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Women's experiences of living with chronic obstructive pulmonary disease stage III or IV and the experiences of their close relatives

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DOCTORAL THESIS

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Abstract

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This doctoral thesis is in nursing and the overall aim was to explore, describe, and generate knowledge about women's experiences of living with chronic obstructive pulmonary disease (COPD) stages III or IV, and about the experiences of their close relatives. Living with a serious long-term illness such as COPD profoundly affects a person's everyday life and thereby their health and wellbeing. Data have been collected through qualitative individual interviews (I, IV) and narrative interviews (II, III). The interviews have been analyzed via qualitative content analysis (I, IV) and phenomenological hermeneutical interpretation (II, III). The findings show that women with COPD stage III or IV and their close relatives experienced both suffering and moments of health during their everyday lives (I–IV), despite the unpredictability of their severe illness and their ever-present breathlessness (I). Women were the experts of their own illness, managing their everyday lives to enable moments of feeling well (II). In addition, being seen as diagnose rather than as a person made the women feel neglected by healthcare personnel which influenced their health and wellbeing in negative way (III). Close relatives experienced difficulties in fully understanding the women's struggle of living with COPD. In efforts to comprehend their ill health and stress, they must contend with a lack of tailored information and uncertainty while providing practical and emotional support (IV). The findings in this doctoral thesis show that women with COPD stages III or IV were living with an unpredictable ever-present breathlessness that causes suffering in their everyday lives. Despite this woman experienced moments of feeling well. Meanings of healthcare encounters for women with COPD stage III or IV showed that women wished to be seen as a person not as a diagnosis. Feeling disrespected and unjust leaves women unsupported and could mean serious health risks. Close relatives asked for tailormade information and knowledge to further understand women's ill health.

Keywords: chronic obstructive pulmonary disease; confirmation; everyday life; experiences; healthcare encounters; health; interviews; lived experience; phenomenological hermeneutics; qualitative content analysis; well-being; women.