

The opinion of patients with COPD: the process of becoming chronically sick

Vozes das pessoas com DPOC:
o processo de tornar-se doente crónico

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Abstract *Many earlier studies have contributed to a general understanding of the symptoms and signs of chronic obstructive pulmonary disease (COPD), yet very little is known about the transition from a healthy to a chronically sick individual. The scope of this study was to understand how people live with their chronic illness, using Grounded Theory¹. Twenty-two participants with COPD were interviewed. Findings revealed “the basic social process” of becoming sick with COPD: The significance of living with COPD; Stages of becoming a sick individual; Strategies for management of the process used by participants. The conclusion reached is that understanding the process of “becoming sick” from the person’s perspective assists nurses to develop personalized interventions with individuals suffering from COPD, focussing on the subject of care.*

Key words *Nursing, Community nursing, COPD patient, Public health, Chronic disease, Transition*

Resumo *Os vários estudos realizados no âmbito da DPOC têm focalizado o seu objeto de estudo na compreensão dos sinais e sintomas da doença, no entanto pouco se conhece sobre a transição de saudável a doente. Então como é que as pessoas com DPOC vivem o processo de transição de saudável a doente? O método utilizado foi a Teoria Fundamentada. Realizámos 22 entrevistas abertas a pessoas com DPOC. O Processo Social Básico (PSB), encontrado neste estudo é “tornar-se doente” expressa o conceito central do estudo e procura dar resposta à questão de investigação: O significado de viver com a DPOC; Estádios do processo de tornar-se doente; Estratégias de gestão do processo. Consideramos que o conhecimento do processo de “tornar-se doente”, ajuda os enfermeiros a desenvolver intervenções individualizadas às pessoas com DPOC, focalizando-se no sujeito de cuidados.*
Palavras-chave *Enfermagem, Enfermagem comunitária, Pessoa com DPOC, Saúde Pública, Doença crónica, Transição*

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Introduction

Chronic obstructive pulmonary disease (COPD) is the fifth leading cause of death worldwide and is a major personal and Public Health problem. The prevalence and incidence of COPD continues to increase not only in Portugal but also worldwide.

In Portugal, COPD is the seventh cause of death, increasing 2% over 5 years (1998-2002). Several international studies have explored patients' experiences on living with COPD¹⁻¹⁵. All these studies add new knowledge to understand people with COPD living transitions experience. Still, there is a need to study further the lived experience of people with COPD from a nursing perspective, specifically as a way of helping people going through transitions. The research question that guided the present study was: *How do persons with COPD live through the transition from wellness to illness?*

Background

The main health problem of people suffering from chronic respiratory disease is dyspnoea. Dyspnoea affects all aspects of life psychological, social, and physical. Patients with breathing alternations must be seen as unique¹⁶ and at the same time, as persons in transition¹⁷. Transition from feeling healthy to feeling sick, represent a life process with complex interactions between environment and person. Transition is influenced by the social context and the person's health situation^{17,18}. The concept of transition represents a process that involves a change in the life of a person. Understanding the transition process allows healthcare professionals to help their patients to change; nurses can plan activities according to their knowledge of the transition¹⁹. Doing so will not only enable nurses to better help patients deal successfully with problems they may encounter as the disease progresses but also will help nurses stimulate their patients' potential.

Nursing is defined "as being concerned with the processes and experiences of human beings undergoing transitions where health and perceived well-being is the outcome"¹⁷ as well as "the art and science of facilitating the transition of populations' health and well-being"²⁰. Understanding and identifying life transitions that people experience enables nurses to develop innovative therapeutic interventions based squarely on what people are living and feeling. This understanding also gives nurses direction to help pa-

tients self-manage during the transition, thereby facilitating the passage through life.

Purpose

The aim of the study was to understand the transitional experiences of persons with COPD in order to contribute to a higher quality of nursing care.

Methodology

Design and sample

The research question called for a qualitative approach, grounded theory being appropriate to understand psycho-social processes²¹. Through a qualitative approach, interviews were held with a convenience sample of 22 participants, 17 were men and five women with chronic obstructive pulmonary disease with confirmed diagnosis at least two years before the study, regardless of level, as defined by the Global Initiative for Chronic Obstructive Lung Disease²². The youngest was 26 years old and the oldest 72 years old. This way a theoretical sampling was formed by 22 participants, all of them were informed about the study and accepted to participate. One participant refused to participate after the interview.

Setting

We contacted two hospitals in Lisbon, Portugal, with outpatient facilities for persons with respiratory diseases and RESPIRA, a Portuguese association of persons with COPD and other respiratory diseases formed in 2007, all of them agreeing to take part in our study. Professionals from one hospital indicated four patients in home care that could participate in our study; the researcher visited them at home with the hospital home team and did two interviews. Other hospital referred 11 outpatients and we contacted them in the hospital. The RESPIRA President referred 15 potential participants that were contacted by phone. From these 15 we only contacted 11 participants, and one was on holiday so we did 10 interviews in the participant's home.

Data collection

Data were collected over 6 months, between June 30, 2008, and December 7, 2008. The author conducted face to face interviews at different lo-

cations, which were chosen by the participants according to their availability. The length of the interviews was between 15 minutes and one hour and 40 minutes. A semi structured interview guide was used throughout the interview. The interview questions focused on the effect of COPD on everyday activities and relationships, the emotional feelings associated with the disease and the participants' experiences with dyspnoea. However interviews were conducted in a very flexible manner to allow participants to share topics, perspectives, and meanings that were important to them, and to allow the interviewer to explore all issues raised throughout the interview process. Open-ended questions were asked to encourage participants to describe their subjective experiences without being led by the interviewer, and to obtain as much data as possible. After the interviews, the tapes were transcribed by the author with the participants' permission. Interview tapes and transcripts were not identified in order to ensure participant confidentiality.

Data analysis

Transcripts from the personal interviews served as the raw data in this study. Data were analyzed during data collection, and were analyzed line by line to form categories, search for and identify processes, meanings, actions, change, and consequences²¹. Using theoretical coding, the relationship between the categories and concepts were identified, and the focused codes integrated and organized into at the Basic Social Process that emerged: "Becoming a sick person". To ensure the Basic Social Process had fit, relevance, and modifiability, trustworthiness of the data was sought using the criteria of credibility and reliability. Reliability was verified through debriefing with two colleagues, good interview techniques, coherence, and referential adequacy. These colleagues were not involved in the study. Credibility was assured by a referential adequacy of the data obtained by gathering rich, in-depth information from interviews, field notes, and memos, and by transcribing verbatim and coding line by line using the participant's words as much as possible. After that, our colleagues analysed the data. There was 85% of consensus with the findings. The researcher decided to do some modifications based on colleagues evaluation.

Ethical considerations

Both hospitals Institutional Review Boards approved this study. No patient identifying information is reported here, and all names were coded into number designators for the study. Participants knew their own number.

Findings

The participants gave descriptions about how they become sick and how the illness influenced every aspect of their daily activities. We used the transition concept to understand the process of becoming a sick person. This Basic Social Process expresses the Central Concept of the study and answers to the research question: *How do persons with COPD live through the transition from wellness to illness?* Our findings revealed a process that persons with COPD passed through during his/her life.

This Basic Social process is compounded by three theoretical codes:

- . Meanings of living with COPD;
- . Stages of becoming a sick person;
- . Management strategies used by participants (Figure 1).

Meanings of living with COPD

In order to understand how a person becomes sick, we must understand the meanings of their bodily experiences and social context as these meanings are constructed in a dialectic relation to their biographies¹. They expressed how COPD affected their lives, acknowledging the progressive nature of the disease. These interpretations mediated their experience²¹.

During this transitional experience, people with COPD may find that their limitations may also lead to some newly found benefits²³. These benefits were highlighted by one participant:

... [Having COPD afforded me] *the 'privilege' of not climbing the stairs, as there was no lift. So a doctor, met me at the beginning of the work-day downstairs at the entrance [...] For me this was an **advantage** [...] it was more profitable to talk to the doctor at the beginning [of the day] than at the end of his consultation [day], since it was more likely he [the doctor] would buy something that I was going to offer him [as part of his role as a laboratory salesman]. (E5)*

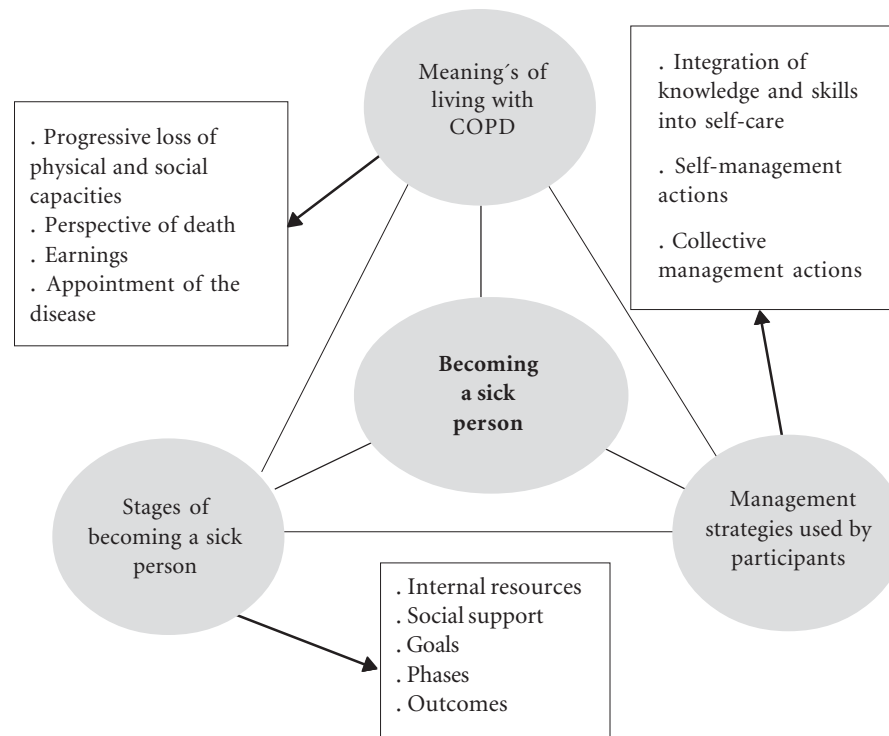


Figure 1. Diagram of the study findings.

Another important aspect, which can affect the meaning of the experience of being a sick person is the ability of people with COPD to know the name of the disease and the testes that contribute to the diagnosis of the disease:

[...] *I've been dragging for 6 or 8 months, and it was becoming increasingly worse. And then when I decided to get treatment, that was when I was told I had chronic obstructive pulmonary disease.* (Silence). (E19)

The way each of us lives depends in part on how we approach life, even when confronted with a chronic disease such as COPD. Some participants experienced changes in their quality of life. Interpretations of experience depend on how people have been living their lives. We consider that understanding the meaning of lived experience of being a COPD patient gives nurses information that helps them to understand individuality and integrity of each person and when nurses have this comprehension they can help people to follow their path in the process of becoming a sick person.

Stages of becoming a sick person

COPD is a progressive disease that worsens with time. Becoming sick can be considered a learning process, during which a person acquires knowledge and experience, becoming an expert about his/her disease. The idea that this process depends largely on internal skills that compel persons to deal with their disease at different levels, emerges from the data analysis. However, this process will only occur if the person is aware that he/she really needs to change, as reflected in the comments of comments of one participant:

[...] *each person must find their way* [on how] *to live with these things.* [Chronic respiratory diseases like COPD] *are [...] very much like any [other] disease: [It] stirs up a lot in us and not what others say is what we get [...]* [Getting through the disease] *is an inner process of acceptance and moving forward.* [...] [It requires] *a lot of fortitude and a lot of decisions [...]*. (E8)

It is important for nurses to understand that suffering may be the driving force that triggers this process, it is also equally important for nurses

to understand that this process help patients with COPD to grow as a person and to develop coping skills.

Findings suggest that environment of persons with COPD can influence person's experience process of feeling sick, one of the participants said:

[...] *the stagnant air keeps me from going out* [...]. (E1)

Other says: *I seldom go to parties or gatherings. I don't like to drive out in restaurants that are filled with smoke* [...]. (E8)

Patients integrate environmental control behaviours in their lives¹¹.

People with COPD commit themselves to achieving their goals during the process. Objectives are *goals* that people reach out for when they start this process. The data collected also indicated that the objectives of a person with COPD change in accordance with the experiences he/she acquires. One participant reflected this:

Since the TAC [computed axial tomography], [...] [the doctor] [...] clarified any doubts, [she] was very direct, I had to think 'what do you want for your life' and then [I] had to decide. (E8)

For people with COPD, the illness begins to reflect on their identity, on their awareness of self^{17,19,24}. This statement reflects that it is important to have *self-determination* to do things and this influences the process of becoming a sick person.

We identified *two phases in this process: Crisis and Chronic states*. Participants referred that they were different but with three common elements: symptoms, feelings and constrains. These elements have been identified previously in other studies.

During crisis participants said that dyspnoea was the main principle symptom, anxiety and panic were the main principal feelings. It was interesting that all the 19 participants referred some constrains in this phase such as: they didn't know they were sick, they went to hospital over and over again with dyspnoea and after that they went home with medication, but without a diagnosis and they didn't care about it, they didn't pay attention. In the chronic phase they referred physical limitations as principal complains and they were sad and angry with themselves.

During the process of becoming a sick person, persons diagnosed as suffering from COPD had obtained experience and knowledge and these are outcomes of the process. Patients with COPD chose suitable disease self-management behaviors, based on experience, wisdom and professional guidance¹. This results will enable nurses to select strategies that will enhance patient care

and their management and promote the best quality of life possible within the limits set by individual capabilities²⁵.

Management strategies used by participants

The integration of knowledge and skills into self-care were important strategies for persons with COPD. The interviews revealed that the ability to solve problems was developed over time. On participant stated:

[...] *solve the [congestion] problems* [with] *Finatux [carbocisteine], [...] and avoid the Augmentin-Duo; clean everything, there is no infection that can withstand anything* [...]. (E6)

He had integrated information he received from healthcare providers and incorporated it into his life. In the context of solving problems related to one's health, another participant claimed that he was able to self-assess his health.

I see how I get if I'm more relieved or attacked, and I take [medication] according to my symptoms. We must do according to our experiences, as our own machinery [dictates] and [as according to what] we need. (E20)

Thus, some COPD patients are able to solve their health problems by assessing their situation and responding based on their experience. Knowledge of their disease and how to treat it is acquired over time. Another way patients with COPD can integrate knowledge about their disease into their disease-management skills is through self-care. Self-care is the practice of activities that an individual adheres to for his/her own benefit and to maintain life, health, and wellness²⁶.

We noted that a person with COPD himself could create conditions to manage his/her disease and live with it. One participant stated:

So there must be conditions [...] [I'm] prohibited from having the flu. [I] cannot let emphysema or COPD develop, or at least symptoms like a temperature, quench temperature (Laughs) [...] **Be careful not to catch cold, [...]** [I] **do not take anything for the disease so it does not evolve.** (E11)

The participants viewed the self-management of therapy as actions that allow them to control symptoms and the disease itself, leading to stabilisation. This view was also reported by some authors^{1,10}. One participant stated:

[...] *do drug therapy, I use ... a product that I inhale every morning... I do well; I feel that [this product] has the power to dilate my [pulmonary] veins.* (E11)

Another participant also mentioned using non-invasive ventilation to control symptoms:

Now I am using bip bap [mechanical ventilator]. [I feel] a little [better] a bit, but I think it is not well at all [...]. I will do the sleep study now in September, and then they will set the bip bap parameters [...]. (E13)

Regarding the importance of managing one's emotions, the participants reported that stress interfered with their breathing:

[...] [I] can sometimes be a bit more stressed ... Or may not be [...]. When you're talking to sponsors, tension is very different from what I now have [...] at home, [where I can] talk [...] freely [...] I feel that the oxygen helps me in the sense that it helps me to relax. (E4)

Other studies also observed that stress and changes in patients' daily activities affected the breathing of patients with COPD^{5,7,8,10,11,27-29}. COPD patient's advocate associations like RESPIRA to promote the strategy of encouraging persons with COPD to take accountability for their own health. In Portugal, the National Health Service (NHS) has taken on the role of promoting accountability through health policies and programmes such as the Prevention of Chronic Obstructive Pulmonary Disease Programme. The participants of the present study voiced frustration at such programmes and noted that patient-advocate associations need to play a more empowering role in promoting programmes applicable to the COPD context. Indeed, leadership is essential in order for such associations to fulfil their mission, as one of the participants noted:

[...] we [people with COPD] are 500 thousand, yet no one gets together, nobody is organised! We are many here, but we walk in the wind [...] It makes little sense. (E4)

Participants clearly emphasised the importance of integrating knowledge and skills into self-care. Expertise can be defined as the skills that people acquire over the management of their new situation or environment²⁴. The management strategies described by the study participants give information to nurses about ways that persons integrate knowledge about their experience and developed competences to self manage the process of becoming sick.

Discussion

The process of becoming sick is it a passage, a transition and it is characterised by having a beginning, middle, and end²⁹⁻³². The transition seems to start long before the characteristic symptoms of COPD appear. Over time persons with

COPD begin to realise that something is not right with their health. This realisation often begins with the "crisis" phase. Subsequently, over time their health begins to deteriorate, crises become more frequent, as do trips to the emergency department. The chronic phase begins when the person with COPD experiences limitations and needs medication, oxygen therapy, and other therapeutic interventions. Even before the crisis phase and before symptoms become apparent, health-care professionals must implement interventions intended to prevent the onset of disease, such as programmes that screen for COPD using spirometry and smoking cessation programmes. In the present study, we considered knowledge and experience were related to the outcomes of the transition process. By going through this process, a person with COPD gains the knowledge and experience needed to integrate this disease into his/her life. This is consistent with the findings that transition processes are characterised by the development of expertise or acquisition of new skills³³. Later, those with COPD transform these skills into strategies for managing the process of becoming sick

Living with COPD is a complex and dynamic experience of learning. Some authors say that experience is a very important element for learning adult's process^{34,35}. Health professionals have a large contribution to make in this learning process^{35,36}.

Patient-advocate associations, such as RESPIRA, make it possible for many people to voice their opinions about healthcare issues, allowing them to participate actively and more formally in determining healthcare policy and social issues. Patient-advocate organisations that are interested in the same issues identify and often provide guidance and/or the means (resources and opportunities) to resolve these issues³⁷. Essentially, they fight for the rights of special interest groups, such as persons with COPD, by trying to influence health policies not only for the benefit of individual persons but also for the benefit of all. Meanings of living with COPD are relevant. They are the social context of the findings from what had emerged as the Social Basic Process – Becoming a sick person. Clarification of meanings of living can contribute to the development of self-management strategies for use during the process of becoming sick as the disease progressively worsens³⁸. The inclusion of meanings in a theory of transition draws attention to the importance of understanding a transition from the perspective of those experiencing it. In this per-

spective, the chronic illness provokes a biographical disruption³⁹, the illness's experience meanings reflect different individual life trajectories, that happens in a sociocultural context possibilities. This disruption can't be necessarily negative but a self discovery moment, it gives an opportunity for person to show his/ her capacity to deal with illness and being well succeeded⁴⁰.

In our study, person's with COPD experience losses and gains in the process of becoming sick. Meanings are very important because knowing them gives nurses useful information about how a person is living his / her experience of becoming a sick. Meanings must also be understood from the perspective of the cultural context of the transition¹⁸.

Our study is a portrait of COPD persons, some of them are empowered and are activists, and they had founded an Organization: RESPIRA. We are observing a paradigm transition in health field: patient's empowerment and participation in Health politics are a reality, relations between health and society are changing. Nurses need to change: from a information paradigm, where we use to say what to do, to an empowerment paradigm, where we "walk side by side" with person, we are facilitators, we help people managing their health /illness. In their care, nurses need to incorporate patient's illness's meanings, their practices and experience. They need to es-

tablish a dialog between two worlds, the cultural model and professional one; it contributes to plan effective cultural nursing interventions.

Study limitations

Chronic populations with COPD may have different transition experience according to their culture as well as from people with advanced cancer or other diseases. Further research is needed to determine if the process identified in this study is unique to persons with COPD, in similar contexts or what varies in different cultural contexts.

Conclusion

The findings of the present study address a gap in the literature on the nature of experiencing a transition from feeling healthy to feeling sick. Meanings of living with COPD influence the process of becoming sick and we consider that participants are experts on their lives and, as such, they adopt management strategies, during the process of becoming sick, based on their experience and mastery, as well as integrate the disease and symptoms into their lives. We think that knowing the process of becoming sick from a person's perspective helps nurses to develop better interventions with COPD persons.

Collaborations

EL Luz did the research study and participated in the conception of the article and the final writing and ML Basto participated in the conception of the article and the final writing and English revision.

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