English summary

Difficulties in breathing.

An investigation of significance of existential and spiritual phenomena for seriously ill patients with chronic obstructive pulmonary disease.

Patients with severe chronic obstructive pulmonary disease (COPD) experience a life that is marked by an obtrusive fear of suffocation and an everyday life characterised by a decreased ability to function and isolation due to loss of social relations and identity. When living with severe COPD, one belongs to a large group of people who are often unnoticeable, lonely or isolated in the community, and who are incapable of taking care of themselves when the disease reaches its final stages.

The idea of this project is to present knowledge on how people with COPD experience the significance of existential and spiritual phenomena when life is threatened. The project is empirically based, which here means that emphasis is at on describing and understanding the meaning of common phenomena of patients with COPD. This means that the analytical phenomena worked with take form through the empirical observations. Focus is get on what is documented and less on developing theory, which presumably would require further empirical studies, and therefore must belong to a later phase. The theoretical scientific basis of the study is phenomenological in the parts of the study that are descriptive and hermeneutical in the parts that reflect on the understanding of the meaning of the phenomena for the existential situation of the patients. The phenomenological descriptions derive their contents from embodied, concrete experiences in the everyday lives of the patients. A counterpart these embodied experiences remains to the patient as existential experience.

The phenomenological descriptions are not always so complete in themselves that we can understand what is at risk in the patients' lives. Particularly the existential borderline situations of life and death cannot be understood by means of phenomenological terminology alone. Therefore, a number of analytical, primarily philosophical contributions to the illumination of existential and spiritual phenomena are initially presented. Next, the empirical collection of material is described and carried out in 27 research interviews with 17 informants. Next, the interview material is organised, categorised and analysed in order to see which existential and spiritual phenomena are apparent, surprising or particularly predominant. The selected phenomena *faith, hope, dependence, death and stigma* are reflected on by means of the proposed theory, which contributes to shed on the understanding of the meaning of the phenomenon and transcending the knowledge we already have about living with severe COPD. Finally, the

results of the project are discussed with regard to two contexts: 1) the health science, especially nursing care and 2) the tradition of the humanistic and theology, in particular diakonia.

The result of the study shows that the existential and spiritual phenomena play a crucial role in the lives of the patients with COPD. When imagining the difficult conditions under which patients with life-threatening COPD live, it would be obvious to assume that nothing but dejection and disillusion were left. On the contrary, we can find that patients with COPD – as everyone else – constantly reflect, especially existentially, on their lives and conditions of life. Not one of them is entirely without courage to live on. They have a fundamental trust that life is good – that it is worth living for them, too. Their experience from the lives they have led conveys these them – and to most of them, this experience is confirmed daily, at least on the good days. Were it not so, they would presumably seek to end their lives – or they would live a meaningless life entirely without self-esteem.

Patients with COPD also have, but now to highly varying degrees, some interpretive horizons from which to understand their lives. The ambivalence of secularisation and the use of changing and more or less vague interpretations are common to most people. Secular interpretations of existence coexist with different forms of religious interpretations. Often, several forms exist side by side in the individual.

The patients have a difficult life with severe COPD. They experience a troublesome everyday life where their lives are often threatened, not only physically by virtue of the functional decay of the body, but also existentially and spiritually as a result of the stressful bodily experiences. Experiences of suffocation with black outs become deeply rooted as existential experiences filled with fear, powerlessness, despair and vulnerability. The extreme respiratory distress that has almost killed them resides in their bodies as a constant reminder of how terrible their life and death may become. A person is a body that thinks. The awareness with which the severely ill patients with COPD live also influences their existential and spiritual life. We know from many recent studies among severely ill patients, including Danish cancer patients that as a rule, existential reflection is intensified when health and life are threatened. This study also points clearly to the fact that an intensification of existential reflection occurs in patients with COPD as the disease progresses. Spiritual and existential contemplation pervade the patients' lives. Verbalising feelings the patients experience is difficult, and very often they lack someone to talk to and they receive little or no spiritual care. However, existential reflection tied to human life cannot be suppressed. People think, and the way they think influences their illness, or at least the way they manage to live with their illness.

However isolated some of the interviews are, the patients with COPD have not isolated themselves on islands. They live off the social life they used to have – and they wish that just some aspects of it could still function. They not only feel isolated but often stigmatised. In the patients' statements, it becomes clear that – as Løgstrup expresses it – we hold the life of the other in our hand or by avoiding to when we meet face to face. One does this not only actively by contributing to stigmatisation, but also passively by staying away or avoiding looking the other person in the eyes. Whereas for the interviewees' positive experiences of faith and hope we can view their lives as a laboratory giving food for thought about many forms of existential and religious philosophy. We can hardly ignore the ethical demand for action found in the statements when the patients talk about their dependency, their fear of agonizing death, and their experience of stigmatisation. Patients with COPD in its final stages are deeply dependent on help from others in their daily lives. They are simultaneously afflicted with physical suffering and existential challenges that make life difficult to live. They cannot move freely due to the lack of oxygen to the body. They belong to a group of citizens who find it very difficult to be heard and understood, both by those closest to them and by the authorities, because the mere act of speaking is a strenuous task that often requires energy beyond their capacity. It is apparent that there is a possibility to make an effort and create a better life for this group of patients. Many of the principles practiced within hospice care can be transferred to this group of severely ill people with COPD, and new ones can be developed. There is here a diaconal task in close collaboration with specialised pulmonary care units with primary health service.