Using patient experiences as an outcome of integrated care. How to measure it?

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Introduction: When is integrated care successful? Many studies have focused on clinicians’ perspective whether initiatives to sustain integrated care are successfully implemented and whether the initiatives have an effect. One of the primary aims in integrated care is to deliver a person-focused and population-based care. The foremost to assess whether integrated care initiatives enhance clinical integration, are the patients themselves. The Region of Southern Denmark has initiated a project focusing on the patient perspective, so that clinical integration is based on both patient and clinical perspective on the micro level. Moreover, the project deliver important knowledge to both the meso level and the macro level enhancing normative integration. In this project, clinical integration is composed by health care being hospital admissions and outpatient treatments, and social care being home care and rehabilitation.

The purpose of this project is to identify how patients conceptualize clinical integration and how this resembles key features for clinical integration identified by clinicians. Further, we want to develop a patient questionnaire measuring their experience of clinical integration.

Method: We performed a qualitative literature review to identify articles and reports concerning patient experiences in clinical pathways entailing clinical integration in-between health care and social care. Based on the literature we developed a semi-structured interview guide and conducted 12 patient interviews. Inclusion criteria for respondents were, ≥ 18 years, able to read and speak Danish, and having experienced a clinical pathway that included services from both health and social care. The study population include patients being admitted to hospital acute or scheduled, patients in outpatient clinical pathways, and patients with chronic and transitory conditions.

Data from the semi-structured interviews will be analyzed using grounded theory identifying themes that are important to patients in inter-sectorial clinical pathways. The identified themes will be compared to themes identified in the literature and the three subscales of the Nijmegen Continuity Questionnaire (NCQ)(2).

Based on the comparison of themes, we will develop a questionnaire and do a pilot test.

Progress report: We searched the literature for articles and reports surveys measuring different aspects of patient experiences on clinical integration. Several questionnaires
measured patient experiences on selected themes such as hospital care coordination, patient education, or for selected patient groups. We found a number of reports describing qualitative studies of patient experiences in clinical integration in-between health care, social care and primary care. These reports provided the background for the interview guide together with the NCQ. We choose the NCQ as inspiration for the development of the survey because it had elements general to all patients in inter-sectorial clinical pathways. The NCQ is translated from Dutch to Danish in a forward-backward procedure.

Patients for the qualitative semi-structured interviews were recruited from hospital departments specialized in orthopaedic surgery, neurology, cardiology, general medicine, and pulmonary medicine. From social care, we recruited patients with clinical pathways related to diabetes and oncology.

Discussion: It is challenging to identify themes that are sensitive to changes in clinical integration involving health care and social care. In other surveys of patient experiences, the quantitative data often provide a picture of general high patient satisfaction. We will try to take into account that some item must be very specific to be able to detect differences. In future assessment it would be beneficial to use both quantitative and qualitative data of patient experiences.

There is a risk of selection bias in the population that we wish to interview. However, in the selection process, we tried to included a population that reflects the general population with regard to age, socio-economic level and gender. However, the interviewed patients are in general older and do have comorbidity.

The data analysis is ongoing and results will be presented at the conference.

**Keywords:** research protocol; patient experience; integrated care; clinical integration; questionnaire