

## CONFERENCE ABSTRACT

# Patient involvement in home health care: Elderly patients' perspectives on roles and responsibilities in the collaboration with home care nurses

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**Introduction:** Home health care has become a cornerstone in the organization of healthcare across the European countries and is seen as a strategy to meet the economical challenge of the growing number of chronically ill patients. Home health care aligns with the health political agenda of 'patient involvement' and related terms such as 'patient-centered care', 'patient participation', and 'shared decision-making', which emphasize patients' key role and responsibility in health management. However, elderly chronically ill patients, who are the main recipients of home health care, are often described as a 'vulnerable' group with limited desire or capacity to involve themselves in treatment and care. As such they are regarded as a 'passive' patient group in risk of being marginalized in the contemporary mantra of 'patient involvement', which demands active and responsible patients. However, we have limited insight into elderly chronically ill patients' perspectives on their role and responsibilities in relation to home health care. This study explores the perspectives of elderly chronically ill patients who receive home health care in Denmark. The paper focuses on how the patients perceive the distribution of roles between themselves and home nurses and their responsibilities in relation to care and treatment.

**Method:** The study builds on qualitative semi-structured interviews with 14 elderly chronically ill patients, who receive ongoing care and treatment at home in the capital region of Denmark. The inclusion criteria were: elderly patients (+65 years old) with one or more of three chronic conditions (diabetes, COPD, renal or cardiovascular diseases). The analysis is based on a social constructivist approach with focus on the different roles and responsibilities that patients ascribe to themselves and the nurses.

**Results:** Elderly chronically ill patients express a certain ambiguity when they describe their roles and collaboration with the nurses. On the one hand, the relationship is described in terms of a traditional 'nurse/patient' relation, where the patients express confidence in nurses' professional expertise. In regard to specific treatment and care tasks, the patients, to some degree, subject themselves to the nurses' authority as a health professional, who 'knows best' and takes responsibility. On the other hand, patients describe their relationship with the nurses in terms of a 'host /guest' relation. Here, patients play the active role of a host who determines the conditions for the nurses' visits and expect the nurse to take the role as

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'guest'. This guest-role implies that nurses show courtesy and good manners and respect the house rules, daily routines and preferences of the patient.

**Discussion:** The traditional 'nurse/patient' relationship that patients describe corresponds with the widespread perception of elderly chronically ill patients as a vulnerable group who takes a passive role in their health management and who rely uncritically on the professionals' judgment. However, the 'host/guest' relationship that patients also describe exposes an active engagement when it comes to the nurses' presence and behavior in their home. In this way, the home, as a clinical context, enables elderly chronically ill patients to make demands and set up conditions for the collaboration with health professionals. Thus, the ambiguity that elderly chronically ill patients express regarding roles and responsibilities in the collaboration with home nurses challenges the one-sided perception of elderly chronically ill patients as a vulnerable and passive group.

**Conclusion:** The study offers important insight into elderly chronically ill patients' perspectives on roles, responsibilities and relationships in home health care which highlights the centrality of the home as a context that empowers elder chronically ill patients' involvement in care and treatment even if they are in a dependent position.

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**Keywords:** home health care; elderly patients; patient involvement; nursing; qualitative interview

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