

Palliative care needs of patients with advanced COPD

An exploration of illness experiences

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Chapter 6

***Coaching in end-stage COPD:
improving palliative care provision
by using the metaphor of athletics***



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Abstract

Background

In discussions about the palliative care provision for patients with end-stage COPD, hardly any attention is being paid to supporting patients in living as actively as possible until death. We aim to address this aspect of palliative care. The research question is: To what extent can the concept of patient work be used in describing the palliative phase of COPD, and in which way can this concept be used to improve palliative care provision?

Methods

Using a nested mixed methods design, patients enrolled in a former quantitative study were interviewed about their illness experiences. A primary inductive analysis of the research material, focussing on situations in which patients did or did not succeed in keeping up their daily activities, lead to the metaphor of athletics which we used as our analytical framework.

Results

Living with end-stage COPD may be compared to athletes improving their achievements. First, prerequisites have to be met. Second, patients develop skills in technique, tactics and mentality in the same way athletes are. Likewise, health care professionals involved in caring for COPD patients may be compared to coaches.

Conclusions

We recommend a supportive coaching approach in end-stage COPD. The position of the coach – right next to the patient – enables a tailor-made approach. The coaching approach should be introduced early in the disease trajectory to avoid problems in the timing of the palliative phase and to prevent unnecessary loss of activity level and physical condition in later stages.

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is one of the most important causes of morbidity and mortality in the western world¹. Palliative care has historically focused on cancer disease trajectories, and specialised services for patients with a non-malignant disease like COPD are still in a developing stage²⁻⁴. Several studies have shown that patients in the end-stage of COPD do not have similar access to specific palliative care services when compared to patients suffering from advanced lung cancer⁵⁻⁷. One of the most important difficulties in providing high quality palliative care to patients with advanced COPD is the highly unpredictable disease trajectory. Prognoses for individual patients with COPD are described to be inaccurate^{3,8}. However, it is increasingly recognised that patients with advanced COPD may benefit from the provision of the palliative care approach^{9,10} because they suffer from poor symptom control¹¹, especially breathlessness^{6,9,12-14}, anxiety¹³⁻¹⁵ and depression^{13,14,16} which often leads to social isolation⁹, increased dependency on others¹⁷ and poor quality of life^{5,18}.

In palliative care, the main focus is on improving the quality of life of patients and their families during the final stages of life¹⁹. The palliative care approach is holistic and targets physical, psychological, social and spiritual dimensions²⁰. According to the World Health Organisation, one of the aspects of palliative care is that it should support patients in living as actively as possible until death¹⁹. However, in discussions about palliative care provision, hardly any attention is being paid to this aspect. As a first start, Willems et al. show how much work patients with advanced heart failure need to perform in order to live with their illness and remain active²¹. They state that when caregivers have an understanding of the work patients have to perform to achieve mobility and activity, they may be more able to help patients live as actively as possible until death. The aim of the current paper is to better understand how the concept of patient work can improve the provision of palliative care in COPD. The research question is: To what extent can the concept of patient work be used in describing the palliative phase of COPD, and in which way can this concept be used to improve palliative care provision?

Methods

Setting and participants

Using a nested mixed methods design, patients with end-stage COPD were collected from a sample of 82 COPD patients with GOLD stage IV (defined as FEV1 < 30% of predicted), and age 60 years or older who participated in a quantitative study measuring their quality



of life²². These 82 patients were recruited from outpatient clinics of four participating hospitals and one centre specialising in asthma and COPD in the Netherlands. Data collection took place in the period 2004-2006. Eleven patients from this quantitative sample were approached for an interview about their illness experiences²³. The sampling was done purposefully to ensure a mix of male and female patients, patients living alone and living with their partner, and patients with and without long-term oxygen therapy. Five patients were interviewed twice with a 6 months interval, for example because the first interview did not cover all topics from the topic list, or because something changed in the patient's situation. We were able to monitor these changes in patients' situations because of the longitudinal aspect of the original study, in which patients received a questionnaire every three months. All patients provided informed consent.

Interviews

Semi-structured in-depth interviews were performed by one researcher (JH) at the patients' homes and lasted 1.5 – 2.5 hours. The aim of the interviews was to provide an in-depth perspective on personal experience with living with COPD. This was done by using open-ended questions that were guided by a topic list that contained, amongst other things, questions about activities in daily life. The interview process consisted of a repeated cycle of interviewing, transcribing, analysing and adjusting the topic list. The first question in every interview was: 'can you describe a normal day?' All interviews were audio-taped and fully transcribed.

Data-analysis

To familiarise with the research material²⁴, all transcripts were first read by the first author and a selection was read by MvZ. The analysis continued by structuring the material, in a deductive way, focussing on patient work. A software programme for analyzing qualitative data, MaxQda, was used for this purpose²⁵. The first analysis was done by the first author and checked by MvZ. Further steps in the analysis were discussed among all authors. After the first familiarisation phase, the analysis continued in an inductive way and focussed on how patients managed to live their daily life and on the problems they encounter in doing so. We identified situations in which patients did not succeed in keeping up their daily activities. We analysed these situations and compared them to situations in which patients did succeed in keeping up daily activities. Comparisons of these successful and unsuccessful situations led to the identification of enhancing and limiting factors.

Analysing these factors lead to the metaphor of athletics. From there, we worked backwards and described patient experiences in line with this metaphor which we used as our final analytical framework.

Analytical framework

Four categories can apply to athletics in general (loosely based on a tactical games approach²⁶): prerequisites, skilfulness, tactics and mentality. By using these categories as our analytical framework, we describe the skills that COPD patients need in order to be able to live with their illness. We describe these skills in analogy of the skills that are necessary for sports(wo)men to become successful in athletics.

Metaphor of athletics

It may seem awkward to compare patients in the end-stage of COPD to athletes, but living with advanced COPD is often described by patients themselves as a continuous struggle because getting enough air is extremely hard work for them. Besides, this is work that never stops. In athletics, sports(wo)men are keen to improve their skills in order to reach some kind of achievement. The nature of this achievement may differ according to the level of the sports(wo)man. For beginners, their goal may be to reach a higher level of playing, or entering a prestigious tournament. For professional athletes, the goal may be to win a gold medal at the Olympics. For patients with end-stage COPD, the goal they are trying to achieve is not to win a gold medal, nor to achieve something extraordinary. Mostly, their goal is to maintain a certain level of daily activities.

Respondent nr 30: *'I get by. Let's put it that way. But I wouldn't say that I have a fantastic life. Because I don't. They've just repaved the market square, but I haven't been out there to see it yet. Because I cannot get there, it's too far!'*

Interviewer: *'What would you consider to be a fantastic life?'*

Respondent: *'Well, if I could walk one kilometre. Just one kilometre, for the entire day. So that I could walk to the supermarket, or the pharmacist, and back. That's all I want. But I can't do it, I really can't. When I leave the house here, there's a bench on the next corner and when I get there, I really need to sit down. If I want to walk to the supermarket, I need to sit down four times before I get there! And that's not even a kilometre away.'*



Results

In total, 16 interviews with 11 patients were conducted by the first author (JH) during a period of 2 years (2004-2006). See Table 6.1 for patient characteristics and lung function.

Table 6.1. *Patient characteristics and lung function*

Patient number	Age	Sex	Marital status	Oxygen dependent	Number of inter-views	FEV1 L (% pred)	BMI
11	70	Male	Married	No	2	0.86 (28)	21
17	74	Male	Married	Yes	1	0.75 (29)	20
22	81	Female	Single	No	1	0.52 (27)	25
23	61	Female	Married	No	2	0.67 (29)	24
30	72	Male	Widowed	No	2	0.83 (25)	23
38	72	Female	Widowed	No	1	0.66 (30)	28
50	64	Male	Married	Yes	2	0.75 (23)	19
54	74	Male	Single	No	1	0.89 (28)	33
59	65	Male	Married	No	1	0.95 (29)	26
60	83	Male	Married	Yes	2	0.69 (22)	21
70	69	Male	Married	No	1	0.85 (28)	27

To be able to live with a slowly progressive disease like COPD requires a lot of practice, experience and perseverance. Adaptation to deteriorating health is an ongoing process that requires skills such as flexibility and creativity²³. Where athletes are trying to improve their achievements to become more successful in athletics, patients with end-stage COPD are trying to maintain their level of daily functioning despite their deteriorating health. In their case, the level of achievement they are trying to reach stays the same while the efforts they have to make in order to reach this same level will increase as their illness progresses. In both cases, the level of strain and effort increases over time. Table 6.2 summarises the key components of sports in athletics and COPD that we used in our analysis.

Table 6.2. Athletics and COPD compared

	Athletics	COPD
Prerequisites	A place to play sports, such as a tennis court or a swimming pool	Accessibility of public places, aids and appliances such as stair lift or parking places for the physically disabled
Skilfulness	Training to improve personal skills and to recognise own strengths and weaknesses	Training to improve breathing techniques and physical condition and to recognise exacerbations
Tactics	Identifying optimal training schedule in order to perform optimally at the right time	Setting appropriate goals and dosing energy
Mentality	To stay motivated, learning how to perform under pressure	Maintaining a positive attitude, developing perseverance and dealing with emotions

Prerequisites

An athlete needs some basic facilities, such as proper material and an appropriate location for playing that particular sport. Likewise, for a COPD patient, some basic conditions will have to be met in order for the patient to be able to live his or her everyday life. Because of their severe physical limitations, it is important for patients to have access to appropriate aids and appliances that enable them to maintain their daily life. Walking aids like a motorised wheelchair or a stair lift are basic facilities that may help patients to keep up their daily activities. Facilities that stimulate accessibility of public places like parking places for the physically disabled or public benches – like the ones respondent number 30 uses to go to the supermarket – are examples of prerequisites that a COPD patient in the end-stage needs in order to be able to conduct basic daily activities. Still, patients talk about how these prerequisites are not always available. Respondent number 59 talks about the parking problems he encounters at the hospital.

Respondent nr 59: *'I have a parking permit for the physically disabled. But still, at the hospital, there's never any parking space. Never'.*



These parking problems make it extremely difficult for him to get to his lung physician in time when he has to park his car further away from the entrance. However, by being creative, he has solved this problem himself.

'I rescheduled my appointments from winter to summer. Now, I have my annual appointment in June. That's much better because in June I can go to the hospital by moped, instead of by car. I can park it right outside the emergency room so I can walk from there to my lung physician in only one go.'

Skilfulness

To become successful in athletics, developing skills is most important. Most sports(women) begin playing their favourite sport out of interest in the game. If they want to improve their achievements, they will have to practise. Patients with end-stage COPD also need to develop skills in order to be able to improve their achievements. Patients learn to deal with their deteriorating health by trial and error. There is no one to teach them the necessary skills to overcome the limitations they encounter, caused by their symptoms. They develop their own expertise, like respondents 17 and 50.

Respondent nr 17: *'When I want to walk up the stairs, it takes me about 10 minutes. It's only 15 steps! When you (interviewer) would do it, it would only take you half a second. And my brain wants to do it more quickly too, because my brain knows it's only 15 steps. But if I do it more quickly, I get myself into trouble. Because then, when I get upstairs, I really cannot get any air at all. And that's terrifying! You know that, you learn that. So that's why I don't do it in 5 minutes, but I do it in 10'.*

Respondent nr 50: *'When I'm out of breath, I always sit in a particular way, like King Kong, with my arms spread wide open! That works for me, although I don't know if it will also work for someone else. But I have a lot of experience of course, and good results. I also do it in hospital, and sometimes I see other patients looking at me funnily'.*

Tactics

When the sports(woman) has achieved a certain level by developing technical skills, tactical decisions need to be made in order to be able to perform at the right time. A tailor made, optimal training schedule needs to be set up to ensure he or she will be in optimal

form at just the right time. The balance between training, strain, gain and focus is a delicate one. Likewise, in patients with end-stage COPD, developing technical skills is important, but not always enough to reach their goals. When patients have learnt the best way to catch their breath, this is usually only the first step in order to reach their goal, such as walking to the supermarket like respondent number 30. To be able to do that, tactical decisions need to be made, with regard to balancing training, strain, gain and focus. One of the most important tactical skills that patients need in reaching their goals, is to dose their energy in such a way that they can perform at just the right moment. If a desired goal is to walk to the supermarket, this goal will not be met if getting up in the morning and getting washed and dressed takes up so much energy that the patient is confined to a chair for the rest of the day. Respondent number 23 describes how she is so tired in the evening that she cannot attend the course she intended to follow.

Respondent nr 23: *'My husband is from Egypt. And I always had the intention to learn Arabic once I was retired. So I started an evening course, but I can't keep it up. In the evening, I'm just too tired. So I gave up that study'.*

Another aspect of tactical skills is to set appropriate goals. Sometimes, patients set goals for themselves that are not realistic given their physical condition. Patients may then end up frustrated and angry. Otherwise, patients may set goals that are too low. That way, they are least confronted with their limitations. However, this may result in a physical condition which is worse than it could be because of lack of exercise.

Frustration

Respondent nr 11: *'What I used to do in one day takes me two, three days now. Everything is different now. They don't have to ask me for help with anything, because every movement is difficult for me. Every movement takes space and time. If I move, it's impossible to repeat that movement right away. And that's hard. You have to learn to live with that, but that's really hard'.*

Respondent nr 30: *'I'm not worth anything anymore! I used to trade in old furniture, I went to houses when the people who had been living there had died and I would buy all the furniture. I would have three of those places empty in just one day. And now I am moving house myself, and it takes me three days just to pack a few boxes. That's my problem'.*



Low goals

Respondent nr 60: *'I feel that I gave up physical exercise too easily. I used to do some exercises on the treadmill and I still drove my car. But then, when I had to have oxygen 24 hours a day, it all became much more difficult. To go out with oxygen you know. I had to call the people I was visiting in advance to ask them to help me getting out of the car with my bottles of oxygen. So, I stopped doing that. But now, I feel that I have gotten worse sooner than I expected. For example, going to the toilet is a real challenge. And to get from here to the kitchen and back, that seems like a huge distance although it is only ten steps.'*

Mentality

When athletes have developed technical and tactical skills, and the prerequisites are met, another major influence in winning or losing the match is the mental component, which includes skills such as positive thinking, ambition and perseverance. Also for patients with end-stage COPD, the mental component is crucial in reaching the desired goal. It is important to maintain a positive attitude. Ambition and perseverance are important characteristics for achieving goals.

Respondent nr 38: *'There aren't many activities I had to give up because of my lungs, because I always keep on trying to do things. And sometimes I hit my nose while trying, but I always try first. Only if I really can't do something anymore, then I accept it and think "Well, that's too bad".'*

Respondent nr 30: *'I always cook my own food. Even when I've had a terrible day, I still do it! Because I think that eating healthy is very important. That's why I do it, despite everything'.*

Respondent nr 50: *'I always see the point in going on. Yes, sometimes all my energy is gone, that's true. But the next day I will be busy in building up new energy to do what I want. Because I want to leave the house with my wife, so I have to get new energy'.*

While patients report that they do have a positive outlook and do not give up easily, they also report about the fear that breathlessness induces, and which limits them in their daily activities.

Respondent nr 60: *'I hope to improve my condition so I can walk a bit further. But, you know, it is also often psychological. Because of fear, you know. When you get breathless somewhere, then you feel it every time you pass that same point. That's typical'.*

Discussion

As an answer to the first part of our research question, "To what extent can the concept of patient work be used in describing the palliative phase of COPD?", this study shows that living with end-stage COPD may be compared to sports(wo)men trying to improve their skills in athletics. First, prerequisites have to be met by means of accessibility of public places and the availability of appropriate aids and appliances. When these prerequisites are met, patients develop skills in technique, tactics and mentality in the same way sports(wo)men do.

Coaching

In which way can these findings be used to improve palliative care provision? Patients are able to develop many skills by themselves. However, just like sports(wo)man will never win a gold medal without the support of a coach – despite their own talent and ambition – COPD patients in the end-stage will never be able to reach their own goals and set other goals for themselves without proper guidance and support. A coaching approach would be beneficial for COPD patients in all four categories of our analytical framework.

First of all, a coach would be the appropriate person for a COPD patient to address problems in accessibility and other prerequisites for conducting daily activities.

Secondly, a coach could help patients in developing the right technical skills. The coach would have to be an expert in techniques that improve breathing and physical condition and provide targeted training. The coach could support patients in their own creativity to deal with symptoms, but could also act as the provider of information and knowledge about best practices for patients with less creativity or less understanding of how their own body reacts to the illness.

Thirdly, in tactics, one of the most important tasks of the COPD coach would be to design a tailor made training program to help the patients dosing their energy and to make sure the energy the patient puts into the training program results in maximal gain. The coach should also identify the personal possibilities of each patient, and support patients in choosing their goals appropriately. Most importantly, the coach needs to have a clear



vision of the overall picture in order to support and guide patients appropriately. This overall picture is essential to be able to initiate targeted interventions when necessary. In athletics, a coach can involve external help like a masseur to recover from a muscle injury. In COPD, the coach overlooking the overall picture can also initiate external help where appropriate, such as a physical therapist to improve physical condition or a dietician for dietary advice.

Fourthly, the last important task would be to encourage positive mental characteristics of patients and to address fear of breathlessness and other emotional aspects of the illness such as talking about death and dying. The importance of psychosocial care should in no way be underestimated in this group of patients, since a positive mentality can increase performance but the opposite can also occur.

In summary, the coaching approach we recommend is a holistic, multidisciplinary type of care. The COPD coach will be able to provide shoulder to shoulder care, supportive in nature. This is in line with the definition of palliative care by the World Health Organisation, including the emphasis on staying as active as possible until death¹⁹. The position of the coach – right next to the patient – enables a tailor-made approach. By introducing the coaching approach early in the disease trajectory, problems concerning the timing of the palliative phase and the prognosis of death become less relevant because the coach can modify the training programme to each individual patient from the onset of the illness onwards. This also has the advantage that patients learn proper skills early on in their illness trajectory so that loss of activity level and physical condition can be prevented as much as possible. The coaching approach can therefore be seen as a continuum for each COPD patient uniquely, which will fluctuate according to the patient's preference.

A well-known intervention in COPD care that also provides care in a holistic and multidisciplinary matter is pulmonary rehabilitation. Pulmonary rehabilitation programmes are proved to be effective in improving dyspnea, exercise tolerance, functional capacity and health-related quality of life, also in patients with advanced COPD^{27,28}. However, pulmonary rehabilitation is not a part of usual care and is therefore only accessible for a few COPD patients^{9,28}, despite international recommendations^{29,30}. Besides, these programmes have a fixed duration and sufficient follow up is usually not provided³¹. The coaching approach we recommend in this paper will therefore need to be integrated into regular general care.

This study provides a new perspective on the provision of palliative care in patients with end-stage COPD, building on the concept of 'patient work'³². Our study has a small sample of 16 interviews with 11 patients. Still, the sampling was done purposefully to ensure a variety in male and female patients, patients living alone and living with their partner, and patients with and without long-term oxygen therapy. Besides, we have no reason to assume that our sample is deviant from most COPD patients in the end-stage. Most importantly, the data we generated from these 11 patients proved to be rich enough to enable us to develop the fruitful concept of the COPD coach.

We are aware that not all patient experiences that we came across during the interviews, could be fitted into the metaphor of athletics. For example, patients often describe how they encounter difficulties in daily life because they suffer from an illness that is invisible to others²³. While this is an important aspect of the illness experience of patients with end-stage COPD, we could not fit it into our metaphor of athletics. Our aim however was not to develop a metaphor in order to describe all aspects of end-stage COPD, but to propose an alternative way of looking at health care provision for this group of patients. In conclusion, we believe that the image of a COPD coach is a powerful concept that can help to improve palliative care provision to the vulnerable group of end-stage COPD patients towards a more tailor-made, supportive and multidisciplinary type of care.



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