

## ORIGINAL ARTICLE

# Use of the incomplete sentences and the 'three wishes' approach in the identification of the subjective perception and impact of cystic fibrosis. The first open methodological experience in Czech voluntary patients: a pilot study

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## Competing interest

None declared

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## Abstract

**Aim.** Cystic fibrosis (CF) brings numerous limitations and changes in the perception and behaviour. The present study aimed to use a specific qualitative approach to describe the main dimensions and categories in the area of perception/presence of CF in 25 cases. **Methods.** The research (a pilot study) used the open methodological approach of the incomplete sentences (a total of 15) and the 'three wishes' technique in 25 voluntary patients (20 women and 5 men). Two items identified the current condition and sources of support. **Results.** Main dimensions emphasised/signified by cases included particularly health assistance/support and life satisfaction/wishes. The categories of family and patient themselves were the main sources of patients' support. **Conclusions.** The given methodological approach seemed as a highly specific and valuable tool for obtaining the data of subjective nature. The knowledge and understanding of the specifics can help mutual effectiveness in the context of communication, diagnostic and compliance processes in treatment, health/special education and other areas.

## Key words

Cystic fibrosis, methodology, impact, subjective perception, incomplete sentences test, three wishes technique.

## Background

Cystic fibrosis (CF) is a hereditary disease, which is considered rare. The overall worldwide incidence is between 1:2,500-4,500 of live-borns. In the Czech Republic the incidence is between 1:2,736 (epidemiological and genetic studies) and 1:4,023 (prenatal diagnosis and neonatal screening) of live-borns; in the Czech CF register the current proportion of adults is 39% [1]. At present, the disease can be suppressed, but is not curable. CF is a life-shortening, multisystem genetic disease [2] with the natural course of progressive deterioration in health [3] and leads to respiratory failure and premature death [4]. The dominant symptom is a total failure of the function of the exocrine glands. A typical feature is a high concentration of chlorides in sweat and abnormally viscous mucus in the respiratory, digestive and sexual systems [1, 2]. If the disease is untreated, it often leads to respiratory failure. It should be noted, however, that the treatment and the possibility of a comprehensive approach and interventions are being developed and aim to achieve the highest possible level of the quality of life [3]. The published median survival age indicator is between 30 and 35 years; regarding the progress mentioned above, children born today would probably live up to 40 to 50 years of age [5]. For comparison, the median age of death among individuals suffering from CF followed in the US and UK patients' registries was 27-28 years in 2012 [6, 7]. Although the lifespan for people suffering from CF has markedly improved in recent years [8], CF causes numerous limitations of everyday activities, self-reliance and lifestyle. Last but not least, a very stressful factor is the incurability of the disease and its prognosis. CF is the most common genetically conditioned fatal disease of the Indo-European population [9]. Even in relatively recent times CF was a children's disease and a vast majority of patients died in early childhood [9].

The symptomatology of CF is highly variable. Traditional forms of CF are usually diagnosed at an early age and the symptoms are dominant (together with the presence of two mutations of the CFTR gene) [2]. The most common type of gene mutation is F508del – in more than 66-70% of cases [9, 10]. Atypical forms of CF are often diagnosed in adolescence, or even adulthood. Aggravating conditions and complications include the development of bronchopulmonary disease, often also pulmonary exacerbation [11], pneumothorax, hemoptysis, the so-called cepacia syndrome, pulmonary mycobacteriosis, presence of nasal polyps, insufficiency of external pancreatic secretion, diabetes mellitus, gastroesophageal reflux, chronic metabolic alkalosis, infertility/reduced fertility and many other specific symptoms and syndromes, which depend on the form, severity and presence of complications with the basic disease. In October 2009, nationwide neonatal screening was introduced in the Czech Republic. The immunoreactive trypsin (IRT) in a dry drop of blood was examined. CF patients must adhere to a highly specific hygienic and sanitary-epidemiological regimen, the main purpose of which is to prevent disease transmission (CF itself is not a communicable disease). A very important aspect is the psychosocial support provided to the patients (for deterioration of the health conditions, the issue of terminal conditions, choice and fulfilment of job, disability or partnerships). Psychological and psychiatric support accompanied by medication with anxiolytics and antidepressants are often encountered [12]. Disease progression is reported in infancy and childhood [2]. Finally, adherence to treatment involves a variety of complex behaviours and is time consuming as well, placing a significant treatment burden on the patients [8].

The objective of this study was (i) to use specific methodological qualitative based approach in a target group of CF patients, and (ii) to identify, analyse and describe the current status of subjective perception and impact of CF. The research question was compiled as follows: “What are the specifics/aspects of the main dimensions/categories in the perception/description of the presence of disease in Czech adult (15 years and older) voluntary CF patients participating in an on-line survey (a pilot study)?”

## Materials and methods

### Participants

The research included a total of 25 voluntary CF patients (closed group of patients on a social network – no further details provided for anonymity reasons) anywhere from Czech Republic (it was not important for the purpose of the research). The research sample included 20 women (80%) and 5 men (20%). The advantage is the fact that no direct meeting took place (the cases had an opportunity to be much more open and give true responses), which eliminated any shyness or greater age differences between

the researcher and the case. The researcher (the author of the paper) became a member of that group, but is not a patient himself. The mean age of the research sample was 26.52 years (range 15-37 years; med = 27; mode = 36; SD = 7.51). Individuals were eligible for participation if they were 15 years of age or older, had a confirmed diagnosis of CF (expressed by own consent obtained prior to the testing – in the first part of testing battery). Attributes of gender, socioeconomic status, religion, and so on were not investigated because of their non-significance of the saturation of the research question. According to physician diagnosis of the disease the values were as follows: range 1-35 years; average value = 13.29 years; med = 15; mode = 1; SD = 11.70.

### Research design and procedures

The research (a pilot study) used a qualitative approach. The reason is the intent of this approach (i.e. descriptive nature), as well as the investigated phenomenon, which is subjective in nature (i.e. perception/projection). Another reason is an effort to understand the investigated phenomenon in all its depth, and to present the uniqueness of perception of reality by the cases. The research was of an exploratory-descriptive nature and used incomplete sentences and ‘three wishes’ techniques. The incomplete sentences approach (also published as a separate research method [13]) is based on a principle of completing incomplete sentences according to own opinions, beliefs and health condition. The method provides a high degree of freedom and independence in completing the sentences.

An advantage of this method is also the fact that incomplete sentences evoke a kind of initial stimulation to comment on issues that could be omitted in free writing or interview.

The incomplete sentences and ‘three wishes’ approach was used to obtain the responses from patients with CF. Data collection was anonymous and performed by means of a closed group of patients on a social network. The data were collected in July 2015 by electronic means and the transcribed version was qualitatively analysed using thematic analysis [14]. From thematic analysis approach, searching for themes, reviewing themes, defining and refining themes, and describing findings were used [14]. All data materials were collected by the author. The test battery consisted of several parts: the first part (introduction of the research plan, request for cooperation, instructions for completion) was followed by 15 incomplete sentences, formulation of three wishes and socio-demographic characteristics (sex, age, presence of CF according to the initial symptoms and physician diagnosis), including one scale item (Likert type) that identified the current condition (*At the moment: I feel: (1) poorly – (5) great*). One item was focused on identification of the current sources of support for the patients. The incomplete sentences focused on: (i) limitations/contributions of CF; (ii) area of responsibilities; (iii) area of joy; (iv) area of sadness;

(v) area of possible suffering; (vi) area of opinions of the society/people in the surroundings; (vii) area of near future and (viii) area of wishes in the time to come. The three wishes technique was designed in a way that the cases were asked to complete three wishes according to the assignment (*If I had 3 magic wishes that would come true, I would go for*). The numerical data were classified and subjected to a basic statistical description, the non-numerical data were analysed by a qualitative approach. Regarding the fact that we chose an approach capturing the highest possible degree of subjectivity (i.e. very short beginnings of incomplete sentences), the responses were coded (open coding), classified and categorized into semantic units. An additional approach was the application of a selective and summary protocol in order to abstract the similar/same semantic dimension while maintaining the original meaning due to thematic analysis. Moreover, regarding the fact that all items (incomplete sentences) had to be completed with a response, it was possible to obtain only a complete data set for further analyses. Prior to application, the incomplete sentences used in the research were subject to semantic and syntactic review (consultation with a methodologist and a psychologist - one patient did not participated in research). The participants' statements were analysed by means of coding and categorization. The results included only those responses whose significance matched the concept of the research and the research question. By means of triangulation (of perspectives) the interpreted dimensions were consulted with two professionals-clinical psychologists and a special education teacher (from two different institutions to ensure objectiveness of opinions). According to the conformity requirement, the statements were formally adjusted, only in terms of categories but not of codes, which were saturated by fragments of direct quotes. There were no changes in terms of content, but only in terms of identification in order to make the areas clear.

## Results

### *Qualitative analysis protocol*

The results are arranged in a selective protocol table for simplicity of presentation (Table 1). The results included only valid and complete information with response relevance to the presence of CF and saturation of the research question.

### *Degree of estimation of the current condition*

We also analysed the degree of estimation of the current condition (Likert type scale *At the moment: I feel poorly* (1) – *great* (5)). The average value was 3.44, which may indicate a sort of “neutrality” in the responses of the subjects (central value). An interesting finding was that none of the participants indicated the current perceived condition as “poor”. As a result, higher scaled responses were used. A total of three participants indicated the highest degree

(“great”), the largest proportion of the research sample (10 cases) indicated value 4 on the Likert scale. The reason might be various health conditions of the participants (CF progression, disability of organs, etc.), as well as selecting “getting used to the fact that I am unwell and at other times it can be even worse,” which could have affected the estimates on the Likert scale. At the time of data collection another influence could have been the degree of social support. This provides space for another research survey that could address only this specific phenomenon with a subsequent secondary analysis. In a study by Abbott et al [15], a total of 50 patients (83% of a sample of 60 adult patients with CF) rated their health as “above/well above average”. The responses are shown in Figure 1.

### *Main dimensions and its categories: the three wishes approach*

The methodological approach also included the three wishes technique. Table 2 summarizes the results of this approach. Given that all three wishes had to be completed, we obtained a complete set of valid responses.

### *Main sources of support*

One specific question, in the test battery, examined the main resources providing support expressed by the patients themselves. After analysing the obtained data, the main areas of support are: “family”, “patient himself/herself and (less frequently mentioned) “close persons” and “animal”. The content of individual sources (unquantified) are indicated in Table 3. Surprisingly, the second source of support was “patient himself/herself”, despite the incurable nature of the disease.

## Discussion

To our knowledge this was the first qualitative study (using given methodological approach) that identified and described subjective perception and impact of CF in adult (15 years and older) patients. The realised qualitative study brought high valuable data. The findings revealed everyday perceptions of own health condition, wishes and needs towards the own person, as well as people around, or other people (society). We have not identified any publications/studies that would use the same research design. A qualitative research of wishes and concerns (in 15 young adults with CF) using the embedded theory was performed by Higham et al [16]. A frequently discussed issue in adults with CF is also the area of employment [17-19]. Regarding the nature of CF and the time of onset/dominance of symptoms, psycho-social aspects are most often addressed in childhood [20]. The cases repeatedly mentioned the need for regularity, regimen and supervision. This finding is in direct agreement with a study by Hunter [21]. Regarding the fact that the research included only few children (<15 years of age), the findings could not be compared with

**Table 1.** Main dimensions and categories of incomplete sentences – summary protocol (expressed by patients with cystic fibrosis (n = 25), participating in an on-line survey (a pilot study))

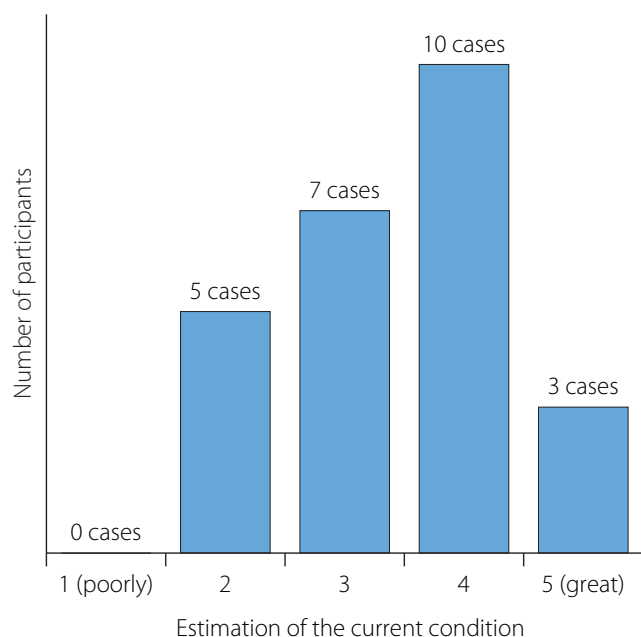
Incomplete sentence	Dimension	Category
CF means to me... (1)	Neutrality	• life; disease; "my life"
	Negativity	• poisoning; difference from the others; restrictions; burden; complication; "bad luck but also motivation"
	Self-perception	• self-denial; challenge and (lifelong, eternal) fight; discipline; "not to give up"; fear; fear of the future
	Vis major	• life control and management
CF gave me... (2)	Relationship with CF	• inhalation; medication; rehabilitation
	Approach to life and own health	• humility; respect for life; enjoying today (uncertainty of the future); faith; strength; to change (a different style); detachment; emphasis on substantial matters; power to fight; another view of the world
	Life complications	• difficulties; "lesson"
	Social support	• friends; "new good people"; learning
CF took away from me... (3)	Neutrality/benefit	• "nothing"; "apologize in school for falling behind"; experience; "a lot"
	Life attributes	• freedom; "a lot of friends"; carelessness; friendship; right to a normal life; superficiality; independence; ideas about life; joy; possibilities
	Family aspect	• "possibility to have a child in a natural way"; have another child
	Time	• "prospects for survival up to 90 years"; future; time; "a piece of life of a normal person"; plans for the future
	Interests	• sport; dancing; travelling; flying; restrictions of lifestyle
	Work related activities	• work in my field of expertise; work with children
	Health	• "my health"
I am usually sad when... (4)	Loss	• "it took everything"; taste for life
	Comparison, failure	• I'm not doing well; I'm not successful in working with horses • "I understand things in context"; "what others can do and I can't"; people around me are concerned about me; people around me are sad because of my disease; I don't want to hurt people around me; I envy healthy people
	Disease	• disease (as a complication of CF); poor prognosis; I'm sick; I'm not well
	Time/finiteness	• "I know that my time is running out"; "how long will I be here with my children"; thoughts about the future; I think about death; death of a sick friend (with CF)
My greatest wish is... (5)	Neutrality	• "I'm not sad – I believe"
	Relationship with the disease	• find a cure/(available) medication; "get close to a kind of life that other (healthy) people have"; live;
	Relationship with health	• recover; stay healthy; never lose control over CF; "live as long as possible (I'm 37 years old)"
	Relationship with the health and life of others	• "I wish my children were healthy"; health for all; "I wish everybody was happy"
	Relationship with the family	• to have and raise a child; "to be here as long as possible for my children and grow old with my husband"; live to senior age, see my grandchildren; have a happy family
It bothers me that... (6)	Vis major	• "I wish I wasn't forgotten"; "to achieve something in life and be a known person in the Czech Republic"; already accomplished
	Other people/society	• misunderstanding of the health condition/disease; physicians in the Czech Republic are not at such level of development as abroad; people do not know much about CF; the media focus on CF mostly in the children's population
	Other qualities	• inability
	Disease	• new drugs are very expensive; searching for a cure is very slow; the need to inhale, taking Creon, sometimes being excluded from a group of people; there is no individualized institutional care in the Czech Republic; poor-quality medical equipment/material; there is still no cure; "I hate inhaling"; often I can't breathe
	Life aspects	• life is not fair; I don't know what to expect in the future; "CF takes so much time (also future time) of my life"; "spend a lot of time with CF"; loss of energy; "CF reminds me of how different I am"; "because of cepacia I can't go for transplantation"
	People around me	• "It's not just my affliction – I also bring suffering to the family, friends, etc."
	Family	• I'm not going to have my own child; "I won't see my son grow"
I would praise myself for... (7)	Success	• marks in school; endurance; effort to help others; good mood; I don't succumb to depression as a result of CF; "how do I manage"; "the fact that I still haven't terminated my life"; "as a female CF patient I gave birth to a healthy child"; psyche; persistence and stubbornness; strong will; detachment; "the fact that I haven't gone crazy after being on oxygen for three years"
	Mask	• "the fact that I'm a good actress and I can conceal things"
	Perspective of others	• "the smiling girl"; "the fact that my mother has taken care of me – this extended my life"
	Life	• previous way of life; attitude to treatment; the fact that I live – regarding my condition – very actively; strength to undergo daily treatment; activity; positivity; "I praise myself for everything"

Continues

Table 1. Continued

Incomplete sentence	Dimension	Category
I am most happy when... (8)	Disease	• when I don't cough too much; good results of medical examination; better spirometry results; when I feel good; when CF does not show symptoms
	Myself - success Joy	• when I'm doing well; when my plans come true; when I do sports • when I'm with animals (they're not bad as people); when I can be with the family and friends; when I see people around me happy; when I see the family happy
	Myself - values	• "when I can be somewhere on my own and think about life – somewhere where no one can hear me coughing and crying, somewhere where I'm free"
At home I have to... (9)	CF symptoms	• depression; when I cough; when I can't breathe very well; fatigue
	Duties	• clean up; do everything as normal people do (sometimes even more than my peers)
	Time	• "manage a lot of things which I'm not good at"; often be home for inhalations
	Care/health	• "fortunately I no longer have to care for anybody else but me"; to follow the treatment/hygienic regimen; get up too early; inhale; take medication; listen to prohibitions and orders – my parents are concerned about me; have the fridge full of high-calorie healthy food
	Neutrality	• common things; it depends; I don't have to do anything – my wife takes care of everything
Sometimes bothers me ... (10)	CF symptoms	• diarrhoea; insomnia; vomiting; mucous blockage; fear; anxiety; depression; cough; constipation
	Time	• falling behind with things; "the older I am the more the disease progresses"; thoughts about what is going to come;
	Questions	• "why me?"; "how long will my insides last and how long will I be strong enough to start the fight with my body every morning"
	Duties	• be dependent on electricity and hygiene; ordinary worries; concerns about what is going to come
	Other people	• "no one understands me and nobody knows what it's like to live with CF"
	Myself	• carelessness; my helplessness; bad thoughts; inability to do more sports
I am weakest... (11)	CF symptoms	• depression; when I cough; when I can't breathe very well; fatigue
	Duties	• cleaning up; physical work
	Myself	• "I'm overwhelmed by my own matters"; when I admit that the health condition of my child may deteriorate irreversibly any time; I don't have enough time to fulfil my own wishes
	Complications	• flu; when it's very hot; when my son is ill; when there is a problem; when I'm sick; when I'm lying in the Motol hospital and think about what is going to come...; when I'm in hospital on oxygen; I don't want to eat and everything is exhausting
	Neutrality/strength	• "I'm not – I live and fight"; I'm not the weakest; I don't know
	Other people/other	• when people laugh at me; compare me with those without CF; autumn period
I believe that many people... (12)	Relationship with CF	• concerns of others about infection; there are other people in a worse condition (compared with CF)
	Other people	• "they're checking me out"; they don't know about CF; they don't know what is important in life; they don't think as a sick person; "they're wasting time"; they deal with stupid things; they don't appreciate life and health
	Neutrality	• "he has a lot of ideas"; they're idiots
I wish I... (13)	Disease	• recover; live a normal life; "be here as long as possible"; "to wake up in the morning"; extend my life by a new drug; "wake up and find out that CF was just a bad dream"
	Other people	• "be healthy for the family"; "give my son a normal childhood without restrictions"; have a normal family; eradicate diseases; have strength for other people
	Myself	• be happy and be of benefit to others; ability to show others that it is possible to live with CF; finish all planned things; not to feel sorry for myself at the end of my life
	Finiteness	• die; "live at least to 30 years – I'm 16"
If only I could... (14)	Possibilities	• have supernatural abilities; have more money; have millions to find a cure
	Health/relationship with CF	• healthy; I wish CF was curable; be helpful in finding a cure; to win the jackpot and buy equipment for other patients; have quality physicians; be able to meet other patients with CF
	Time	• have many years of life ahead; have more time; see a happy and full life of my children; to be able to control time
	Wishes	• know what it's like to breathe normally; fulfil my own dreams; be happy and contented; have a better physical condition; be able to travel; have a family and be able to take care of them; have more strength and function better
	Neutrality	• I can't think of anything; have a magic ring; have one magic wish
Sometimes I think about... (15)	Priority	• the value of life; CF makes me a better person; about the meaning of life
	Finiteness	• about death; "about death, quite often. Everybody has to die, but perhaps it won't be tomorrow for me"; about dying
	Cure to CF	• when a cure is finally found
	Future	• "live to 50 years"; what will come; about the future; "about what will be then" (after death)
	Myself	• "what would it be like to have a child"; "what would it be like if I didn't know anything about CF"; about why I?; "why cannot I be a normal-healthy person"
	Other Neutrality	• about how I and my CF is actually perceived by others; about people who are in a worse condition • about everything





**Figure 1.** Degree of subjective estimation of the current condition (Likert scale) expressed by patients with cystic fibrosis (n = 25), participating in an on-line survey (a pilot study).

the two main problems of the health condition: diabetes with CF and growth disorders [22]; accordingly, it is not necessary to investigate the association with the quality of life [3, 23-25], including close relatives [26]. The issue of perception of the illness by patients with CF was

addressed in a study by Cepuch et al [27]; however, this study included those who have undergone, or are waiting for lung transplantation. The importance of social support, which was often emphasised by the patients participating in the research, was pointed out by Barker et al [28] in the age category of adolescents. A serious problem – stigmatization of CF patients – was highlighted in a research study by Pakhale et al [29]. The perceptions of adults suffering from CF were qualitatively analysed by Abbott et al [11], regarding pulmonary exacerbation. Another study on a similar research topic was conducted by Gee et al [3]. The perception was captured in a view of “general health perceptions” in combination with the impact of gender and disease severity connected with a concept of quality of life. A qualitative analysis similar to author’s topic was used by Filigno et al [30], but in a view of parent experiences with achieving CF nutrition recommendations; and experiences, perceptions and assessments (but of different topic: medical treatment) among patients with CF were discussed by Grotenborg et al [31]. In the socio-cultural context of the Czech Republic, Hodková et al [32] bring interesting findings of coping with CF, but using a quantitative approach (the Cystic Fibrosis Coping Scale). Finally, one similar study focused on perceptions of barriers and facilitators in older adolescents and adults with CF was made by George et al [8], but in a view of self-management decisions.

Partial results suggest a correlation between the severity of the disease (type and progression of CF) and performance of everyday activities. These are limited by the current health condition. The results of our study are in

**Table 2.** Results of the ‘three wishes’ (W) technique (main dimensions – categories) expressed by patients with cystic fibrosis (n = 25), participating in an on-line survey (a pilot study)

(W)	Dimension	Category
1st W	CF	• health; possibility to recover; cure; live as long as possible (after lung transplantation); live my life as best as I can; “new lungs”
	Other people	• medications for diseases; good health for all people; “I wish my parents and my brother (also with CF) lived as long as possible”
	Other	• have an own apartment/house; meadow behind the house
2nd W	Values	• happiness; no wars; “make people around me happy”
	Family	• have a family; to have a healthy child; have a happy marriage; health for my family; “have a happy family without everyday concerns about somebody”; I wish nothing happened to my children
	Improvement	• “live a luxurious lifestyle”; be rich; higher pension; fulfil the wishes of people around me
	CF	• cure to CF
	Finiteness	• “I wish I was here a little longer”; “I wish people took me seriously and remembered the good of me”
	Miscellaneous	• visit America
3rd W	People around me	• “I wish I could give my son a childhood that he deserves. Because he is the most amazing and brave child in the world”; have a family with children
	Unused wish	• “I’ll leave it to someone else”
	CF	• medicine to cure CF; health; not have CF
	Time/future	• “live to at least 60 years of age”; “be here for many years”; grow old with my family
	Other wishes	• some other wishes; have good luck in my life; “avoid disasters”; world peace; “I wish all people loved each other and were nice”; be smarter; “it’s impossible to live without CF, so nothing”
	Miscellaneous	• house by the sea; own a farm; go to Iceland; respect from other people

**Table 3.** Individual sources supported CF patients (n = 25), participating in an on-line survey (a pilot study)

Family	Patient himself / herself	Close persons	Animal
The family itself; husband/wife; grandmother; boyfriend/girlfriend; brother; parents	Myself ("Sometimes I have to be my own hero")	Friends; My faithful friend (female)	A horse

agreement with those of Abbott et al [33, 34]. They also discovered that daily activities were affected by disease exacerbations, which the patients considered a significant limitation. A frequent requirement indicated by the patients in our study was an adequate and high quality care for all patients with CF. These results are consistent with the partial results of a study by Bucks et al [35] (questionnaire survey in 38 patients with CF) where the patients reported strong doubts about the necessity of chest physiotherapy. The research focused on illness perceptions and treatment beliefs; however, the target group consisted of adolescents with CF. The agreement of our study with the results of a study by Swisher and Erickson [36] can be found in frequent statements of the patients concerning annoying symptoms. Another notable finding of our study was "limitation of freedom" as a result of CF. For comparison reasons, only a single study was found that describes this attribute – this is a research study by Gabatz and Ritter [37] performed only in children with CF. Concerns about the future suggested by the patients in our study are also present in the results of several other studies. In the context of adult persons (i.e. older than 15 years) only a single study was found that highlighted this fact [38], but from the perspective of gender (greater concerns were suggested by women, which is consistent with the women's statement in our study). For patients with long-term chronic and incurable diseases, "their disease" becomes part of their lifestyle and perspective of their own health. This attitude was also suggested in several cases in our study; CF as a 'normal' health state in adult patients with CF was also suggested by Lowton and Gabe [39], and Abbott et al [34]. However, it should be noted that none of the studies discussed above was performed as an online survey in patients with CF, as in the Czech Republic, and using the same (or similar) methodology.

### Study limitations

Several limitations should be acknowledged. A limitation of the study might be the absence of a control group. In that case however, the design of the study would be changed, i.e. a case control study or cross-sectional study (quantitative approach). Only after implementation of such type of research the author could identify the specifics of subjective perception typical only for patients with CF (not the objective of this study). Moreover, we are aware of a degree of similarity of the content components of attitudes of patients with CF and attitudes of patients with another disease, including rare diseases.

The study was based on the assessment of direct patients' statements; therefore, the findings cannot be generalized. The validity is related only to the specific group of patients studied. Another limitation might be that the researcher did not differentiate the participants' attitudes and experiences by age (i.e. younger and older patients). During the pilot testing the age criterion was set at older than 15 years. The overall concept of the research study – to explore the possibilities of using the specific methodology in the target group of patients with CF – did not include patient differentiation by the criterion of "age".

Information data was analysed as reported by cases with CF, the testimonies should not correspond with actual behaviour and cases may not be aware of or unwilling to discuss some topics that influence their attitudes and behaviour. A certain limit of the study also derives from the current health status of patients, as well as the fact that the study might have involved motivated and talkative patients in a close social network group. A limitation not specific to a qualitative approach was the risk of selection bias, as cases had to be reachable by on-line contact and motivated enough to complete on-line testing via research form (sample size was dependent on participants being sourced from a closed group). Despite these limitations, this research offers the first experiences with highly specific methodological combination, which proved highly sensitive and valuable. It has been able to identify information of a subjective nature that cannot be obtained by quantitative approaches. A novel methodological approach was applied to a target group of CF patients, that can provide essential new opportunity for researchers and clinicians. Further quantitative research is needed for a global statement of valid reality of subjective nature in research action in CF patients.

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