not only considered to be important for the patient but also for treatment motivation and adherence, as well as for the planning of treatment goals (1,2,3,4). The illness, however, not only affects the lives of the patients, but also impacts on the lives of the informal caregivers of these patients, like parents and spouses. Consequences experienced by these caregivers are also relevant for treatment planning and evaluation.

7.2 Research questions

In spite of an increased popularity and ongoing number of studies on QoL and needs for care several scientific gaps existed at the time this study started, namely:
1. Definition and conceptualisation of the concepts needs for care, QoL as well as consequences for patient's informal caregivers;
2. A lack of reliable, feasible and culturally adapted instruments to evaluate and compare outcome in different countries;
3. Relations between the concepts and relations with patient- and external variables. Part of these questions were addressed by the EPSILON Study on schizophrenia, a study preceding and in part overlapping with the study described in this thesis (5,6). The EPSILON study resulted in a package of instruments (7,8,9,10,11,12,13,14) covering different concepts important for mental health service evaluation. The psychometric properties of these instruments proved to be satisfactory. The international character of the study allowed comparisons between five sites from different countries with regard to concepts as QoL and needs for care (15,16). These results were summarised in the introduction of this thesis.

In The Netherlands an additional study was carried out following the EPSILON study described above. The aims of this Dutch extended study described in this thesis were:
1. To make an urban / non-urban comparison with the Amsterdam sample that was part of the EPSILON study by adding a population from a suburban catchment area;
2. To investigate the stability of needs and QoL over time by adding a second assessment after an 18-month time interval;
3. To compare two QoL instruments regarding reliability, feasibility and underlying structure;
4. To determine in more detail relations between needs for care, QoL and caregiver consequences and their respective relationships to patient- and illness characteristics.
The first question was addressed in the introduction of this thesis. In chapter 2 we addressed the concept and measurement of QoL by comparing a general and a health related QoL instrument stemming from different traditions. These instruments were evaluated in terms of feasibility, reliability and validity and to what extent they actually reflected different dimensions of the QoL construct. In chapter 3 we constructed a prediction model of QoL. Associations of several patient- and illness characteristics with QoL were investigated. We also studied to what extent the variance in general QoL explained by these predictors is mediated by health related QoL. In chapter 4 we focused on needs for care and on the stability of individual needs over an 18-month time period. Additionally associations between (changes in) the overall level and specific types of needs and QoL were assessed. In chapter 5 we extended our study on needs for care to caregivers, by investigating associations between needs of patients and the consequences experienced by their informal caregivers. We studied whether specific types of needs experienced by patients are associated with specific caregiver consequences. In chapter 6 patient profiles were constructed based on symptoms patterns by means of both cluster analysis and a-priori defined criteria for the construction of patient groups. Subgroups resulting from the latter analyses were accordingly compared on functioning, service use, QoL and needs for care.

In this final chapter we first summarize and discuss the concept of QoL and its history in psychiatry research, followed by a discussion of the results of chapters 2 and 3 on the comparison of two QoL instruments and predictors of QoL. We discuss some methodological issues and give several recommendations with regard to QoL measurement in schizophrenia. Next we focus on the concept of needs for care and discuss our studies on the stability of needs over time and its respective relationships with patient’s QoL and subjective caregiver consequences. Here also some methodological issues are discussed and recommendations are given. In paragraph four we discuss the results of chapter 6, dealing with the construction of symptom profiles and the comparison of patient groups resulting from this on the above described concepts. In paragraph five we elaborate on the strengths and the limitations of this study and on its clinical implications. In the final paragraph we give some suggestions for future research.

7.3 Quality of life

The major goal of contemporary mental health services for patients with schizophrenia is to maintain function, to promote rehabilitation and to maximise quality of life (QoL) (17). The history of QoL measurement in psychiatry has a tradition of about 30 years. However, it took until the nineties of the last century before the concept was seriously put on the agenda in The Netherlands in health care evaluations for people with chronic mental illnesses. Although it was considered a valuable addition to the assessment of symptoms and social functioning, it became clear that differences in QoL and QoL measurement exist on: 1. the definition and conceptualization of QoL; 2. the coverage of a particular QoL instrument and 3. the characteristics of the instruments.

As for the conceptualization, an important distinction is that between general and health related QoL (see figure 1). Where health related QoL (HRQoL) focuses on the consequences of health or health problems on a person’s QoL, general QoL does not (exclusively) address health aspects. In psychiatry a general domain-specific QoL tradition has developed with instruments focusing on several life domains, such as social participation, daytime activities, finance, living arrangements and also health, but only as one of the different life domains to
be assessed. The concept of HRQoL on the contrary links QoL in particular to health status (although it is often confused with the latter), focusing on those aspects of functioning and wellbeing directly related to health or health problems. An example is the extent to which a person suffers from social role limitations as a consequence of mental or physical health problems. As for the distinction between HRQoL and health status, we agree with Gill and Feinstein (18) that many researchers who claim to measure HRQoL actually measure different components of health status. What distinguishes HRQoL from health status is that in the latter values, subjective evaluations and preferences of the patients are weighted in the final assessment.

A second distinction refers to the ‘coverage’ of an instrument. QoL instruments can be developed for a particular type of patient’s and are therefore called disease-specific. Generic instruments on the other hand can be administered in varying diagnostic groups as well as in the general population. To make it somewhat more complicated, some instruments do not focus exclusively on one particular disease, but on patients with similar diseases. Many QoL instruments in psychiatry were not exclusively developed for patients with schizophrenia or depression, but are suitable for all patients with (chronic) psychiatric disorders. The advantages of generic instruments above disease specific instruments is that these can be used to evaluate alternatives for organization and financing services, for monitoring the health of the general population, for comparing patient groups with the general population and for comparing specific aspects of illness consequences or burden experienced by different patient groups. A disadvantage of generic measures is that specific consequences of a particular disease or treatment that may influence a person’s QoL could be missed.

A third issue related to the conceptualization of QoL is the distinction between subjective (perceived) QoL and objective (indicators of) QoL. When for instance QoL is assessed on the life domain ‘social relationships’, the objective indicator could inform about the actual number of social contacts or friends a person has, whereas the subjective indicator addresses satisfaction with that social network. In general, relationships between objective and subjective indicators of QoL of the same life domain were often found to be only weakly associated (19).

A final distinction in QoL measurement pertains to characteristics of a particular QoL instrument. Instruments vary in format (e.g. self report questionnaires; structured interview), in time frame and administration time.

For this study we used the Lancashire Quality of Life Profile (20,21) and the MOS SF-36 (22,23). The LQoLP is a general QoL instrument developed from the domain-specific QoL tradition in psychiatry. It captures subjective (life satisfaction) as well as objective indicators of QoL on several life domains. The instrument was developed for use in populations with serious mental illnesses. It cannot be characterized as entirely disease specific because it was developed for a group of psychiatric diseases. The LQoLP has the format of a structured interview, requiring trained interviewers. The original LQoLP has been evaluated for its psychometric properties (14). The extended Dutch version of this instrument, as we use in our study, has also shown good psychometric properties in a Dutch sample of patients with serious mental illness (24). Instruments from this tradition are based on Lehman’s QoL theory (25), which distinguishes 3 components that are expected to constitute QoL: personal characteristics, objective living conditions and people’s satisfaction with life on diverse life domains. A person’s QoL is considered as a reflection of the extent to which his actual life
circumstances are in line with his expectations, needs and wishes. The MOS Short Form-36, is a shorter questionnaire with a long-standing tradition of evaluation and psychometric testing in general populations as well as in many (chronic) patient samples. This instrument is considered health related as it focuses on the perceived consequences of health and health problems on life. It captures aspects of mental health and physical health as well as role limitations resulting from health problems. At the start of this study only few had used the SF-36 in patients with schizophrenia, although it had already proven its value in depressive samples. Although we described differences between the LQoLP and the SF-36 on four dimensions, in the following paragraphs we will briefly refer to the LQoLP as measuring general QoL and the SF-36 measuring HRQoL.

**Figure 7.1** Characteristics of the LQoLP and the MOS SF-36.

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<tr>
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7.3.1 The MOS SF-36 and the LQoLP
This study showed that both the LQoLP and the SF-36 had satisfactory psychometric properties in a sample of (ambulant) patients with schizophrenia. With regard to the SF-36, our results confirm its adequate reliability in groups of patients with schizophrenia reported in other studies (26, 27, 28). Where the original LQoLP as developed by Oliver et al (20) had been used in patients with schizophrenia, the extended Dutch version of the LQoLP used in this study so far was only tested in a more heterogeneous psychiatric population (24). The results of our study give additional information with regard to the psychometric properties and results of the extended Dutch LQoLP in a diagnostically homogeneous population. These results hold for a selected sample of outpatients with schizophrenia that are generally in a stabilised phase of their illness and that have all been in regular health care for at least three months preceding the study.

Regarding the underlying dimensions of the LQoLP and the MOS SF-36 with factor analysis we found one factor covering external and material aspects of QoL (like 'living arrangements' and 'finance') which could be distinguished from a second factor covering internal and autonomy related aspects of QoL (like 'satisfaction with health', 'self-esteem' and 'fulfilment'). The third factor represented HRQoL or functioning, in which both mental and physical health components as well as satisfaction with health were included. Another comparable study also resulted in an 'internal' factor (comprising for example self-esteem and fulfillment) and a second factor comprising the other life domains (32). A conceptual exploration of QoL by means of a concept-map preceding the latter study (33) resulted in domains of QoL reflecting more external and material aspects as well as personal autonomy, self-worth, and non-material needs. Although there was no clear domain reflecting health problems or health related QoL as measured in this study, there is a resemblance with the dimension 'self-care', which captures aspects of good health and other elements of physical
and mental hygiene. However, in a more recent study Pukrop et al (34) performed a factor analysis on 8 QoL instruments in a heterogeneous sample of healthy controls, patients with depression and schizophrenia. The LQoLP and the SF-36 were both used in this study. The study resulted in 7 factors comprising the following domains:
1. General QoL (comprising several LQoLP domains);
2. Health-related QoL (i.e. LQoLP: physical problems and satisfaction with health as well as SF-36 subscales general health, and physical health);
3. Vitality (i.e. SF-36: vitality);
4. Psychosocial QoL (i.e. LQoLP: social relations);
5. Material QoL (i.e. LQoLP: finances and living);
6. Emotional QoL (i.e. SF-36 mental health),
7. Spare time QoL (i.e. LQoLP: spare time).
This study provides valuable additive information regarding QoL dimensions, and confirms the distinction between material and non-material and general versus health-related aspects of QoL.

As we found QoL measured by the LQoLP and HRQoL measured by the SF-36 to reflect at least in part different QoL dimensions, we further explored these two conceptualisations and their relation to patient and illness characteristics. The two main predictors of General QoL in this study were anxiety / depression and self-esteem. About two-third of the variance of General QoL explained by patient characteristics was mediated by HRQoL. Since psychopathology (anxiety / depression) and self esteem are the most important predictors of General QoL, the variance mediated by HRQoL pertains mainly to these predictors.

There seems to be some discrepancy between the results found in the previous study (that the two instruments reflect different dimensions of QoL) and the regression analytic results (that the main predictors of general QoL were found to be mediated by HRQoL). This discrepancy may in part be explained by the choice of our variables: our main predictors may both be considered as indicators of mood / affect; the BPRS-scale reflecting directly reported and observed signs of both anxiety and depression and the self esteem scale reflecting a subjective self related concept. As the SF-36 also comprises items referring to mental health problems (especially mood), the mediating role of the SF-36 on general QoL is not completely unexpected. Elements not directly related to health, like social integration variables, were indeed not or only to a small extent mediated by HRQoL. However, it is important to put this explanation in perspective, as only about 50% of general QoL was explained by the patient- and illness characteristics used in this study. Adding more (non-health related) predictors such as social integration and rehabilitation variables might have explained an additional part of general QoL not mediated by HRQoL.

7.3.2 Predictors of QoL of patients with schizophrenia
Depression and anxiety
Of the four BPRS symptom scales, only anxiety and depression were associated with QoL; we did not find significant amounts of predicted variance by positive-, negative-, cognitive or disorganized symptoms. Although in general results found in the literature regarding the influence of psychopathology on QoL in patients with schizophrenia are not equivocal, several studies found associations with depression and / or anxiety (35, 36). This consistently found relationship between QoL and depression has raised the discussion whether (subjective) QoL is not mere an epiphenomenon of a depressed mood. We agree with Priebe (37) that QoL and mood are different concepts that may share
underlying (cognitive) processes, like appraisal, coping, trait-like concepts influencing the way the self and life are perceived and the amount of control patients experience.

**Positive and negative symptoms**
The absence of significant relations between QoL and positive symptoms may be attributed to the fact that we sampled in a relatively stabilized outpatient population. Another explanation is that the extent to which QoL is affected by positive symptoms is dependent on the content of the psychotic symptoms (38). For example the idea of being 'possessed by demons' may cause severe anxiety and therefore decrease QoL, whereas the idea of 'being an Angel of God' and having 'special powers', may have a (temporal) opposite effect on life satisfaction. Therefore these varying effects may not be expressed in decreased levels of QoL at an average group level, whereas they may actually be reflected in subjective QoL at an individual level. Also, understanding that psychosis is derived from illness will probably lead to different reactions from the people around the patient compared to their labeling within a culturally accepted context in which for example, hallucinations are labeled as 'hearing voices of ancestors'. In some cultures hearing voices may actually provide patients with some positive status within the social network and therefore 'symptoms' may not at all be considered amenable for (pharmacological) treatment.

**Self-related constructs**
In addition to anxiety / depression we found self esteem to be another important predictor of life satisfaction. Other studies also report an association between QoL and self esteem, as well as with other constructs such as mastery (39), self efficacy (40) and autonomy (41). As the above constructs reflect elements of subjective perceptions, characteristics and qualities of the self, we will refer to them as 'self related'. In addition Zissi et al (42) point at the mediating role of self related constructs in associations between QoL and objective indicators. External changes in objective circumstances may impact on self related constructs and in turn influence QoL. Time leaps and longitudinal aspects of these mediating influences and their responsiveness to changes in illness and objective circumstances (such as changes in living situation) are topics to be investigated in more detail in future research.

**Social integration**
In our study one social integration variable, ‘having a reliable friend’, contributed to the predictive QoL model, although explained variance was small. This variable does not pertain so much to a quantity as well as to a quality characteristic of the network. Results of other studies also suggest that it is not only the availability but also the adequacy of social support that is important for QoL (43). Although associations of QoL with the social integration variables used in this study were modest, others (44, 45, 46, 47) point at the importance of work rehabilitation for social existence. Those studies provide indications that meaningful activities make contributions towards re-establishment and maintenance of mental stability: participants of rehabilitation services (especially those with competitive work) experienced greater life satisfaction not only with regard to work and leisure, physical ability and income but also independence, recognition and acceptance by others.

**Illness insight**
Illness insight is an important clinical concept which causes however scepticism about the use of subjective measures in patients with schizophrenia. Results with regard to insight suggest complex relationships with QoL: mediating effects of insight on life satisfaction that may exist can turn in different directions. On the one hand poorer insight may protect
people from being aware of the loss of skills and possibilities and of the long term impact of the illness; from this view poorer insight could prevent mourning and possibly depressed mood and so 'improve' QoL. On the other hand, lack of insight was found to be related to more non-compliance, greater social isolation and poorer psychosocial functioning (48). The repeated finding that QoL (life satisfaction) ratings in schizophrenia are usually unexpectedly high has also been brought into connection with lack of illness insight. However, it has also been suggested that other cognitive processes reflecting for example social comparison or resignation can alter standards for what constitutes a good QoL. Although these processes complicate QoL measurement, they should not be confused with a lack of insight in psychiatric patients.

7.3.3 Methodological issues and recommendations

Levels of score aggregation in QoL instruments

In this study we used both the subscale scores pertaining to separate QoL domains and the more aggregated scores of the instruments (LQoLP total score and SF-36 summary components). In all cases aggregate scores were based on summations of different domains of life satisfaction and HRQoL. An important point of discussion in QoL measurement is whether more elaborate instruments resulting in several domain- or subscale scores (which can mostly be summed in a 'total score') are to be preferred above shorter and highly aggregated measures. An example of this is the 'total life satisfaction' scale of the LQoLP based on all its items, versus a one-item scale about satisfaction with life in general. In general, domain-specific measures such as the LQoLP provide more detailed information with regard to service evaluation and potential improvements in service provision. Also, QoL profiles capturing different life domains can be useful on an individual patient level (create clinically meaningful patient profiles). A highly aggregated QoL scale on the contrary does not provide much information about which elements of a person's life contributed to this evaluation.

Models of QoL

The LQoLP is based on Lehman's QoL Interview (49). From Lehman's viewpoint, objective indicators of QoL, domain-specific life satisfaction and overall wellbeing are components that constitute a persons' QoL. However, there has been increasing debate about the validity of this model (50). For instance it does not explain the often very modest relationships between objective and subjective indicators of QoL pertaining to a particular life domain. Also it does not account for the fact that different life domains may have differential personal relevance for the evaluation of overall QoL. Furthermore the model does not incorporate a dynamic component, comprising the adaptation and re-evaluation of standards, values and wishes as well as other cognitive processes that influence QoL evaluations over time. Other models, for example the 'mediational model' (51) do focus on the link between self-related constructs and subjective evaluations of QoL. Self efficacy, self esteem and perceived control are, from this point of view, considered to contribute to a person's QoL. Personal and clinical characteristics in turn contribute to the self related constructs a person has. These aspects form mediating variables that in turn are expected to influence the appraisal process of a person's objective life conditions.

Adaptational processes and response shift in QoL

We also found subjective life satisfaction to be generally high; only a minority of the patients reported actual dissatisfaction on life domains of the LQoLP, in spite of the sometimes unfavourable life circumstances and severe handicaps as a consequence of their illness. Also
the patients with most pronounced symptomatology and deteriorated functioning reported to be 'only' slightly more dissatisfied (at group level) compared to patients with relatively higher levels of functioning and less symptomatology. We again mention cognitive processes influencing perceived QoL of patients with chronic disorders such as schizophrenia. Levels of expectation, aspiration and perceived control may act as 'internal referents', which influence ratings of satisfaction. These standards by which people assess their QoL can change over time or as a response to changes in circumstances. Processes as 'response shift', are particularly important when one aims to measure changes in QoL over time. Response shift is defined as a change in the meaning of an individual’s self reported QoL (52); this means that equal levels of QoL at different time points may have different meanings. For the patients we studied, resignation to relatively deprived living conditions and social comparison with others (53) may alter their standards for what constitutes a desirable QoL. Future longitudinal research should elaborate further on the extent to which General QoL and/or HRQoL are 'susceptible' to these processes in patients with schizophrenia.

Where response shift here is described as a methodological ‘pitfall’ that needs to be dealt with in interpretations of QoL data, things are somewhat more complicated. Of course adaptive cognitive processes can help patients adjust to altered circumstances and loss of skills, possibilities and future plans and from this perspective be considered an effective coping style that should be interpreted as such. Considering this topic from a ‘coping style’ point of view, adapting to changed circumstances can be beneficial as long as it is not a passive resilience to adverse circumstances that keeps people from exploring the skills and possibilities that remain and seek ways to use them such a way as to maximise levels of QoL.

The choice of an instrument
As for the choice of an instrument our study confirmed that both the LQoLP and the SF-36 can be reliably assessed in a group of outpatients with schizophrenia. A few points regarding feasibility: Compared to the SF-36, the LQoLP has a substantially longer administration time and requires trained interviewers. However, while the SF-36 is shorter and can be filled out at home, we recommend to have patients fill out (or at least check) the questionnaire in the presence of a clinician or researcher, as several patients forgot to fill in one or more items or had difficulties understanding the content.

Above aspects of feasibility, the choice of an instrument to measure QoL in schizophrenia should be based on the particular questions under study. Our study showed that this choice is not only one of feasibility but also one of content. Advantages of the LQoLP are: 1. It refers to a broad area of domains that are relevant and allow specific recommendations for mental health service evaluations and improvements. 2. The domain-profiles that can be distracted from the LQoLP can be useful on a population-, a service- as well as well as on an individual level. 3. As the LQoLP was developed for chronic psychiatric populations it can also be used to compare profiles of QoL for different diagnostic groups within psychiatry. 4. The LQoLP provides information about subjective QoL as well as objective indicators of QoL, allowing complementary (descriptive) information. 5. The extended Dutch version of the LQoLP was modified according to a concept mapping procedure on QoL, which contributes to its content validity. 6. The instrument captures several self-related constructs, with have been shown to be important for the evaluation of overall life satisfaction. So far the LQoLP has been used for many different purposes in psychiatry: medical trials, service evaluations, evaluations of specific interventions, comparisons of patient samples from different countries or cultural groups. A disadvantage of the LQoLP is its length and the fact that it
requires trained interviewers. Also, the instrument's sensitivity to detect small changes over time still needs further clarification, an aspect important for its suitability as an outcome measure in the evaluation of service programs or specific interventions.

A first advantage of the SF-36 compared to the LQoLP regards its feasibility: it is less time-consuming and does not require trained interviewers. Second, the SF-36 captures important aspects of both physical and mental health as well as consequences of these health problems for functioning and (social) roles. These aspects are all known to be relevant for patients with schizophrenia. Third, several of these aspects may be especially relevant for studies on side effects of anti-psychotic medication. Fourth, as the instrument has a generic character, it allows for comparisons with different diagnostic groups as well with the general population. And fifth, the SF-36 can be used for cost effectiveness studies (health state utilities). As the SF-36 was only beginning to be used in schizophrenia studies at the time this study started, in the past years the instrument has been increasingly used in studies on patients with schizophrenia and other severe mental illnesses. It was used: in several (QoL) instrument validity studies (54,55,56,57,58); to compare the sensitivity with regard to changes in symptomatology (59), to measure physical characteristics such as body mass index and associations with QoL (60) and finally it was used in several medication trials and cost-effectiveness studies (61,62,63,64,65,66,67,68,69).

A disadvantage of the SF-36 can be that, because of its generic character, the instrument does not capture disease consequences specific for schizophrenia. Also, the instrument's sensitivity to detect small changes in schizophrenia symptoms (other than mood-related) still needs further clarification. Finally, the SF-36 captures social and every-day limitations that are considered to result from health problems, and therefore are formulated as such. However, as we discussed before, distinguishing direct and more indirect consequences resulting from both physical and mental health problems is often much less straightforward in schizophrenia compared to most somatic illnesses.

7.4 Needs for care

Need assessment started to become important in psychiatry in the late eighties/ nineties, with the introduction of the concept by Brewin and others (70,71,72). The first systematic need assessment studies in The Netherlands were performed by Wiersma et al (73). Like with QoL, the definition of needs and the use of the concept in psychiatry has been the subject of much discussion and controversy: How should needs be defined, and by whom? What importance should be accorded to both met and unmet needs in the assessment of individual patients, and in the planning and evaluation of mental health services as a whole? How are the needs of those suffering from schizophrenia related to other subjective constructs important for mental health outcome? In this thesis we focused on changes and stability of needs for care over time and on associations with other constructs such as QoL and caregiver consequences.

7.4.1 Definitions

According to Brewin & Wing (70) needs for care can be viewed as (1) shortcomings or lacks in upholding general goals of health and well-being, (2) a lack of access to recourses or appropriate forms of care or (3) a reflection of a lack of specific activities by mental health care professionals. There is only a need for care in case an appropriate intervention exists to meet the particular need. Also, the distinction between a need and a demand is impor-
tant: a need is what people benefit from instead of what they ask for (their 'demands') (72). Systematic assessment of these needs for care can be used to measure and compare needs of populations, to identify (individual) goals in mental health care, to evaluate service programs, or to assess changes in needs over time (74,75,76,77,78,79,80).

7.4.2 Stability of needs for care
In this thesis we explored the dynamics of needs for care of patients with schizophrenia at different time points. A repeated assessment of needs can be important on a service level, to measure (changes) in needs of different groups, to measure the effectiveness of specific interventions or to evaluate changes in individual needs for care over time.

Changes in the point-prevalence of needs for care appear to be only one aspect of the temporal dynamics of these needs and seriously underestimate actual changes over time. The distinction between the prevalence of unmet needs and the persistence of unmet needs is important from a clinical point of view. The former has implications for treatment planning at the organisational level. If, at different moments, a large proportion of a patient population has unmet needs pertaining to physical health, it may be necessary to extend the physical treatment facilities in the service. The latter, the persistence of unmet needs, applies to the individual patient. If unmet needs pertaining to psychological distress are persistent, this should be discussed with the patient in order to set (more) realistic treatment goals or look for alternative treatment options that may solve these needs. In their study on the stability and changes in needs for care of patients with schizophrenia, Wiersma et al (80) approached the (measurement of) 'stability' in two ways. They found high stability in individual needs after a two-year period (mostly because of the absence of a need on both occasions). However, many changes were found in 'need status' which in their study was based on the following criteria: 1. No problems, 2. Met needs only, 3. At least one non-meetatable need, 4. At least one unmet need. Although many (disappearing) and emerging needs were observed according to the above criteria, overall there was less improvement than deterioration. Our definition of need status was based on different criteria. We for example approached the dynamics in needs from a domain level. Also the Wiersma et al study assessed changes in needs with the Needs for Care Assessment Schedule, which is an investigator-based instrument, whereas we used the patient-version of the CAN.

7.4.3 The relationship between needs for care and QoL
Slade et al (81) and Lasalvia et al (92) pointed out that mental health treatment should be provided on the basis of need, with an intended goal of improving subjective QoL. This however is only feasible when in general patients with the most needs actually have the lowest subjective QoL. We assessed whether low QoL is mainly related to more persistent unmet needs and whether the ratio of unmet needs to the total number of needs is associated with QoL.

QoL was found to be related to the total number of unmet needs, to unmet needs on several individual domains and to the ratio of unmet / total needs. So, not only the number of life areas with an unmet need per se, but also the extent to which a person feels that his overall needs are taken care of, is (to some extent) important for his QoL. The finding that QoL of patients with severe mental illness is mainly associated with unmet needs and not so much with met needs was corroborated by several other studies (81,82,83,84). The fact that the number of unmet needs and not the number of met needs is associated with QoL suggests that it are the 'problem-areas' (in which no adequate help is provided) that have
a negative influence on QoL. In one study, Slade et al (81) not only found cross-sectional associations between needs and QoL, but also that patient’s base line needs do predict QoL after a one-year time interval. However, the magnitude of the effect found was limited: meeting one additional unmet need would ’lead’ to a one percentage change in subjective QoL. Unfortunately the sample in this study was too small to allow a more detailed investigation of the associations between dynamics in needs and dynamics in QoL over time.

7.4.4 Associations between needs for care and subjective caregiver consequences. Taking care of a patient with schizophrenia can be experienced as burdensome by the informal caregivers (85). Although mental disorders, particularly if they are long-term, disrupt family life, not all relatives experience their caring role as burdensome. Therefore we prefer the more neutral term ‘caregiving consequences’. In this thesis we explored whether the amount and / or the specific types of patient needs should be considered as important predictors of caregiver consequences. ‘Caregiver consequences’ was operationalised in terms of 1. the frequency of defined caregiving behaviours (supervising the patient on for example medication intake and urging patients to participate in healthy behaviours) and 2. the extent to which the caregiving role leads to excessive worrying about the patient and to interpersonal strain in the relationship with the patient.

Higher levels of patient needs were associated with higher levels of negative consequences for their informal caregivers. Secondly, some types of patient needs appeared to be better predictors of caregiver consequences than others: patient’s health needs, basic needs and functioning needs, but not patient’s social needs and services needs. Thirdly, more patient needs was associated in particular with more worrying about the patient and with urging the patient to participate in healthy behaviours. Although supervision on the patient’s behaviours and tension in the relationship with the patient were reported by a substantial proportion of the caregivers, caregiver consequences were to a lesser extent associated with the amount and type of patient’s needs. The relationships found, although statistically significant, were only weak in terms of explained variance however.

In another study negative consequences for caregivers of patients with schizophrenia were found to be related to patient’s symptomatology, caregiver characteristics and the amount of time spent together (85). These factors explained part of the variance in caregiver consequences (21 to 31% on average). If professional caregivers want to reduce informal caregiver’s burden they should concentrate on reducing patient’s Health, Basic and Functioning needs, by assisting or taking over part of the care addressed by the informal caregiver. Also, support directed at effective coping strategies may be helpful to prevent mental and physical health problems of caregivers resulting from the carer role. In the long run such support may be important as it aims to reduce the risk for the (often fragile) balance in the care system surrounding the patient to fall apart. However, reducing patient symptomatology and reducing the time spent together may still be of most (direct) influence on caregiver burden.

7.4.5 Methodological issues and recommendations

Different levels of score aggregation.

Needs can be assessed at a global level (the total number of needs for care on a variety of life domains) or on a very detailed level (the need for care on a specific life domain). With needs as well as with QoL, the choice for the level of score aggregation should depend on the specific aim of a study. In our study we explored the balance between optimal specificity
and some way of aggregating the highly detailed domain-specific information. For service evaluation, it is probably important to obtain detailed information about specific areas of needs for care and about the extent to which these individual needs are met by caregivers. Proportions of unmet needs of certain patient groups provide information for services with regard to where care could be improved. Also, at the individual level it can be useful to perform a detailed evaluation of life domains and the extent to which associated needs are currently (un)met.

For other purposes a certain level of score aggregation may be more useful (for example when needs for care are used as outcome measure for the evaluation of health services). Domain-specific assessment (according to the CAN) has the disadvantage of skewed score distributions and comprises many domains on which only a small to modest proportion of the patients reports a need for care. However, 'total score'-levels do not permit any specific suggestions regarding service improvement. The 'dimensional'-approach as suggested in this thesis is a 'compromise' between aggregation and clinical usefulness because this approach still permits some information about types of need domains. The feasibility and validity of the dimensions as we used them should be further explored in future research. Another possibility to achieve score aggregation is to apply factor analysis on the individual CAN-domains. Recently several factor analysis studies have been performed on the CAN among patients with schizophrenia and/ or severe mental illness (86,87,88). These studies resulted in different factor solutions which are not always easy to interpret. For example, Wennstrom et al (87) found a three-factor model, referring to 1. functional disability (broadly capturing domains of ADL), 2. social loneliness (referring to the absence of meaningful friendships and work-related relationships (usually associated with depression and aimlessness) and 3. emotional loneliness (absence of romantic relationships or intimate attachment). Korkeila et al (88) warn that separate factor analyses should be performed for patient- and clinician rated needs, as they found somewhat different factor structures for patient- and staff ratings (comprising factors referring to skills, coping, illness and substance abuse).

Adaptational processes and response shift in needs for care
The cognitive adaptational processes described earlier with regard to the way people evaluate their QoL (such as response shift) may in part influence subjective evaluations of needs for care as well. The influence of these processes is expected to be less pronounced however, because measures of needs for care focus on specified problem areas and also comprise actual received help. However, some influence of these kinds of processes cannot be ruled out here either. Whether a particular need is considered as a serious problem or not may reflect (to some extent) the patient’s state of mind at that particular moment, a tendency to be more or less satisfied (with care), or an inclination to resign and alter expectations regarding one’s life situation and opportunities. On the other hand it is possible that the very presence of a particular service or intervention itself may raise the awareness of a need that otherwise would not have been expressed (72).

Recommendations on the use of the CAN
Although the instrument provides the opportunity to screen a wide range of needs for care of patients in a relatively short time period, for clinical use the CAN has some disadvantages. First, no clear distinction is made between needs that cannot be met (unmeetable) because of irreversible and irremediable defects, and needs that are not met because of patient’s refusal of help. In the last case the subjective rating would not reflect a need, leading to an expected discrepancy with objectively rated need. Second, problems may arise when we are faced with ‘future need’: a need for which a potentially effective intervention...
exists is overruled by another intervention that has been given higher momentary priority (for example the need for social skills training in times of acute psychotic decompensation that warrants crisis intervention). Third, there is some normative reference required when defining the existence of a need; as Van Haaster et al (89) put it: 'we speak of a need when the subject's level of functioning falls or threatens to fall below some minimum specified level and this is due to some potentially remediable cause'. We encountered that in spite of some general criteria provided in the CAN, this minimum specified level of functioning is not described in detail. Therefore it is not always easy for the interviewer to distinguish between an expressed 'demand' and a need for care. Finally, the CAN does not inquire about effective and acceptable interventions in case of an unmet need. Other instruments like the NFCAS (70) do provide this possibility. A disadvantage of the latter instrument however is that it is time consuming, that it has complex rating procedures and must be administered by a well trained clinician.

When using the CAN in a clinical instead of a research context (whether on a service level or on an individual level), the following questions should be kept in mind:

Do we possess adequate, complete (and evidence based) information about what kind of services / specific interventions may reduce the defined domains of need? Secondly, with regard to met needs, unmet needs, overmet needs, unmeetable needs and future needs it may be good to define some hierarchy in needs in line with Maslow's hierarchy of human needs (90). Third, it is important to carefully decide about the use of patient- versus clinician-rated needs (or both) for the purpose of the particular questions under study. Since differential results were found with the CAN on patient- and clinician or observer-rated needs, the following should be kept in mind: several studies found clinicians to rate somewhat more needs than the patients, and there were considerable inconsistencies in scores on individual domains (91,92).

When needs are considered as a 'socially negotiated concept with no single 'correct' perspective' as Slade et al (93) put it, information from both patients and clinicians may provide valuable complementary information. At the individual level, assessing and discussing need profiles of patients and caregivers together (especially life areas on which disagreement exists) may be beneficial for the therapeutic relationship, for medication compliance and other outcome (94). By explicitly negotiating needs for care at the individual level, patients feel their opinions are being appreciated and that they are approached as active partners in care planning. These ingredients may in turn build self esteem, improve relationships with caregivers, encourage empowerment and increase treatment adherence. All aspects that have been shown to be closely associated with subjective QoL.

As the above concentrates mainly on need assessment at the individual level, need assessment on a service level may provide valuable information for services as it comes to a clearer understanding of amount, profiles and unmet needs for care of patients requiring long-term care. The results can be used to inform developments in supported accommodation, employment and day care services; a longitudinal case register and routine assessment of the short form version of the instrument (the CAN-SAS) can give valuable and more extensive information about needs and changes in needs in a population as well as to closely monitor changes in service provision or service structure (86).
7.5 Symptom patterns and associations with needs, QoL and service use

In chapter 6 we investigated the existence of clinically meaningful patient groups. We used two different methods of patient group allocation based on empirical and on a-priori defined criteria. The latter allowed the most straightforward clinical interpretation. We described these four patient groups in terms of overall functioning, QoL, service use and needs for care as well as socio-demographic characteristics. Although associations of the symptom patterns for the three patient groups with subjective criteria were generally in the expected direction, group differences were small and did not discriminate between patients with positive and negative symptoms. Patients with both clinically relevant positive and negative symptoms reported most problems: they had on average more health problems, more psychological distress, more unmet needs and more problems in social functioning. Surprisingly, no significant group differences were found for other basic need domains (such as accommodation, food etc.) and daytime activities and social contacts. Although substantial proportions of patients reported a need on these domains (40% or more of the patients in each of the four groups), the need prevalence did not discriminate between the groups. Our study showed that, even in a sample of rather stable outpatients with schizophrenia, patient profiles based on symptom patterns can be constructed. However, on variables relevant for health care (such as QoL) differences are generally marginal, and therefore should be interpreted with caution. The relatively small patient subgroups as well as the homogeneity of the study sample may all have contributed to this. Working with larger and more (diagnostically) heterogeneous patient groups will allow more detailed criteria for actual disease-state descriptions that can be used to guide clinical judgement, to measure the impact of interventions and to elicit judgements about the effect of different manifestations of the illness on QoL (95).

Methodological issues and recommendations

The first method of group allocation, cluster analysis, is an empirical technique to allocate patients to clusters according to similarity in underlying scoring patterns (in this study symptomatology according to the BPRS-E). Clusters could not easily be interpreted because differences between the groups were marginal and were not mutually exclusive in terms of discriminating characteristics. While cluster analysis is an adequate technique to construct subgroups or patient profiles, low overall variance can limit the value and interpretability of the findings. The other method we used was based on a-priori defined criteria for group allocation based on symptom severity, using the criterion of at least one 'clinically relevant' symptom (BPRS item scores of ≥4, indicating moderate to severe pathology). We chose to adjust the more stringent criteria suggested by Opler and Lindemayer (based on positive and negative schizophrenia 'syndromes') (96) to the characteristics of the group under study, outpatients in a stabilised phase of their illness. Our main goal was to distillate patient groups with varying symptom patterns, not finding groups fulfilling criteria for schizophrenia syndromes. We feel that, where average subscale scores may mask the presence of clinically relevant symptoms in outpatient groups with low overall pathology, our criteria are of particular clinical value; suffering from one or more positive or negative symptoms fulfilling criteria for a BPRS-score of at least 4, implies that this particular symptom has interfered with the patient's daily functioning during the past four weeks. For future research theory-based conceptual frameworks of patient profiles or disease states could be combined / confirmed by empirical methods as cluster analysis in order to maintain a clinical intuitive conceptual framework as was done in a recent study by Mohr et al (95). For these kind of studies larger (and more heterogeneous) patient samples are required however than were used in this study.
7.6 Strengths and weaknesses

Our study contributed to a better understanding of several concepts and instruments that are generally considered of importance in the evaluation of community care for patients with schizophrenia. This was done in a rather homogeneous sample of outpatients with schizophrenia, following a well described sampling procedure. Where schizophrenia studies often rely on patients in urbanized catchment areas surrounding academic hospitals or research centres, this study included a representative random sample of patients from two different catchment areas in The Netherlands, varying in urbanisation level. We not only described in detail the QoL, needs for care and consequences for informal caregivers of patients with schizophrenia, but also evaluated the reliability and feasibility of several instruments. Accordingly we offered suggestions for the choice of a particular QoL instrument. Further this study contributed to a better understanding of relationships between the concepts and offered some explanations for processes underlying these associations. In accordance, we gave more insight in predictors of QoL and needs, resulting in suggestions for improvements in health care for patients with schizophrenia. Third, the study allowed suggestions about the stability and change in the concepts needs and QoL over an 18-month time period, resulting for example in detailed information regarding prevalence and persistence of needs for care over time. As for the measurement of the concepts and associated methodological issues, several ways for score aggregation were explored and suggestions were offered regarding their clinical applicability and relevance. We further introduced a method for assessing stability of needs for care over time and evaluated different methods for the construction of patient groups based on similarity of score patterns (in this study on symptomatology).

This study had several weaknesses that may have influenced our results. First, although we used a clearly described sampling procedure, we cannot fully guarantee that all patients in the different centres who fulfilled inclusion criteria were actually screened and asked for study participation. Also, since participation was on a voluntary basis, selective patient refusal may have caused some selection bias (for example because patients felt too ill to take part in a rather extended assessment procedure). Also, patients who were very unsatisfied with their mental health service may have been less motivated for participation in a research project as suggested by that same service. Patients with positive symptoms may have refused because of psychotic or paranoid interpretations of the study or reluctance to share personal information. The above factors may have resulted in some selection bias.

Second, although the final sample consisting of 143 patients gave important information about needs and QoL and their associations, our sample was not large enough to investigate in detail subgroups of patients with different need profiles and associations with QoL over time. Accordingly a larger sample will allow more refined patient profiles based on both symptom patterns (extending the 'positive-negative symptom' dichotomy) and/or other patient and illness characteristics, which would increase their clinical meaningfulness.

Third, in our prediction model of QoL we used a limited number of predictors. Although our relatively small patient sample would make the validity of a larger prediction model questionable, several recent studies have found predictors of QoL not assessed in this study (see paragraph 7.2); these variables pertain especially to social and rehabilitation variables, self related constructs (such as mastery and coping styles), personality traits and socio economic and neighbourhood characteristics.
7.7 Clinical implications

Although average QoL scores were generally high, individual item scores revealed that dissatisfaction was reported by a substantial proportion of the patients on one or more aspects of life. The LQoL objective as well as the subjective life domain scores suggest that (in spite of ongoing developments in mental health care) QoL could be improved on domains of health, social participation and activity level. Patients are also relatively unsatisfied with regard to finance, partly (as many patients mentioned) because their limited budgets further hamper their social and societal participation. With regard to HRQoL, reduced scores on most domains of the SF-36 in comparison to the general population warrant the necessity of careful health assessment and confirms the importance of newly developed interventions focusing on health information as well as active training in healthy life styles (for example healthy food, exercise etc.).

Apart from adequate attention for physical health problems in schizophrenia and consequences resulting from this, our prediction study further suggests that by treating anxiety and depression and supporting or strengthening self esteem, professionals may indirectly help patients (or provide the necessary conditions) to improve subjective HRQoL aspects such as mental health perceptions, vitality, role problems due to emotional limitations and social functioning. Further development and implementation of services and interventions directed at improving affect and self esteem and decreasing psychological distress may also be beneficial for patient’s life satisfaction. As social integration was also found to be associated with (general) QoL, psychosocial interventions may be particularly important where they focus on improvement of personal recourses and self esteem by helping patients to fulfil new, more desirable roles as community members.

In spite of ongoing developments in services for patients with schizophrenia, it seems difficult to meet their (perceived) needs on several important life domains. The high proportions of unmet needs with regard to symptom management as well as social integration and daytime activities suggest that careful monitoring of these needs on an individual level could be beneficial for a substantial group of the patients. For example: as it comes to social contacts, many patients commented that key workers generally refer them to Day Activity Centres. However these patients expressed a specific need for care directed at improvement of their ‘community social network’ (meeting people not suffering from a mental illness). Services like ‘buddy’ projects were perceived as a good first step in this direction by a number of them. Another example on rehabilitation: several people who had developed very well in job- or education rehabilitation projects became very de-motivated as they found that finding a regular (paid) job was still very difficult, in spite of help and support from services.

Many patients expressed a need for care on domains that may generally not be addressed in a treatment context: information about dealing with sexual problems and problems with finding or maintaining a satisfactory intimate relationship. Many patients mentioned that, although they find it difficult to bring this theme up during the sessions with their key worker, they would like to put it on the agenda. Another point mentioned by many patients was that adequate (‘normal language’) information about diagnosis and treatment is not always provided on a routine basis. Another important area that needs careful assessment and should be a focus of service provision is physical health and medical co-morbidity in schizophrenia. Compared to the general population, patients in our study had reduced levels of HRQoL, not only related to mental but also to their physical health and a substantial
 proportion of them reported a perceived unmet physical health care need. Impaired physical health in this case might be a consequence of an unhealthy lifestyle (insufficient self-care and personal hygiene, unhealthy food, excessive smoking etc), difficulties in getting or finding adequate medical treatment, or side effects of anti-psychotic medication. Several studies have reported that patients with schizophrenia are at an increased risk of developing several illnesses or somatic complaints (97,98,99). Poorer physical health status in patients with schizophrenia may in turn lead to worse mental health status as it can arouse worrying and depressed mood as well as induce paranoia. In addition poor attention, increased perceived pain levels, inability to self monitor and/or to take appropriate actions in case of physical problems may cause physical complaints to turn into more serious physical illness. Of the patients with medical problems, many did not discuss these with their key worker or general practitioner. In general, patients often attributed physical complaints to side effects of medication. Careful monitoring and examining somatic problems as well as providing information about medication side effects may prevent part of the treatment non-compliance in schizophrenia.

A close monitoring of needs and QoL over time may not only be beneficial on a service level but also on an individual level. In a previous paragraph we mentioned the burden of extensive assessment batteries on the patients. Whereas this is a legitimate worry and we agree that ‘assessment burden’ for patients should be kept to a minimum, many patients expressed that being asked about their QoL and needs for care had some intrinsic value as people felt their needs and problems were being heard and taken seriously. Although patients found it sometimes difficult and confrontational to answer questions about affect, self esteem and life regard, they appreciated a lot of the content of QoL and need assessment instruments.

As for need assessment, a frequently heard comment was patient’s unawareness of service provision in several areas; need assessment ‘helped’ them to get a better view on discrepancies between their current situation and future goals / desired achievements. Accordingly several patients expressed a ‘need’ for regular need assessment by their own key worker. Although in this discussion the discrepancy between ‘need’ versus ‘demand’ for care comes up, several patients explicitly mentioned that a regular need assessment session with key workers could be beneficial for realistic future goal setting and evaluation. However, the above does illustrate the ‘danger’ of higher (unmet) need expression as a consequence of increased awareness of service provision.

A final word concerning informal caregivers and the consequences of taking care of a family member or spouse with schizophrenia. The fact that patient's needs were only weekly associated with caregiver consequences suggests that other characteristics of both caregivers and patients should be further investigated in order to make specific improvements in contemporary care / support for caregivers. However, some scales of the IEQ were more strongly related to patient's needs than others: caregivers tend to respond to patient's needs by worrying and urging them to participate in healthy behaviours. Especially the 'urging' part may take the form of 'telling the patient what is best for him'; an interactive style that may result in resistance from the site of the patient and therefore be counterproductive in terms of both 'desired' behaviour and family interactions. Worrying on the other hand is an often ineffective (not problem-focused) coping strategy that may lead to much burden on the site of the caregiver. This suggests that support directed at caregivers may need to concentrate on caregiver coping strategies as well as on motivational techniques that provide ways to interact with the patient in a more productive and non-critical way.
7.8 Suggestions for future research

Finally some suggestions for future research. First, this study captured a rather homogeneous subgroup of outpatients, who (in general) were in a stabilized phase of their illness. It would be interesting to assess predictors of QoL and HRQoL as well as stability in needs for care in a more heterogeneous sample of patients in different phases of the illness. Also, it should be investigated whether the distinction of patient groups based on their symptom pattern (by means of empirical and a-priori methods) would lead to different results in a more heterogeneous sample of patients with schizophrenia.

Second, future research should elaborate further on models of QoL, HRQoL and needs for care and on a better theoretical framework to explain the differences between and interrelationships of subjective evaluation criteria. Although our study offered some suggestions for models of QoL, more extensive prediction models should be explored. Especially methods that allow a dynamic component would add to contemporary QoL research in schizophrenia. In these models more self-related constructs (such as coping, self efficacy and mastery) should be included as well as a more elaborate set of social integration variables as was used in the present study. In addition, longer follow up studies should give more insight into the complex relationship between symptom patterns of schizophrenia over time and their longitudinal relationships with QoL as well as other factors that influence QoL at different stages of the illness.

A third suggestion for future research regards the use of preference weights to instruments as the LQoLP and the CAN (let patients 'rate' the individual perceived importance of the domains addressed in these instruments); this may provide more information on predictors and associations between the concepts.

Fourth, the studies described in this thesis focused primarily on subjective concepts of QoL and needs for care; it would be interesting for future research to investigate associations with objective (clinician- or caregiver-rated) needs and QoL.

Finally, an ongoing issue in QoL research is the role of adaptational processes in the evaluation of subjective QoL and needs for care, and the definition of criteria to determine the quality of these adaptational processes as well as ways to detect and influence inadequate adaptational styles. For example when the ability to satisfy human needs is limited, people will use strategies for the satisfaction of one need that may lead to restrictions in the satisfaction of others, and possibly to complete suppression of particular needs. These aspects should be acknowledged and critically evaluated in the assessment of needs for care and QoL. Another factor inherent to adaptational processes in mental illness is adaptation to the so-called 'sick role' pattern. A controversy between feelings of autonomy and advantages related to the sick role should be acknowledged. Therefore in order to assess the QoL of people with schizophrenia it will be necessary to combine measures of their objective living conditions with a more in-depth analysis of their subjective meaning system and need structures.
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