Abstract

Introduction: Chronic diseases tend to increase with old age. Older people with chronic disease are commonly suffering from conditions which produce a multiplicity of symptoms and a decreased health-related quality of life. Nurses have a responsibility to prevent, ease or delay a negative outcome through symptom management, or assist in achieving an acceptable level of symptom relief.

Aim: The overall aim of the thesis was to describe different aspects of symptom burden from the perspective of community-dwelling people with chronic disease.

Methods: This thesis is based upon four papers that used both quantitative and qualitative data to describe different aspects of symptom burden experienced by people with chronic diseases. Paper (I) is a cross-sectional study with 91 participants diagnosed with chronic obstructive pulmonary disease. Papers (II and IV) are based upon secondary outcome data from a randomized controlled trial with 382 community-dwelling older people with multimorbidity. Paper (III) is a cross-sectional study and Paper (IV) has a descriptive and an explorative design reporting on the trajectory of symptom prevalence and symptom burden. Paper (III) is a qualitative study with participants from the Age-FIT.

Results: Among people diagnosed with COPD the most prevalent symptoms with the highest symptom burden scores were shortness of breath, dry mouth, cough, sleep problems, and lack of energy, with just a few differences between participants with moderate and severe airflow limitation (I). For older people with multimorbidity, pain was the symptom with the highest prevalence and burden. Other highly prevalent symptoms were lack of energy and a dry mouth. Poor vision, likelihood of depression, and diagnoses of the digestive system were independently related to the total symptom burden score (II). The symptoms experienced by the older people were persistent and the symptom burden remained high over time (IV). The experience of living with a high symptom burden was described as an endless struggle. The analysis revealed an overall theme, “to adjust and endure” and three sub-themes, “to feel inadequate and limited”, “to feel dependent”, and “to feel dejected” (III).

Conclusions: The results of this thesis indicate the importance of early symptom identification. People with chronic diseases have an unmet need for optimized treatment that focuses on the total symptom burden, and not only disease specific symptoms. A large proportion of older people with multimorbidity suffer a high and persistent symptom burden, and the prevalence and trajectory of pain are high. Older people sometimes think their high age is the reason they experience a diversity of symptoms, and they do not always communicate these to their health-care provider.

Keywords: Symptom experience, Symptom burden, Chronic disease, Community-dwelling.

The Faculty of Medicine and Health Sciences

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Division of Health, Activity and Care
Department of Social and Welfare Studies

Linköping University
SE-581 83 Linköping, Sweden
www.liu.se
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