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THE ADAPTATIONS OF A QUALITY OF LIFE QUESTIONNAIRE FOR ROUTINE USE IN CLINICAL PRACTICE: THE CHRONIC RESPIRATORY DISEASE QUESTIONNAIRE IN CYSTIC FIBROSIS

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Running Heading: Adapting the CRDQ for clinical practice.

ABSTRACT

The assessment of quality of life (QOL) is necessary to monitor the course of disease and to assess the effect of new and existing interventions in clinical practice. This will only be achieved if QOL can be measured accurately and routinely.

The aim of this study was to demonstrate the methodology involved in the adaptation and shortening of the Chronic Respiratory Disease Questionnaire (CRDQ) in a population of adults with cystic fibrosis (CF).

A single interviewer administered the CRDQ to a sample of 45 adult patients (32 males) with CF prior to assessment of spirometric measures of lung function. Those patients whose lung function was stable at the time of study, and who could attend for a retest within 14 days, were asked to complete the questionnaire at a subsequent visit (n=10). The average interval between visits was 7 days (range 5-14 days).

Correlations between spirometry and CRDQ dimensions ranged from -0.003 to 0.426. The fatigue, emotion and mastery dimensions showed high internal consistency, and adequate construct validity. In the small number of patients suitable for retest, the results indicated that the dimensions exhibited adequate test retest reliability. In contrast low internal consistency was demonstrated for the dyspnoea dimension. The fatigue, emotion and mastery dimensions could be reduced, in terms of their number of items without a substantial loss in explanatory power.

This study suggests that QOL measurement can be made convenient, and so more easily accessible for routine clinical assessment.

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INTRODUCTION

Early diagnosis and better treatment of cystic fibrosis (CF) has improved the life expectancy of people with this condition. The median life expectancy of a person born with CF in the 1990s may extend to forty years[1]. As the disease progresses, respiratory infection causes symptoms such as coughing, breathlessness, weight loss, and decreased exercise tolerance. These impair patient's quality of life (QOL), and eventually result in premature death[2]. Many existing treatments for CF are likely to affect QOL, as they are time consuming, require hospitalisation, and have associated side effects. It is therefore essential, that in parallel with increasing patients' quantity of life, attention is also paid to optimising patients' quality of life. It is also important that new therapies are assessed for their impact on QOL. To achieve this aim it is vital that QOL is quantified in a valid and reliable manner.

Previous studies in CF have used QOL measures to evaluate the effects of interventions, to compare the QOL of people with CF to the QOL of people in other population groups, and to investigate the determinants of QOL in CF[3-15]. This research has employed both generic and disease specific health status instruments.

The chronic respiratory disease questionnaire (CRDQ)[16] is a widely used disease specific QOL instrument that has been used to assess QOL in patients with chronic obstructive pulmonary disease (COPD). The CRDQ has also been shown to successfully track changes in QOL over time following antibiotic treatment of respiratory exacerbations in CF[10]. The CRDQ is an established and frequently used disease specific QOL assessment tool but the psychometric properties of this questionnaire have not been investigated in patients with CF. In addition the questionnaire can take up to thirty minutes to complete and its results are not immediately interpretable[16]. The primary aim of the present study was to demonstrate the methodology involved in the adaptation and shortening of a QOL questionnaire. This is a necessary step to make QOL questionnaires more "user-friendly" for clinicians to ensure that this important aspect of a patient's health status is regularly monitored.

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METHOD

A single interviewer administered the CRDQ to a sample of 45 adult patients (32 males) with CF. In all cases the questionnaire was administered before any other assessment procedures, such as spirometry, were carried out. Those patients, whose lung function was stable at the time of study, and who could attend for a retest within 14 days, were asked to complete the questionnaire at a subsequent visit (n=10). The average interval between visits was 7 days (range 5-14 days).

The CRDQ consists of 19 items which measure four dimensions of QOL: dyspnoea, fatigue, emotion, and mastery. The dyspnoea scale is the only individualised part of the questionnaire and includes asking the patients to quantify their dyspnoea during five self selected activities that are frequently performed and are important to their daily lives. The other three dimensions consist of standard, fixed items (See Appendix). For all questions patients were asked to rate their function on a seven point category scale. The blind method of administration was used during the follow up assessment. Spirometric measures of lung function (Forced expiratory volume in 1 second, FEV_1, forced vital capacity, FVC) were measured by a Vitalograph Spirometer and were recorded as absolute values and as percentages of E.C.C.S. predicted normal.

STATISTICAL ANALYSES

Internal consistency was assessed using Cronbach's Alpha and factor analysis was utilised to determine the unidimensionality of each dimension under investigation. The intercorrelations between items within each dimension were assessed using Pearson's Product Moment Correlation Coefficient (Pearson's r).

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RESULTS

Forty five patients with CF (mean, SD: age 27, 9 years; FEV_1 2.03, 1.10 $lmin^{-1}$; FEV_1 percentage of predicted normal 57, 27%; FVC 2.93, 1.32 $lmin^{-1}$; FVC percentage of predicted normal 67, 27) completed the CRDQ. The correlations obtained between FEV_1 (percentage of predicted normal) and the CRDQ dimensions were FEV_1 vs fatigue: $r = 0.009$, $p = 0.475$; FEV_1 vs emotion: $r = -0.0029$, $p = 0.426$; FEV_1 vs mastery: $r = 0.266$, $p = 0.041$; FEV_1 vs dyspnoea: $r = 0.245$, $p = 0.13$.

The CRDQ data were initially submitted to a test of internal consistency, using Cronbach's alpha. An alpha value of 0.777 was returned for the dyspnoea dimension. An explanation of this relatively low alpha value cannot be discerned, as the individualised nature of the dyspnoea dimension, does not lend itself to any investigation of the item total correlations. The dyspnoea dimension was therefore omitted from further analysis. The other three dimensions had high estimates of internal consistency, with corresponding high item-total correlation values within each dimension (Table 1). However, item 8 "How often during the last week have you felt embarrassed by your coughing or heavy breathing", on the emotion dimension, had an item-total correlation of 0.186. This suggests that the emotion scale is not unidimensional, and this was confirmed through factor analysis. Analysis of the face validity of this item led us to believe that it could be interpreted ambiguously by patients, and therefore should be excluded from the emotion dimension. Subsequently, the internal consistency of the emotion dimension was once again estimated, without item 8, and it increased from 0.880 to 0.919. Item 8 was left out of any further analysis.

In order to test the construct validity, exploratory factor analysis using the principal components method of extraction, with varimax rotation, was performed on all of the items from the CRDQ, excluding those comprising the dyspnoea dimension and Item 8. Exploratory factor analysis was used because the number of factors underlying these CRDQ items has not been investigated previously within the population of adults with CF. The results of this factor analysis are shown in Table 2. The factor analysis extracted three factors, with a total of 78.2% variance explained. All of the items comprising the original fatigue dimension load most heavily on factor 1, and

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all of the items comprising the original mastery dimension load most heavily on factor 3. All of the remaining items comprising the original emotion dimension, with the exception of item 13, load most heavily on factor 2. However item 13 still loads quite heavily (0.533) on factor 2. This analysis suggests that the factor structure of the original CRDQ (with the exclusion of item 8) is appropriate for this population of adults with CF.

To investigate if reducing the number of items within each dimension, would make the CRDQ easier to use, the 'best' item was chosen from each dimension, and correlated with the total dimension score. The 'best' item was considered to be that item which displayed the highest factor loading for that dimension (factor). This item was then added to the second 'best' item, and the two item total was correlated with the total dimension score. This strategy continued until no items were left within that dimension (as shown in Table 3 to Table 5). By this method, it was possible to estimate the cumulative percentage of total variance explained which was calculated by multiplying the appropriate cumulative r^2 with the total percentage of variance explained by that dimension (obtained from the factor analysis).

The results show that if each dimension is reduced to just one item, item 15 explains just over 78% of the variance within the emotion dimension, which equates to an explanation of 22% of the total variance. Item 14 explains almost 91% of the variance within the fatigue dimension (27.5% of total variance explained), and item 6 explains 75% of the variance within the mastery dimension (15% of total variance explained). Therefore by selecting only the "best" item for each dimension we can explain 64.5% of the total variance, compared to an explanation of 78.2% of the total variance when all items are included. The tables display the extra percentage of variance explained by the addition of the rest of the items, so it is evident how much explanatory power is gained by the addition of items within each dimension.

The CRDQ dimensions of fatigue, emotion, and mastery showed a high test-retest reliability, Pearsons r ranging from 0.948-0.986. The coefficient of variation was 4% for emotion, 3% for mastery, and 7% for fatigue[17]. An investigation of the test retest reliability of each dimension, as measured by the single item scale was also high, (Pearson's r ranging from 0.901-0.969) and comparable to their multiple item counterparts.

DISCUSSION

There was a low to moderate correlation between spirometric measures of lung function (FEV$_1$, FVC) and QOL. Similar correlation coefficients have been reported previously[18]. This has important implications for clinical practice as it suggests that the impact of a disease, or its treatment, on QOL cannot be estimated from measures of disease impairment (in this instance, lung function parameters). QOL is an important endpoint in its own right which must be assessed directly if we are to quantify the impact of a disease or the outcome of a treatment for a patient.

On this basis, the present study investigated the possibility of reducing the number of items within the CRDQ to enable routine assessment of QOL.

It was demonstrated that item 8 does not fit well into the emotion dimension of the CRDQ and so it was excluded. Additionally, item 13 does not load as heavily as the other items on this dimension. This may be because item 13 asks the patient how often they are "relaxed and free of tension". This is an extreme emotional state that is unlikely to occur very often. Nevertheless, item 13 does load heavily enough on this dimension to warrant its inclusion. With the exclusion of item 8 factor analysis generated a factor structure which conformed to the factor structure of the original CRDQ. The fatigue, emotion, and mastery dimensions were shown to have high internal consistency. Therefore, these three dimensions of the CRDQ, with the exclusion of item 8, appear to have good construct validity within the population of adults with CF.

The test-retest reliability was conducted with small numbers, but the coefficients of variation for each of the three dimensions in CF compare very favourably with the coefficients of variation found in the three dimensions when applied to COPD in a larger scale study[17]. This study and the present study use a single interviewer design and, as multiple interviewers is more typical of clinical practice inter observer test-retest reliability should be further studied.

The internal consistency of the dyspnoea dimension is less when compared to the other dimensions of the CRDQ. The test-retest reliability of this dimension was not assessed as all the patients did not adhere to the self selected

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activities during the test-retest interval. This highlights the importance of ensuring that the self selected activities chosen by the patients are in fact activities that they do frequently, particularly when the dimension is being used to track changes in dyspnoea over time.

It was demonstrated that the number of items in the CRDQ can be reduced, with little loss in the explanatory power of the dimensions. This is a necessary step to allow the CRDQ to be used routinely in clinical practice. One of the main perceived problems with QOL is that very few clinicians have the time to obtain a routine measurement of this variable, even though most agree that QOL is an important aspect of medical care. The problem is due to the fact that most QOL questionnaires are lengthy, and so take a great deal of time to administer and score. There is little value in researchers generating many different dimensions to measure QOL if they cannot be used in clinical practice. Therefore reducing items within each dimension is justified as it attempts to make the instrument more convenient for routine use in practice.

A possible solution is to take a single item measure for each dimension, and this study has identified the best item to represent the emotion (item 15), fatigue (item 14), and mastery (item 6) dimensions. Of course, some explanatory power will be lost, compared to an inclusion of all the items, but are the total dimensions a valid yardstick of QOL, with which we should be making comparisons? The only way to answer this question is by further research to compare the criterion related validity of the single item dimensions with the criterion related validity of the multiple item dimensions, within specific population groups.

The construction of single item measures would have advantages for administration and scoring within clinical practice. Nevertheless, if single item dimensions are used to investigate changes in QOL, then it will be necessary to ensure that they are sensitive to change. This seems unlikely with a single item using a Likert type response scale, divided into discrete categories. Previous research suggests that a single continuous item such as the visual analogue scale (VAS) is as sensitive to change as a multiple item Likert type response scale[19]. Therefore, it may be better to change the response scale in the CRDQ to a continuous measurement single item scale, such as a VAS.

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In summary, the fatigue, emotion and mastery dimensions of the CRDQ appear psychometrically sound for use within the field of CF. However, like most QOL instruments, they are too long for routine clinical assessments. This study has taken a step towards the development of a shorter form of the CRDQ and has provided a model for shortening other QOL questionnaires for routine use in clinical practice. Perhaps all QOL instruments should have a research form and a clinical form if the regular measurement of this important concept in clinical practice is to be encouraged.

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Table 1: Internal Consistency Estimates of the Emotion, Fatigue, and Mastery

Dimensions of the CRDQ

Dimension Name	Item No.	Corrected Item- Total Correlation	Cronbach's Alpha
Emotion	5	0.646	0.880
	8	0.186	
	11	0.808	
	13	0.807	
	15	0.793	
	17	0.667	
	19	0.808	
Fatigue	7	0.860	0.934
	10	0.731	
	14	0.910	
	16	0.893	
Mastery	9	0.641	0.850
	6	0.763	
	12	0.623	
	18	0.702	
Dyspnoea	4a	N/A[1]	0.777
	4b		
	4c		
	4d		
	4e		

[1] Item-total correlations are not useful within the dyspnoea dimension, as the content of each item will vary between individuals because of the individualised nature of this dimension.

Table 2: Exploratory Factor Analysis of the Emotion (excluding item 8), Fatigue and Mastery Scales of the

CRDQ

Original CRDQ Dimension	Item No.	Factor 1	Factor 2	Factor 3	
Fatigue	14	0.885	0.309	0.179	
	7	0.884	0.224	<0.001	
	16	0.879	0.259	0.174	
	10	0.722	0.248	0.257	
Emotion	15	0.282	0.793	0.346	
	17	0.270	0.775	<0.001	
	5	<0.001	0.763	0.382	
	11	0.523	0.762	<0.001	
	19	0.378	0.738	0.195	
	13	0.588	0.533	0.377	
Mastery	6	0.162	0.260	0.849	
	18	<0.001	0.394	0.822	
	12	0.537	<0.001	0.721	
	9	0.390	0.439	0.539	
Total % Variance Explained		**30.3**	**28.0**	**19.9**	**Total 78.2**

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Table 3: Correlations Between the Total Emotion Dimension and Items from this Dimension

	Emotion Dimension	Cum.r^2	Cum.% Total Var. Explained.
Item 15	0.886	0.784	21.9
Item 15+Item 17	0.934	0.872	24.4
Item 15+Item 17+Item 5	0.960	0.922	25.8
Item 15+Item 17+Item 5+Item 11	0.981	0.962	26.9
Item 15+Item 17+Item 5+Item 11+Item 19	0.992	0.984	27.6
Item 15+Item 17+Item 5+Item 11+Item 19+Item 13	1.000	1.000	28.0

All correlations are significant at the 0.01 level (1 tailed).

Table 4: Correlations Between the Total Fatigue Dimension and Items from this Dimension

	Fatigue Dimension	Cum.r^2	Cum.% Total Var. Explained.
Item 14	0.952	0.906	27.5
Item 14+Item 7	0.975	0.950	28.5
Item 14+Item 7+Item 16	0.987	0.974	29.5
Item 14+Item 16+Item 7+Item 10	1.000	1.000	30.3

All correlations are significant at the 0.01 level (1 tailed).

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Table 5: Correlations Between the Total Mastery Dimension and Items from this Dimension

	Mastery Dimension	Cum.r^2	Cum.% Total Var. Explained.
Item 6	0.866	0.750	14.9
Item 6+Item 18	0.893	0.797	15.9
Item 6+Item 18+Item 12	0.962	0.925	18.4
Item 6+Item 18+Item 12+Item 9	1.000	1.000	19.9

All correlations are significant at the 0.01 level (1 tailed).

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LIST OF ABBREVIATIONS

CF   Cystic Fibrosis

QOL   Quality of life

CRDQ   Chronic respiratory disease questionnaire

COPD   Chronic obstructive airway disease

SGRQ   St Georges respiratory questionnaire

SPSS   Statistical Package for the Social Sciences

FEV_1 Forced expiratory volume in 1 second

SD   standard deviation

E.C.C.S European Commission for Coal and Steel

APPENDIX

Questions 1-5 (DYSPNOEA DIMENSION)

5. In general, how much of the time during the last 2 weeks have you felt frustrated or impatient ? Please indicate how often during the last 2 weeks you have felt frustrated or impatient by choosing one of the following options in the card in front of you:

1   All of the time

2   Most of the time

3   A good bit of the time

4   Some of the time

5   A little of the time

6   Hardly any of the time

7   None of the time

The wording structure of the other questions in the Emotion, Fatigue, and Mastery dimensions is identical, and appropriate seven point scales are offered for each question. The content of the remaining 14 questions is as follows:

6. How often during the past 2 weeks did you have a feeling or panic when you had difficulty getting your breath ?

7. What about fatigue ? How tired have you felt over the last 2 weeks ?

8. How often during the last 2 weeks, have you felt embarrassed by your coughing or heavy breathing ?

9. In the last 2 weeks, how much of the time did you feel very confident and sure that you could deal with your illness ?

10. How much energy have you had in the last 2 weeks ?

11. In general, how much of the time did you feel upset, worried, or depressed during the last 2 weeks ?

12. How often during the last 2 weeks did you feel you had complete control of your breathing problems with shortness of breath and tiredness ?

13. How much of the time during the last 2 weeks did you feel relaxed and free of tension ?

14. How often during the last 2 weeks have you felt low in energy ?

15. In general, how often during the last 2 weeks have you felt discouraged or down in the dumps ?

16. How often during the last 2 weeks have you felt worn out or sluggish ?

17. How happy, satisfied, or pleased have you been with your personal life during the last 2 weeks ?

18. How often during the last 2 weeks did you feel upset or scared when you had difficulty getting your breath ?

19. In general, how often during the last 2 weeks have you felt, restless, tense, or uptight ?

Emotion Dimension - Question Number 5, 8, 11, 13, 15, 17, 19.

Fatigue Dimension - Question Number 7, 10, 14, 16.
Mastery Dimension - Question Number 6, 9, 12, 18.