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Title: Incontinence care as a viable quality indicator for nursing home care quality: Looking at the past, present and the future.

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Hypothesis / aims of study: The present project is focusing on quality of care for nursing home residents suffering from urinary and/or fecal incontinence, and continues previous research within the field quality indicators in nursing homes. The primary aim is to investigate how quality indicators for incontinence in nursing home residents can be used as indicators for quality of care in nursing homes. Further, we aim at developing ICT and software for data collection that also gives feedback to staff needed for quality improvements. In the planned project we will evaluate the usability of the ICT, and staff experience with the feedback. Finally we will investigate the effect of using the quality indicator system for incontinence on patient outcomes.

Study design, materials and methods: A systematic review of literature, policy and practice regarding the development of quality indicators in nursing homes in different countries was conducted in 2009. A review of quality indicators presently used in nursing homes and potential new indicators regarding urinary and/or fecal incontinence will be performed. We have designed a project to test the validity, reliability and sensitivity of the quality indicators. Finally we will test the effectiveness of using quality indicators for incontinence care on patient outcomes and quality improvements. In total, 1200 nursing home residents in 20 nursing homes will be included in the study.

Results: As of 2009, over 44,000 Norwegian citizens lived in nursing homes. The long-term care nursing home population is a vulnerable patient group with extensive complex care needs. Nearly 73 % are 80 years and older. Most patients have advanced chronic illnesses and multiple diagnoses with as many as 80 % of these individuals suffering from dementia. There is an increasing demand for measures to monitor quality of care in nursing homes in Norway, but there is a lack of adequate care quality measures. Quality indicators are defined as indirect measures for quality for a particular area of interest, which is one of several measures that are used to monitor and document quality of health services. The usefulness of quality indicators depend on their relevance and efficacy. Therefore, effort must be put into developing robust, sensitive quality indicators. When developing quality measures it is recommended that the most relevant clinical areas for quality improvement are selected. Such areas are problems that are common for the target population, e.g. large volume, important because of high risk of adverse events, or areas with large variation. Incontinence is a clinical area that affects a large number of nursing home patients, and there is large variation in care. Published prevalence rates for urinary incontinence are ranging from 43% to 77%, and prevalence rates for fecal incontinence between 40-64 % are documented. A substantial number of nursing home residents have "double incontinence" – that is both fecal and urinary incontinence.

Some work is done to develop national quality indicators that can meet the needs. In Norway, reporting statistical data based on patient assessment has been in place since 2006. Each municipality reports individual patient data annually in a pseudonymous database administered by Statistics Norway. However, data quality is still low, and there are doubts about the reliability, especially regarding assessment of functional status. Other countries comparable to Norway have used measures for incontinence in nursing homes. However, these differ considerably in how they are defined and how detailed they are

described. As an example, Australia's indicator is that "Resident's continence is managed effectively", while the USA has quality indicators for low-risk residents who lost control of their bowels or bladder, residents who have indwelling catheters, incontinence without a toileting plan, fecal impaction, and urinary tract infection. In a report from the Norwegian Knowledge Centre, the conclusion was that the only recommended set of quality indicators for monitoring quality of care in nursing homes is the indicator set developed in USA, based on Resident Assessment Instrument – Minimum Data Set, RAI-MDS. RAI-MDS includes measures for incontinence in section H. Quality indicators from RAI-MDS have not been used in Norway, and more research is needed to validate the quality indicators for their applicability in Norwegian nursing homes. The two most problematic issues are obtaining evidence that the quality indicator can demonstrate meaningful differences in care and whether the information can be extracted with minimal extra efforts. These issues have not been addressed in the literature. As well, construct validity is problematic for most quality indicators, largely because there are few, if any, valid "gold standard" measurements of quality nursing home care that can be used for comparison. There have been studies testing how well specific quality indicators for urinary incontinence perform compared to other instruments. Urinary incontinence presence and its quantification can be reliably determined by using the 24-hour pad weighting test. However, for fecal incontinence there are no such equivalent tests, and presence and quantification will rely on self-reporting or information from nursing home staff.

The planned project consists of two parts:

Study I is a validation study where we will elicit indicators for incontinence care, develop ICT software for data collection and feedback, and then assess the validity, reliability and feasibility of quality indicators for incontinence care in nursing homes. The methodological approaches encompass three stages: 1) Determining the significance of urinary and fecal incontinence as an indicator for quality of care by conducting a clinical consensus process with experts, professionals, users and their representatives (a modified Delphi process); 2) Describing the indicator and operationalize the criteria and measurement method, including analysis strategy and risk-adjustment methods. This procedure will be based on the results in stage 1. ICT and software will be developed, possibly as an application for tablet PC/iPad; 3) Implementing indicators for incontinence and establishing the validity and reliability of the quality indicator.

Study II is an evaluation study regarding implementation of quality indicators for incontinence care in nursing homes, included response to feedback from the system; and a comparative effectiveness study investigating the effect of such implementation of quality indicators. The study encompasses two parts: 1) Evaluating the experiences with quarterly electronic registration over one year at selected nursing homes; and 2) Study the effect of implementing quality indicators for incontinence care on patient outcomes through a comparative effectiveness study with assessment at two points in time (baseline and 12 months after inclusion) using paired nursing homes.

Interpretation of results: The prevalence of urinary and/or fecal incontinence is high among nursing home residents. There is a lack of research regarding implementation of guidelines for incontinence care in nursing homes. Measuring quality of care by quality indicators is basis for monitoring quality of care and is facilitating quality improvements. Valid and reliable quality measures for incontinence care needs to be developed, and their sensitivity to change in nursing care needs to be tested. Tools and ICT to ease the use of quality indicators in clinical settings need to be developed. The effect of using quality indicators

depends on whether they are used correctly and feedback is responded to by implementing improvements.

Concluding message: The use of nursing sensitive quality indicators to monitor care quality in nursing homes is held back because of concerns about validity and reliability of measures used in the past and present. The review found that indicator development and testing is sparsely documented, and gaps in knowledge exist. With our planned study, we have a unique opportunity to expand the knowledge base on how to use quality indicators to improve quality of care for nursing home residents suffering from incontinence. The approach is transferable to other clinical areas where quality of care is low, and the study can demonstrate exemplary ways to monitor and improve quality of care.