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Journal of Cystic Fibrosis 3 (2004) 29–36

JOURNAL OF CYSTIC FIBROSIS

www.elsevier.com/locate/jcf

Validation of the Dutch cystic fibrosis questionnaire (CFQ) in adolescents and adults

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Accepted 17 December 2003

Abstract

Background: This study assesses the reliability and validity of the Dutch version of a disease-specific measure of health-related quality of life (HRQOL) for adolescents and adults with CF (CFQ-14+). The 47-item CFQ-14+ covers nine domains, three symptom scales and one health perception scale. *Methods:* To assess psychometric characteristics of the CFQ-14+, cross-sectional (homogeneity, discriminative and construct validity) and test–retest designs were used. Eighty-four adolescents and adults with CF (mean age: 21.4 years, range 14.0–46.5 years) and a wide range of lung function (mean FEV_1: 59,9% predicted, range 15–121%) completed the questionnaire during a routine visit. *Results:* Internal consistency was acceptable for most domains of the CFQ-14+ ($\alpha = 0.43$–0.92) and test–retest reliability was high for all domain scores (0.72–0.98). Several domains of the CFQ-14+ were able to differentiate between individuals with varying disease severity and between nourished and malnourished patients. Construct validity of the questionnaire was fair, with moderate to strong correlation between physically orientated domains and pulmonary function ($r_s = 0.36$–0.62). *Conclusion:* The results demonstrate that the CFQ-14+ questionnaire is a well-validated measure of HRQOL assessment in adolescents and adults with CF.

Keywords: Cystic fibrosis; Health-related quality of life; Psychometrics

1. Introduction

Advances in therapy and treatment of cystic fibrosis (CF) have led to improved patient survival into adulthood [1]. However, therapy and treatment of CF, coupled with the progressive nature of the disease, which can require hospitalization, makes management of CF time-consuming and difficult [1,2]. Traditional clinical measures are important but they do not capture the broader impact of the disease [3–5]. The measurement of health-related quality of life (HRQOL) in CF provides additional information about the impact of the disease on physical, social and psychological functioning [2,5,6]. Studies on HRQOL in patients with CF have typically used generic or specific respiratory questionnaires which were not specifically developed for CF [7–12]. Generic health measures allow for comparisons between a variety of diseases, but are not sensitive for specific problems associated with CF [6] and may not be sufficiently responsive to the effects of clinical interventions. Recently, a reliable and valid CF-specific health-related measure was developed and validated in France, the Cystic Fibrosis Questionnaire (CFQ) [13]. In addition, the CFQ has been validated in Germany [14] and is presently being validated in the United States and Spain. The CFQ consists of three quality of life measures: an adolescent/adult version (14 years of age or older), a child version (6–13 years of age) and a parent version (used in conjunction with the child measure). The

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1569-1993/04/$30.00
doi:10.1016/j.jcf.2003.12.006

advantage of the CFQ is that it takes into account differences in developmental stages and makes it possible to monitor the health status and quality of life in CF patients from the age of 6 years throughout adulthood [6,15]. This allows health care professionals to analyze long-term outcome and efficacy of early intervention.

Cross-cultural validation of an existing measure has the advantage of avoiding the initial stages of development of a new questionnaire, which is a long process [16,17]. Furthermore, translation into different languages makes it possible to use the CFQ questionnaires in comparative international multi-center studies [16].

The aims of the present study were: (1) to develop a conceptually equivalent Dutch version of the CFQ for adolescents and adults with CF and (2) to evaluate the following characteristics: homogeneity, reproducibility (10–14 days test–retest reliability), discriminative and construct validity.

The Dutch CFQ for children with CF and their parents is presently being validated.

2. Methods

2.1. Patients and procedure

Eighty-four patients were recruited from the children and adult CF-Center of the University Medical Center Utrecht. All patients were approached during routine visits between 2001 and 2002 and asked for consent to complete the CFQ. Patients who had problems understanding the Dutch language were excluded from the study. In a subset of clinically stable patients, as determined by a pulmonologist, the questionnaire was administered twice within 10–14 days. The study was approved by the institutional Medical Ethics Committee.

2.2. Translation

Backward and forward translations were completed. The French CFQ was translated into Dutch and a second independent translator made a backward translation into French. A third expert compared the original French list to the backward translated French list. Discussions were held between the translators to resolve semantic and conceptual discrepancies and to develop a consensus forward translation.

2.3. Cystic fibrosis questionnaire

The CFQ for adolescents and adults (CFQ-14+) consists of 47 items divided into nine domains: physical functioning (8 items), energy and well-being (4), emotional state (5), social limitations (4), role limitations (2), body image (3), eating disturbances (2), treatment burden (2), and embarrassment (3). Three symptom scales are included, respiratory (7), digestive (2), and weight (1), and overall health perception (4). Items require either a frequency response on a 4-point scale ('all the time' to 'never'), a difficulty rating on a 4-point scale ('a lot of difficulty' to 'no difficulty'), a true–false rating on a 4-point scale, or the selection of a statement that describes the patient (on a 3-or 4-point scale) [6]. Completing the questionnaire took approximately 15 min.Scores are standardized by adding the ratings of all items within a domain to facilitate comparison of scores across domains. The scores range from 0 to 100 with higher scores corresponding to higher quality of life. Scores for each domain are calculated if at least two-thirds of the items are completed. There is no total score.

Appendix A outlines the distribution of the questions by domain for CFQ-14+.

2.4. Homogeneity

Internal consistency of each domain was assessed using Cronbach alpha coefficients (i.e. the strength of the associations between items and their respective domains). Generally the internal reliability is acceptable with a Cronbach alpha coefficient of 0.7 or above [18]. However, slightly lower coefficients (0.6 or higher) are acceptable for newly developed scales [19]. Furthermore, item to domain correlations were calculated. These correlations assess whether items are more strongly associated with their hypothesized vs. competing scale. Psychometric guidelines suggest that item to domain correlations should be 0.40 or greater [19].

2.5. Reproducibility

Test–retest reliability measures the stability of the scores on the CFQ questionnaires over time. Twenty-one patients with a stable clinical condition (i.e. no need for oral or intravenous antibiotic treatment in 3 months prior to testing) completed the CFQ 10–14 days apart. This period is long enough not to introduce memory as a confounding factor while being short enough to prevent deterioration in disease status [20].

2.6. Discriminative and construct validity

To assess whether the measure could discriminate between patients with varying levels of disease severity, patients were categorized according to their level of pulmonary impairment: mildly impaired group (FEV1 $\geq$ 71%pred), moderately impaired group (FEV1 41–70%pred) and severely impaired group (FEV1 $\leq$ 40%pred) [20]. In addition, patients were categorized according to their nutritional status: nourished group (BMI $\geq$ 19) and malnourished group (BMI $<$ 19).

Since disease severity is related to older age comparisons were made between age groups: adolescents (14–17 years), young adults (18–25 years) and adults (26 years of age and older). Comparisons were also made between males and females.

Construct validity was assessed by correlating CFQ scores with pulmonary functioning.

2.7. Pulmonary function

Forced vital capacity (FVC) and forced expiratory volume in one second (FEV1) were obtained from maximal expiratory flow–volume curves (Masterscreen; Jaeger, Wuerzburg, Germany). Values are expressed as the percent of predicted values [21,22].

3. Statistical analyses

The Statistical Package for the Social Sciences (SPSS for Windows version 10.1) was used for data management and analyses. The internal consistency reliability was evaluated using Cronbach's α. Spearman (rs) correlation coefficients were used to describe relationships between outcome measures. Correlations were interpreted as described by Guyatt and colleagues: less than 0.2 as very weak, from 0.2 to 0.35 as weak, from 0.35 to 0.5 as moderate, and 0.5 or greater as strong [23]. Intraclass correlation coefficients were used to estimate the reproducibility (test–retest reliability) [24]. Domain comparisons between groups were made using *t*-tests for unrelated samples and one-way analysis of variance (ANOVA). *Post hoc* testing was done with Tukey's honest significant difference, which corrects for multiple comparisons. Effect sizes (ES, i.e. the ratio of difference in mean scores to the pooled baseline standard deviation [25] were calculated to assess the relative magnitude of observed differences. ES is interpreted using criteria described by Cohen: 0.2 represents a small relevant difference; 0.5 a moderate difference and differences of 0.8 or higher are interpreted as a large difference [26]. Differences were considered significant if $P<0.05$ (two-tailed). Data are presented as mean ±S.D. unless otherwise indicated.

4. Results

Eighty-four patients with CF (mean age: 21.4 years, range 14.0–46.5 years) who had moderate to severe airway obstruction (mean FEV1: 58.5%, range 15–121%; mean FVC: 74.1%, range 26–121%) completed the CFQ-14+. Table 1 shows mean values of the different domains. The lowest scores on the CFQ-14+ were found for vitality and respiratory symptoms, while the highest scores were found for digestion and embarrassment.

Table 1
CFQ-14+ scores, Cronbach alpha and test–retest reliability for each domain

	CFQ score (mean ± S.D.)	Alpha coefficient	Test–retest reliability
Physical functioning	64.4 ± 25.7	0.92	0.98
Vitality	56.3 ± 17.6	0.81	0.90
Emotional state	77.7 ± 15.6	0.69	0.84
Social functioning	63.1 ± 24.8	0.64	0.97
Role limitations	60.6 ± 27.2	0.74	0.98
Body image	68.7 ± 21.2	0.45	0.89
Eating disturbances	78.0 ± 22.9	0.66	0.87
Treatment constraints	61.7 ± 22.3	0.53	0.83
Embarrassment	80.1 ± 18.6	0.53	0.90
Respiratory constraints	53.0 ± 13.4	0.79	0.92
Digestion	84.1 ± 18.5	0.69	0.72
Weight	72.6 ± 32.8	#	#
Health problems	70.6 ± 23.6	0.73	0.98

is single item scale.

4.1. Internal consistency

The internal consistency reliability levels (Cronbach alpha) for the domains of the CFQ-14+ are shown in Table 1. Most domains had an acceptable Cronbach alpha coefficient (0.60 or above). The exceptions to this were body image, treatment burden and embarrassment. Overall, items in the CFQ-14+ loaded conceptually on their respective domains with all of the loadings above 0.40.

4.2. Reproducibility

Twenty-one patients (22.8 ± 8.9 years; range 13.9–36.4 years) with moderate pulmonary dysfunction (FEV1 62.1% ± 20.0%; range 29.2–87.0%) agreed to participate in the test–retest reliability phase. The intraclass correlation coefficients were high for all domains, ranging from 0.72 to 0.98 (Table 1). This means that the domain scores of the CFQ-14+ are highly reproducible.

4.3. Discriminative and construct validity

To assess whether the measure could differentiate between patients with varying degrees of disease severity, patients were categorized according to the level of pulmonary impairment (Table 2). Three groups were formed: mildly impaired group ($N=28$, FEV1 89.1% ± 14.0%), moderately impaired group ($N=36$, FEV1 56.0% ± 8.6%) and severely impaired group ($N=20$, FEV1 26.4% ± 7.1%). ANOVA tests indicated significant main effects for physical functioning ($F=27.34$, $P<0.001$), body image ($F=13.43$, $P<0.001$), eat disturbances ($F=5.17$, $P<0.01$), respiratory symptoms ($F=5.78$, $P<0.01$), health problems ($F=4.16$, $P<0.015$) and weight ($F=5.57$, $P<0.01$). Table 3 shows

Table 2
Comparison between CFQ-14+ scores and disease severity

	Mild CF (mean ± S.D.)	Moderate CF (mean ± S.D.)	Severe CF (mean ± S.D.)
Physical functioning	78.5 ± 20.5	69.0 ± 19.4	36.3 ± 21.1
Vitality	58.9 ± 19.4	55.2 ± 16.2	54.6 ± 17.6
Emotional state	79.8 ± 19.7	77.2 ± 12.1	75.7 ± 15.3
Social functioning	66.4 ± 24.3	60.6 ± 26.7	62.9 ± 22.5
Role limitations	66.0 ± 27.4	54.9 ± 26.8	65.3 ± 27.0
Body image	81.0 ± 19.1	67.9 ± 17.6	52.8 ± 19.7
Eating disturbances	88.7 ± 19.8	73.6 ± 22.3	70.8 ± 23.4
Treatment burden	67.9 ± 26.0	60.6 ± 19.1	55.0 ± 21.0
Embarrassment	83.3 ± 17.5	71.0 ± 20.7	80.8 ± 18.3
Respiratory constraints	58.5 ± 11.7	52.7 ± 12.2	45.8 ± 14.7
Digestion	81.5 ± 18.3	81.9 ± 21.2	91.7 ± 10.1
Weight	88.1 ± 22.6	67.6 ± 33.3	60.0 ± 36.8
Health problems	78.2 ± 22.7	71.0 ± 20.7	59.1 ± 26.0

The scores range from 0 to 100 with higher scores corresponding to higher quality of life.

Table 3
Comparison between CFQ-14+ scores and disease severity

	Mild CF vs. moderate CF d_i (95%CI)	Mild CF vs. severe CF d_i (95%CI)	Moderate CF vs. severe CF d_i (95%CI)
Physical functioning	9.6 (−2.5 to 21.7)	***42.3* (*28.3 to 56.4*)**	***32.7* (*19.3 to 46.2*)**
Vitality	3.8 (−6.9 to 14.4)	4.3 (−0.8 to 16.7)	0.6 (−11.2 to 12.4)
Emotional state	2.5 (−6.9 to 12.0)	4.1 (−6.9 to 15.1)	1.6 (−8.9 to 12.0)
Social functioning	5.7 (−9.3 to 20.8)	3.5 (−14.0 to 20.9)	−2.3 (−18.9 to 14.4)
Role limitations	11.1 (−6.0 to 28.2)	0.7 (−22.0 to 23.5)	−10.4 (−32.1 to 11.4)
Body image	***13.1* (*1.9 to 24.2*)**	***28.2* (*15.2 to 41.2*)**	***15.1* (*2.7 to 27.5*)**
Eating disturbances	***15.1* (*2.0 to 28.2*)**	***17.9* (*2.6 to 33.1*)**	2.7 (−11.7 to 17.3)
Treatment burden	7.2 (−6.1 to 20.5)	12.9 (−2.6 to 28.3)	5.6 (−9.1 to 20.4)
Embarrassment	6.2 (−5.1 to 17.4)	2.5 (−10.5 to 15.5)	−3.7 (−16.1 to 8.8)
Respiratory constraints	6.8 (−1.1 to 14.7)	***13.1* (*4.0 to 22.2*)**	6.3 (−2.3 to 14.9)
Digestion	−0.4 (−11.3 to 10.9)	−10.1 (−22.8 to 2.6)	−9.7 (−21.8 to 2.4)
Weight	***20.5* (*1.8 to 39.2*)**	***28.1* (*6.3 to 49.8*)**	7.6 (−13.1 to 28.3)
Health problems	7.3 (−6.3 to 20.9)	***19.2* (*3.3 to 35.0*)**	11.9 (−3.3 to 27.0)

d_i (95%) = difference between means with 95% confidence interval. Significant interaction effects in bold.

Table 4
Effect sizes between mild, moderate and severe CF for CFQ-14+ domains

	ES mild CF vs. moderate CF	ES mild CF vs. severe CF	ES moderate CF vs. severe CF
Physical functioning	**0.48**	**2.03**	**1.61**
Vitality	**0.21**	**0.23**	0.04
Emotional state	0.16	**0.23**	0.11
Social functioning	**0.23**	0.15	−0.09
Role limitations	**0.41**	0.03	**−0.39**
Body image	**0.71**	**1.45**	**0.81**
Eating disturbances	**0.72**	**0.83**	0.12
Treatment burden	**0.32**	**0.55**	**0.28**
Embarrassment	**0.64**	0.14	**−0.50**
Respiratory constraints	**0.49**	**0.96**	**0.51**
Digestion	−0.02	**−0.69**	**−0.59**
Weight	**0.72**	**0.92**	**0.22**
Health problems	**0.33**	**0.78**	**0.51**

ES: effect size. ES-benchmarks: 0.2 is a small relevant difference, 0.5 is a moderate difference and 0.8 is a large difference.

Table 5
Correlation between CFQ-14+ scores and pulmonary function[#]

	PF	BI	ED	TB	RC	W	HP
FEV_1%pred	0.62***	0.52***	0.33**	0.26*	0.36**	0.40***	0.34**
FVC% pred	0.58***	0.41***	0.24*	–	0.23*	0.40***	0.27*

PF: physical functioning; BI: body image; ED: eating disturbances; TB: treatment burden; RC: respiratory constraints; W: weight; HP: health problems; FEV_1: forced expiratory volume in one second; FVC: forced vital capacity. [#]Only significant correlations are reported. *$P<0.05$, **$P<0.01$, ***$P<0.001$.

significant post-hoc comparisons between CFQ domains and disease severity.

ES's of the CFQ-14+ are shown in Table 4. Most domains showed at least a small relevant difference between categories of pulmonary impairment (27 out of 39 comparisons).

With respect to nutritional status, comparisons between the nourished ($N=41$, BMI 26.6 ± 2.1 kg m2) and malnourished group ($N=43$, BMI 17.7 ± 1.0 kg m2) demonstrated that the nourished group had higher scores for body image (72.2 ± 16.8 vs. 65.1 ± 18.3, $P<0.05$), eating disturbances (83.3 ± 20.1 vs. 72.4 ± 21.3, $P<0.05$) and weight (77.5 ± 21.3 vs. 67.1 ± 22.1, $P<0.05$).

Comparisons were made between adolescents ($N=35$; 15.4 ± 1.1 years), young adults ($N=31$; 20.5 ± 1.4 years) and adults ($N=18$; 34.5 ± 6.3 years). ANOVA tests indicated significant main effects for physical functioning ($F=13.56$, $P<0.001$), vitality ($F=4.44$, $P<0.05$), body image ($F=6.29$, $P<0.01$), treatment burden ($F=3.58$, $P<0.05$), respiratory symptoms ($F=9.87$, $P<0.01$), health perceptions ($F=10.17$, $P<0.01$). Post hoc analyses revealed the following differences between age groups: (1) adolescents reported higher quality of life than young adults for the body image domain; (2) adolescents reported higher quality of life than adults for the domains of physical functioning, vitality, body image, treatment burden, respiratory symptoms, digestion and health perception; (3) young adults reported higher quality of life than adults for the domains of physical functioning, vitality, respiratory symptoms and health perception.

Comparisons between male ($N=44$) and female ($N=40$) patients demonstrated that males had higher scores for the emotional functioning domain (80.9 ± 12.2 vs. 74.2 ± 18.1, $P<0.05$) and lower scores for the body image domain (62.9 ± 24.3 vs. 75.0 ± 15.0, $P<0.01$).

Table 5 shows weak to moderate correlations for pulmonary function with treatment burden, health perceptions, weight, eating disturbances, respiratory symptoms, and strong correlations with physical functioning, and body image. The results indicated that patients with worse pulmonary function reported poorer quality of life on these domains.

5. Discussion

This study assesses the reliability and validity of the Dutch version of a disease-specific measure of HRQOL for adolescents and adults with CF (CFQ-14+). The conceptual model of the CFQ was confirmed and the internal consistency was acceptable for most domains. Strong test–retest reliability was obtained and discriminative validity with pulmonary function, nutritional status and age was demonstrated.

The homogeneity and the internal consistency reliability estimates of the CFQ-14+ were adequate. However, three domains showed a low Cronbach alpha coefficient. Internal consistency coefficients of the treatment burden domain have found to be even lower in previous studies [27]. One possible reason for this is that early detection of CF leads the initiation of treatment regimens at a very young age. Patients may slowly accommodate to deterioration in their health status and a concomitant increase in the treatment regimen. Therefore, they may not perceive this as limiting their daily functioning. Internal consistency on the body image domain was also poor. The low alpha coefficient was, in part, caused by a gender effect. The Cronbach alpha for males and females was 0.56 and 0.10, respectively. However, deleting gender-based items or scales could lead to losing important information related to males and females with CF. For example, there is a significant gender difference in morbidity and mortality among males and females with CF which may be better understood in relation to their HRQOL scores [28]. Recently, revisions were made in the body image, treatment burden and Embarrassment domains to improve validity. These items will be tested in subsequent studies with the CFQ.

Currently, there is only one other validated CF-specific HRQOL measure for adolescents and adults (CFQoL) [20]. The authors reported high Cronbach alpha coefficients on all domains. However, this measure does not have a version for children with CF. After evaluation of the Dutch child version, which is presently underway, the CFQ questionnaires make it possible to follow individual patients throughout their life span and to capture the impact of the disease on the patient's ability to cope with various aspects of the illness. Furthermore, there was no effort to counterbalance positively and negatively worded items on the CFQoL, which can skew the wording of the items in a negative direction ('CF makes it difficult for me to…').

The analysis of test–retest reliability showed high intraclass correlations, indicating that the assessment of HRQOL is stable over a 10–14 day period. However, the patients who participated in the test–retest reliability phase were only moderately impaired which might have effected the results. Further testing of the test–retest reliability of the CFQ in patients with a greater variety of respiratory impairment is, therefore indicated.

The CFQ-14+ questionnaire seems applicable to a broad population of patients with CF since differences in CFQ scores were not only found for all severity groups (as measured by FEV1) but also for nourished and malnourished patients. It is important to note that the discriminative validity with respect to pulmonary function only showed significant differences between severity groups for six domains. However, the sample size for this study was relatively small and in order to account for the effect of sample size effect sizes were calculated. Small effect sizes (<0.5) indicate that statistically significant outcome might be a function of sample size. Stronger evidence of discriminative validity might have been found in the vitality, social functioning, emotional state and role limitations domains with a larger sample size. However, CFQ scores on these domains were clearly reduced. Although respiratory involvement is of major importance because pulminary disease is primarly responsible for morbidity and mortality in patients with CF [1], pulmonary function measurements are possibly not sensitive enough to detect differences on these domains between subgroups patients with this multi-systemic disease.

Important differences were also found age and sex. These findings converge with the results of other studies, showing that gender differences exist in morbidity and mortality with CF [28,29]. Clinicians should beware of the fact that thinness and low body weight are perceived by women as less of a problem than males [6], although this condition is unfavarouble for their health [30–32].

Some issues in the present study need further comment. Although the construct validity of the CFQ-14+ with pulmonary function is good, assessment of its relationship to generic health status and psychological well-being should be conducted. Data are also needed on the responsiveness of the CFQ-14+, which measures whether a questionnaire is able to detect changes brought about by an intervention. However, a prerequisite of sensitivity testing is the establishment of the reliability and stability of the measure, which in this study, appears to be very good. Evaluation of the child and parent versions of the CFQ is presently underway.

Generic HRQOL and respiratory-specific questionnaires are unlikely to reflect adequately the symptoms and areas of functioning that are relevant for majority of patients with CF [5,33]. Incorporating disease-specific HRQOL measurements with the CFQ-14+ questionnaire in the care of patients may improve our understanding of the impact of CF on the lives of these patients in several ways. Firstly, it may be helpful in detecting transient changes in health status caused by worsening in pulmonary function or pulmonary exacerbations that are both associated with deterioration in psychosocial and physical functioning. Secondly, our understanding of the basic pathophysiological mechanisms and significant improvements in diagnosis and treatment have increased. These developments improved prognosis and median survival. Recent estimates have projected a median survival of 40 years for children born in 1990 who are receiving current standard therapy for CF [34,35]. However, the quality of this improved survival has not been assessed. The CFQ-14+ can be used to describe longitudinal changes as a function of deterioration in disease status [20]. Changes on a psychosocial level that take place over time may thereby supplement traditional physiological measurements like pulmonary function. Thirdly, the CFQ-14+ may be useful in understanding more clearly how clinical trials or specific interventions (e.g. aerosol therapy, tube feeding) may impact patient perceptions of HRQOL. Fourthly, the CFQ-14+ may improve communication between clinicians and patients by facilitating discussion on issues that are of importance to patients. This enables clinicians to focus more attention on patient's individual perceptions of illness and prioritize problems by their importance to patients and thereby informing medical decision-making. Moreover, patient's perceptions of improved functioning that are not reflected in conventional medical outcomes may be an important factor in promoting adherence to time-consuming and tedious therapy [5].

We conclude that the results show adequate validity and reliability of the CFQ-14+ questionnaire. This measure holds promise for assessing HRQOL in multicenter international studies.

Appendix A: List of items of the Dutch CFQ-14+

Domain	Question	Content of questions
Physical	1	Difficulty performing vigorous activities such as running or sports
	2	Difficulty to walk as fast as others
	3	Difficulty carrying or lifting heavy things such as books
	4	Difficulty climbing one flight of stairs
	5	Difficulty to climb stairs as fast as others
	13	Difficulty walking
	19	Trouble recovering after physical effort
	20	Limit vigorous activities such as running or sports
Vitality	6	Felt happy
	9	Felt tired
	10	Felt energetic
	11	Felt exhausted
Emotional state	7	Felt worried
	8	Felt useless
	12	Felt sad
	28	Difficult to make plans for the future
	33	Feel lonely
Social	22	Stayed at home more than you wanted
	26	Feel comfortable sleeping away from home…

	30	To get together with friends a lot
	32	Feel comfortable going out at night
Role	37	Absent from school or work because of illness or treatments
	39	Trouble keeping up with school, work or daily activities
Body image	23	Think you are too thin
	24	Think you are physically different from others your age
	25	Feel bad about physical appearance
Eating	14	Feel about eating
	21	Force myself to eat
Treatment burden	15	Treatment makes daily life more difficult
	16	Time spend on treatment each day compared to one year ago
Embarrassment	27	People ask uncomfortable questions
	29	People are afraid that my illness may be contagious
	31	Think coughing bothers others
Health	17	Health at this moment
	18	Health compared to three months ago
	34	Feel healthy
	35	Lead a normal life
Weight	40	Trouble gaining weight
Respiratory	41	Felt congested
	42	Coughing during the day
	43	Cough up mucus
	44	Color mucus
	45	Wheezing
	46	Trouble breathing
	47	Woke up during the night because of coughing
Digestion	48	Diarrhea
	49	Abdominal pain

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