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ORIGINAL ARTICLE

LATE EFFECTS ON THE QUALITY OF LIFE OF PULMONARY CHRONIC DISEASE CARRIERS AFTER PULMONARY REHABILITATION

REPERCUSSÕES TARDIAS NA QUALIDADE DE VIDA DE PORTADORES DE DOENÇA PULMONAR CRÔNICA APÓS REABILITAÇÃO PULMONAR

EFFECTOS TARDÍOS EN LA CALIDAD DE VIDA DE PACIENTES CON ENFERMEDAD PULMONAR CRÓNICA DESPUÉS DE LA REHABILITACIÓN PULMONAR

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ABSTRACT

Objective: analyzing the quality of life of patients with chronic obstructive pulmonary disease, 24 months after the pulmonary rehabilitation program. **Method:** an exploratory and descriptive study of a qualitative approach conducted with seven patients through semi-structured interview. The statements were recorded and transcribed for later categorization. The research project was approved by the Research Ethics Committee, Protocol 4.08.03.08.1281. **Results:** after data analysis the following categories emerged << Quality of Life - Satisfaction and Wellness >>, << The overcoming of fear and insecurity >>, << Return to social life >>, << The independence and performance in ADLs >>, << Leisure >>, << Dyspnea - the loser obstacle >>, << Self-esteem recovered >>. **Conclusion:** employees regained their independence, self-esteem and social life, and feel more safe and quiet, rediscovering the feeling of pleasure in moments of life. **Descriptors:** Chronic Obstructive Pulmonary Disease; Rehabilitation; Quality of Life.

RESUMO

Objetivo: analisar a qualidade de vida de portadores de doença pulmonar obstrutiva crônica, 24 meses após o programa de reabilitação pulmonar. **Método:** estudo exploratório e descritivo de abordagem qualitativa realizado com sete pacientes por meio de entrevista semiestruturada. Os depoimentos foram gravados e transcritos para uma posterior categorização. O projeto de pesquisa foi aprovado pelo Comitê de Ética em Pesquisa, protocolo nº 4.08.03.08.1281. **Resultados:** após a análise dos dados emergiram as categorias << Qualidade de Vida - Satisfação e Bem-Estar >>, << A superação do medo e da insegurança >>, << O retorno à vida social >>, << A independência e o desempenho nas AVD's >>, << O Lazer >>, << Dispneia - o obstáculo vencido >>, << A autoestima recuperada >>. **Conclusão:** os colaboradores recuperaram sua independência, autoestima e vida social, além de sentirem-se mais seguros e tranquilos, reencontrando o sentimento de prazer nos momentos da vida. **Descritores:** Doença Pulmonar Obstrutiva Crônica; Reabilitação; Qualidade de Vida.

RESUMEN

Objetivo: analizar la calidad de vida de los pacientes con enfermedad pulmonar obstructiva crónica, 24 meses después del programa de rehabilitación pulmonar. **Método:** un estudio exploratorio y descriptivo con enfoque cualitativo realizado con siete pacientes a través de entrevista semi-estructurada. Las declaraciones fueron grabadas y transcritas para posterior categorización. El proyecto de investigación fue aprobado por el Comité de Ética en la Investigación, Protocolo 4.08.03.08.1281. **Resultados:** después de analizar los datos surgieron las siguientes categorías << Calidad de Vida - Satisfacción y Bienestar >>, << La superación del miedo y la inseguridad >>, << Volver a la vida social >>, << La independencia y el desempeño en las AVD >>, << El Ocio >>, << La disnea - el obstáculo perdedor >>, << La autoestima recuperada >>. **Conclusión:** los empleados recuperaron su independencia, la autoestima y la vida social, y se sienten más seguros y tranquilos, redescubriendo la sensación de placer en los momentos de la vida. **Descriptores:** Enfermedad Pulmonar Obstrutiva Crónica; Rehabilitación; Calidad de Vida.

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INTRODUCTION

Chronic Obstructive Pulmonary Disease (COPD) is characterized by airflow limitation that is not fully reversible and is usually progressive and associated with abnormal inflammatory response of the lungs to noxious particles or gases. Exacerbations and comorbidities contribute to the overall disease severity.¹

With the evolution of the disease, the effects are felt permanently. The progressive intensification of dyspnea causes the patient need to modify its lifestyle, because its feel unable to keep its life in the same way that kept before the first manifestations of the disease. As the patient is faced with significant limitations to perform activities of daily living (ADL) and the effort required to adjust to the disability, appears to depression. With the gradual deterioration caused by the disease, the patient has "losses" in several areas: leisure, social, professional, sexual, interpersonal.²⁻³

Anxiety and depression appear in percentages that ranges respectively, from 21% to 96% and from 27% to 79% in these patients, which comes to further erode of quality of life of these people.⁴

The Pulmonary Rehabilitation Program (PRP) is a multidisciplinary therapeutic approach of care for patients with chronic respiratory diseases, individually designed to optimize physical performance, social and autonomy of these patients.⁵⁻⁶

It is known that chronic obstructive patients are at greater risk of returning to a sleep stage and physical deconditioning after completion of a training program. The success of the intervention is based on the change of sedentary living habits to healthier living habits. Throughout the program should be prepared patients to maintain physical activity after discharge.⁷

The possibility of QOL change through clinical intervention has led to the expansion of the objectives of the treatment of lung diseases in addition to the improvement in organ function, looking also act in the recovery of functional impairments that are clearly important to the well-being of patients.⁸

The objective of this study is to analyze the quality of life of patients with COPD 24 months after a PRP. In order to identify how much the influence of PRP remains in everyday life of these patients with COPD.

METHOD

An exploratory and descriptive study of a qualitative approach developed in the exercise of Physical Activity Studies Laboratory and Sports (LEAFES), University of Feevale in Novo Hamburgo, State of Rio Grande do Sul, in the months of March and April 2011. Participants this study were part of the Support Group for Patients previously rehabilitated PRP with a psychologist and orientation matches a frequency of once a week. Employees were of both genders and age over 45 years old. Were selected for this study patients participating in the Support Group, which had significant clinical improvement in the Questionnaire of the Saint George's Respiratory (SGRQ) after PRP and who were rehabilitated two (2) years. Exclusion criteria were of patients who did not participate willingly on the Support Group.

The data production was conducted by means of individualized structured interviews, recorded and transcribed, with the authorization of the participant. After transcription, the text of the interview was presented to it, so it could make corrections, and agreeing to sign it.

The interviews were analyzed from the Content Analysis Technic⁹ that consists of a set of methodological tools aimed at qualitative research. Content analysis is a set of communication analysis techniques, aiming for systematic procedures and description of the objectives of message content, to obtain quantitative indicators or not, that allow the inference of knowledge related to the conditions of production/reception (inferred variables) messages.⁹

The interviews were classified into categories, and the participants of this research were cited as follows: C1 to C7, which is number of participants interviewed patients and analyzed in this study, to maintain confidentiality of the identity thereof. Thus, after electing the categories there was the interpretation of the information collected.

The study had the research project approved by the Ethics Committee for Research in Humans of the University of Feevale, No. process. 4.08.03.08.1281. The research and the inclusion of subjects followed the Resolution 196/96 of the National Council of the Ministry of Health, which provides for regulatory guidelines and standards of research involving humans. Regarding the commitments of the research subjects, they were obtained through the Term of Consent, composed of 2-way, and a

copy was with the researcher and the other with the patient. It was guaranteed to everyone the freedom to participate or not and give up at any time, without prejudice. Also were assured confidentiality and anonymity, using fictitious names.

RESULTS AND DISCUSSION

The following is the profile of the employees and the category that emerged in this study, with their respective subcategories.

The participants in this study were all female, aged between 54 and 68 years old, who participated in a support group after completing the PRP. Regarding the severity of the disease by airflow limitation, measured by spirometry, two collaborators presented Gold 1 two collaborators presented Gold 2, a collaborative presented Gold 3 and a collaborator presented Gold 4. With respect to physical activity three collaborators perform walks regularly, 3 times a week and three collaborators do not perform any physical activity. The content analysis of the interviews enabled the construction of quality of life category and other six sub-categories:

♦ Category: Quality of Life Satisfaction and Well-Being

Quality of life is a concept deeply marked by subjectivity, involving all the essential components of the human condition, whether physical, psychological, social, cultural or spiritual.¹⁰

It is a dynamic concept that changes in the process of living of the people. The life satisfaction and well-being of sensation can often be a momentary feeling. The achievement of a quality life can go being built and consolidated, a process that includes reflection on what is essential to their quality of life and the establishment of goals to be achieved, taking as inspiration the desire to be happy.¹¹ Particularly in chronic lung disease, quality of life is never merely a consequence of its severity: multiple factors that are interrelated are involved in this concept. Pulmonary rehabilitation (PR) allowed the collaborators C3 and C4 the conquest of a life with quality, as shown by their statements.

Having QoL involves overcoming and control of conflicting feelings that are brought by chronic respiratory disease.¹² Overcoming and control of conflicting feelings, the author cites as can be observed in the C5 collaborator's testimony.

Below is the statement about the perception of QOL of employees after PR:

Great, improved everything, my living with the family, society, was a door that opened up [...] Since I started here, was in March last year, mute everything in my life, I raised up in the feed, change everything. (C3)

Ah, I think I feel very good, I felt very well, and I'm still feeling pretty good, both emotionally and physically, I have managed to get this letter, it was wonderful, was one of the best things that ever happened to me. (C4)

Oh, my life is great, really good. (C5)

♦ Subcategory

• The overcoming of fear and insecurity

Insecurity and fear always accompany chronic diseases because people care about what's wrong with them, with the development and progression of the disease, especially when they realize that treatment is not effective and when they cannot keep control of the situation. Fear is a feeling of helplessness; a watch is threatened by an impending evil that is more powerful than oneself.¹²

Living well with a chronic disease is possible, since the fears can be overcome and that the person can live independently and who, aware of the fact, take control of your life.¹² Just as the author describes, below the testimony of overcoming rehabilitated patients:

I was shy, I was afraid to talk to people, fear of boarding a bus, now today. Today I take the bus, I feel that a good deal of people, thank God. (C3)

I have more peace of mind, confidence. (C5)

Thus, improve the mood [...] I was afraid, so oh [...] All I have to better, quiet. (C6)

♦ Subcategory

• The return to social life

Fatigue or lack of energy influences both the gradual decline in physical activities, as causing irritability and frustration. Moreover, it can cause withdrawal from social activities. As a reflection of the removal of social activities, people can end up isolating themselves.¹² The body is a reflection of society, it is not possible to conceiving exclusively biological, instrumental or aesthetic processes in human behavior. The body applies feelings, discourses and practices that form the basis of our social life.¹⁴

Humans provide sensory stimulation to prevent life is dull, offer solidarity, security and protection, social support, actually facilitates the recovery of a crisis or an illness. People who value very social relationships help others more often than those who place more emphasis on other values, such as aesthetic or political.¹⁵

The ladies collaborators of this study felt intimidated and annoyed by the condition they were in. Not allowed to maintain a social relationship with others, but after PRP, they feel more willing to have a social life again, as demonstrates the following statements:

I didn't go out, did nothing, now take sides on things in life [...] today I participate of the 3rd Age Group, go out more. (C1)

Today I talk to people [...] (C3)

Now I want to go out I bathe me clean and I'm leaving. (C5)

◆ Subcategory

● Independence and performance in the ADL's

The inability to perform tasks considered simple and ordinary, become extremely stressful and a source of suffering and anguish for patients with COPD.¹⁶ The lack of energy to maintain their daily activities is also highlighted as having strong negative impact on quality of life of these people.¹¹

Activities of Daily Living (ADLs) are defined as tasks of occupational performance that a person carries out every day, to prepare or as adjuncts to the tasks of their role. They are part of the ADL's: the individual's ability dressing, feeding, bathing, combing, and abilities as meeting phone, communicating through writing, handling correspondence, money, books and newspapers, in addition to own body mobility, such as: the ability to turn around in bed, sit, move or transfer from one place to another. Importantly, patients with COPD have greater difficulty in performing them, always proportional to the pulmonary and physical impairment that feature.¹⁷ The study collaborators report some ADLs not performed before the PRP, which currently can perform, as shown by some testimonials:

I got tired and had shortness of breath to clean house, not now, now thank God [...] (C2)

Put my washing and showers also, today I can. (C5)

I was so attacked when I was going to bed, take a bath, there's some days I'd lay in bed, when I slept I had to jump out of bed of shortness of breath and I never had that after I started the treatment here. (C6)

◆ Subcategory

● Leisure

Leisure is related to the act of living in relative freedom of external compulsive forces to the culture of a person and physical environments, making it possible to act upon an inner attitude of love, who personally brings you pleasure, and provides a basis for adoption of new values.¹⁸

If there is a great similarity in the genesis of leisure and quality of life is the pursuit of

happiness. If the objectivity of both constructions - Leisure and quality of life - lays the possibility of joining a new lifestyle, is the subjectivity of everyone who inhabits the "grip". That is, the adoption of a new lifestyle over time, essential characteristic to achieve quality of life.¹⁹ For subjects of the investigation, the small changes, are great achievements, leisure relationship and quality of life appears clearly, as demonstrates some excerpts below:

Look, because it is [...] today I'm dealing with in the garden, planting my flowers, my tea, I'm moving on Earth, before I couldn't just stay inside, I spent all winter indoors. Already last year, that cold, I spent all winter walking, for me it was good, really good [...] (C3)

Ah, it was walking [...] today I can. (C5)

So oh, walking very far, I walked [...]. (C6)

◆ Subcategory

● Dyspnea - the obstacle won

Dyspnea is the main symptom associated with disability, reduced quality of life and worse prognosis.³ It is generally observed during intense activities, however, for individuals with COPD, this is a situation experienced in day-to-activities day or even at home, is the main causal agent of physical fitness and this is mainly due to muscle inactivity.²⁰

It corresponds to the sensation experienced by the patient when the act of breathing passes the sphere of consciousness to an unpleasant effort. There is therefore an important affective dimension of displeasure, shaped by cognitive and contextual factors. This experience of breathlessness is extremely distressing for the patient; leading to fear and anxiety that the patient tries to avoid at all costs.²⁰⁻² PRP obtained important contribution to the collaborators of the study in relation to dyspnea, as shown some testimonials:

Look, I speak frankly, I don't even have almost short of breath today, I don't have [...], and very difficult I have shortness of breath. (C2)

I can get along better with her, after I got here, the teachers taught me to breathe, and I couldn't breathe. (C3)

I practically got no sense yet, but so I have control now, before I ran inside the House to make the inhaler, I despaired, today before I stop, try to do a proper breathing, and many times I have gotten with that there is the need to make the inhaler. (C4)

◆ Subcategory

● Self-esteem recovered

Chronic diseases can interfere with self-esteem because of changes in emotional state such as sadness, discourage, demotivation, nervousness, anger, loss of pleasure,

insecurity, feeling of worthlessness and dissatisfaction.¹⁰ Collaborative C5, from your testimony shows how much self-esteem was affected and how the PRP helped improve this subcategory.

The person when feels unable to care for itself has affected their self-esteem and self-confidence. Learning to deal with the disease through modifications or adaptations of our habits is an essential factor so there is autonomy.¹²

In other words, self-esteem is the sum of the self with self-respect; reflecting the implicit judgment of our ability to coping with life's challenges (understanding and mastering the problems) and the right to be happy (respecting and defending our own interests and needs).²² Collaborative C4 feels happier with oneself after the PRP, as demonstrated by one's testimony.

The higher our self-esteem, more joy we will have, for the simple fact of being, awakening in the morning, to live within our own bodies. These are the rewards that our self-confidence and self-respect offer us.²² Collaborative C6 shows us his testimony changes.

Ah! Today I'm fine telling people [...] I feel like a girl, I want to get ready, mute everything even. (C3)

I had prejudice against myself, huh, I saw myself very badly today I accepted, I know my limitations, I'm looking into it to develop my activities, is quietly [...] I feel happier, higher, quietly, much more, even. (C4)

I have more available [...] more cheerful, more peaceful. (C5)

One can see that the rehabilitated patients who participated in this research expressed improvements before their QOL. Faced suddenly with the feeling of fear, feeling embarrassed about to be isolated, unable to perform even the most basic daily tasks, is a great emotional shock. The interviews demonstrate feelings of fragility, of worthlessness and dependence. However, this barrier was overcome; participation in the PRP changed their lives.

CONCLUSION

We found that, after the PRP patients returned to perform ADLs, such as bathing alone, cleaning the house and extend the clothing independently, regain self-esteem, overcame fear and insecurity, won the shame recovered their social life and have more control front dyspnea, and these changes mentioned, are more than achievements are victories.

It was also concluded that, certainly the success of PR on the life of these patients is

due to the fact the program is interdisciplinary, occurring so exchange of information between the various health care professionals working in the PRP, an important contribution to the rehabilitation of these patients.

The work also has its importance for health professionals, who always want the highest level of independence for patients, to improve the quality of life for them. For the patients who participated in a PRP, usually are found with best and emotionally stable physical condition, relevant aspects when we receive COPD.

Thus, only the testimony of the participants could show how the PRP has changed their lives and more than that provided a significant improvement in the perception of their quality of life.

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