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Telemediated Training in the Home as a Part of the Everyday Life and Practice With Very Severe Chronic Obstructive Pulmonary Disease

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Abstract

Patients with very severe chronic obstructive pulmonary disease (COPD) conduct their everyday lives under shortness of breath. Aim of the study was to explore telemediated exercise training to patients at home, with the conduct of everyday life as theoretical framework. Based on ethnographic fieldwork involving a hospital, two municipalities, and homes of eleven patients from 2013-2017, this article shows how telemediated training became part of patients' and partners' everyday lives and the prioritization of time and resources for basic activities. Most of the patients found telemediated training meaningful, that it can work as an agent of hope in holding on to essential everyday life activities, but also that it may be experienced as burdensome and disciplining. The physiotherapists' understanding of the patients' circumstances and needs for rehabilitation changed. The article argues that telemediated training should be offered as part of a palliative approach for those severely affected by COPD.

Introduction

Chronic obstructive pulmonary disease (COPD) is a common, worldwide, chronic disease causing morbidity and mortality, and has a substantial negative impact on people's level of physical activity (Miravittles & Ribera, 2017). Very severe COPD is the last stage prior to death, and conducting everyday life at this stage is continuously challenging and progressive. Patients experience a debilitating shortness of breath that increases over time, causing, among multiple effects, productive coughing, recurrent chest infections, fatigue and muscle wasting (McCarthy et al., 2015). This leads to loss of daily activities related to personal preferences, plans, and dreams (Dunger et al., 2015; Ek, Sahlberg-Blom, Andershed, & Ternstedt, 2011). The very severe breathlessness slows down the pace of everyday activity. Even routine tasks, like getting up, dressing, and eating breakfast may take several hours including time for breaks, resting, or simply pausing to catch one's breath. To maintain workable everyday routines, patients need to continually adapt to their declining physical condition, by developing new strategies to manage and stay in control. Fighting distress and resignation is a real challenge for the patients. As the illness slowly progresses over many years, living with very severe shortness of breath comes to be experienced as a *way of life*, by patients, their partners and health professionals (Pinnock et al., 2011). Pulmonary rehabilitation (PR) involving exercise training is important for patients with COPD as it strengthens the muscles, increases the ability to carry out activities in everyday life, and is recognized as 'good clinical practice' (S. Bernard et al., 1999; Rabe, 2007; The Danish Health Authority, 2018). It has also been found that PR nurtures hope for a future with opportunities and well-being in circumstances where patients tend towards a fatalistic view on what is to come (Halding & Heggdal, 2012). Clinical moments that "allow hope for healing even in the face of a grim clinical prognosis" can qualify as "healing dramas" (Mattingly, 2010), which could be training that is meaningful in the context of the everyday life. A meta-ethnography showed that, when physi-

cal capabilities decrease, patients try to remain active within their boundaries with help from others or by participating in PR (Lindenmeyer, Greenfield, Greenfield, & Jolly, 2017). Yet, patients with very severe COPD often have to decline PR, because the journey to the rehabilitation unit is too exhausting (Rosenbek Minet et al., 2015). This means that PR is less accessible to this group.

To overcome the barrier of accessibility, home-based telemediated exercise training has been developed as an alternative to PR and offered to patients with COPD at rehabilitation units situated in the hospitals. Research into these services has focused on the effectiveness of the exercise training (Bourne et al., 2017; Rosenbek Minet et al., 2015; Vasilopoulou et al., 2017) and on patient satisfaction (Rosenbek Minet et al., 2015; Tsai et al., 2016). Less attention has been devoted to exploring the complexity of introducing a telemediated training technology; for example, exploring users' experiences and perspectives (patients with COPD, informal caregivers and health professionals), and how the technology becomes or does not become a part of everyday life. This is despite the fact that the general political aims of introducing telehealth technologies into services for patients with COPD have been to support independent living and reduce health care costs (Brunton, Bower, & Sanders, 2015). Nelly Oudshoorn (Oudshoorn, 2012) has explored how places where monitoring technology is situated, influence patients with COPD and Jeannette Pols (Pols, 2011, 2012) what can characterize the practice in videoconferencing for patients with COPD, asthma and heart failure. Another study has taken a closer look at how patients with very severe COPD come to understand, make use of, and integrate self-monitored readings into their conduct of everyday life while participating in a telemediated rehabilitation program (Hunniche, Dinesen, Nielsen, Grann, & Toft, 2013). The mentioned studies explore teleconsultations and not teletraining which are two different practices. To our knowledge, the question of how home-based tele-

mediated training becomes part of patients' and their partners' everyday lives has not been explored.

The aim of this study was to explore how home-based telemediated exercise training offered by a physiotherapist (PT) becomes part of the conduct of everyday lives of patients with very severe COPD, and what it means to them and their partners. Furthermore, what this kind of training practice means for PTs' perspectives on the patients is also explored. Hereby, the study advances the field by contributing to the qualification of home-based telemediated exercise training offered by a PT.

Theoretical Framework

The theoretical framework of critical psychology (CP) was developed with the purpose of understanding human subjects from a first person perspective (Klaus Holzkamp, 1985; Tolman, 2013). The overall analytical focus in CP is on *personal reasons* for acting in particular ways that are related to *personal life conditions* and what these conditions *mean* to the subject (Mørck & Huniche, 2006). The interrelatedness of life conditions, what they mean to subjects, and reasons for acting in specific ways urges an analysis focussing on 'parts of a whole', rather than on 'causal factors'. The "conditions, meanings, and reasons analysis" (Mørck & Huniche, 2006) directs focus at personal ways of acting, making choices, and living everyday lives in personal circumstances, including relations, occupation, physical well-being, etc. Focus is thus on everyday activities and the circumstances they are part of, rather than on broader sociological life forms. Furthermore, this analysis points to what these life circumstances mean to the subject, to their interests, priorities, and abilities. The methodological approach to empirical research in CP is termed *practice research*, a way of generating knowledge whilst developing practice in a specific area, in collaboration with users, i.e. informal carers, health professionals, etc. (Mørck & Huniche, 2006). In the present study, the

concept of *conduct of everyday life* (Klaus Holzkamp, 1985, 1995), is central to the analysis, as the aim is to gain insight into how telemediated training becomes part of the lives of patients with very severe COPD and the lives of their partners. In addition, the analysis focuses on what telemediated training means for PTs' everyday work practices, and how patients' reason about it.

In CP, *conduct of everyday life* is conceptually developed to stress the fact that everyday lives are formed by the subjects' active engagement in upholding everyday living throughout life (K Holzkamp, 1998). The subject's personal life trajectory can be understood as the sum of what he or she has been involved in, along with others, in various contexts (Dreier, 2008, 2009). For patients with very severe COPD, activities typically traverse family life, domestic work, leisure activities, treatment, and training. Ole Dreier (2008) points out that subjects are faced with a variety of roles and responsibilities that often come with contrasting demands and make for conflictual relationships. Given limitations on time and resources, conducting everyday life entails choosing between, leaving out, juggling, and prioritizing relations and activities in the overall economy of daily living (K Holzkamp, 1998). This is a highly relevant challenge for patients with very severe COPD, because of their very limited personal resources. Furthermore, *conduct of everyday life* means navigating in and around conflicts of interests as human lives are essentially social and connected to other subjects living their lives (Højholt & Schraube, 2016). Understanding the complexity of how patients with very severe COPD engage in and across contexts of daily living is central to discovering possibilities and limitations to their activities and relationships in everyday life and as their illness progresses.

Højholt and Schraube have developed Holzkamp's conceptualization of *the conduct of everyday life* by further, specifying three dimensions (2016). The first dimension involves the *cyclical organization of everyday life*, with rhythms, routines, and habits that

have been found meaningful in response to particular life circumstances. The repetitious character of this dimension relieves the subject of constantly having to make decisions about what to do or not to do, and how, when and for what reason. The second dimension entails the subject coming to terms with unforeseen demands, challenges, and disruptions which are experienced as *transcendence and extra-ordinary activities*. As Højholt and Schraube (2016) point out, finding oneself in extra-ordinary circumstances contrasts with finding oneself as part of upholding the cyclical organization of everyday life. The third dimension includes the subject's specific *integrative sensibility and way of sense-making*, as the cyclical and extra-ordinary aspects are integrated in the conduct of everyday life.

Patients handling emotional and practical obstacles relates to matters concerning themselves and their immediate life conditions: How they understand themselves as persons, see themselves in the past and in the future, and how they view their current situation (Højholt & Schraube, 2016); whether they live alone or with a partner, what other relations they have with family members, friends, and neighbors, if they depend on permanent oxygen treatment, whether they have their own means of transport, or depend on public or private transport, how easy or hard it is to access a grocery store, get to their GP, etc. For patients in this study, COPD adds a specific set of life condition; it limits the extent and nature of activities patients can engage in on a daily basis. Telemediated training is one of many basic activities the patients prioritize among.

Telemediated Training Setting

After a structural reform in 2007, Danish municipalities were declared the main responsible for primary care. As the research project was about to get under way, two different municipalities had just taken over the rehabilitation of patients with very severe COPD and three rehabilitation units (outpatient clinics) were interested in delivering supervised telemediated *group* training. They were included in the research project. The rehabilitation unit

at the hospital delivered home-based *individual* telemediated exercise training for patients with very severe COPD as part of their discharge plan. The hospital's and the municipalities' telemediated training were all time limited. The intention with the training was to keep the patients in the training trajectory and hereby strengthen them in managing the everyday life. This intention was based on the general practice of rehabilitation in Denmark when dealing with patients with COPD of mild to moderate degree. Thus, the plan for rehabilitating patients with very severe COPD was modelled on this practice.

General for telemediated training, group or individual, patient and PT went online at the same time, from patient's home and at the rehabilitation unit, respectively. Both could see and hear each other and communicate. The camera was exterior and placed on top of the screen. The camera could be moved a little, manually, to change the angle, but it was not possible to zoom. The image on the screen of the patients and PT included the background of where they were situated, but as patients often sat close to the screen they filled out most of the screen. In group training, a maximum of four patients, each situated in their home, participated. The PT was situated in the rehabilitation unit and all were able to see and talk with each other. The screen was divided into four larger spaces and a smaller space in the lower right-hand corner, where the person watching the particular screen was pictured. Exercise training for patients with very severe COPD involved sitting on a chair, warming up exercises, cardio training (swing exercises, exercises for upper extremities, lower extremities and neck/shoulder), and stand and sit exercises. The training typically lasted between 30-60 minutes and consisted of a talk of how the patient(s) were doing, warming up, training, stretching and making a new appointment.

In the following, *home-based telemediated exercise training* is named *telemediated training* and, when relevant, individual or group training is mentioned.

Method

On the basis of critical psychological *practice research*, the methodology of the study took inspiration from ethnographic fieldwork (H. R. Bernard, 1995; Jefferson & Huniche, 2009; Taylor & Bogdan, 1998). Inspired by Jefferson and Huniche (Jefferson & Huniche, 2009) we found it important to investigate the sites where the telemediated training was practiced: the homes and the rehabilitation units of the PTs, as different aspects of the telemediated training came into focus, depending on the context it was situated in. Participant observation and interviews were conducted in the homes of the patients and their partners, and at the rehabilitation units. Over a five year period (2013-2017), the focus was how and where patients and PTs engaged in telemediated training, either individually or in groups.

Four rehabilitation units performing individual or group telemediated training were involved; one at a hospital and three in two different municipalities, and in 11 patients' homes.



Figure 1: Overview over practice research (locations, training activity, participants, observation, and interviews).

The first site involved in the practice research project (2013-2016) was the rehabilitation unit at the hospital. Here the patients were asked if it was acceptable for them to be observed while training or if they preferred not to be observed. All patients agreed. Twenty

two participant observations of the individual telemediated training sessions were carried out, observing both patients and the PT from the rehabilitation unit. One interview with the PT supervising the training sessions were also conducted at the hospital's rehabilitation unit.

The primary body of empirical data was generated from October 2016 till June 2017 in the municipalities. As the methodology of this research project was to generate knowledge *while* developing practice the patients offered telemediated group training by the physiotherapists were involved in the practice research if they consented after being informed. Hence, the patients were included in the training by the physiotherapists, not by the researcher. Forty-six participant observations of telemediated group training were carried out in the rehabilitation units, involving two groups of patients (seven in all) and six PTs. Six interviews were conducted, one with each of the PTs.

In the patients' homes, 15 participant observations and 32 interviews with patients and spouses or partners (hereafter partner) were carried out. The first four of the interviews were with patients training individually with the PT from the hospital. The PT preferred to ask the patients herself if they would participate in an interview in their home, conducted by the PI, as the PT knew the patients and thought they would give her an honest answer. The patients were free to decline with no consequences for their telemediated training, or any other treatment, however none of them did. The four patients from the hospital were the first in the project and interviewing them a way to get a notion of the field. In the municipalities, the rest of the interviews in the patients' homes (28) were conducted over a period of eight months, as the patients here were followed over time. The PI introduced herself and the research project in the telemediated training session, and also introduced the possibility of visiting the patients in their homes to observe the training and to interview them about it. The patients were informed about their right to decline, but no one did. The patients were interviewed two to five times in their training period: in the beginning, in the middle and at the

end – or shortly after their training period had ended. Two of the follow-up interviews were conducted over the phone, as this was more convenient for these patients.

Typically, the patients and the partners were interviewed before and after the training session. The first part of the interview started after the PI had arrived in the patient's home and lasted until the telemediated training started. During the training the PI was situated behind the patient, visible to the other patients and the PT, and able to see what was happening on the screen. After the training the second part of the interview followed. This was an opportunity to ask the patients and their partners how they had experienced the training, and to ask for explanations of what had been observed during the sessions. Doing participant observation and interviews in the patients' and their partners' homes differed from watching them from the PT's unit or alternatively on a video recording, as the PI was able to observe and sense the context of training and how it mattered for patient participation. Situated in their homes the patients and partners included talk about their everyday lives during interviews and small talk with the PI.

The interviews lasted between 60-90 minutes, on average. The patients and partners that chose to participate were very engaged in the interviews. Several mentioned that they felt it had a therapeutic effect on them, and no interviews ended up being unfinished or shorter than expected. The interviews and the participant observations in the patients' homes were guided by the following research question: telemediated training as a part of the conduct of everyday life, i.e. expectations and experiences with this and descriptions of well-being in everyday life (Table 1).

Initially, 13 patients participated in the practice research; however, two patients stopped the telemediated training; one because she felt that the exercise training exhausted her, the other because he had health issues to attend to and did not have time for the telemediated training. Of the 11 patients participating in the study, seven were women, nine patients

were between 70 and 85 years old and two patients were under 60 years of age. Seven patients had partners, who were invited to participate in the interview with the patients. Four out of seven accepted, two of them were women. Four patients lived alone.

All the PTs were interviewed once, after having a minimum of two to three months of experience with the training and after several sessions of participant observations in the rehabilitation units and in the homes of their patients, had been done. Observing the PTs and their patients from both sites gave data on how they appeared through the screen in the homes and how the PT experienced training telemediated from the rehabilitation unit. The interviews and the participant observations were guided by the following research questions: the overall experience with telemediated training, the aim of telemediated training, to what degree to which the conduct of everyday life for the patients was included in telemediated training, and life conditions (Table 1).

INSERT TABLE 1 here

Telemediated training was explored as expressed by the patients, their partners and PTs during participant observation and interviews (formal and informal) (Taylor & Bogdan, 1998), and as practiced at telemediated training sessions in the homes of the patients and partners, and at the PTs in the rehabilitation units (H. R. Bernard, 1995; Taylor & Bogdan, 1998). The participant observations brought forward themes and questions that were explored in the interviews and the interviews brought up areas to be curious of during the participant observation. In this way, an iterative process played out.

The interviews and training sessions were audio-recorded, and the interviews were transcribed verbatim. Field notes were written during observations and subsequently integrated with the transcribed audio recordings. As some of the scheduled sessions in the rehabilitation units took place on the same day and time, a research assistant –and not the principal investigator (PI) - performed participant observation in one of them 16 out of 26

times. Theoretical framework and analytical approach were discussed with the research assistant in advance to make sure data production and the understanding of the material were aligned. Sessions were audio-recorded, transcribed or summarized, combined with the field notes and discussed between the PI (KR) and research assistant.

Ethical Concerns:

Carrying out participant observation and interviews in the homes of patients with very severe COPD brought on ethical concerns. Patients appeared to use up available resources just breathing. When introducing the research project, the PI stressed that visits to participants homes were optional and not a condition for participating in telemediated training. None of the patients declined home visits, and seemed genuinely interested in sharing their experiences.

All patients' and their partners' names were changed to pseudonyms. Information that could lead to an identification of informants was changed to preserve anonymity. The project was reported to the Danish Data Protection Agency (Approval number: 18/28775). No further approval was required. All informants gave their informed consent.

Data analysis

The theoretical approach to the analysis was CP with the procedural inspiration taken from ethnography. Data, generated in the municipalities and at the hospital, were coded separately three times and according to whether the informants were PTs, patients or the patient's partner, by the PI, and discussed regularly with two of the co-authors, (LH and LRM). Inspired by Emerson and colleagues, we worked towards coherence in the data through open coding, writing memos, selecting themes, and finally through focused coding (Emerson, Fretz, & Shaw, 1995) in developing categories and concepts, however not theory (Charmaz, 2014). The process of analyzing data was iterative, and memos and coding themes were regu-

larly discussed and adjusted with the co-authors. For coding examples, see Table 2. Nvivo 11 was used for managing data.

INSERT TABLE 2 HERE

Findings

A fundamental condition for patients with very severe COPD is distinct breathlessness which entails few resources for carrying out the most basic everyday activities such as getting dressed or preparing a meal. This was also evident in our study. In the following *I* is the abbreviation for *interviews*, and *PO* the abbreviations for *participant observation* (I):

Patient: ... “Well, lots of times I have been cooking my own food. And then I’m just too tired to eat ... (laughs)... But then, many times, I take a break [sleeps on the sofa], and then I eat.”

PI: “Does that work ok for you?”

Patient: “Well. It would be nice if you could just sit down and eat the food while it was warm.”

PI: “Of course. You don’t shower every day, so you don’t always have to both shower and cook?”

Patient: “No, because ... that would be impossible too. But... that’s what I really wish for, to be able to do something *more*, not just one thing each day.

For some of the patients, carrying out such basic activities could last from morning till noon. This meant that attending PR twice a week outside the home was not possible, as it would exhaust them and leave no resources for conducting other aspects of an everyday life. With CP as theoretical and analytical framework we found the following themes: (a) telemediated training as a feasible routine in the conduct of the everyday life (b) telemediated training involves the partner (c) telemediated training as hope for holding on to essential ac-

tivities (d) telemediated training as a potential reminder of getting worse (e) feeling obliged to train (f) how telemediated training changes PTs' perspectives on the patients.

Telemediated Training as a Feasible Routine in the Conduct of Everyday Life

Having to leave home meant more activities needed to be done faster: Waking up, getting washed, looking presentable for going out, and eating breakfast. When training was telemediated, the patients felt that washing themselves could be postponed until after the training. They felt presentable enough on the screen by just combing their hair and putting on a t-shirt. One patient, in particular, articulated aspects of having telemediated training as a routine in her conduct of everyday life. She offered several perspectives on the matter, which will be shown in the following. The first perspective was about the possibility of having breaks in the routines of getting ready for training (I):

Patient: "No, 10 a.m. is ok. The problem occurs when I have to go somewhere afterwards. Because then I'll have to shower before [the telemediated training] instead of after... I have been thinking that it is an odd time of the day but, on the other hand, the day will be ruined if the training is at 12 o'clock. You can't really go anywhere in the morning, not to mention the afternoon."

The telemediated training made it possible to slow down the speed of doing things and save energy for other activities. The routines could be tackled in steps. Nevertheless, additional activities that were to happen right after the telemediated training could limit her participation, and she once declined one of the sessions because she had to see her GP immediately after (PO):

"The patient has logged on to the group training, even though she is not able to participate today. She is going to see her GP right after training. Her husband is standing behind her. He is wearing a morning robe. The PT asks her when she is going to her GP, trying

to start a conversation about her planning. She briefly explains that she needs time for a shower and stops any further talk on the subject. Determinedly, she starts to log off the device. The PT accepts this and the patient logs off.”

The PTs had been used to a high rate of cancellations in PR from this group of patients and were therefore used to motivating them to train. Now that the training was indisputably accessible, it raised the PTs’ expectations regarding patients’ participation. In one of the municipalities, the PT instructed the patients to log on to the telemediated group training, even if they had to decline the session that day. Few patients did this. Instead, they phoned the PTs when they had to decline a session. Telemediated training gave the PTs insight into what was meaningful for each of the patients in their conduct of everyday life. Conversely, telemediated group training could cause unnecessary interference from the PTs in the patients’ prioritization of daily activities. The telemediated group training was less flexible than individual training, as rescheduling was not possible when one of the patients could not attend.

The patients integrated their training with their other activities. A patient told the PT that the morning training meant that she had the chance to do other things that day (PO):

Patient: “When I train, I actually feel... It actually was like this right from the beginning: I have energy when I am done training. So I plan what I really need to do today, and the things I have difficulties doing, I do right after training. Because then it goes like this: Pssst! This could be emptying the dishwasher or sweeping the floor or something like that. I get this done right after training.”

The patient’s *integrative sensibility and way of sense-making* in her conduct of everyday life is shown in this example, as she had come to terms with the limitations of her breathlessness and altered her routines accordingly by doing chores right after telemediated training.

In the other municipality, group training was at 1 p.m. Training later than that did not appeal to a patient and his wife. He explains: “So it fits into the everyday. What doesn’t suit me is if we have to train at 2 p.m.” And he reasons: “...it ruins the afternoon [...] It’s too late.” For the patient and his wife *the cyclical organization of living* was a distinct and important structure for them. The afternoon was their time for coffee and chatting, and family and friends often dropped by during telemediated training or afterwards, which happened several times during the practice research.

Telemediated Training Involves the Partner

By conducting telemediated training in patients’ homes, all the patients’ partners were in some way affected by its presence. A patient’s wife used to do chores in the kitchen at around 10 a.m., after helping him out of bed and into the shower. When telemediated training started, she felt she had to rearrange her rhythm of activities, because she did not want to disturb the training. However, she was still being nearby for questions or information from the PT or to help her husband, e.g., with some water.

Another patient’s husband was involved in the telemediated training because he felt obliged to sit and watch the training, now that it was in their home. This was how all four partners felt. The partner saw it as a way of showing his interest in, and care for, his wife and her well-being; not being there would be rude (I):

Partner: “I do get irritated... When she isn’t well. I have to postpone what I am doing. It is not going my way. I will have to live with that... I also think, that even though I have to do all this extra work... Suppose I just said no, she would be in trouble. Then I would feel even worse. That’s why you do it. But that’s not the only reason. It’s also because, of course, I have to give something back.”

A partner gave his wife all the attention she had given him and their son in their life until now. Getting insights into his wife's training made him interfere more in what she should do, which changed some aspects of his role as a husband. His wife's condition had worsened the past couple of months. He eagerly commented during her training, as he did not think she did enough to exercise. His wife resented his comments and kept saying that she was doing the best she could. His involvement in his wife's training was based on hope; hope that she would get better and that they would get their life back to normal.

Telemediated Training as Hope for Holding on to Essential Activities or as a Reminder of Getting Worse

During the practice research, one of the first things that caught the eye was the hard work all the patients did in telemediated training. Not only did they have very severe breathing problems, but also they all tried very hard when training, gasping for air. Why? The answer was simple and straightforward from all the patients: they hoped for a stable or better everyday life. Hope for improvement took many shapes and forms, depending on whose conduct of everyday life it was part of. One patient illustrated his hope when he explained his expectations for the telemediated training: "My expectations are that I am able to maintain my physical condition as it is now. That it doesn't go downhill from here. I want to keep it stable." This patient was humble in his hopes, as he and his wife had experienced a rough fall and winter with him being hospitalized three times. This was a change for them. For almost two decades, they had been conducting their everyday lives without severe exacerbations and had, therefore, a conviction that they were in control. This conviction had been shaken. He was now back home, but with oxygen. Telemediated training gave them a hope of leaving the oxygen and a hard period in life behind, and returning to the dear rhythms and routines of everyday life about which he and his wife loved to talk.

A patient and her husband both had COPD. The patient's COPD was very severe while her husband's was mild. The patient had individual telemediated training in which her husband also took part, partly because he thought he could benefit from it, and partly because he wanted to support his wife. He often had many questions for the PT about what could be done to improve his wife's severely altered condition. Their usual rhythms and routines were no longer possible; they were on unknown territory. The dimension of *transcendence and extra-ordinary experience and activity* was very visible, right there, in their everyday lives, as they tried to hold on to the hope of improvement. In one of the sessions, the PT had taught the patient a new breathing technique (I):

Patient: "Actually, I could feel that, after she was here [individual telemediated training], I felt better, right at the end of the training! I could get up [sit-to-stand] ten times!"

PI: "Yes, very nice! Nice going!"

Husband: "I also hope that it will improve (name of his wife) appetite... Because..."

Patient: "I am not very hungry."

Husband: "A little bowl of oatmeal with milk in the morning, and then two half slices of rye bread [at lunch], and if it was her own decision, she would live from protein drinks."

Patient: "No! I eat as much as I can!"

She and her husband associated individual telemediated training with improvement in basic areas in the conduct of everyday life such as building up an appetite. To have individual telemediated training as a fixture supported this hope.

The PTs played a significant role in creating hope (PO):

"The PT asks if they would be ready to do a round of sit-to-stand. A patient says that, this time, they should do it only for 30 seconds. The PT's conclusion is that they will give all they have for 30 seconds [...]. The PT counts down with the stopwatch. She makes

notes of how many sit-to-stands each of them did. One patient did 10; another, the same as last time, 12, and yet another patient, quite a few – as the PT commented on his speed: “Wow! That was fast! I understand why you were out of breath. I understand that about all of you. I’m writing the date and everything down... It’s great, that you agreed to do this exercise today!” The patients comment on her remark and she says, “You are right. It’s a really good exercise. It is good to train legs. They are the ones that carry us around all day, right?””

Not only did the PTs help the patients push their endurance to the limit. The PTs also added words to the use of the exercises, relating them to important activities in the conduct of everyday life.

When the patients felt unable to exercise or unable to do a specific exercise, their hope faded, and they felt sad. A patient was experienced in training, and after a discharge from the hospital, she accepted individual telemediated training. While doing sit-to-stand, the PT told her not to touch the chair on standing up. This resulted in her not being able to do the exercise. A while after the telemediated training had ended; the patient discovered that the chair she had been using was lower than the usual one she used (I):

Patient: “No, it really made me sad when she [PT] told me this, because I wasn’t aware of it... She said something about not using my fingers. I did remember that I used to be able to [do sit-to-stand], because I did it like this [shows PI], when I got up and sat down on this chair. And I was able to do 10 without touching. But I couldn’t get up from the other chair. So, I was really sad. And I have been sad for a long time, because I couldn’t do sit-to-stands anymore. So... But now I’ve found out that I am able to do them anyway (laughs)... So stupid that I didn’t try before; because then I wouldn’t have been sad for such a long time...”

The fear of getting worse was latent in all the patients and when they had difficulty in doing the familiar exercises, this fear was awakened, leading to worry and sadness.

Feeling Obligated to Train: I'll do what I can".

Whether the telemediated training meant hope or sadness or both, all the patients demonstrated a sense of obligation to take part. For most of them, this feeling was related to grasping the opportunity given (and hope) for a better everyday life. However, for three of them, this feeling seemed strongly related to their partners and health professionals, more than to themselves.

A patient trained in telemediated group training on his wife's initiative and she helped him with everything. She seemed worn out. Her husband hardly talked to her; she had trouble getting answers to simple questions, like what he would like to eat. He had never been very social, but the past year, he had been even more reluctant to go anywhere. Not even outside in the garden, which he used to love. In connection with her husband's last discharge from the hospital, she expressed her views to the health professionals and they referred her husband to training in the municipality (I):

Wife: "Actually, I told them that I thought that he should get some training at the rehabilitation unit. He needs to get out among other people; because he never is."

PI: "Is it dull for you, Jens; not to go out among other people?"

Patient: "No."

Wife: "He has always been a homebody. Maybe it's just me who thinks that he could benefit from going out, being just a little social."

The patient did not feel a need to go out, but his wife thought it would be good for him and their life together if he would interact with other people. However, he was not strong enough to train outside the home and was offered telemediated group training. He did

not object and trained at every session even though he was extremely strained. The PTs were impressed with his effort and attentive to him (PO):

“The PT asks him if he has the strength for another round [walking on the spot]. He says no. The PT starts swinging her arms. The patient is out of breath. The PT’s voice is quiet: “Will you remember to tell me when you can’t do anymore [exercises]?” She is in doubt about how much he can do. “Yes”, he says in one breath. She does not hear his yes. He repeats on her command. It is a great exertion for him. The PT watches him intently and regularly asks him if he can do another round.”

When asked why he kept on training despite his severe breathlessness, the patient expressed an obligation involved in his prioritization of the training related to the health professionals: “It’s because they [health professionals] make us believe that we should train [...] It should get better.” He did not do this for his pleasure, he said, and he often felt like declining a session. Also, he was a bit skeptical about getting better, even though he demonstrated hope in this regard in the telemediated training. During the time he had been involved, he had not felt any improvement. Small activities in everyday life and more demanding ones, like climbing the five steps to the bedroom and bathroom, were still as exhausting as they always had been.

Feeling the obligation related to the hope of improvement could also create frustration and anxiety in some of the patients. A patient dutifully logged on to the telemediated group training every time, even though most of the time she was incapable of any substantial participation. At a participant observation in her home, the PT instructed the patients in a breathing exercise. Afterwards, all the patients were asked individually if they knew the trick?

PT: [asks the patient’s name]

Patient: “Yeees?” (She makes her voice sound little and thin)

Husband (sighing): “[says his wife’s name]...” (Pleading and blaming her that she is not taking the session seriously enough). She snaps out of the thin voice and answers in her normal way.

Due to her feeling of powerlessness, her frustration at the training sessions and toward her husband was visible. Once, during an interview, she told her husband to go away, if he was going to criticize her. She often defended herself and said: “I am doing what I can.” This was something many of the patients said during the training sessions and interviews. This patient was having difficulties enduring the training because of her severe breathing trouble, which was a dilemma, as telemediated training was, for her, a hope for a better daily life. The telemediated training was a confrontation with seriously declining strength and also hope. Four months later, she stopped participating in the training and quit smoking. Her lung function rose by 17% and she started hoping to be able to go down town again with her husband, sit on a bench, and watch people – as she stressed an important point for her: “Now that I’m better, it is important that we have more time together.” The couple found another way to have quality in their everyday life together.

How Telemediated Group Training Changes PTs’ Perspectives on the Patients

Initially, PTs regarded telemediated group training as an opportunity to introduce or restart training for the patients, improve their strength, and enable them to be more active in everyday life and participate in PR. However, the PTs found that most of the patients were fond of training telemediated at home and that leaving home for PR was still a problem for them (I):

PT: “Actually, that’s something I have wondered about [not being able to refer them to PR]. I’m also very surprised that they like it [telemediated group training] that much. That’s really cool. Before starting, I wasn’t aware of which group of patients we would help

the most. It's been such an eye-opener, that it's the psychologically fragile [patients] that we take by the hand here."

Therefore, ending telemediated group training for these patients was a challenge for the PTs and they often discussed it with each other (PO):

PT: "[the name of a patient] is also a challenge. First he's better, then he's ill; it's hard having him referred to PR; he is so unstable... If we, one way or another, could find out how to move them on ... if not, this [telemediated group training] is going to be a group for maintenance training; some of them would really benefit from that."

Six out of seven patients training in the municipalities were very unstable and not improving perceptibly. However, the PTs were part of a system where rehabilitation involved moving the patients on. In one of the municipalities, a PT had noted that one of the patients could pull the elastic band way up over his head and said to her colleague: "A new patient has just been referred to the telemediated group training, so it's a bit crowded so... So, you could say: [the name of the patient who could pull the elastic band way up over his head], you are probably the next [who has to stop], because we need your place, right?" Her colleague agreed. The PTs knew this patient as an active patient for some years. Now they saw him active in telemediated training, even though he had worsened after his hospitalizations and did not have the strength to endure the transport to and from PR.

Given the PTs' organizational conditions, it was necessary to maintain patient flow-through, to make room for new patients in telemediated group training. The PTs knew that the patients would benefit from continuing the telemediated training, but did not have the possibility to offer it. This sometimes made them feel bad (I):

PI: "And then, what we have talked about: How long do you think they may keep on training telemediated group training? It's not that I ask for any limits, but you have been discuss-

ing...” [that the patients cannot continue with the telemediated training]

PT: “Well, that’s what I expected: That we could finish them and get them on the PR. But we can’t.”

PI: “The same thing is happening in the other municipality ...”

PT: “Well, I think it’s because we have found the patients that have the level of functioning that they have physically and psychologically. But the thing is that they *really* need maintenance training.”

PI: “And when I discuss this with you and the other municipality, the explanation I hear is: You don’t offer maintenance training.”

PT: “It’s terrible.”

The PTs had realized that the patients could perhaps improve in more basic activities in their conduct of the everyday life and that the telemediated training in this connection could function as maintenance training.

Discussion

A life condition for the patients in this study was that they were confined to their homes because of severe breathing difficulties. This meant that they had few resources to carry out basic activities, such as getting dressed or preparing a meal. By employing the theoretical framework of the concept *the conduct of everyday life* from CP, we have investigated how telemediated training found its way into these patients’ conduct of everyday life. We found that the majority considered the telemediated training to be meaningful, as it had the potential to function as an agent of hope for holding on to the elements of everyday life that the patients and their partners most valued. They therefore made an effort to integrate it into their lives and routines. The key to hope was improvement through enduring telemediated training. Patients’ hope for improvement has also been shown in another study where patients with

COPD have been told by their physician that their condition will not get better, rather that it will get worse (Williams, Bruton, Ellis-Hill, & McPherson, 2011). A lack of improvement can therefore be experienced as concerning. Hope arises when “healing [...] becomes reimagined in the course of illness” (Mattingly, 2010) (p.142). Mattingly calls it “healing dramas” and explains that this happened when patients experienced episodes that to them felt “highly eventful” and became “significant” in their “transformative journey” (Mattingly, 2010) (p. 142). According to Mattingly, it is possible to reimagine healing, despite a bad prognosis ((Mattingly, 2010). This is also clear in our study. The PTs explained and related the exercises and improvements in telemediated training to examples of important activities in the conduct of everyday life and with the patients created hope of enough healing so that there was potential for an enhancement in the everyday quality of life. Similarly Mattingly found that occupational therapists translated the medical world into something related to the patients’ everyday life so that the medical knowledge could become useful for the patients (Mattingly, 1998). She points out that practicing and expressing hope is powerful when it is related to patients’ home narratives (Mattingly, 2010). However, this study also showed that telemediated training can be experienced as a burden when it does not function as a co-creator of hope, but as a reminder of decreasing strength or an activity without significant meaning in the subject’s conduct of everyday life.

The patients’ partners in this study were part in what Mattingly defined as the healing dramas, as the telemediated training took place in their homes and they too hoped for a stable or better everyday life. During the sessions, the partners were always nearby and on hand to help or get information. Other studies have shown that living with a patient with very severe COPD brings with it a role as a caregiver and difficulties in conducting everyday life as usual (Barnett, 2005; Gysels & Higginson, 2011). Conflicts of interest occur as the partner’s and the patient’s conduct of everyday life are intertwined (Højholt & Schraube, 2016).

This is also the case when care involves telehealth technology in the home (Brunton et al., 2015). Oudshoorn (2012) has shown that relatives become the “*co-inspectors of bodies*” (p. 131), when monitoring devices are installed in the patients’ homes (Oudshoorn, 2012). Even though telemediated training is not defined as a monitoring service, this research shows it can have this effect on partners; Oudshoorn (2012) found that “*joint watching* enabled them to share with their partners how successful they were in *adhering*” (p.131). This occurred often, given that telemediated training in the home took place either in the living room or kitchen and therefore was very visible to the partner. Therefore, telemediated training cannot be seen as training only involving the patients, but also as a practice that involves their partners and offers them a responsibility they find meaningful in hoping for a better everyday life and therefore often take on. Oudshoorn has also shown that the partners take responsibility, and the way they do it is related to gendered roles (Oudshoorn, 2012). In the present study, this could also be the case, however it is also evident that the partners took on a responsibility related to their existing role or to their interests, hope or worries, whether gendered or not.

The fact that the telemediated training was made accessible in the home of the patients who normally declined PR cannot be seen solely as a clear advantage. Oudshoorn (2012) points out that a monitoring device in the home “...introduces a technogeographical configuration of care, in which the home is transformed into a place where patients are made responsible for monitoring their own bodies. Consequently, patients are expected to become disciplined in order to monitor their bodies” (p. 129). In this study, we have seen how the partners became co-inspectors of the training. The disciplining also lies in some of the PTs’ interest in managing cancellations, not as a phone call from the patient, but online at the beginning of the telemediated training session. The patients preferred the phone because it added some distance, in contrast to the authority that faced the patients when they logged on the telemediated training screen; an authority who felt it meaningful to engage or interfere, de-

pending from which perspective it is understood, in the patients' prioritizations of activities in the everyday life. It can be argued that the PTs, on the screen, were virtually in the patient's home ready for training. In this light, the telemediated training is linked not only to hope but also to a sense of obligation – in terms of being compliant with treatment, and living up to the expectations from partners and PTs. It can also be argued that telemediated training, by its presence at home, can be experienced as a reminder to include telemediated training in everyday life.

The Danish municipalities' work with patients with COPD is built on the concept of rehabilitation (The Danish Health Authority, 2018). Rehabilitation can be essential in enabling people experiencing limitations in their functioning to live independently in their home or community, and maybe participate in education, the labor market and civic life (World Health Organization, 2011). Some of these goals may be meaningful, even for patients diagnosed with very severe COPD. In addition, a palliative understanding of and care for those severely affected by their COPD, which is often overlooked, may be needed (Pinnock et al., 2011). As Pinnock and the present study show, a palliative understanding is not dominant among the patients, their partners, or health professionals due to the slow progression of COPD: it is experienced as a way of life (Pinnock et al., 2011). Linking a holistic palliative assessment, such as long-term oxygen treatment, medical related retirement, and hospital admissions, to what Pinnock and colleagues (2011) call "milestones throughout the patient journey" (p.9) could be helpful for the patients and their families. In this light, telemediated training could function as maintenance training for this group of patients, keeping levels of functioning stable, improving the ability to carry out basic and meaningful activities, and improving everyday quality of life. Telemediated training thus provides an alternative to time-limited PR aimed at radical improvement.

Strengths and Limitations

Qualitative investigations into user experiences of telehealth technologies that clarify the perspectives of patients with COPD, their partners, and clinicians are limited (Brunton et al., 2015). In the present study, using CP as the theoretical framework, all three perspectives related to the same telehealth technology are shown and analyzed with respect to their importance for patients' and their partners' conduct of everyday life and for their importance to the PTs' perspectives of the patients. This is a contribution to both understanding the complexity of introducing a telehealth technology, and understanding what is at stake in the everyday living for those involved. As this study is the first of its kind, future studies on the current topic are therefore recommended.

What this article does not explore is what kind of service telemediated training becomes by being mediated through a technology and used by PTs, patients, and partners. In addition, further research should be undertaken to investigate how patients experience their journey through the health care system when telemediated training is added.

Implications for Practice

For patients who are very severely affected by their COPD, telemediated training can function as maintenance training, keeping levels of functioning stable, improving the ability to carry out basic and meaningful activities, and improving everyday quality of life and, thereby, it can serve as an alternative to time-limited PR that is aimed at radical improvement. However, this is subject to whether the patients experience the telemediated training as meaningful to their conduct of everyday life: either as an activity that creates hope or a reminder of the decreasing strength and disciplining in the home. Awareness of this should be taken into considerations when telemediated training is offered to patients with very severe COPD.

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The authors declared no conflicts of interest with respect to the research, authorship, and/or publication of this article.

References

- Barnett, M. (2005). Chronic obstructive pulmonary disease: a phenomenological study of patients' experiences. *J Clin Nurs*, *14*(7), 805-812. doi:10.1111/j.1365-2702.2005.01125.x
- Bernard, H. R. (1995). Participant observation. In *Methods in Anthropology. Qualitative and Quantitative Approaches* (pp. 136-164): Altamira Press.
- Bernard, S., Whittom, F., Leblanc, P., Jobin, J., Belleau, R., Berube, C., . . . Maltais, F. (1999). Aerobic and strength training in patients with chronic obstructive pulmonary disease. *Am J Respir Crit Care Med*, *159*(3), 896-901. doi:10.1164/ajrccm.159.3.9807034
- Bourne, S., DeVos, R., North, M., Chauhan, A., Green, B., Brown, T., . . . Wilkinson, T. (2017). Online versus face-to-face pulmonary rehabilitation for patients with chronic obstructive pulmonary disease: randomised controlled trial. *BMJ Open*, *7*(7), e014580. doi:10.1136/bmjopen-2016-014580
- Brunton, L., Bower, P., & Sanders, C. (2015). The Contradictions of Telehealth User Experience in Chronic Obstructive Pulmonary Disease (COPD): A Qualitative Meta-Synthesis. *PLoS One*, *10*(10), e0139561. doi:10.1371/journal.pone.0139561
- Charmaz, K. (2014). *Constructing grounded theory*: Sage.
- Dreier, O. (2008). *Psychotherapy in everyday life*: Cambridge University Press.
- Dreier, O. (2009). Persons in Structures of Social Practice. *Theory & Psychology*, *19*(2), 193-212. doi:10.1177/0959354309103539
- Dunger, C., Higginson, I. J., Gysels, M., Booth, S., Simon, S. T., & Bausewein, C. (2015). Breathlessness and crises in the context of advanced illness: A comparison between COPD and lung cancer patients. *Palliat Support Care*, *13*(2), 229-237. doi:10.1017/s147895151300120x
- Ek, K., Sahlberg-Blom, E., Andershed, B., & Ternstedt, B. M. (2011). Struggling to retain living space: patients' stories about living with advanced chronic obstructive pulmonary disease. *J Adv Nurs*, *67*(7), 1480-1490. doi:10.1111/j.1365-2648.2010.05604.x
- Emerson, R. M., Fretz, R. I., & Shaw, L. L. (1995). Processing Fieldnotes: Coding and Memoing. In *Writing Ethnographic Fieldnotes* (pp. 142-168): University of Chicago Press.
- Gysels, M. H., & Higginson, I. J. (2011). The lived experience of breathlessness and its implications for care: a qualitative comparison in cancer, COPD, heart failure and MND. *BMC Palliat Care*, *10*, 15. doi:10.1186/1472-684x-10-15
- Halding, A. G., & Heggdal, K. (2012). Patients' experiences of health transitions in pulmonary rehabilitation. *Nurs Inq*, *19*(4), 345-356. doi:10.1111/j.1440-1800.2011.00573.x
- Holzkamp, K. (1985). *Foundations of Psychology [Grundlegung der psychologie]*. Frankfurt/Main/New York: Campus-Verlag.
- Holzkamp, K. (1995). *Conduct of everyday life as a basic concept in the science of the subject [Alltägliche Lebensführung als subjektwissenschaftliches Grundkonzept]* (Vol. 37).
- Holzkamp, K. (1998). Conduct of everyday life by the standpoint of the subject [Daglig livsførelse som subjektvidenskabeligt grundkoncept]. *Nordiske Udkast* (2), 3-31.
- Hunice, L., Dinesen, B., Nielsen, C., Grann, O., & Toft, E. (2013). Patients' use of self-monitored readings for managing everyday life with COPD: a qualitative study. *Telemedicine and E-Health*, *19*(5), 396-402. doi:10.1089/tmj.2012.0135
- Højholt, C., & Schraube, E. (2016). Introduction. In E. Schraube & C. Højholt (Eds.), *Psychology and the conduct of everyday life* (pp. 3-14). London: Routledge.
- Jefferson, A. M., & Hunice, L. (2009). (Re) searching for persons in practice: field-based methods for critical psychological practice research. *Qualitative research in Psychology*, *6*(1-2), 12-27. Retrieved from <https://www.tandfonline.com/doi/pdf/10.1080/14780880902896507?needAccess=true>
- Lindenmeyer, A., Greenfield, S. M., Greenfield, C., & Jolly, K. (2017). How Do People With COPD Value Different Activities? An Adapted Meta-Ethnography of Qualitative Research. *Qual Health Res*, *27*(1), 37-50. doi:10.1177/1049732316644430

- Mattingly, C. (1998). *Healing dramas and clinical plots: The narrative structure of experience* (Vol. 7): Cambridge University Press.
- Mattingly, C. (2010). The paradox of hope: Journeys through a clinical borderland. In (pp. 141-174): Univ of California Press.
- McCarthy, B., Casey, D., Devane, D., Murphy, K., Murphy, E., & Lacasse, Y. (2015). Pulmonary rehabilitation for chronic obstructive pulmonary disease. *Cochrane Database Syst Rev*(2), Cd003793. doi:10.1002/14651858.CD003793.pub3
- Miravittles, M., & Ribera, A. (2017). Understanding the impact of symptoms on the burden of COPD. *Respir Res*, 18(1), 67. doi:10.1186/s12931-017-0548-3
- Mørck, L. L., & Huniche, L. (2006). Critical psychology in a Danish context. *Annual Review of Critical Psychology (online)*. Retrieved from <https://discourseunit.com/annual-review/5-2006/>
- Oudshoorn, N. (2012). How places matter: Telecare technologies and the changing spatial dimensions of healthcare. *Social Studies of Science*, 42(1), 121-142.
- Pinnock, H., Kendall, M., Murray, S. A., Worth, A., Levack, P., Porter, M., . . . Sheikh, A. (2011). Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *Bmj*, 342, d142. doi:10.1136/bmj.d142
- Pols, J. (2011). Wonderful webcams: about active gazes and invisible technologies. *Science, Technology & Human Values*, 36(4), 451-473. doi:10.1177/0162243910366134
- Pols, J. (2012). *Care at a distance. On the closeness of technology*. Amsterdam: Amsterdam University Press.
- Rabe, K. F. (2007). Global Initiative for Chronic Obstructive Lung Disease. Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease. GOLD executive summary. *Am J Respir Crit Care Med*, 176, 532-555.
- Rosenbek Minet, L., Hansen, L. W., Pedersen, C. D., Titlestad, I. L., Christensen, J. K., Kidholm, K., . . . Mollegaard, L. (2015). Early telemedicine training and counselling after hospitalization in patients with severe chronic obstructive pulmonary disease: a feasibility study. *BMC Med Inform Decis Mak*, 15, 3. doi:10.1186/s12911-014-0124-4
- Taylor, S. J., & Bogdan, R. (1998). In-Depth Interviewing. In *Qualitative Research Methods. A guidebook and Ressource* (3rd ed.). New York: John Wiley & Sons, Inc.
- The Danish Health Authority. (2018). *National klinisk retningslinje for rehabilitering af patienter med KOL - Sundhedsstyrelsen [National Clinical Guidelines for Rehabilitating Patients with COPD]*. Islands Brygge 67, 2300 København S, nkrsekretariat@sst.dk
- Tolman, C. (2013). *Psychology, society and subjectivity: An introduction to German critical psychology*: Routledge.
- Tsai, L. L. Y., McNamara, R. J., Dennis, S. M., Moddel, C., Alison, J. A., McKenzie, D. K., & McKeough, Z. J. (2016). Satisfaction and Experience With a Supervised Home-Based Real-Time Videoconferencing Telerehabilitation Exercise Program in People with Chronic Obstructive Pulmonary Disease (COPD). *Int J Telerehabil*, 8(2), 27-38. doi:10.5195/ijt.2016.6213
- Vasilopoulou, M., Papaioannou, A. I., Kaltsakas, G., Louvaris, Z., Chynkiamis, N., Spetsioti, S., . . . Vogiatzis, I. (2017). Home-based maintenance tele-rehabilitation reduces the risk for acute exacerbations of COPD, hospitalisations and emergency department visits. *Eur Respir J*, 49(5). doi:10.1183/13993003.02129-2016
- Williams, V., Bruton, A., Ellis-Hill, C., & McPherson, K. (2011). The Importance of Movement for People Living With Chronic Obstructive Pulmonary Disease. *Qualitative Health Research*, 21(9), 1239-1248. doi:10.1177/1049732311405801
- World Health Organization. (2011). *The World Bank. World report on disability. 2011*. Retrieved from https://www.who.int/disabilities/world_report/2011/report.pdf

For publication of article in QHR (Table 1)

Table 1: Semi-structured interview guide for PTs, patients and partners concerning telemediated training as a part of everyday life

Semi-structured interview guide for PTs in the hospital and municipalities concerning telemediated training as a part of everyday life	Semi-structured interview guide for patients and partners training telemediated (group) training concerning telemediated training as a part of everyday life
<ul style="list-style-type: none"> - The PT's over all experience of telemediated training - The aim of telemediated training - What characterized the specific target group for telemediated training? - How much is the conduct of everyday life for the patient included in telemediated training? - Anything that surprised you when training telemediated? - The experiences with training with the specific technology - Experience with patients' partners in the telemediated training - The conditions for telemediated training - Breaks in the telemediated training: Reflections on the negotiations of these - Why do the patients train when they are so breathless? 	<ul style="list-style-type: none"> - The telemediated training timewise in everyday life - The connection between telemediated training and everyday life - Expectations toward telemediated training - Experiences of training telemediated - Training despite shortness of breath - The technology in the home - Descriptions of well-being in everyday life - Follow-up on important activities/issues of everyday life - Training after telemediated training is ended: is it feasible? - The role of the partner in connection to telemediated training

For publication of article in QHR (Table 2)

Table 2: Coding examples from 'open' to 'focused coding' illustrated with a telemediated group training session

Meaning unit	Open code	Themes	Focused code
Patient: "You are torturing us!" PT: "It is self-torture, [one of the patients' names]." [...] So... "Remember to count. I'm starting the timer. Are you ready?" Patient: "We are trying." (They train while breathing hard.) PT: "Five seconds. And a break." Patient: "19!" PI: "Way to go. You rock, [one of the patients' names]!" Patient: "As long as it lasts." [...] (Sit-to-stand: They work and breathe very hard and the PT counts down to a stop). Patient: "Ooohhh no!" (One of the patients is breathing hard) PT: "In through your nose and calmly out though your mouth." (Patient is breathing hard) (A break where their breathing calms) PT: "Do you have your breath back now? [one of the patients' names]?" Patient: "I did 15-16 each time." PT: "Good." Patient: "31." PT: "Ok, and [one of the patients' names]?" Patient: "2 times 19." PT: "Yep. Good. And [one of the patients' names]?" PT: "We are improving again, so even though it wasn't your best day, you did well. This is really nice, everyone. The weather today is heavy and despite that, you all managed what you usually do or equal to what you did last time." [...] PT: "It's good, right? Can you feel it in your legs?" [they all answer yes] PT: "It actually gives you a whole lot to sit and stand here; it is going to be easier to get up from the toilet or the sofa."	Therapist is evil patient's own choice Trying to be ready Humble To his limit PT sets structure Result-oriented Training hard despite the odds is good Links between training and daily activities	Endurance Endurance Fleeting strength Endurance PT as the expert and discipliner Improvement is good Endurance pays off Training's relevance for the everyday life	Hope Obliged to improve Hope Hope PT as the authority Improvement is needed PT create hope Hope