

## Quality of life as an instrument for need assessment and outcome assessment of health care in chronic patients

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### Introduction

Quality of life is generally acknowledged as a central concept in health care, but its full application in healthcare research and clinical practice are still being debated. With an increasing prevalence of chronic diseases and the focus of health care expanding from “adding years to life” to “adding life to years”, there is a growing interest in assessments of quality of life in health care.

Measures of quality of life have been used almost exclusively in health services research to assess outcomes of care—that is, effectiveness of care. Arguments in favour of this “outcome approach” are based upon the growth of the healthcare system, the need for cost containment, and the ensuing call for evidence-based health care. Less attention has been given to the use of quality of life for monitoring health needs as an index of the relative appropriateness of health care. Although the “outcome approach” is already widely established, the “need approach” has only recently gained attention.<sup>1–6</sup> Chronically ill patients are particularly likely to benefit from need assessment and the routine use of patient derived data in making decisions about the distribution, access, and content of long term care. Comprehensive evaluations of health care must involve assessments of outcomes and needs. It is only by including both these assessments that the process of care for patients with a chronic disease can be improved.

This article aims to clarify the interrelation between quality of life and quality of care. To elucidate this association we will use examples from our research on patients with stroke. The objectives are (a) to describe the necessity and use of measures of quality of life in health services research; (b) to examine the use of measures of quality of life to study outcomes of care and to illustrate how these measures can be used to assess the need for care; and (c) to discuss problems in quality assurance that are related to the comprehensiveness of chronic care.

### Quality of life assessments

#### NEED FOR COMPREHENSIVE ASSESSMENT

Improving quality of life and promoting quality of care are central issues in the current health-care debate. Paradoxically, the call for good

quality of care has become stronger since there has been remarkable progress in both our wealth and health. Advances in public health and medicine have contributed to a longer average life span; and scientific developments, new technologies, and treatment options have continued to raise the standard of health care. At the same time, doubts and concerns have arisen when considering the implications of these successes.

The success in reducing mortality rates further has inadvertently increased the burden of chronic diseases.<sup>7</sup> A comprehensive forecasting study on the public health status of the Dutch population showed that chronic somatic and psychiatric diseases account for about 80% of the number of unhealthy years.<sup>8</sup> Major disorders encompass diabetes, heart diseases, musculoskeletal disorders, asthma and chronic obstructive pulmonary diseases, dementia, and depression. The forecasts reveal that by 2015 the total number of people with chronic diseases will have increased by 20–60%.

The rising numbers of chronic patients will result in growing demands on health care.<sup>9</sup> The planned expansion of healthcare capacity appears to be insufficient to meet the specific healthcare needs of the aging population with its growing number of chronically ill. Choices in health care and quality assurance are becoming urgent issues in many societies.<sup>10</sup> A growing need exists for chronic care and suitable methods to evaluate this complex care. Chronic care differs from acute care in various ways that influence how quality of care is assessed. Chronic patients rely on many different healthcare services for a prolonged period of time. Assuring quality of care means a focus on the integrated comprehensive continuum of care and not only on the single components—that is, the individual services or professions.

In particular, quality assurance of chronic care requires a broadening of our focus by including a wide range of health assessments. The goals in chronic care are to control disease and prevent complications, to reduce or postpone disabilities, and to promote wellbeing in the presence of chronic illness. Traditionally, we have studied mortality and clinical variables as barometers of health care (adding years to life). These standard measures need to be sup-

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plemented with information on physical, psychological, and social functioning, particularly in the case of chronic disorders (adding life to years). Such a multidimensional assessment of health related quality of life is needed to obtain a more comprehensive view of the burden of chronic illness.

#### MEASUREMENT

Although quality of life is increasingly used as an instrument to evaluate health care, the concept of quality of life is subject to different definitions and interpretations. Although quality of life was originally conceptualised in terms of psychosocial wellbeing and subjective perceptions of one's life situation, current definitions also include variables of physical functioning.<sup>11,12</sup> Thought of in this broad sense, the concept of quality of life is strongly related to the *International Classification of Impairments, Disabilities and Handicaps (ICIDH)* of the World Health Organisation, which provides systematic information on the long term, non-fatal consequences of chronic and degenerative diseases.<sup>13,14</sup>

Throughout the years, quality of life assessments have gained an established position in clinical care and healthcare research. There is a broad consensus that assessments of quality of life encompass three major domains: physical, psychological, and social functioning.<sup>11</sup> Physical functioning refers to symptoms, such as pain, fatigue, or chest tightness, as well as to functional status. Functional status covers a broad range of activities; the main categories include instrumental activities of daily living (for example, housework, cooking), mobility (for example, walking, climbing stairs), and basic activities in daily functioning (for example, dressing, feeding). Psychological functioning refers to wellbeing, psychological distress, and mental abilities. Related measures focus on anxiety, depression, and cognitive functioning. Social functioning represents the performance of social roles, and is defined in terms of interpersonal relationships, family functioning, sexual functioning, and social participation. These domain specific measures, together with global, overall measures of perceived health and wellbeing, are seen as the pillars of the concept of health related quality of life.

Many generic and disease specific instruments have been developed for measuring quality of life. Generic scales—such as the commonly used Sickness Impact Profile<sup>15</sup> or the Short Form-36 Health Survey Questionnaire<sup>16</sup>—encompass the dimensions of physical, psychological, and social health. Generic domain specific scales include subscales from these multidimensional instruments or specially developed scales, such as the Barthel Index.<sup>17</sup> Generic scales have important advantages because they provide measures that can be compared across patient groups and with normative data for the general population to quantify the specific impact of a disease in patients' daily lives. For example, comparative research in this field showed that stroke is one of the most disabling chronic diseases, causing long term dependency on a wide variety of

healthcare services. These findings are observed both at a population level<sup>18,19</sup> and at the level of patient groups.<sup>20,21</sup>

Using only domain specific instruments is likely to underestimate the impact of a disease on quality of life. In stroke, for example, the measurement of only neurological impairments appeared to underestimate health related quality of life. Six months after stroke, these impairments explained 25–45% of the variation in disabilities, 35% of handicaps, and 10% of psychosocial function.<sup>21</sup> These findings provide empirical support for the need of a multidimensional assessment of quality of life to establish the severity of diseases.

The use of generic instruments requires supplementation with disease specific symptoms to ensure sensitivity to clinically significant changes in health status and to enable comparisons within patient groups.<sup>12</sup> Disease specific aspects range from self reporting of fatigue, pain, nausea, and vomiting among patients with cancer (for example, Rotterdam Symptom Checklist<sup>22</sup>) to assessments of functional ability among patients with rheumatoid arthritis (for example, HAQ: Stanford Arthritis Center Health Assessment Questionnaire<sup>23</sup>). In addition, generic measures are adapted for specific patient groups, such as the stroke adapted 30 item version of the Sickness Impact Profile.<sup>24</sup>

Recently, considerable progress has been made in harmonising concepts and psychometric testing of instruments for international application. Systematic data collection will enhance our knowledge about the impact of chronic conditions on health related quality of life. This, in turn, will stimulate the practical application of quality of life in promoting the quality of health care. The assessment of physical, psychological, and social functioning of the patient is an essential part of clinical diagnosis, a major determinant of therapeutic choices, a measure of their efficacy, and a guide in planning long term care.<sup>25</sup> This statement of the American College of Physicians shows the importance of linking the concepts of quality of life and quality of care. In our view the relation between quality of life and quality of care should be denoted not only in terms of outcome assessment but also in terms of need assessment.

#### Quality of life and quality of care

##### OUTCOME APPROACH

The outcome approach focuses on the effectiveness of health care. Effectiveness is specified as the degree to which the care for which quality is to be assessed attains the level of health improvement that studies of efficacy have established as attainable.<sup>26</sup> The ultimate way to assess effectiveness is through randomised controlled trials. Although randomised controlled trials are scarce in the field of chronic care due to the comprehensiveness of chronic care and the complexity of research strategies, some interesting studies have been done, for example looking at patients with stroke. Stroke units have been developed to improve the management of inpatients with stroke. These units involve a specialist multi-

disciplinary team that provides continuity of care during the first weeks of illness. Systematic reviews of randomised trials have been done to examine whether stroke units could improve patient outcomes compared with contemporary conventional care.<sup>27-28</sup> The analyses examined death, dependency, and the requirement for institutional care as primary outcome values. The reviews showed that organised stroke unit care resulted in long term reductions in death, dependency, and institutionalisation. The observed benefits were not restricted to any particular subgroup of patients or model of stroke unit care.

The inclusion of measures of quality of life in studies on comprehensive care requires a consideration of a range of methodological issues.<sup>29-31</sup> Quality assurance presupposes advanced knowledge of the link between needs, interventions, and outcomes. The interrelations between these components are complex, particularly in chronic care. Health is generally acknowledged to be affected by many factors,<sup>32</sup> such as the course of the disease and the characteristics of the person with the disease (for example, coping styles, compliance). Disentangling care related, disease related, and personal characteristics is a prerequisite for establishing the quality of chronic care. Quality assessment of chronic care is further complicated by the long timeframe. Outcome studies usually include a reference period of three to 12 months, whereas for chronic conditions longer time periods are necessary.<sup>33</sup> This problem is exacerbated by the fact that treatments and health care, by definition, tend to be less effective for chronic conditions than for acute conditions. Finally, additional problems may arise in cases of comorbidity and cointerventions. These issues create important obstacles in evaluating health care among the chronically ill. Randomised trials of comprehensive care have rarely been conducted, as opposed to randomised clinical trials of specific or "isolated" treatments, such as drug treatment or surgical treatments. Systematic efforts have to be made to encourage proper designs that can be used to study quality indicators that are associated with the process of care. Assuring quality of care will be facilitated by agreement on standardised health related quality of life measures.

The increasing emphasis on outcome assessment has to do with the growing call for accountability. Early attempts to evaluate health care focused on the process of care, whereas recent efforts in quality management are directed to the outcome of care. The problems in assessing quality of life in chronic patients have raised doubts about the increasing emphasis on outcomes. In the rush to embrace outcomes, the examination of the process has been neglected.<sup>34</sup> In chronic care, however, it is sensible to focus on process rather than on outcomes. In the absence of studies of efficacy, it is considered as appropriate to consider standards of care for their contribution to comprehensiveness, coordination, and continuity as to see them as goals in their own right.<sup>35</sup> Process measures therefore should gain more weight in quality assurance of

chronic care. Apart from this discussion on process and outcome indicators, more attention should be paid to quality assessments on the basis of the need approach.

#### NEED APPROACH

The need approach determines the appropriateness of health care by examining the association between healthcare needs and use of health care. The detection of discrepancies between needs and delivered care will help to identify inequities in access to care. These assessments are used to analyse underuse and overuse of health care, and to promote equal use for equal need. Healthcare needs can be identified as health related needs, professionally defined needs, and patient defined needs.

Health related needs refer to health deficits that are assessed by means of standardised measurements of health related quality of life. Several studies have explored this approach<sup>36</sup> using the model of Andersen and Newman.<sup>37-38</sup> According to this model, equity in access to health care is shown when the use of health care is merely explained by need factors (for example, functional health, emotional distress) and need related sociodemographic variables (for example, age); inequity of care exists when the use of care is primarily explained by enabling factors (for example, income, availability of services). We applied this model to the acute episode<sup>39</sup> and the chronic episode (Scholte op Reimer WJM, Haan RJ de, Limburg M, Bos GAM van den. Use of long-term care after stroke; submitted for publication, 1999) of care for stroke patients. We found strong associations between needs in health related quality of life and the use of specific health services. The use of rehabilitation and aids were highly related to disability, whereas emotional distress increased the use of psychosocial support. These findings support the principle of equal use for equal need on an aggregated level, though some inequalities in care could not be ruled out, especially in the field of rehabilitative care where patients of older age and a lower income had lower access.

Furthermore, we observed a relatively high percentage of unmet care demands in stroke patients who did not use long term care.<sup>40</sup> To assess the relevance of unmet demands as an indicator of appropriateness, we compared the "unmet care demanders" with the users on the one hand and with the "no demanders" (that is, non-users without care demands) on the other hand. Our results showed that the unmet demanders were more comparable with the users than with the no demanders for their quality of life characteristics. Compared with no demanders, unmet demanders for rehabilitation and aids were more likely to be disabled, whereas unmet demanders for psychosocial support were more likely to report emotional distress. These findings indicate that health care does not fully respond to the healthcare needs of patients.

Need assessment is not just a method of measuring health related quality of life problems. It is a systematic method of identifying healthcare needs and unmet healthcare de-

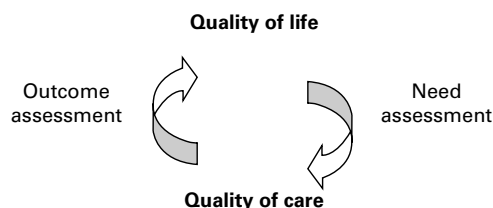


Figure 1 The reciprocal relation between quality of life and quality of care.

mands of a population. This method involves professional and patient judgments. Professionals define needs in terms of standards of care, clinical guidelines, and evidence-based medicine. Scientific literature in the field of chronic care, however, does not provide sufficient evidence to justify the indications for which interventions and procedures should or should not be done. Although for acute care we can do an evidence-based case by case review of the quality of care,<sup>41</sup> quality assurance of chronic care, as yet, relies more on opinion based than on evidence-based judgments. Patients may have different views than professionals, especially when they are affected with a chronic disease and their health problems are not amenable to medical cure. Subsequently, in healthcare need assessments, the focus will shift towards measures of quality of life that reflect the perceptions of patients. Good quality of care requires a balance between professionally defined needs and patient defined needs.

#### Quality of life and quality assurance

Need assessment and outcome assessment actually reflect two sides of the same coin in quality assurance of care (fig 1). The measurement of needs takes place before the start of an intervention, and the assessment of outcomes occurs after the intervention. The need approach is linked to the appropriateness of health care and will help to uncover deficits in the entry or access to health care. The outcome approach, however, is linked to the effectiveness of health care and will help to identify shortcomings in the impact or exit of health care. Another, more subtle, difference lies in the evaluation of care. Need oriented research is particularly directed at underuse (for example, unmet demands). The detection of unmet needs serves as a flag that the healthcare system does not respond appropriately to the needs of all subgroups of the population. On the other hand, outcome focused research has frequently been undertaken to reverse incentives which had encouraged overuse, particularly of inpatient procedures and technology care.<sup>42</sup>

Need assessment and outcome assessment are in essence a cyclical process for quality assurance. Healthcare need is commonly defined as the capacity to benefit from health care.<sup>43</sup> This definition assumes that healthcare needs can only be met if information is available about the effectiveness of care. Directing services to those who need these services requires a better understanding of the potential benefit from health care. Health care arrangements for chronic patients, however,

often lack scientific support. Difficulties in providing a scientific basis are related to the comprehensiveness of chronic care.

#### COMPREHENSIVENESS OF CHRONIC CARE

Chronic care encompasses various interventions and associated services involving medical treatment, rehabilitation, nursing care, supportive care in home settings, and institutional care. It is misleading to suggest that medical care has little to offer to chronic patients. The conventional distinctions between prevention, cure, and care seem to dissolve in the face of the complex health problems. The main characteristic of long term care is the multidisciplinary involvement. Long term care goes beyond the traditional boundaries of medicine, and requires a deliberate balance between medical and non-medical needs.

Specifically, for the purpose of quality assurance in long term care, a comprehensive model of health measures is required. Broad agreement exists about the components of this model. The model usually encompasses four domains—that is, mortality; clinical symptoms; physical functioning; and psychological and social functioning, which are often indicated by the four Ds: death, disease, disability, and discomfort.<sup>44</sup> This multilevel model of comprehensive health assessments represents a hierarchical structure ranging from the cellular level to the individual level and from the individual level to the societal level. As one moves from the biological level to the societal level, disease specific differences will fade. Quantifying the relation between clinical variables and measures of health related quality of life will help to identify risk factors for poor health status and should facilitate the establishment of the important link between diagnosis and treatment.<sup>45</sup>

The relevance or sensibility of a health variable is strongly determined by the nature of a chronic condition, severity of disorders, the purpose of the care, and patients' preferences and expectations.<sup>46</sup> Review studies of quality indicators in the management of chronic patients have shown how health measures vary for different patient groups.<sup>47-48</sup> The relative weight that should be given to the distinguished domains of health measures as indicators of the quality of care varies not only according to the type of disease but also according to the type of discipline or health care facility. For example, acute care for patients with stroke is aimed at reducing mortality and preventing clinical complications, whereas chronic care encompasses multidisciplinary efforts to improve or preserve functioning for as long as possible.

Results from the review studies could be used to relate the four domains of health measures to specific patient groups and healthcare facilities. The first group, which consists of mortality or survival rates, is primarily relevant for diseases with a relatively high fatality rate, such as cancer, diabetes, stroke, or heart failure; mortality is less relevant for quality assurance in cases of chronic obstructive pulmonary diseases, rheumatoid arthritis, or

multiple sclerosis. Mortality rates are often taken as an indicator of the quality of emergency hospital care, acute oncological treatments, or surgical operations; mortality rates are less relevant to evaluate ambulatory care. The second group of health variables, encompassing clinical symptoms and pathophysiological variables, vary strongly with the condition under study. Clinical measures are of great importance in the care for patients with diabetes mellitus (HbA<sub>1c</sub>), hypertension (blood pressure), chronic obstructive pulmonary diseases (forced expiratory volume, chest tightness), cancer (metastasis), or rheumatoid arthritis (erythrocyte sedimentation rate, pain). These variables are less relevant for quality assurance of chronic care for patients with stroke, chronic psychiatric care, or nursing home care. The third group of health measures refers to physical functioning, and is predominantly of importance for disabling diseases such as rheumatoid arthritis or neurological disorders, and this domain acts as a major quality variable in rehabilitation. Disability measures have little relevance for evaluating inpatient care, whereas functional limitations or bed restrictions are part of therapeutic interventions. The fourth group, consisting of measures of psychological and social functioning, is in essence of importance for all chronic patients, but the psychosocial functioning is specifically relevant for quality assurance of chronic psychiatric care or residential care. Measures of wellbeing and autonomy are important for studying long term care in nursing homes. In geriatric medical service the patients' quality of life—their general feeling of wellbeing—is judged to be the most important measure (that is, outcome), and the lowest priority is given to measures of activity and mortality rates.<sup>49</sup>

These disease specific and discipline specific applications of health status measures aim to provide professionals with a comprehensive summary of the health status of their patients and should guide clinical decisions. However, although the value of quality of life measures has been amply shown for quality assessment of chronic care, their possible use in clinical practice is less clear. There is broad agreement about the overall usefulness of health status reports as an aid to patient management. In contrast, there is less agreement about the usefulness of these reports for specific aspects of patient assessment and for making decisions about referrals in clinical practice.<sup>50</sup> Strengthening clinical usefulness requires a further understanding of health status scores in relation to clinical decisions, indications, and referrals. The Barthel Index is one of the measures with clear clinical utility for patients with stroke. This disability scale was proved to contribute substantially to interdisciplinary communication and, in particular, to the identification of the need for care and rehabilitation that is tailored to the individual patient.<sup>51</sup> Application of the Barthel Index makes sense only if disability is an expected component of the health status of the patient; in non-disabling conditions, measures of disability have little or

no informative value. A further challenge in strengthening clinical utility is the application of feasible instruments. Although most of the multidimensional instruments consist of a broad range of items, which may pose practical problems for clinicians and their patients, there are possible solutions. In one study, for example, we constructed a short (30 item) version of the Sickness Impact Profile for patients with stroke.<sup>24</sup> In the future, greater efforts should be made to enhance the clinical usefulness of quality of life measures. This can be accomplished by relating health status scores to clinical decisions. This will underscore, in turn, the important link between diagnosis and treatment.

In conclusion, quality of life, as an instrument for assessing health care outcomes, has become a well established part of quality management and serves as an index of the relative effectiveness of care. None the less, there is growing criticism about the dominant emphasis of the outcome approach. There is a recognition that more attention should be paid to the need approach as an index of the relative appropriateness of health care. Quality assurance of chronic care requires a broadening of our focus to include a wide range of health assessments—that is, not only traditional measures of mortality and clinical indices but also measures of physical, psychological, and social functioning. Health assessment as applied to patients with chronic diseases must be done repeatedly over the course of a disease because these patients are often taking part in an ongoing chain of healthcare interventions. Measures of quality of life that are associated with interventions could indicate potential areas for quality assurance of chronic care. We have to move from assessment and evaluation to improvement of the quality of care. More efforts are needed to understand the disease specific and discipline specific profiles of health to provide clinically useful tools for optimising chronic care.

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