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# Health-Related Quality of Life of Patients Suffering from Cystic Fibrosis

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**A** – research concept and design; **B** – collection and/or assembly of data; **C** – data analysis and interpretation; **D** – writing the article; **E** – critical revision of the article; **F** – final approval of article; **G** – other

## Abstract

**Background.** Cystic fibrosis (CF) is a particular example of a chronic disease with progressive course. Current statistical data shows that the life span of patients with CF has extended. Therefore, it is necessary to undertake interdisciplinary actions aiming at improving the efficiency of medical activities as well as minimalizing the influence of those interventions on the patients' quality of prolonged life.
**Objectives.** The aim of the study was to depict the QoL of patients suffering from mucoviscidosis and show the differences in the assessment of patients' QoL depending on age and sex.
**Material and Methods.** The study covered 30 patients with CF. Mean age of the respondent group was 24.83 ± 6.98; mean age of females 25.8 ± 7.27, whereas of males – 23.5 ± 6.56. A specific questionnaire for testing cystic fibrosis quality of life (CFQoL) of patients was used in the study.
**Results.** Generally patients with CF evaluated their QoL as low. In the study with the use of a CFQoL questionnaire they evaluated their QoL as the lowest in a subscale: future concerns. In most domains women got lower mean values than men. A dependence between patients' QoL and their age was ascertained. The older the patient is, the lower QoL is in the case of subscales (CFQoL): physical, emotional and social functioning, chest symptoms, interpersonal relationships, body image, career concerns.
**Conclusions.** Patients with CF generally evaluate their QoL as low; there are differences in the evaluation of QoL between women and men. There is a relation between patients' QoL their age. The older the patient is, the worse his QoL in most subscales is (**Adv Clin Exp Med 2015, 24, 1, 147–152**).

**Key words:** cystic fibrosis, health related quality of life, conditioned chronic disease.

Due to its character, chronic disease interferes in all spheres of human life; it affects not only a sick person but also his closest surroundings. Since there is no possibility of causal treatment, a particular role is played by the capability to accept the disease, which results from personality features as well as from skills related to coping with its consequences. Chronic patients must meet a number of limitations and sacrifices and subjective sensations resulting from them; these emotional states may affect both the course of the disease and the whole life and they often generate a lower quality of life. Because of that, as far as chronic diseases are concerned, a great significance is ascribed to studies concerning the quality of life [1–3]. Cystic disease is a particular example of chronic disease with progressive course, which was considered a fatal disease of childhood even a few years ago. However, current statistical data shows that nowadays 50% of patients with cystic fibrosis have a chance to survive up to 30$^{th}$ year of life and the life span of children born in the 90s might be at least 40 years. We can observe the increase of the number of adult patients with cystic fibrosis. In 1998 they were 18% of all patients registered in the Polish Register of Cystic Fibrosis and

in 2010 there were as many as 32.3% [4–6]. So it is necessary to undertake interdisciplinary actions aiming at improving the effectiveness of medical activities as well as minimizing the influence of those interventions on quality of prolonging life of patients [5, 7]. Factors affecting the quality of life of patients with cystic fibrosis can be divided into subjective and objective [7]. The subjective factors include all ailments sensed by the patient and connected with the disease, influence of the disease and effect on emotions, moods, self-esteem, satisfaction from professional and personal life, influence of economic situation, sense of fulfilment, sense of support and relations with other people. The objective factors include state of health and its reflections, such as research and test results, psychopathological image, amount of income or quantity and quality of social contacts. The influence of cystic fibrosis on all crucial functioning areas necessitates complex monitoring of patients' quality of life, which would emphasize their needs and also, if necessary, would make a modification of therapeutic approach possible [7].

## Aim of the Study

The aim of the study was to assess the health-related quality of life (HRQOL) of patients suffering from cystic fibrosis depending on sex and age.

## Material and Methods

The study was carried out among patients hospitalized in the Clinic of Pneumonology and Cystic Fibrosis of the Tuberculosis and Pulmonary Diseases Institute in Rabka-Zdrój from February to April 2012. The research covered 30 patients (19 females and 11 males) with progression of CF at the age between 16 and 42. Patients were examined in the final stage of hospital treatment of CF exacerbations reasons. The respondents were divided into groups depending on sex and age (≤ 25 years and > 25 years).

Participation in the study was voluntary. All participants were informed about the research goals and assured of absolute anonymity.

In the research a specific questionnaire assigned for the assessment of quality of life determined by the state of health of patients suffering from cystic fibrosis was used. The specific CFQoL (Cystic Fibrosis Quality of Life) questionnaire consisted of 52 questions covering 9 subscales: PF (physical functioning), SF (social functioning), TI (treatment issues), CS (chest symptoms), EF (emotional functioning), FC (future concerns), IR (interpersonal relationships), BI (body image), CI (career concerns). Responses are measured according to six-level Likert scale: 1 means the worst grade whereas 6 is the best (in question 6 – the other way round). After the results are converted, the results are expressed in the scale from 0 to 100 points, where 100 means the most optimal quality of life [8].

An analysis of statistical data was performed with the use of STATISTICA 10 PL packet and Microsoft Office Excel 2007. Basic statistical parameters were calculated i.e. arithmetic mean, median, standard deviation, minimum, maximum. For comparison of particular groups a nonparametric test of Mann Whitney was used while correlations were assessed on the basis of coefficient of Spearman's rank correlation. $P < 0.05$ was assumed as statistically significant.

For conducting the research a permission of Bioethics Committee of the Wroclaw Medical University No. 320/ 2012 was obtained.

## Results

### Statistical Characteristics of Groups Participating in the Research

Thirty patients suffering from cystic fibrosis took part in the study. Among them there were 19 women and girls (63.3%) and 11 men and boys (36.7%). The average age of the respondent group was 24.83 ± 6.98, the mean age of women – 25.8 ± ± 7.27, whereas of men – 23.5 ± 6.56. Thirteen women and 7 men were at the age ≤ 25 and 6 women and 4 men in the group >25 (Table 1).

Detailed characteristics of women and men suffering from cystic fibrosis in particular age brackets is presented in Table 1.

**Table 1.** Statistical characteristics of the group

| | **People with CF** |
|---|---|
| ≤ 25 years | |
| females (n) | 13 |
| age x ± SD | 21 ± 2 |
| males (n) | 7 |
| age x ± SD | 19 ± 3 |
| ≥ 25 years | |
| females (n) | 6 |
| age x ± SD | 35 ± 5 |
| males (n) | 4 |
| age x ± SD | 29 ± 5 |

CF – cystic fibrosis, x ± SD mean + standard deviation.

**Table 2.** Quality of life of patients with cystic fibrosis with division into sex

| Subscales | Females | Males | *P* |
|---|---|---|---|
| PF<br>x ± SD<br>Me | <br>53.9 ± 26<br>54 | <br>66.5 ± 24.1<br>72 | <br><br>0.22 |
| SF<br>x ± SD<br>Me | <br>47 ± 31.7<br>40 | <br>62.7 ± 35.2<br>75 | <br><br>0.21 |
| TI<br>x ± SD<br>Me | <br>50.9 ± 23.9<br>53.3 | <br>60 ± 73.3<br>30.1 | <br><br>0.33 |
| CS<br>x ± SD<br>Me | <br>50.3 ± 25<br>45 | <br>53.6 ± 25.5<br>55 | <br><br>0.64 |
| EF<br>x ± SD<br>Me | <br>52.8 ± 25.1<br>50 | <br>58.9 ± 30<br>57.5 | <br><br>0.58 |
| FC<br>x ± SD<br>Me | <br>35.1 ± 19.5<br>33.3 | <br>45.8 ± 21.2<br>46.7 | <br><br>0.14 |
| IR<br>x ± SD<br>Me | <br>56.1 ± 16.2<br>56 | <br>54.5 ± 29.3<br>56 | <br><br>0.98 |
| BI<br>x ± SD<br>Me | <br>47 ± 26.4<br>46.7 | <br>48.5 ± 22.9<br>22.9 | <br><br>0.82 |
| CI<br>x ± SD<br>Me | <br>50 ± 26.8<br>50 | <br>57.3 ± 27.3<br>55 | <br><br>0.50 |

PF – physical functioning, SF – social functioning, TI – treatment issues, CS – chest symptoms, EF – emotional functioning, FC – future concerns, IR – interpersonal relationships, BI – body image, CI – career concerns, CF – cystic fibrosis, x ± SD mean + standard deviation.

Assessment of patients' quality of life was made with the use of CFQoL (Cystic Fibrosis Quality of Life) questionnaire.

An analysis of general assessment of quality of life of patients suffering from cystic fibrosis with the use of CFQoL questionnaire has revealed that patients generally evaluate their quality of life as low since mean measurement values in all subscales reach a similar, low value close to 50. The lowest value is observed for subscale FC – future concerns (39 ± 20.5) and the highest for subscale PF – physical functioning (58.5 ± 25.7). The results in particular subscales concerning the quality of life of patients with cystic fibrosis are presented in Table 2.

In all subscales, apart from IR – interpersonal relationships, women evaluated their quality of life lower than men. Both women and men obtained the lowest values for subscale FC – future concerns (35.1 ± 19.5 vs 45.8 ± 21.2). Women evaluated their quality of life best for subscale IR – interpersonal relationships and men in subscale PF – physical functioning. The results below 50 proving low quality of life in women occurred in domains: SF – social functioning, FC – future concerns, BI – body image, CI – career concerns, whereas in men in domains FC – future concerns and BI – body image. In none of subscales statistically significant differences were stated (Table 2.)

Assessment of quality of life of patients with cystic fibrosis aged ≤ 25 and > 25 shows that patients in the age bracket: ≤ 25 evaluate their quality of life better in all subscales, except subscale FC – future concerns, where values for both age groups are similar (38.7 ± 21.1 vs 39.7 ± 20.2). In the case of patients > 25, the mean values for all subscales are close to 50, which proves a low quality of life; in the case of patients ≤ 25, results close to 50 occur in subscales FC – future concerns and BI – body image. Statistically significant differences were revealed ($p < 0.05$) within PF – physical functioning (66.5 ± 25 vs 42.6 ± 19.4), SF – social functioning (63.3 ± 32.9 vs 33 ± 24.3) and IR – interpersonal relationships (60.4 ± 23,3 vs 45.8 ± 13.3). Assessment of quality of life of patients suffering from cystic fibrosis in the age brackets ≤ 25 and < 25 is shown in Table 3.

In the case of women > 25 the results in all subscales prove a low quality of life since they are below 50; the lowest was the quality of life in subscale SF – social functioning (16.7 ± 12.5); moreover, women from this age group evaluate their quality of life worse within all domains than women ≤ 25. In case of subscale BI – body image, assessment is the same for all women. Women ≤ 25 evaluate their quality of life below 50 within FC – future concerns and BI – body image. Statistically significant differences in the assessment of quality of life depending on the age bracket for women were found in subscale PF – physical functioning and SF – social functioning (Table 4).

An analysis of the assessment of quality of life of men aged > 25 shows that only in the case of IR – interpersonal relationships and CI – career concerns they evaluate their quality of life below 50. The lowest results occur in subscale BI – body image and the highest in subscale TI – treatment issues. Men ≤ 25 evaluate their quality of life worse only in the case of two domains: TI – treatment issues and FC – future concerns; in the other subscales they obtain higher grades than men > 25. Despite that, any statistically significant differences were not stated here (Table 4).

**Table 3.** Quality of life of patients with cystic fibrosis depending on age

| Subscales | ≤ 25 years | ≥ 25 years | *P* |
|---|---|---|---|
| PF | | | |
| x ± SD | 66.5 ± 25 | 42.6 ± 19.4 | |
| Me | 77 | 45 | 0.001 |
| SF | | | |
| x ± SD | 63.3 ± 32.9 | 33 ± 24.3 | |
| Me | 72.5 | 30 | 0.019 |
| TI | | | |
| x ± SD | 56 ± 26.2 | 51 ± 27.2 | |
| Me | 57 | 53 | 0.069 |
| CS | | | |
| x ± SD | 53 ± 28.5 | 49 ± 15.5 | |
| Me | 50 | 53 | 0.065 |
| EF | | | |
| x ± SD | 60 ± 30.2 | 45 ± 14 | |
| Me | 62.5 | 43.8 | 0.172 |
| FC | | | |
| x ± SD | 38.7 ± 21.1 | 39.7 ± 20.2 | |
| Me | 43.3 | 46.7 | 0.825 |
| IR | | | |
| x ± SD | 60.4 ± 23.3 | 45.8 ± 13.3 | |
| Me | 57 | 49 | 0.036 |
| BI | | | |
| x ± SD | 49 ± 22.6 | 45 ± 33 | |
| Me | 47 | 30.8 | 0.367 |
| CI | | | |
| x ± SD | 58.3 ± 28.5 | 41.5 ± 19.6 | |
| Me | 60 | 40 | 0.146 |

PF – physical functioning, SF – social functioning, TI – treatment issues, CS – chest symptoms, EF – emotional functioning, FC – future concerns, IR – interpersonal relationships, BI – body image, CI career concerns, CF – cystic fibrosis, x ± SD mean + standard deviation.

Patients with cystic fibrosis ≤ 25 evaluate their quality of life particularly low in subscale FC – future concerns, regardless of sex (39.9 ± 18.9 vs 41.9 ± 26). Low results can also be observed in case of BI – body image, whereas women ≤ 25 evaluate it worse than men. Women ≤ 25 evaluate their quality of life worse in all dimensions compared to men. However, these are not statistically significant differences (Table 4).

The research results included in Table 4 show that quality of life of women > 25 is low in all dimensions since no result reaches 50. The lowest assessed subscale by women was SF – social functioning and the highest was BI – body image. Men in the same age bracket evaluate their quality of life better than women, except subscale BI – body image where mean values are slightly lower and subscale IR – interpersonal relationships, where values are similar for both sexes. In the case of men, the results below 50 appear in subscales: IR – interpersonal relationships, BI – body image, CI – career concerns. One can notice great differences in assessment of quality of life between women and men > 25 for PF – physical functioning, SF – social functioning, TI – treatment issues, FC – future concerns but only in the case of subscale SF – social functioning it is a statistically significant difference ($p < 0.05$).

An analysis of the influence of age on the quality of life of patients with cystic fibrosis has revealed that there are statistically significant dependences (with $p < 0.05$) between age and subscales: PF – physical functioning, SF – social functioning, CS – chest symptoms, EF– emotional functioning, IR – interpersonal relationships, BI – body image and CI – career concerns. On the basis of the results we can state that the older the patient is, the lower quality of life is in the above mentioned subscales. However, no statistically significant dependences were found between age and domains: TI – treatment issues and FC – future concerns.

Statistically significant data is presented in Table 5.

## Discussion

The study conducted with the use of a specific CFQoL (Cystic Fibrosis Quality of Life) questionnaire has proved that patients generally evaluate their quality of life as low. The mean results obtained in all subscales are close to 50. The lowest assessed subscale was the one connected with future concerns and the highest applied to physical functioning. In a study by Abbot et al. [9] patients evaluated their quality of life better but just like in this study they obtained the lowest results in the subscale connected with future concerns and high in the subscale: physical functioning. In the assessment by a questionnaire SF – 36 the highest obtained results also applied to physical functioning and in the other subscales they were close to 50, whereas the lowest in the subscale associated with general health state and limitations of activity due to physical health. This result is comparable with the studies by Abbot et al. [9] and Britto et al. [10], where patients recorded the lowest results also in the subscale concerning general assessment of health state. In the study by Britto et al. [10], as in our own research, the subscale applying to physical functioning is one of the highest among the ones assessed. It is worth emphasizing that in this study mean values recorded in all subscales are lower than in the research by Abbot et al. [9] and Britto et al. [10]. It may indicate an assumption of being some exceptions in quality of life between the Polish group of patients and the

**Table 4.** Quality of life of women and men suffering from cystic fibrosis aged ≤ 25 and > 25

| Subscales | Female | | Male | | *P*-value | | | |
|---|---|---|---|---|---|---|---|---|
| | age | | age | | female | male | age ≤ 25 | age > 25 |
| | 25 | > 25 | ≤ 25 | > 25 | ≤ 25 vs >25 | ≤ 25 vs >25 | f vs m | f vs m |
| PF mean ± SD<br>Me | 64 ± 24<br>70 | 32 ± 17<br>28 | 71 ± 29<br>86 | 59 ± 10<br>57 | 0.012 | 0.299 | 0.405 | 0.055 |
| SF mean ± SD<br>Me | 62 ± 27<br>65 | 17 ± 12<br>18 | 66 ± 44<br>85 | 58 ± 13<br>55 | 0.002 | 0.345 | 0.552 | 0.014 |
| TI mean ± SD<br>Me | 54 ± 22<br>53 | 43 ± 27<br>40 | 58 ± 34<br>73 | 63 ± 26<br>70 | 0.357 | 0.925 | 0.721 | 0.286 |
| CS mean ± SD<br>Me | 53 ± 28<br>45 | 45 ± 20<br>45 | 54 ± 33<br>70 | 54 ± 6<br>55 | 0.630 | 0.705 | 0.968 | 0.522 |
| EF mean ± SD<br>Me | 59 ± 27<br>60 | 40 ± 15<br>42 | 62 ± 38<br>78 | 52 ± 9<br>55 | 0.096 | 0.777 | 0.579 | 0.337 |
| FC mean ± SD<br>Me | 40 ± 19<br>33 | 31 ± 22<br>30 | 42 ± 26<br>47 | 52 ± 7<br>50 | 0.599 | 0.395 | 0.579 | 0.110 |
| IR mean ± SD<br>Me | 61 ± 15<br>56 | 46 ± 14<br>51 | 60 ± 35<br>72 | 46 ± 13<br>44 | 0.096 | 0.395 | 0.692 | 0.915 |
| BI mean ± SD<br>Me | 47 ± 23<br>47 | 47 ± 36<br>33 | 52 ± 22<br>53 | 42 ± 26<br>33 | 0.630 | 0.450 | 0.526 | 1.000 |
| CI mean ± SD<br>Me | 56 ± 29<br>55 | 38 ± 42<br>19 | 63 ± 30<br>65 | 48 ± 22<br>40 | 0.219 | 0.508 | 0.606 | 0.915 |

PF – physical functioning, SF – social functioning, TI – treatment issues, CS – chest symptoms, EF – emotional functioning, FC – future concerns, IR – interpersonal relationships, BI – body image, CI – career concerns, CF – cystic fibrosis; x ± SD mean + standard deviation.

**Table 5.** Correlation indicators between subscales of CFQoL questionnaire and age

| Subscales | Age/R Spearman |
|---|---|
| PF | 0.707 |
| SF | 0.636 |
| TI | 0.264 |
| CS | 0.431 |
| EF | 0.453 |
| FC | 0.221 |
| IR | 0.610 |
| BI | 0.422 |
| I | –0.562 |

PF – physical functioning, SF – social functioning, TI – treatment issues, CS – chest symptoms, EF – emotional functioning, FC – future concerns, IR – interpersonal relationships, BI – body image, CI – career concerns.

group of patients from other countries although for confirmation it would be necessary to conduct an additional analysis. Confirmation of a lower assessment of quality of life among the Polish patients can also be found in the research by Dębska et al. [11]; the results of quality of life are similar to the ones obtained in this study. Again, like in the mentioned analyses, one of the lowest assessed subscales is the one applying to general assessment of health state and physical functioning is one of the highest. Analyzing self-evaluation of quality of life between women and men one can notice that women in both questionnaires got worse mean results than men; the only subscale where they obtained higher results is the subscale concerning interpersonal relations in the CFQoL questionnaire. However, in no case was there a statistically significant difference found. According to Gee et al. [12] there are exceptions in the assessment of quality of life between women and men, which is proved in the study by statistically significant differences in subscales connected with chest symptoms, emotional functioning, future concerns, body image and career concerns. Similarly, Arrington-Sanders et al. [13], while studying quality of life with the use of The Child Health Questionnaire, revealed the existence of statistical differences in the assessment of quality of life between adolescent boys and girls in subscales concerning mainly: general assessment of health state, physical functioning, behaviour, mental health, self-respect and family ties. Dębska et al. [11] in her study also mentions the differences in the assessment of quality of life between women and men although a statistically significant difference occurs only in the subscale: physical functioning. It is considered that women can reach lower results of the quality of life level because of some characterological exceptions occurring between them and men.

In the study with the CFQoL questionnaire statistically significant differences were found which claim that women over 25 evaluate their quality of life worse than women under 25 within physical and social functioning; while a self-assessment of the quality of life of women over 25 within social functioning is worse than that of men over 25 year of age. In the study with the CFQoL questionnaire this applies to: physical functioning, social functioning, chest symptoms, emotional functioning, interpersonal relationships, body image, career concerns. A decrease of self-evaluation of quality of life within physical parameters can be explained by the disease progression along with age. What is important, in their studies Tobiasz-Adamczyk et al. [14] revealed that a functional state significantly affects an emotional state of patients with chronic diseases of respiratory system. With reference to extending the age of patients with cystic fibrosis, this information seems to be crucial. It is noticed that patients with cystic fibrosis obtain low mean results in the subscale connected with future concerns; future concerns do not intensify along with age which is shown by correlation indicators. This can mean that patients with cystic fibrosis, regardless of sex and age, are accompanied by constant future concerns. Much like in the studies by Abbott et al. [9], patients suffering from cystic fibrosis evaluate their quality of life worse in the subscale: future concerns.

Therefore, there is a necessity of constantly monitoring the quality of life determined by health state among patients with cystic fibrosis. Due to a small amount of publications concerning this issue in Poland, this study could become the basis for conducting further analyses.

The authors concluded that patients with cystic fibrosis generally evaluate their quality of life as low. Regardless of age and sex, patients evaluate their quality of life as low in subscale: future concerns. There are differences in assessment of quality of life between women and men. There is a relation between the quality of life and the patients' age. The older the patient is, the worse his quality of life in most subscales is.

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