

**Accommodating to a troubled life – chronic obstructive pulmonary disease patients' experiences and perceptions of self-image during the course of rehabilitation**

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**Title: Accommodating to a Troubled Life - Chronic Obstructive Pulmonary Disease Patients' Experiences and Perceptions of Self-image During the Course of Rehabilitation**

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## **Abstract**

**Background:** To tailor future rehabilitation programmes for patients with chronic pulmonary obstructive disease, there is a need for more in-depth knowledge about what is essential to these patients and how they perceive their self-image while participating in rehabilitation. Therefore, this study aims to explore patients' experiences and perception of self-image during pulmonary rehabilitation.

**Methods:** Twenty-one patients were followed by participant observations during standard rehabilitation complicity supplemented with final individual interviews. Phenomenological-hermeneutic analysis and interpretation were applied.

**Results:** Through a rewarding peer fellowship, patients became engaged in rehabilitation and improved their capacity to embrace and manage their illness. Through a humorous interplay, encouragement to live with the life-threatening disease developed. While understanding themselves in a wider perspective, patients enhanced enablement to shape life according to personal satisfaction. Although participating in the group-based programme was mostly invigorating, it was, however, sometimes perceived as a stressful overload. More individualized support from healthcare professionals was warranted.

**Conclusions:** Group-based pulmonary rehabilitation can support chronic pulmonary obstructive disease patients towards significant change in self-image and health behaviour, leading to improved illness management. Enlarged opportunities to benefit from peer-fellowship and enhanced focus on what is essential to the participants might expand the rehabilitation yields.

**Keywords:** pulmonary rehabilitation, peer-fellowship, humour, participant observations, interviews, health behaviour.

## **Introduction**

The focus of this paper is to better understand the efforts that patients with chronic obstructive pulmonary disease (COPD) face when learning how to promote own health and well-being during a Danish standard pulmonary rehabilitation programme. It contributes new knowledge on how the self-image of COPD patients changes during the rehabilitation period, how the patients perceive their illness and experience the rehabilitation programme. The study is part of a larger research project, which aims to improve future rehabilitation to better address wishes, concerns and needs of COPD patients.

COPD is a heterogeneous, chronic disease associated with severe morbidity and mortality, and contributes to considerable personal and societal economic and social challenges (1). Since it is predicted that by 2030 COPD will be the third leading cause of death worldwide, there is a need for a global focus on continuously optimising COPD prevention, treatment, and management (1,2).

COPD significantly changes one's life and generates a need to adapt continuously to a fluctuating course of illness (3). Besides physical symptoms, exempli gratia dyspnoea, cough, fatigue, and functional limitations, patients report anxiety, depressed emotions and social isolation as a significant burden of living with COPD (3).

With an intent to motivate and empower patients to cope effectively with COPD, pulmonary rehabilitation is a recommended standard of care for patients with moderate to very severe COPD (1). According to the current consensus among experts within the area, comprehensive pulmonary rehabilitation programmes should include patient assessment, exercise training, smoking cessation, education and psychosocial support (4). Typically, pulmonary rehabilitation is offered to groups of patients by a multidisciplinary team. Hereby, combined expertise and group dynamics provide an appropriate platform for delivering comprehensive self-management interventions. The intention is to give patients the possibility to learn from healthcare professionals and fellow patients in a safe environment, allowing experimenting with new behavior and coping strategies (5,6).

Existing reviews have shown that pulmonary rehabilitation is capable of improving exercise tolerance and health-related quality of life, reduce perceived dyspnoea, anxiety and depression, and decrease the need for hospital admissions (7,8). Similarly, qualitative research investigating the patients' perspective, clearly suggests that engagement in pulmonary rehabilitation activities is invigorating (9,10). Besides these clinically relevant positive outcomes, there are also reported challenges mainly related to long-term effects and the patients' approach to the rehabilitation. For example, in a Norwegian qualitative study, it was noted to be a considerable challenge, up to a year after attending a programme, to maintain self-management, hope and trust in having proper support (10). Moreover, previous qualitative research has described potential challenges in how COPD patients' perceptions of illness influence adherence to treatment and other healthcare interventions, thus determining function and quality of life (11). Accordingly, it is shown that patients with clinically significant COPD and negative expectations are challenged in finding the motivation for self-management, understood as being able to maintain or obtain proper skills and behaviour to deal with their illness (12,13). It is also documented that patients who trust that they can affect their COPD positively, present better motivation and self-confidence (11,13). These findings highlight a need for elucidating new ways to improve pulmonary rehabilitation and the empowerment of COPD patients. Hence, it seems relevant to explore patients' view of themselves and their life with illness as it appears and changes during a programme of pulmonary rehabilitation. To examine further, this study will refer to the concept of self-image as it is described in a caring context. According to a group of Swedish researchers (14), patients' self-image is acknowledged as important for healthcare professionals to address in the context of palliative care. In this sense, self-image is understood as: *“a person's self-description [that] involves a picture of who the patient is and what is of central importance in his or her life (outlook on life and lifestyle)”* (14 page 156). Such focus on self-image is likely to be incorporated in the planning of pulmonary rehabilitation, to target the support in strengthening the management of life with COPD. Thus, the aim of this study was to explore COPD

patients' rehabilitation experience and perception of self-image during the course of pulmonary rehabilitation.

## **Methods**

The study adopted a qualitative design with a phenomenological-hermeneutic approach. Data were generated through ethnographic fieldwork by use of repeated participant observations and final in-depth interviews (15–18). Analysis and interpretation were applied with inspiration from the French Philosopher Paul Ricoeur's theory of narrative and interpretation (19,20).

### *Setting and Participants*

The study was conducted in a regional Danish hospital, (Slagelse Hospital) from August 2016 to March 2017. Inclusion criteria were: a doctor's diagnosis of COPD, a modified Medical Research Scale of dyspnoea  $\geq 2$ , referred by general practitioner or hospital physician for pulmonary rehabilitation, and fluent in Danish. In total, 27 patients were invited, and 21 patients (women:  $n=10$ ) accepted study participation. The remaining six patients declined due to lack of energy. The patients took part in an eight-week, standard rehabilitation programme (as Table 1 (21)) in three similar, but different groups. In some cases, close relatives participated in the sessions.

### **Insert Table 1 about here**

Table 2 presents information about the participating patients.

### **Insert Table 2 about here**

### *Data Generation*

The first author performed complementary participant observations with inspiration from Hammersley & Atkinson and Spradly (16,17,22) and in-depth interviews guided by the methods of Kvale and Fog (15,18), with the aim of thoroughly covering the patients' experiences of the

rehabilitation and their self-image while they participated in the rehabilitation. A bridled attitude, as described by Dahlberg & Dahlberg, was adopted (23,24). This meant that ‘actively waiting’ for the phenomena and their meanings to show themselves was strived. It included creating an elbow room that loosens up from intentional threads that tie the researcher to the world. Hereby a careful openness and scrutiny to thoroughly dwell upon the experiences expressed by the patients was carried out (23).

### *Participant Observations*

The participant observations ( $n=48$ ) occurred during the sessions of the rehabilitation programme. With the aim of exploring the context and activities during the sessions of rehabilitation and the patients’ experiences, observations ranging from full participation to full observation were performed (16,17,22). Occasionally, the observations included informal conversations with the patients. During the observation-period the researcher established a relationship to the patients that gave the chance to let them carefully open themselves to her in a trustful way. To ensure an accurate description, notes and quotations were made during the sessions and field notes were written immediately after (25). Statements from the randomly participating relatives were included to give nuances to the data. Continuously, thoughts, ideas and emerging interpretations, which gave directions to what should be focused on further, were noted down and considered (16).

### *Interviews*

Phenomenological-hermeneutically inspired interviews were held individually with the patients after their completion of the programme (15,18). The interviewer maintained the established open and trustful atmosphere and encouraged the patients to talk about *how they perceived their life with illness and what it had meant to participate in the rehabilitation programme*. To ensure the focus of the study, a semi-structured interview guide was applied. During the interviews, the patients were invited to elaborate on reactions or remarks that had occurred during the participant observations.

This allowed the interviewer to deepen her understanding of what was at stake for the participants. As preferred by the patients, the interviews were conducted either in a quiet room at the hospital ( $n=12$ ), in their private homes ( $n=6$ ) or by telephone ( $n=3$ ). The interviews lasted for approximately 20 to 60 minutes. They were recorded and transcribed verbatim within few days by the first author. In three interviews spouses participated in agreement with the patients. Their quotes were included to nuance the data.

### *Data Analysis and Interpretation*

The 141 pages of field notes and the 172 pages of transcribed interviews were gathered into one coherent text of 313 pages. The analysis and interpretation involved using what Ricoeur describes as a hermeneutic spiral by following the text and its movements from “*sense*” to “*reference*,” that is, from “*what the text says to what the text talks about*” (20 page 87-88). With constant movements between the whole of the text and its parts, the authors achieved what Ricoeur names a ‘sophisticated understanding’ (20). Such a sophisticated understanding provides a new in-depth and nuanced understanding of what it is like to be a COPD patient when taking part in a rehabilitation programme.

Table 3 illustrates the process of analysis by an example.

### **Insert Table 3 about here**

The authors gained a sophisticated understanding of the patients’ experiences by a dialectical movement between the following three levels:

Naïve reading: The first and the second author read the text as a whole, several times. This made it possible to grasp an initial understanding and establish an overall picture of the content.

Structural analysis: Units of meaning were extracted and put into play with the naïve understanding.

Hereby, it became possible to explain and understand the text further and to generate themes. To achieve the most trustworthy interpretation of the text, all authors contributed to this level.

Critical interpretation and discussion: The themes were interpreted and discussed, by all authors, with relevant theory and other research. To elaborate further on the patients' experiences and development during the rehabilitation programme, perspectives from the philosophy of Personalism were applied (26).

### *Ethical Considerations*

The Ethical Committee (Journal Number: SJ-559) and the Danish Data Supervisory Committee by Region Zealand (REG-071-2016) approved the study. The patients received oral and written information about the study and were given some days at home before informed consent was obtained. They were informed that participation was voluntary, that data would be kept confidential and that anonymity was guaranteed. It was, furthermore, ensured that the patients understood that they could withdraw from the study at all times without adverse complications for their care (27).

### **Results**

The naïve reading indicated that an ongoing change in self-image occurred for COPD patients during rehabilitation. When following the rehabilitation programme, the patients apparently found themselves in a rewarding setting where they were able to achieve a new understanding of their illness. They seemed to mirror their own world in the peers' world and thereby to broaden their own horizons. In the interplay with healthcare professionals, it seemed essential to receive individualized support.

Based on the structural analysis, three themes were derived: "Getting the chance to join a rewarding fellowship," "Grasping the grave with a light tone," *and* "Being invited respectfully to embrace personal challenges." The themes are presented in the following. Citations are referred to in accordance with the indications in Table 2.

### *Getting the Chance to Join a rewarding Fellowship*

Few days before the rehabilitation programme started, the patients were invited together with their close relatives in two separate groups, to perform tests and attend individual consultations with the healthcare professionals. Here they were briefly welcomed in a short, shared session in the waiting room. Afterward, they had the opportunity to have informal conversations with each other when in between consultations and tests they were waiting together. It was observed that the patients paid respectful interest in each other during this phase. They often shared questions regarding the plan for the rehabilitation and worked together on figuring it all out. Some also had conversations about their experiences of living with COPD.

When the sessions of exercise started, the participants were all formally introduced to each other by name calls from the physiotherapist. They learned to know one another's names because they played name games in one or two of the first sessions. It was observed that their relationship developed fast during the first weeks. With civility, and in between conversations about common subjects, the patients increasingly shared experiences about their illness. It was notable how in the waiting room and during breaks, they particularly opened up to one another. It was clear that meeting fellow patients with a similar illness and challenges was of considerable importance.

The patients expressed that they felt included in a rewarding fellowship that made the rehabilitation work as a sanctuary for them. Even though this sanctuary included being confronted with both physical and mental hard work, it had a significant positive impact and was valued in several ways. Predominantly, the patients emphasized the support from other participants, as one male said, after completing the rehabilitation: *“One gets that sense of fellowship out of the exercise, which makes you want to carry on”* (P4<sub>SPR</sub>). The statement highlights, in line with observations and other statements, a remarkably beneficial impact which the group dynamic had because it encouraged the patients to put an effort into the exercises and continue participating in the rehabilitation.

Also, observations and statements indicate that the peer fellowship was experienced to improve the ability to embrace life with the illness. Subsequently to the rehabilitation a male patient highlighted the cohesion in the relationship as rewarding: *“We have become one large family”* (P7<sub>SPR</sub>). This quotation points to the kind of connectedness as given in a good family. In a conspicuous way, the patients developed these family-like feelings, which made space for an edifying kind of intimacy. In this intimacy, the patients had a chance to reflect on how to form and shape their lives striving for their own personal satisfaction. As one patient stated:

*“I have learned that when I work to improve my physical condition, I gain more joy and well-being in everyday life. Therefore I now want to fight with the exercises to improve my health as long as possible”* (P21<sub>SPR</sub>).

Furthermore, the patients ascribed significance to the opportunity to make new acquaintances. A patient spoke about how the COPD had forced him into too early retirement. He missed his former colleagues and expressed a sense of emptiness. After having completed the programme, he said: *“It has been a relief to meet some new people.”* (P11<sub>SPR</sub>). Such sense of relief reflects the significance of being released from a burden of loneliness. The patients expressed that this provided them with a calmness which made life easier to bear.

Being together with peers made the patients compare themselves and thereby achieve an improved understanding of their own situation. This came into expression in their recalls about how it had been an eye-opener for them to observe and share their thoughts with peers. As one patient said:

*“I have discovered that there are others who feel in the same way. We walk around in our own little world. Suddenly, I come down here and see that I wasn’t that bad in relation to some of the others”* (P1<sub>SPR</sub>).

The quotation illustrates that the patients mirrored themselves and thereby came to look upon their own lives in a new and brighter light. Hence, they were enabled to reflect their own world in a

greater and free perspective discovering new ways to tackle the illness. It could, however, also be discouraging to see how others suffered from the illness because it made the patients worried about their own future.

Thus, typically, the fellowship meant that patients became enlightened and encouraged through the rehabilitation in ways that liberated them and made it possible for them to realise their capacity and prioritise what gave them better satisfaction in everyday life. Less typically, being together with peers was perceived as overwhelming. It is noteworthy how in some cases the patients withdrew from the fellowship because it seemed too congestive for them. First, examples from the sessions reflect that in some cases being together was experienced as too 'stressful' when the patients experienced dyspnea or felt tired. Next, a desire not to expose oneself in front of others emerged as another challenge. At last, blaming oneself for the illness meant for some patients that they did not feel entitled to ask for help. Midway during the rehabilitation this was stated by one patient this way:

*"I prefer not to show anyone when I feel unwell, because I fear frightening them. Asking for help sometimes embarrasses me because I blame myself for being sick"*(FN<sub>2</sub>,P16<sub>SPR</sub>).

These aspects included to some extent obstacles to full engagement in the rewarding fellowship.

### *Grasping the Grave in Life With a Light Tone*

The patients shared the challenging and grave troubles in living with the disease but clearly with an increasing use of a light tone. A female patient remembered it in this way: *"It was funny, enjoyable and also a bit serious because we are going there with a serious intent. However, it makes a difference that it becomes a bit of fun – and it did"* (P18<sub>SPR</sub>). The statement covers how the gravity was grasped well by making use of a light tone. This made their time together dominantly a cozy time with moments of pleasure and well-being. Spontaneous rise of fun and a relatable note of

humour developed in the interplay among the patients during the sessions of rehabilitation. In various situations, amusing friendly comments became sources of smiles and contagious laughter. As an example, humour appeared as releasing, when serious situations from the exercise were turned upside down. Such an episode took place in the waiting room one day before an exercise session in the fourth week of rehabilitation. Here it was observed that the patients discussed what activities to expect from the exercise of the day. After a bit of silence, one of the patients pursed her lips and proposed:

*“Probably, we have to kiss!”* This makes them all begin to make a pursed lip breathing. They laugh while demonstrating how they are going to ‘kiss.’ Thereby, they indicate that they actually expect that they have to practice the pursed lip breathing technique“ (FN<sub>3</sub>).

The way in which humour appeared, in this case, shows that it contributed to an unrestrained and relaxed atmosphere. Moreover, it indicates a surplus of energy to make amusement of a joint challenge in learning how to improve their breathing. In line with other observations and statements, this humoristic tone had a positive impact on the sanctuary that the rehabilitation was to the patients. In this case, humour and laughter helped the patients while learning to tackle the difficulties in managing the illness and practicing health promoting activities.

Gradually, when amusement unfolded more spontaneously, the patients appeared to act more freely and better capable of accommodating to their troubles. In that sense, humour functioned as a kind of buffer, which reduced both tensions and distress and made the patients more capable of managing what challenged them regarding the COPD. In the final interviews, the patients also mentioned that the nice atmosphere had been conducive to their engagement and benefits from the programme. Furthermore, the light tone meant that they often felt encouraged and light-hearted when they

returned home after the rehabilitation. A matter, which their relatives also expressed to acknowledge and appreciate.

The overall picture was that humour worked as a source to a joint feeling of joy but also as a kind of a shield, which, as the patients expressed, sheltered them from the grave and supported them to embrace the troubled life with COPD.

### *Being Invited Respectfully to Embrace Personal Challenges*

Throughout the exercise and education, it was clear that the patients received crucial encouragement from the healthcare professionals. It turned out to support them in recognising their potential and problems and to improve their ability to prioritise. This provided them with what they saw to be valuable support leading to growth in skills and knowledge.

Regarding the sessions of education, some of the patients found it as an inspirational input to watch a film about life with COPD followed up by a talk with a nurse about what had touched and been thought-provoking. One of the patients reflected on how the film had given her concrete instruction and made her less worried: *“The film was good... my anxiety decreased when we watched that film. It had reassured me to see the help they got in getting oxygen and so on”* (P16<sub>SPR</sub>). The statement indicates that being shown how others are treated contributed to feelings of calm and faith in help. Moreover, it illustrates that the film and follow-up talk with the nurse engaged the patients and moved them to broaden their horizons.

In the participant observations, the patients clearly expressed that it was a great satisfaction for them to get the opportunity to recognise and learn how to deal with their daily obstacles. In the sessions with the occupational therapist, the main focus was on practicing energy conservation techniques. There were introductory conversations about what challenged the patients in everyday life.

Following, they were asked to consider what was hard for them to manage in their daily life, and consider how to manage this in better ways was assigned as a homework task. In a noteworthy way,

the patients became aware of the importance of slowing down and enduring daily activities with respect to their breath and energy. In an interview after the rehabilitation programme, a patient spoke about the conversations with the occupational therapists in the following way: *“They talk about what to do if you become breathless. It comes all by itself. You sit down and you lie down if needed. Accordingly, you split up your work...it comes all by itself (P6<sub>SPR</sub>).”* The quotation points to a recognition of the need to change habits and to slow down as something obvious in a life with COPD. However, the observations and interviews covered that it was a challenging process in itself for the patients to learn to realise their everyday efforts and to reflect on how the illness could be tackled in better ways.

It was notable that the patients experienced that their benefits of the rehabilitation depended on the time given and the applicability. If for example parts of the programme did not meet their wants, it could be experienced as a waste of time and that it had bothered them unnecessarily. Moreover, a great source of dissatisfaction and discouragement was, if the instructions were perceived to be too general and they thereby did not get the help they asked for. This was the case when the joint sessions of education regarding issues such as the medication or diets were not supplemented with individual explanations and support. As one example a female patient told about her difficulties in getting concrete enough instructions to tackle her troubles with overweight in this way: *“I have stopped smoking and put on 10 kg in weight... it should be healthy, but now I have to struggle with this and I could indeed have needed the dietician more” (P7<sub>SPR</sub>).* The expression illustrates an unfulfilled desire for more applicable help. This related to a feeling of being only superficially supported to deal with a substantial challenge in the cessation of smoking. It reflects that the patients longed for a more in-depth focus on their own personal challenges. Moreover, it indicates that the patients had a natural want for being more fully involved and respected as the person you are. This was important to them in their efforts to be able to understand how to embrace their life with COPD.

The patients were accordingly offered important support to acknowledge the symptoms of the illness and to both embrace and manage this. However, they clearly needed more individualized supervision.

## **Discussion**

The study showed that the time during the rehabilitation included a remarkable change in self-image. The rehabilitation became an edifying sanctuary where COPD patients had the opportunity to improve their capacity to accommodate to a troubled life with illness. Mainly, the patients found the group-based programme to be invigorating. However, it was also to some extent challenging to engage and fully benefit from the rehabilitation.

### *The opportunity to broaden personal engagement and learn from fellow patients*

First and foremost the results of this study point to the significance of COPD patients being given a chance to become a member of a rewarding peer fellowship in rehabilitation. The rewarding element became evident in the motivation and capacity which the patients evolved during the rehabilitation. This can be understood through the philosophical and political thinking of personalism as it is presented by the Danish scientist Jonas Nørgaard Mortensen (26). According to the thoughts behind personalism, human beings are relational and need a close and engaged interplay with their fellow human beings in order to thrive and to fulfill their potential, by means of better understanding their individual needs and capacity. This capacity is realised by freely taking responsibility for ourselves and for others (26). Seen in the light of these thoughts, it seems that one novel attribution of the illuminated rewarding peer-fellowship can be that it holds an important help and support for COPD patients in order to raise their capacity to take more responsibility for their own life with the illness.

Another novel result in our study showed that by mirroring each other, the patients found help to develop a wider view of their own world and thereby became able better to embrace their life with illness. They also came to better understand their illness and recognise health-promoting activities as leading to improved well-being. Thus, by engaging themselves in a fellowship, the patients were able to more engaged participate in rehabilitation and learn from the others in an invigorating way. Their horizon broadened and they became able to find new potentials for moving towards greater levels of satisfaction and individual fulfilment in life. Hence, this study underlines that in rehabilitation peer fellowship, COPD patients can achieve a significant change in self-image that includes the ability to find sustainable motivation for health-promotion and management of the illness.

In this study, it was evident that the way in which the patients connected with new people made them obtain a sense of support and a relief of being able to get rid of unpleasant feelings of loneliness. In the same way, Hogg et al. (28) laid bare that patients in an English pulmonary rehabilitation programme valued support from a peer group as it helped them to reduce feelings of isolation. In our study, it was also made clear that the opportunity to share personal experiences and thoughts with peers was perceived encouraging in a way that made life easier to bear. The Norwegian researchers Halding et al. (29) described that participation in a pulmonary rehabilitation programme provided a sense of belonging, which the patients evolved through dialogue, shared understanding and fellowship. This underpins that a shared understanding achieved in a mutual dialogue between peers may facilitate feelings of belonging and thereby contribute to taking the edge off the many illness-related troubles. A third novel finding in the present study is that the COPD patients, by the peer fellowship, found motivation for keeping attendance to the rehabilitation and the surplus of energy to engagedly work on the management of breathing techniques and other exercises.

A fourth novel finding is that the fellowship between peers is illustrated to be associated with a family-like closeness, including a room for reflections on how to form and shape their lives. The elucidation of such a family-like fellowship, may be considered a new contribution to the previous research investigating the significance of peer support within the context of pulmonary rehabilitation. Both Hogg et al. (28) and Halding et al. (29) demonstrated that the fellowship among peers contributed to how the patients found support to build up confidence. In Hogg et al.'s (28) research, confidence was shown to be an important determinant of physical activity. Furthermore, Halding et al. (29) pointed to increased self-confidence along with motivation for self-care, further social participation and trust in the healthcare system as related to the sense of belonging. This illustrates that a close commonality with peers can involve the development of a strengthened belief in being able successfully to cope with the many troubles of COPD. In this light we provide a significant contribution by underlining that when patients are given a room that provides them with the confidence and courage to look at the way they live their lives and reflect critically on this, it supports them to find new ways to prioritise.

As Birkelund and Larsen showed, a caring and sharing fellowship may develop among hospitalized patients. The study illustrated that when the patients cared for each other and shared information with each other, they prepared the ground for self-care (30). In this light, the ways in which the rewarding peer fellowship is found to be among the COPD patients in the rehabilitation may open up for increased self-care in a rehabilitating setting.

### *The Role of Humour*

Moreover, of novel interest the study showed that during the programme of rehabilitation the patients developed a light and humorous tone that made it easier to grasp the grave elements in their life with COPD. This became visible in how humoristic comments, jokes or laughter made the approach to the difficulties of the illness better. Moreover, it made overcoming the obstacles of

being capable of enduring health-promoting activities easier for the patients. This is in keeping with a recently published Scandinavian study of COPD-patients' self-mangement after hospitalization due to exacerbation, which indicates that the patients struggle with a feeling of hopelessness which is replaced with hope when participating in group-based pulmonary rehabilitation (31). However, the present study sheds new light on how such hope can be anticipated to draw from the humorous milieu in the rehabilitation. First it is shown to provide a surplus of energy during rehabilitation and second it is illustrated to bring a light-hearted tone which the patients benefitted from both in and after rehabilitation, when returning home. This illuminates how significant mental support is provided to the patients not only within but also beyond rehabilitation.

In accordance with other research, the patients emphasized the importance of keeping a sense of humour. Halding et. al revealed likewise that an informal and cheerful atmosphere was facilitating engagement, equal participation, and communication between the participants (29). According to Birkelund and Larsen, the humourous interaction between hospitalized patients appeared as uplifting and life-affirming. Besides, it became a way to diminish anxiety briefly and to give a break from thinking about the illness (30). In line with this, the rise of humour among the patients in the sanctuary of pulmonary rehabilitation can be a source of joy and at the same time act as a shield to serious thoughts, at least for a while.

### *The Troubles of Participation*

In our study, it was not in all cases possible for the patients to participate full-hearted and benefit fully from the rehabilitation. Occasionally, the patients did not manage to be a part of a group, which made full participation difficult. In the research by Halding et al., they noted that different obstacles could appear as a hindrance to obtain a feeling of belonging (29). In addition to our findings, challenges in belonging were linked to different needs, mistrust, or of being intimidated by dominating group members (29). Moreover, this study illustrates that self-blame could keep the patients away from the help they needed. In the context of the pulmonary rehabilitation, self-blame

and stigmatization related to smoking were reported as a key cause of social isolation in COPD patients. Because of the self-inflicted aspect of the illness, patients could believe that they were not worthy of treatments which might improve coping with their condition (32). Thus, the challenges for the patients identified in this study, concerning engaging in rehabilitation, are multifaceted and may leave them without the support which could help them to improve managing life with the illness.

### *The Demand for Individual Support*

The present study sheds light on the importance of being invited respectfully by the healthcare professionals to feel enlightened and empowered to engage in activities during the programme and afterwards at home. As well as the patients felt well-supported in their efforts to learn and develop their skills to manage the illness, they also expressed feelings, reflecting a longing for a more individualized in-depth focus. Returning to the thinking of personalism, it claims that human beings possess an inherent dignity, which fellow human beings and society must not oppress or violate. Hence, within the thinking of personalism it is found crucial that in order to be helpful, institutions and systems must support persons to unfold their lives (26). Based on this point of view, institutions should be organized in a way in which the individual person has the largest possible influence on the decisions which they are involved in (26). In agreement with this, the global guidelines within the area of COPD recommend such a person-centered vision to guide the implementation of education and self-management interventions (1). According to the global guidelines, healthcare professionals must encounter the patients with respect to individual needs, preferences, and goals (5). As a part of that, the official goal for healthcare professionals is to motivate, engage and coach the patients to positively adapt their health behavior and develop their skills to manage their illness better (5). A result of expanded focus on individual needs and enlarged opportunities of participating in rehabilitation peer- fellowship can be expected to be improved well-being and satisfaction in everyday life for the COPD patients.

### *Methodological Considerations*

It might be considered a limitation that the study was based in a single hospital, because the protocols of rehabilitation may differ between institutions. However, it is supposed to have provided diversity to the study that the participants were included from three separate rehabilitation groups. The bridled attitude used in the data generation allowed the researcher to carefully sense and thoroughly dwell upon the meaning of the patients' experiences so no slovenly understandings were taken (23,24). Accordingly, combining participant observations and interviews have facilitated rich and nuanced data of what it is like to be a patient over the time span of the rehabilitation. Furthermore, this combination of methods provides a basis to establish a close relationship between the researcher and the participants, allowing for access to more in-depth data. (33). Not only did the data material allow interpretation based on data triangulation, it also made validation within observations and interviews possible (33). Nevertheless, the limited time period can be considered a weakness in the study. An extended period might have supplemented the study with valuable knowledge about the patients' change in self-image after the rehabilitation (34). Moreover, data about the socio-economic status of the participants could have enhanced the contextualization of the findings since the occurrence of COPD is highly associated with low strata (35), and the development of poorer clinical prognostic data is also associated with low socio-economic status in a Danish context (36).

The inherent validation in the three-leveled analysis and interpretation is considered a strength of the study. According to Ricoeur (20), there is always more than one interpretation of a text, but not all are equally probable. To qualify this process, the first and second author took part in all the levels of the process. Throughout the process, the authors sought to remain open-minded to the text and to reflect critically on each other's interpretation. Hereby, all the authors contributed to the presentation of the most trustworthy results.

## *Conclusions*

This study contributes with new knowledge on how COPD patients can experience a beneficial change in self-image during rehabilitation. A special rewarding peer-fellowship raises the patients' capacity and responsibility to engage in improving managing life with COPD. When the patients take advantage of the opportunity to learn from the encouraging rehabilitation milieu with peer fellowship and healthcare professionals, they can be enabled to broaden their horizons and improve their capacity to embrace life with COPD. Furthermore, group-based rehabilitation enhances motivation for attendance and an expanded willingness for working on the given advice. Hereby they are well-supported to better prioritize and unfold their potential in ways that can lead to improved well-being and satisfaction in everyday life. Thus, the mechanisms and importance of group-based pulmonary rehabilitation are better illuminated. However, such a fellowship-based programme includes obstacles by not being attractive or sufficient in every way. Patients request to be supported more closely with respect to individual needs and challenges. It is crucial to respect the inherent dignity of each patient by targeting the individual needs, preferences and goals. To develop future rehabilitation programmes that are likely to be more applicable to COPD patients, it could be fruitful if the healthcare professionals improve to accommodate the troubled life that each individual patient is in need of accommodating to. Moreover, enlarged possibilities of being a part of a rewarding peer-fellowship might add further potentials to pulmonary rehabilitation.

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**Table 1. Outline of the local standard pulmonary rehabilitation programme**

10-12 patients are enrolled in the COPD-teams, typically within 4 weeks after discharge from the hospital, if they have been admitted to the department of lung medicine or as part of an offer from the pulmonary outpatient clinic. A few days before the start they are invited to an introduction, at the hospital, where they perform start tests and have individual consultations with physiotherapist, nurse, dietician and occupational therapist. On this day they give consent to participating in the programme.

The 8-week programme takes place in the hospital. It consists of 16 physiotherapist-guided exercises for one hour twice a week and 8 occupational therapist-guided exercise sessions for 30 minutes. Furthermore, two 3-hours sessions of psychosocial education content are offered.

The patients can bring their closest relatives to take part in these sessions.

| <b>Content</b>                 | <b>Elements</b>  |
|--------------------------------|--|
| <b>Exercise-based sessions</b> | <p>Each exercise session consists of 10-15 minutes of warm-up activities followed by varied strength and endurance exercises. The exercises consist of e.g. cycling, Nordic walking, ball and elastic exercises.</p> <p>The patients are instructed by the physiotherapist during the exercises either group-based or individually.</p> <p>Each session ends with 5-10 minutes of warm-down with relaxation and stretching exercises. The patients often ask the physiotherapist questions about their illness during this part of the session.</p> <p>Every second week the exercising activities also include a session with the occupational therapist.</p>   |
| <b>Education sessions</b>      | <p><u>1<sup>st</sup> session was held in week 1:</u></p> <p><b>12 pm - 14 pm</b> – by a nurse<br/>Physiological and anatomical factors related to COPD and psychosocial reactions.</p> <p><b>14 pm - 15 pm:</b> - by an occupational therapist<br/>Strategies in order to prevent or minimize respiratory stress during activities.</p> <p><u>2<sup>nd</sup> session was held in week 3:</u></p> <p><b>12 pm -13 pm:</b> - by a nurse<br/>Medicine and inhalation techniques</p> <p><b>13 pm -14 pm:</b> - by a physiotherapist<br/>Exercise principles and respiratory techniques exempli gratia positive expiratory pressure (PEP), Pursed Lip Breathing (PLB), coughing techniques and how to manage the symptoms and become physically active in daily life.</p> <p><b>14 pm -15 pm:</b> - by a dietitian<br/>Nutrition and risk factors related to COPD.</p> <p>The patients are offered individual consultations with the healthcare professionals if deemed relevant.</p> |

The programme is planned according to the Danish National Guidelines for pulmonary Rehabilitation (21). It is free of charge to the patients, and if needed, transport to the hospital is arranged without costs.

**Table 2. Characteristics of the participating patients**

| Participant      | Gender | Age (years) | Married or cohabiting | mMRC (score) | FEV <sub>1</sub> (% predicted) | Group*: | Relatives co-participation                                       |
|------------------|--------|-------------|-----------------------|--------------|--------------------------------|---------|--|
| <b>P1</b> (SPR)  | M      | 78          | +                     | 3            | 25                             | 2       | + wife in interview  |
| <b>P2</b> (SPR)  | M      | 84          | +                     | 3            | 45                             | 3       | + wife in the part of exercise sessions                          |
| <b>P3</b> (SPR)  | W      | 76          | +                     | 3            | 45                             | 3       | + husband in educational session                                 |
| <b>P4</b> (SPR)  | M      | 71          | %                     | 3            | 61                             | 1       | %  |
| <b>P5</b> (SPR)  | W      | 64          | %                     | 3            | 47                             | 2       | %  |
| <b>P6</b> (SPR)  | W      | 75          | +                     | 2            | 81                             | 2       | + husband in educational session                                 |
| <b>P7</b> (SPR)  | W      | 65          | %                     | 1            | 46                             | 2       | %  |
| <b>P8</b> (SPR)  | M      | 71          | %                     | 3            | 39                             | 3       | %  |
| <b>P9</b> (SPR)  | M      | 59          | +                     | 3            | 26                             | 3       | + wife in educational session                                    |
| <b>P10</b> (SPR) | W      | 80          | %                     | 0            | 41                             | 1       | %  |
| <b>P11</b> (SPR) | M      | 64          | +                     | 3            | 46                             | 2       | %  |
| <b>P12</b> (SPR) | M      | 82          | +                     | 2            | 30                             | 3       | + wife in educational session                                    |
| <b>P13</b> (SPR) | M      | 82          | +                     | 3            | 33                             | 3       | + wife in interview and part of exercise and educational session |
| <b>P14</b> (SPR) | M      | 65          | %                     | 2            | 32                             | 3       | %  |
| <b>P15</b> (SPR) | M      | 71          | +                     | 2            | 42                             | 3       | + wife in interview and educational session                      |
| <b>P16</b> (SPR) | W      | 71          | %                     | 4            | 79                             | 2       | %  |
| <b>P17</b> (SPR) | W      | 57          | +                     | 0            | 43                             | 1       | %  |
| <b>P18</b> (SPR) | W      | 71          | %                     | 2            | 65                             | 2       | %  |
| <b>P19</b> (SPR) | W      | 70          | +                     | 4            | 34                             | 2       | %  |
| <b>P20</b> (SPR) | M      | 80          | +                     | 3            | 48                             | 3       | %  |
| <b>P21</b> (SPR) | W      | 55          | +                     | 2            | 66                             | 1       | %  |

M: male; F: female; mMRC: modified Medical Research Council dyspnea scale; FEV<sub>1</sub>: Forced expiratory volume in 1 second.

The patients from the standard pulmonary rehabilitation (SPR) were assigned codes such as P1<sub>(SPR)</sub> in alphabetical order.

\* Indicates which rehabilitation group the participant belonged to:

*Group 1* took place from August 15<sup>th</sup>, 2016 to October 6<sup>th</sup>, 2016, titled FN<sub>1</sub>.

*Group 2* took place from October 11<sup>th</sup>, 2016 to December 19<sup>th</sup>, 2016, titled FN<sub>2</sub>.

The attendance to the rehabilitation was overall 4 out of 5 times. All the participants maintained participation in the rehabilitation programme.

At random occasions some participants brought their close relatives.

**Table 3. An example of the structural analysis**

**A part of the structural analysis regarding the finding: Grasping the grave with a light tone during pulmonary rehabilitation**

| <b>Units of meaning:</b><br>“What is said/what is observed”    | <b>Units of significance:</b><br>“What is being talked about/what is the observation about”    | <b>Theme:</b>                        |
|---|---|--------------------------------------|
| <b>Selected quotations:</b><br><i>It was funny, enjoyable and also a bit serious because we are going there with a serious intent. However, it makes a difference that it becomes a bit of fun – and it did,” (P18<sub>SPR</sub>).</i><br><br><i>“When you have to be together with others, it is essential that you are actually able to be together, talk with each other and tease each other a little bit. Without crossing the line,” (P15<sub>SPR</sub>).</i><br><br><i>“There has to be some fun..he, he...now take him [name of a fellow patient]. He was 2 minutes late for the session and I teased him a bit,” (P20<sub>SPR</sub>).</i><br><br><b>“Probably, we have to kiss!’ This makes them all begin to make pursed lip breathing. They begin to laugh and demonstrate how they are going to “kiss.” Thereby, they indicate that they actually expect that they have to practice the pursed lip breathing technique,“ (FN<sub>3</sub>)</b> | The patients worked hard to improve their knowledge, skills and understanding during the sessions of exercise and education. The time together with their fellow patients made space for fun and moments of pleasure. However, behind the fun, there lied a gravity, which was grasped well by use of a light tone between them.<br><br>After a while, they made amusing comments and teased each other in a friendly way. Between them, there could develop a surplus of energy to make spontaneous amusement of difficult practices and to turn the situation upside down. This contributed to an unrestrained and relaxed atmosphere in which they became freer to unfold themselves. Furthermore, this meant that they felt light-hearted for a longer time after having attended the sessions. Thus, spontaneous humour brought common and personal joy. At the same time, humour sheltered and supported the patients to embrace the troubled life with COPD. | Grasping the grave with a light tone |

Guided by the Ricoeur inspired method developed by Pedersen (37) the text was structured and explained by units of meaning and units of significance. On the basis of these units themes were identified though interpretation. The arrows indicate that the process of structuring the units of meaning and units of significance and themes can be characterized as dialectical.