

Physical therapy for patients dying at home of chronic obstructive pulmonary disease

A Qualitative Study

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BACKGROUND AND PURPOSE: Rising numbers of patients are dying at home of chronic obstructive pulmonary disease. The aim of this study is to determine the wants and needs from the physical therapist of these patients dying at home. **SUBJECTS:** The participants were 3 adults (2 male, 1 female) **METHODS:** Semi-structured interviews were conducted with three patients. **RESULTS:** Four themes were identified: (1) Activity's of daily living (2) Check-up (3) Psychological meaning (4) Communication between health services. **DISCUSSION AND CONCLUSION:** The patients want to improve activities for daily living and therefore be checked regularly. The physical therapist has an important psychological meaning for the patient and has to communicate well with other health services. Future studies should combine patients' wants and needs and physical therapists' expertise and experience.

Keywords: Physical therapy, COPD, dying, qualitative study

Introduction

In the last decade there are rising numbers of incidence, prevalence and mortality in chronic obstructive pulmonary disease. 1, 2, 3 Therefore a lot of scientific research is performed to improve the physical therapy treatment for these patients. 2, 4, 5, 6 The aim for treatment taught in literature and in courses is to activate the patient with COPD. 2, 4 Eventually the disease will get more and more severe and the physical therapy training will be too demanding for the patient. The patient, the physical therapist and the patient's physician will then have to come to consensus about stopping physical therapy training in the practice. 7, 8 Ninety percent of the last year of a patient dying of COPD is spend at home. 8 In contrast, there is a lack of literature about physical therapy and patients dying at home of COPD. Other recent work has been done to interview terminally ill patients (Cancer, HIV etc.) for physicians and physical therapists. 9, 10 Because of the different skills and knowledge needed to treat these patients this study was initiated. 9, 10, 11, 12, 13 To create an insight and basis for physical therapists we chose, from patient empowerment's perspective, to interview these patients first. The aim of this study is to determine what patients who are dying at home of chronic obstructive disease want and need from their physical therapist.

Methods

The study consisted of semi-structured interviews with patients dying of COPD at home. This prospective approach was used. Researchers used purposeful sampling to select the patients who received physical therapy at home from the physical therapy practice "Zwanenzijde" in Leiden, The Netherlands at the beginning of the study. These patients with severe COPD, received an information-letter about the contents of the study. Patients with dementia or difficulties speaking the Dutch language were excluded, as were patients who could not be interviewed in Dutch. The patients had been seen by their lung physician to evaluate if they were not able to participate in physical therapy training anymore. Informed consent was obtained by one of the researchers, who explained the scientific and practical goal of the study. The patients were told that criticism wouldn't affect the care of their physical therapist in any way.

The interviews were done at home without family or relatives present to minimize their influence. The interviews were done until saturation of all relevant information was achieved.

For the development of questions, literature was reviewed about patients dying at home of chronic obstructive disease. The databases Embase and Medline were used with following keywords: "Chronic obstructive pulmonary disease", Severe, "End-of-Life", Dying, "Terminal illness", "Physical therapy", Physiotherapy and "Qualitative study".

Secondly, eight chest physical therapists from the Thorax Peer support group of the University of Utrecht told what in their opinion were the most important labels.

The labels collected from the literature and the peer interviews were all used for the list of questions: breathing exercises, relaxing techniques, advice, emotional support, respiratory muscle training, sputum evacuation techniques and advise/training of transfers.

The interviews were digitally recorded. Directly after interviewing the patients, the interviewer would transcribe the text and complete the text with the emotions of the patient.

Data-triangulation was used during the identification- and interpretation phase. The researchers had to come to consensus about the labels and their analysis from the text. After the interpretation phase a conclusion was written and checked with two participants. The third participant had died.

Results

The three interviews were conducted in the patient's home. The age of the patients varied between 64 and 78 with a mean of 68. One out of three

patients had received both inpatient and outpatient rehabilitation. The interviews had an average length of 40 minutes. The study was carried out in the first half of 2005.

	Male / Female	Age	Diagnosis	Rehabilitation *1	Fev1 (%) *2
1.	Female	68	Emphysema	None	< 22 %
2.	Male	72	Emphysema	Inpatient and outpatient	< 18 %
3.	Male	64	Chronic bronchitis	None	< 25%

*1 Did or did not receive inpatient/outpatient rehabilitation in the past

*2 Last time it was measured, ranged from 2 months till over a year ago

Activities of daily living

The three patients reported the importance of improving functional limitations and limitations on participation level according to ICF. Important functions mentioned were: walking to the toilet, getting up from a chair, getting up out of bed.

"Sometimes it can be so difficult simply getting up out of a chair"

The aim of the improvement must be, according to the three patients, to stay self sufficient.

"I would like to go to the toilet alone for as long as possible"

During the interview patients said to realise that advice would be in place for decreasing some functional limitations .

"I want to be stronger for example to open a jar, but I realise that strength is not the only factor. It must be done in a way that it doesn't cost so much energy, and I don't know how to do this."

Practising and advising are both important factors to reach the goals mentioned by these patients.

Check-up

Patients mentioned they wanted to be visited regularly. The patients from the study didn't think a weekly visit was necessary. Reasons for the visits, according to the patients were: controlling the intensity of exercises, answering questions, checking for abnormalities the patients might not be aware of.

"Once I forced myself with the threshold device because I thought it was too easy and I got pain on my chest because of it."

The patient who mentioned it was satisfied with the explanation about change in intensity of the training and the explanation where the pain came from. Another example of a problem the patient was worried about:

"Why is my heart-rate so high constantly?"

The patients mentioned that the physical therapist should answer these questions.

"A physical therapist who is specialised in lung disease can answer my questions because he has got enough time."

Psychological meaning

Three patients mentioned honesty to be one of the most important characteristics a physical therapist must have.

*"... I heard you say that a physical therapist must be honest. Is that important?"
"Yes, that's very important, because so many times they tell you something, and later you find out that it's not true."*

Besides honesty, the patients emphasized the importance of being straight forward.

"...I will die in the near future but a nurse who visits me regularly wishes me every time that I will be better soon."

In three instances patients talked about wanting the physical therapist to have enough time when they are visited:

"I believe the physical therapist must have enough time for a patient's visit... When I have got the feeling he is in a hurry, I won't ask him questions or tell things that bother me."

In several interviews the patients told about the importance of being on time when they are visited:

"Sometimes I feel like a sick problem. When someone visits me and is very late I get the feeling I should be happy that I still am visited. Then, I would rather not be visited"

Patients said about making promises:

"...Please don't promise me something I can't rely on..."

Finally, a physical therapist should realize that the patient is still part of society:

"Somebody else maybe wouldn't feel like that... but I still am a part of society."

Communication between health services

When a patient can't reach the GP or COPD-nurse for a problem, then it should be normal to have the possibility to contact the physical therapist:

"There was always someone who could help me when I was young. In my time someone would help, also if he was not specialized in it. A physical therapist can't give me medication but can give me some advice and help me to contact my physician... You don't have to fix the problem, but some comfort and help would be great. "

Patients have the experience that the GP, the COPD-nurse and the physical therapist have different ideas about treatment. When there is no communication between each other it will especially become a problem in case of someone being absent.

"When you are not at work I would like my GP and my COPD nurse to know what you do and think."

Discussion

In this study, activities of daily living were discussed by the patients. Decreasing the limitations all had the same aim, namely functioning on their level with as little help as possible. Patients reported this could be improved by advice and by practising the functions.

The results also showed the importance of a regular visit by their physical therapist. Patients said they wanted to have a regular check of the intensity of the exercises and have the opportunity to ask questions. This and the controlling for abnormalities is important according to the patients, because of the fear of doing something wrong that could harm them. The physical therapist is ideal for this task because generally he has more time for a visit than a GP.

To play an important role in the treatment for the patient, the physical therapist should realize the visit has an important psychological meaning to the patient. The patient, who relies partly or completely on health services, has to trust the health care system. Patients highlighted that being on time, having enough time, being honest/straightforward are factors, that strengthen the feeling of being part of society as well as that they are taken serious by there physical therapist. This and having a good

bond with the patient will create, more in-depth conversation and the opportunity for the patient to ask more important questions. Patients reported the benefits of communication between health services. Communication is important, because it strengthens trust in health care. The physical therapist should communicate treatment goals and the status praesens of the patient with the GP and COPD-nurse. This in order to deliver the most appropriate treatment for the patient on time. Our findings are consistent with the work of C. Pettinari et al 12, D.L. Patrick 11 et al and S. Hamilton 8 who described communication and mobility to be important factors for patients with COPD who are dying at home.

Generalizability, of the study is limited because of the qualitative design and the small number of patients who participated in the study. Besides this study from patient empowerments' perspective there is an important role for the physical therapist. The physical therapist has the expertise and the experience for mentioning treatment goals which could be studied and improved for the patient. In this study, the patients didn't mention any treatment goals as: respiratory muscle training and pursed lips breathing. Therefore further investigation should not only focus on treatment goals mentioned by patients. The information gathered will assist further studies, the development of the physical therapy treatment for these patients and give the physical therapist insight in this treatment.

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