Att leva med mycket svår kronisk obstruktiv lungsjukdom
– ett liv i slowmotion

av

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Abstract


The overall aim of this thesis was to describe how people with very severe obstructive pulmonary disease (COPD) experienced their everyday lives and created meaning, with focus on end-of-life. A second aim was to describe how death and dying can be viewed from the perspective of relatives to people with COPD. In study I, eight patients were interviewed about how COPD affected their everyday lives. A phenomenological method was used. In study II, four people with COPD who lived alone were interviewed over time, to illuminate how the illness influenced their everyday life and their existential thoughts about life and death. In study III, four couples of whom one partner in each couple had COPD were interviewed several times to illuminate the affects the illness had on the spousal relationship, their self-expressed needs, and their existential thoughts, from the perspective of two people living together. A phenomenological-hermeneutic method was used for the analyses in studies II and III. Study IV aimed at studying patients’ last six months of life with focus on dying and death, and in this study content analysis was used.

The studies (I-IV) revealed that suffering from very severe COPD can be a daily struggle to survive as well as to maintain the self-image. The studies also explicate experiences of a shrinking life space, and questions of meaning were being challenged (I). Study II showed that living alone provided feelings of independency. However the bodily losses reminded the patients’ about death and raised fears about death of being painful, as they did not want to face death alone. For the couples in study III living with COPD meant living in a changed pace with uncertainty, changed intimate relationship and finding new ways of living together. Study IV outlined the trajectory of illness to be irregular and characterized by periods of sudden deterioration, making it difficult to plan for the future. Death was experienced as an unexpected experience and was described by all as peaceful. The results in this thesis have outlined important insight into the existential challenges of living with COPD as experienced by the ill persons themselves and their next of relatives.

Keywords: advanced chronic obstructive pulmonary disease, palliative care, living alone, couple, relatives, trajectory, nursing, death, dying.

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