

TOWARDS AN ITEM BANK TO MEASURE PATIENT-REPORTED EXPERIENCE OF PERSON-CENTRED CARE

Akademisk avhandling

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Avhandlingen baseras på följande delarbeten

- I. Rosenlund, L., Jakobsson, S., Lloyd, H., Lundgren-Nilsson, Å., Hermansson, M., & Dencker, A. (2022). Measuring patient experiences of person-centred care: Translation, cultural adaption and qualitative evaluation of item candidates for use in England and Sweden. *Scandinavian Journal of Caring Sciences*, 36(1), 235-244.
- II. Rosenlund, L., Jakobsson, S., Lloyd, H., Diffner, A., Lundgren-Nilsson, & Dencker, A. Patient experiences and prerequisites of collaboration as partners in person-centred care in outpatient settings: An interview study. Submitted.
- III. Rosenlund, L., Lundgren-Nilsson, Å., Jakobsson, S., Lloyd, H. & Dencker, A. Initial Rasch analysis of candidate items to measure patient experience of person-centred care in a Swedish sample. In manuscript.
- IV. Rosenlund, L., Statton R., Lloyd, H., Close, J., & Dencker, A. Patient-reported experience measures for person-centred care: The development and testing of a UK-Swedish measure. In manuscript.

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Abstract

The reorienting of healthcare towards a more person-centred approach requires new approaches to evaluate care from the patient perspective. The overall aim of this thesis was to explore care from the perspective of people living with long-term conditions, and to develop and psychometrically test Swedish and English items to measure patient experience of PCC. In Study I, items (n = 155) probing patient experiences of PCC was translated, and a mixed-methods design was used for a qualitative item review involving different stakeholders (n = 84). The content, relevance, and acceptability of the items were evaluated in two validation rounds using questionnaires, a focus group discussion, and cognitive interviews. The item review resulted in 57 Swedish and English candidate items probing person-centred care from the patient perspective. Study II employed individual semi-structured interviews to explore communication and collaboration within a patient-professional partnership from the experiences of persons living with long-term conditions (n = 15). Through an inductive thematic analysis, five themes were identified: Adapting and self-managing in daily life, Handling and carrying information, Building trust and continuity, Acting in a flexible and transparent dialogue, and Sharing the way forward. Study III and Study IV were quantitative and used a cross-sectional design. The candidate items retrieved from Study I, were psychometrically tested against the Rasch measurement model in Study III with data gathered from a hospital in Sweden (n = 140). Data for Study IV was collected via a web panel in the UK (n = 501). Initial analyses revealed poor fit with local dependency and multidimensionality. After the removal of poorly fitting items, a testlet solution with clustered items grouped into dimensions of the conceptual model of person-centred care showed fit to the Rasch measurement model.

The findings presented in this thesis contribute to a better understanding how care is perceived as person-centred from the perspective of people living with long-term conditions and provides a solution and a set of items for a future item bank measuring patient experience of person-centred care for use in Sweden and the UK.

Keywords: Person-centred care, Person-centredness, Patient-reported experience measures, patient experiences