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Disease-specific quality of life: is it one construct?

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The objective of this study was to examine the structure of disease-specific quality of life (QoL). Models of QoL with either one overall construct or more constructs were tested and the relationships (factor loadings) between the constructs and dimensions were established, using structural equation modelling. The models were tested over time to assess the stability of the structure. To generalize the results further, disease-specific questionnaires of two very different chronic diseases have been compared: inflammatory bowel disease (IBD) and Parkinson's disease (PD).

Questionnaires were mailed in 1994 and a repeated measurement was conducted in 1995. Data were obtained from 222 IBD patients and 235 PD patients. The results show that for both diseases, disease-specific QoL can be considered as one construct. The stability over time of the structure of the QoL models was satisfactory. In PD the factor loadings between the dimensions and QoL were within a small range and remained the same over time, while in IBD, the factor loadings had a larger range and fluctuated more. These results imply that one meaningful sum score can be obtained from these questionnaires.

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Key words: Quality of life; inflammatory bowel disease; Parkinson's disease; structural equation modelling.

Introduction

Quality of life (QoL) has become a widely accepted concept in health care research. It is used as an outcome measure in population studies, in descriptive studies of patient groups and in clinical trials. While there is no clear and broadly approved definition of

QoL,¹ it has been accepted that it is a multidimensional concept. The multiple dimensions may not only include the physical, psychological and social functioning specified by the World Health Organization² but also material consequences, cognition, spiritual well-being and structural functioning.^{3–9} Little is known, however, about the structure of QoL. There is controversy about the number of constructs or higher-order factors underlying the dimensions. Some consider the physical, emotional and social dimensions part of one overall QoL construct,^{3–10} while others found two separate constructs underlying the dimensions which are labelled physical health (including physical functioning and symptoms) and mental health (including emotional and social functioning).^{11–15} Still others² presume three dimensions underlying QoL (physical, emotional and social). Empirical results, however,^{12–15} were obtained from generic QoL questionnaires (the SF-19 and Quality of Life Questionnaire) and it is not clear if these results can be generalized to disease-specific questionnaires.

Whether QoL can be considered as one overall construct or separate constructs is relevant to the way sum scores can be aggregated from QoL questionnaires. In some studies researchers are interested in the separate scores of all the subscales of a questionnaire, e.g. the effect of psychological counselling on physical, emotional and/or social well-being. Other studies, however, require one aggregated QoL sum score, as in cost-utility studies or in some clinical trials. If only one construct is underlying the QoL dimensions, one sum score will capture QoL adequately. If, however, QoL should consist of more distinguishable constructs, the appropriate number of sum scores should be calculated.

Several researchers have investigated the importance or relative weights of specific items in relation to the dimensions, for instance by means of factor

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analysis.¹⁶⁻¹⁸ Others used judgement analysis to measure the patient's most important areas of QoL.^{19,20} However, the extent to which the dimensions themselves assess QoL is yet unknown. If physical, emotional and social functioning are as equally important to QoL, this should be reflected in the relations between the dimensions and the construct(s). Whatever structure is found, it should be relatively stable over time and not vary as the disease progresses or fluctuates. Longitudinal testing of a QoL model has, to our knowledge, never been performed. Finally, if disease-specific QoL is a general concept, the structure should be similar across diseases.

The objective of this study is to examine the structure of disease-specific QoL, that is the number of constructs underlying QoL and the relations between the construct(s) and the dimensions. First, QoL models with either one or more underlying constructs will be tested. Second, the models will be tested over time to assess the stability of the structure. These longitudinal models will yield either one or more constructs and the relationships between physical, emotional and social dimensions and the underlying construct(s) will be established. Third, the models of two disease-specific questionnaires for inflammatory bowel disease (IBD) and Parkinson's disease (PD) will be compared to generalize the results.

Methods

Patient recruitment

Patients with IBD and patients with PD participated in this study. IBD is a chronic inflammatory disease of the gut which mainly affects young people. The main symptoms are diarrhoea, abdominal pain and weight loss. Acute exacerbations of varying severity usually occur intermittently. PD is a slowly progressive neurological disease with a mean age of onset of 55 years. The main symptoms are tremor, akinesia and postural abnormalities.

In 1994 we sent self-report questionnaires to consecutive IBD patients who attended the IBD out-patients' clinic of the Academic Medical Center of Amsterdam and to members of the Dutch Parkinson's Disease Society. In 1995 we conducted a repeated measurement.

Measurements

Disease-specific QoL was measured by two instruments. The IBD Questionnaire (IBDQ) consists of 32

items which form four subscales: IBD-related symptoms and functioning (IBD symptoms, e.g. cramps in the abdomen and loose bowel movements, ten items), systemic symptoms (e.g. fatigue and weight problems, five items), emotional functioning (e.g. feeling embarrassed, 12 items) and social functioning (e.g. unable to attend school or work, and need to cancel social activities, five items).²¹⁻²²

The PD Quality of Life Questionnaire (PDQL) consists of 37 items. The PDQL consists of four subscales: Parkinsons related symptoms and functioning (e.g. stiffness and shaking, 14 items), systemic symptoms (e.g. fatigue and obstipation, seven items), emotional functioning (e.g. difficulty accepting illness and feeling embarrassed, nine items) and social functioning (e.g. less holidays and need to cancel social activities, seven items).²³ In both questionnaires the scores are given on five-point Likert scales. They have well-established levels of reliability and validity.²¹⁻²³ Standard demographic questions were used to assess gender, age and disease duration.

Statistical analysis: structural equation modelling

The models for QoL were tested using structural equation modelling (SEM). The greatest advantage of SEM is its ability to test the tenability of a hypothesized model while taking measurement error into account.²⁴

First, two theoretical models will be tested. Figure 1 shows the theoretical model in which one overall QoL construct is underlying the four dimensions. Figure 2 depicts the theoretical model where two constructs, i.e. physical and mental health, underlie the four dimensions. For statistical reasons it was not possible to test a model with three constructs (physical, mental and social), since there would be no degrees of freedom left.

The latent variables, i.e. the representation of constructs, are represented by circles. The observed subscales that operationalize the respective dimensions are represented by boxes. The influence of a latent variable on a subscale is indicated by an arrow and by the path coefficient which is simply a factor loading. For each disease a covariance matrix of two times four variables (disease-specific symptoms and physical functioning, systemic symptoms, emotional functioning and social functioning, assessed in 1994 and 1995) constituted the input data for this study. The variables were checked for violations of normality assumptions. The results of the Kolmogorov-Smirnov

Figure 1. QoL model: one construct

test for normality and inspection of the normality plots indicated normality within an acceptable range for the analyses performed. LISREL 8²⁵ was used to test the structural models. The goodness of fit of the models is judged by three measures: the χ^2 test, the adjusted (for degrees of freedom) goodness of fit index (AGFI) and the root mean square residual (RMSR). The χ^2 test compares the model to an alternative model and should therefore not be significant ($p > 0.05$). The AGFI indicates how much of the covariance matrix is explained by the model and should be at least 0.90. The RMSR is a measure of the fitted residuals and should be very small, with 0 indicating a perfect fit.

Second, the stability of the structure will be examined by fitting longitudinal models with either one or two separate latent variables, depending on the results of the first testing. The relationships (factor loadings) between the subscales and the latent variable(s) will be established and the relationship(s) (correlation) between the 1994 and 1995 latent variables will be examined. Only significant factor loadings and correlations (t -test, $p < 0.05$) will be reported. It is expected that the factor loadings between the latent QoL variable(s) and the subscales are invariant between the 1994 and 1995 assessments. The variances of the subscales are also assumed to remain stable. This will be tested by an equality constraint on the factor loadings and variances. Third, in order to generalize the results, the models of IBD and PD will be compared. No significant differences in the factor loadings are expected between the two diseases. To test this, both longitudinal models will be

Figure 2. QoL model: two constructs

tested simultaneously with an equality constraint on the factor loadings. The correlation between QoL in 1994 and in 1995 is expected to be stronger in PD than in IBD because PD is a slowly progressive disease, whereas the course of IBD can be intermittent.

Results

In March 1994 we sent self-report questionnaires to 309 consecutive IBD patients who attended the IBD out-patients' clinic of the Academic Medical Center of Amsterdam. In all, 271 completed questionnaires were returned (88%). In March 1995 we conducted a repeated measurement: 222 IBD patients (82%) returned the questionnaire again. In November 1994 we sent a similar self-report questionnaire to 529 members of the Dutch Parkinson's Disease Society. Of these 529 questionnaires, 450 were returned (85%) and 384 questionnaires were completed (73%). In November 1995 we conducted a repeated measurement with 298 patients: 235 PD patients returned the questionnaire again (79%).

The age, sex and disease duration are described in Table 1. No data on the patients who declined to participate were available at the first measurements. The IBD patients lost to follow-up were significantly younger and had a shorter disease duration, but no differences in the gender and QoL scores were found. The PD patients lost to follow-up were older, had been ill for a longer period and had worse QoL scores. No differences in gender were found.

Table 1. Patient characteristics of the two patient groups

	IBD		PD	
	1994 (n = 271)	1995 (n = 222)	1994 (n = 384)	1995 (n = 235)
Age (years)	39.6 (SD 13.8)	41.9 (SD 13.4)	67.1 (SD 10.8)	66.6 (SD 10.3)
Gender:				
Female	166 (61.3%)	140 (63%)	181 (47%)	107 (46%)
Male	105 (38.7%)	82 (37%)	202 (53%)	128 (54%)
Disease duration (years)	10.6 (SD 8.4)	12.3 (SD 8.7)	7.9 (SD 6.3)	8.8 (SD 6.6)

QoL model: one latent variable or two separate latent variables

To establish whether one or two latent variables underlie QoL, two structural models (Figures 1 and 2) were tested. Both models were tested on the data collected in 1994 and 1995. The fit statistics for the four models for IBD are reported in Table 2.

The results show that the model with one latent variable fits the data best for IBD: a low χ^2 , small RMSR and high AGFI were found. The two latent variables model appears to show a good fit, but there were serious fitting problems. The estimated correlation between the physical and mental latent variables was higher than 1 (1.03), thus exceeding the upper limit of a correlation coefficient. Moreover, the one latent variable model is more parsimonious.

The goodness of fit statistics for PD are reported in Table 3. The best fitted model for PD was the one with two latent variables: physical and mental health. The model fitted better in 1995 than in 1994: the χ^2 is not significant and the AGFI and RMSR are better.

However, the correlation between the physical and mental latent variables was very high: $r = 0.90$ in 1994 and $r = 0.87$ in 1995. This implies that although this

model describes the data slightly better, the two latent variables are strongly related. For reasons of parsimony, we therefore decided to test a third model with one latent variable. In this model the variances between the physical and systemic subscales (which had the highest subscale correlation, $r = 0.69$) were correlated. This model was found to be equivalent to the two latent variables model with the same good fit statistics.

Longitudinal models

To test the stability of the model over time, one longitudinal model of QoL with one latent variable for each year was fitted on the 1994 and 1995 data for each disease group. Figure 3 depicts the longitudinal QoL model for IBD.

The figure reveals significant factor loadings between the measured subscales of the IBDQ (IBD symptoms, systemic symptoms, emotional functioning and social functioning) and the latent variable QoL. The factor loadings range from 0.56 to 0.95. The factor loadings and variances of the

Table 2. Fit statistics for the models for IBD

Latent variables	Year	n	χ^2	df	p	AGFI	RMSR
1	1994	271	4.26	2	0.12	0.96	0.015
2	1994	271	2.67	1	0.10	0.95	0.012
1	1995	222	2.64	2	0.27	0.97	0.014
2	1995	222	2.29	1	0.13	0.95	0.013
Longitudinal	1994 + 1995	222	14.91	16	0.53	0.96	0.029

n, number of patients; *df*, degrees of freedom; *p*, *p* value; AGFI, adjusted goodness of fit index; RMSR, root mean square residual.

Table 3. Fit statistics for the models for PD

Latent variables	Year	<i>n</i>	χ^2	df	<i>p</i>	AGFI	RMSR
1	1994	384	0.17	2	0.000019	0.87	0.029
2	1994	384	7.40	1	0.006500	0.91	0.014
1	1995	235	16.56	2	0.000250	0.85	0.031
2	1995	235	2.98	1	0.084000	0.94	0.012
1, correlated	1994	384	7.40	1	0.006500	0.91	0.014
1, correlated	1995	235	2.98	1	0.084000	0.94	0.012
Longitudinal	1994 + 1995	235	29.19	20	0.084000	0.95	0.034

n, number of patients; df, degrees of freedom; *p*, *p* value; AGFI, adjusted goodness of fit index; RMSR, root mean square residual.

subscales were expected to be invariant over time. It was indeed found that IBD symptoms and social functioning did have the same factor loadings and variances in both 1994 and 1995. However, the factor loadings for both systemic symptoms and emotional functioning were lower in 1994: the model showed a significantly worse fit when these parameters were constrained to be equal. QoL had the strongest factor loading on the emotional functioning subscale in both 1994 ($r = 0.95$) and 1995 ($r = 0.84$). The goodness of fit statistics are also shown in table 2. The goodness of fit tests indicate a good fit, with $\chi^2(16) = 14.91$ ($p = 0.53$) AGFI = 0.96, and RMSR = 0.029. It should be noted that a good fit was achieved after correlating the variances of the systemic symptoms and emotional functioning subscales. This indicates that both subscales have more in common than just the latent variable QoL.

Next, a longitudinal model with one latent variable was tested on the data of the PD questionnaire. The variances of the PD symptoms and systemic subscales were correlated again. In addition, the variances of the systemic and emotional subscales were also correlated, as was the case with the longitudinal model for IBD. Figure 4 shows the factor loadings between the subscales of the PDQL (Parkinson's symptoms, systemic symptoms, emotional functioning and social functioning) and the underlying latent variable QoL.

The factor loadings range from 0.67 to 0.73. All of the factor loadings and subscale variances were equal in 1994 and 1995: the model showed a non-significant worse fit when these parameters were constrained to be equal. As is shown in Table 3, the longitudinal model has a good fit: $\chi^2(20) = 29.19$ ($p = 0.084$), AGFI = 0.95 and RMSR = 0.034.

Figure 3. Longitudinal QoL model for IBD.

Figure 4. Longitudinal QoL model for PD.

Comparison of the longitudinal IBD and PD models

The longitudinal IBD and PD models were compared, in order to generalize the results further. To test whether the factor loadings of the subscales of the two models are the same, both longitudinal models were tested simultaneously with an equality constraint on the factor loadings. This total model did not fit the data: $\chi^2 (41) = 79.88$ ($p = 0.00026$), AGFI = 0.89 and RMSR = 0.10. When the equality constraints of the factor loadings was lifted and the factor loadings were estimated for each disease group, the total model did fit the data: $\chi^2 (36) = 43.05$ ($p = 0.20$), AGFI = 0.98 and RMSR = 0.033.

The factor loadings in the IBD model have a wide range from 0.56 (systemic symptoms in 1995) to 0.95 (emotional functioning in 1994). In PD they range from 0.67 (emotional functioning) to 0.73 (Parkinson's symptoms). Only the factor loadings for disease-specific symptoms are the same in both groups (0.73 in both 1994 and 1995). However, the factor loadings for systemic symptoms and emotional and social functioning were higher for IBD in 1994 and, except for systemic symptoms, also in 1995. The longitudinal IBD model (Figure 3) shows that QoL was relatively stable over time ($r = 0.64$), but, as expected, the PD model (Figure 4) shows a stronger correlation between the QoL in 1994 and 1995 ($r = 0.91$).

Discussion

The objective of this study was to examine the structure of disease-specific QoL to determine how many constructs underlie QoL and to assess the relations between the construct(s) and the dimensions. We fitted QoL models with either one overall or two separate underlying latent variables. The results show that the model with one overall QoL latent variable fitted the IBD QoL questionnaire best. For the PD questionnaire the model with two latent variables at first seemed to fit the data best. However, the latent variables were highly correlated and it could be shown that a single latent variable model in which the variances of the physical and systemic subscales were correlated was equivalent to and more parsimonious than the two latent variables model.

These results imply that disease-specific QoL can be considered as one construct. This conclusion is different from prior research into the structure of QoL, based on data from generic questionnaires. These earlier studies clearly showed two constructs which were not highly correlated (0.45¹² and range 0.16–0.48¹⁵). Items in disease-specific questionnaires, such as the IBDQ and PDQL, measure QoL more specifically in that specific disease. All of the items (physical, psychological and social) refer to one disease and are intended to be interpreted in the context of that one disease only. It is therefore likely

that items in those disease-specific questionnaires represent one construct. Items in generic instruments, on the other hand, measure QoL more generally and are not formulated in terms of one disease. Consequently, different constructs are more likely to be distinguished in models based on these generic questionnaires.

The stability of the structure was examined by fitting longitudinal models. Relationships between the physical, emotional and social subscales and the underlying latent variable were established and the stability of these relationships over time was examined. A longitudinal model with one latent variable did fit the data in both diseases. In PD the factor loadings between the subscales and QoL were within a small range and remained the same over time. In IBD, the factor loadings of emotional functioning and systemic symptoms were higher in 1994 than in 1995. One might speculate that these differences are a result of the fluctuating course of IBD. It was expected that IBD symptoms would change most and, consequently, the factor loading of this subscale might have changed, but this was not the case.

In both longitudinal models, the variances between the systemic and emotional subscales were also correlated. This means that the systemic and emotional subscales have something in common, which is not shared with the other scales. The systemic scale contains items about fatigue, sleep, energy and feeling generally unwell. The emotional scale contains items about depression, embarrassment and accepting the disease. It is generally accepted that fatigue, energy loss and general feelings of unwellness are symptoms that may concur with feelings of depression. Thus, the systemic and emotional dimension may, to some extent, both draw upon the same information.

The longitudinal models of two diseases were compared. While we found stable models for two very different diseases, IBD and PD, we also came upon differences between the models. No significant differences in the factor loadings were expected between the two diseases, but the results showed that the factor loadings were not equal. In IBD, the range of factor loadings was much larger (0.56–0.95) than in PD (0.67–0.73). In addition, the factor loadings in PD were more stable than in IBD. Moreover, the factor loadings or relative contribution of QoL to the subscales were different in the diseases. The subscales IBD and PD symptoms and systemic symptoms have similar factor loadings, but emotional and social functioning have a higher factor loading in IBD than in PD. Both diseases have severe negative emotional and social consequences. IBD patients often experi-

ence feelings of depression and frustration. The extremely frequent visits to the washroom keep many patients from social activities. In PD, the most severe emotional consequences are depression, insecurity and fear for the progress of PD. Visible shaking and sudden involuntary movements also keep many patients from social activities. It could be, however, that emotional and social functioning are more important to the overall QoL in the IBD patients than in the PD patients, because the IBD patients were much younger (40 years) than the PD patients (67 years).

The relation between the QoL scores of 1994 and 1995 were, as expected, less stable in IBD than in PD (0.64 versus 0.91), which could be explained by the fluctuating nature of IBD. Despite these relatively small differences, the results are highly comparable. Given the fact that these diseases are so different in course, symptoms and treatments, it may well be that these results could be generalized to other diseases. It should be noted, however, that the two questionnaires contain the same four subscales. Although these subscales are the ones used most frequently, in both disease-specific and generic QoL instruments, it could be that questionnaires with different subscales, such as material consequences, cognition or spiritual well-being, have a different structure.

These findings have one major practical implication. The objective of some research projects, such as cost-utility studies, is to establish which treatment or strategy is the best in terms of QoL. For those research purposes, one meaningful sum score can be calculated for each questionnaire by aggregating across the items. This one sum score reflects the physical, emotional and social well-being, that is the QoL of a person. Clearly, this aggregation implies that specific information about physical or psychosocial well-being is lost. Research projects which focus on the effects of a specific physical and/or psychosocial dimension, require the use and computation of subscale scores.

In summary, a model with one overall QoL latent variable adequately fitted the data of the two disease-specific questionnaires. The results show that the relations between the dimensions and the QoL latent variable basically remained the same over time and that the models are stable. The relative contributions of the subscales to the QoL latent variable were, however, different in the two diseases.

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