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Patients' position in care transitions – an analysis of patient participation and patient-centeredness

AKADEMISK AVHANDLING

som för avläggande av medicine doktorsexamen vid Karolinska
Institutet offentligen försvaras i Föreläsningssal B64, Karolinska
Universitetssjukhuset Huddinge.

Fredagen den 31 januari 2014 kl 13.00

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Stockholm 2014

ABSTRACT

Introduction: Patients with chronic diseases need care transitions between primary and hospital care when facing severe exacerbation or acute illness. Such transitions are associated with risks, potentially adverse events and patient suffering. To improve care transitions, patients' and healthcare professionals' experiences and perspectives of patient participation and patient-centeredness need to be explored.

Aim: The general aim of this thesis is to improve the knowledge and understanding of patient participation and patient-centeredness in handovers between primary and hospital care.

Methods: The thesis comprises four papers about patients with chronic diseases (asthma, diabetes mellitus I or II, chronic heart failure, chronic obstructive pulmonary disease) and/or polypharmacy, and the healthcare professionals who treated the patients in the hospital and the primary healthcare. The study was conducted in five European countries: the Netherlands, Spain, Poland, Italy and Sweden. Both qualitative (papers I, II, and III) and quantitative (paper IV) methodology are used. Paper I is a content analysis of individual interviews with 23 Swedish patients. Paper II is a secondary analysis of both individual and focus group data of 90 patients from the five countries. Paper III is a meta-synthesis of both individual and focus group data of 90 patients and 258 healthcare professionals from the five countries. Paper IV includes medical records of 22 Swedish patients by review and assessment of their handover records.

Results: Patients participated through both verbal activities (information exchange) and non-verbal activities (e.g. transfer of medication lists, referrals, and discharge notes). Patients' activity varied from taking responsibility for handover, via shared responsibility, to being passive. The patients' capacity for participation was reduced by health condition and health illiteracy, and strengthened by personality, experience and social network. Patients felt empowered by the knowledge they received through participation. Patients and healthcare professionals experienced both patient-centered handovers (patient needs addressed and discussed; responsive relations in which personalized information was provided; having continuity of care) as well as non patient-centered handovers. Organizational factors such as lack of time; emergent needs of other patients; and shift work forced the healthcare professionals to discharge patients without needs properly assessed; in discharge encounters held in a rush or without encounters; and by healthcare professionals who had not treated the patient at the ward.

Conclusions: Based on the findings, improved handovers – ensuring that information reaches the next setting – would mean having formal discharge encounters, and empowering patients with information, education and clarification of the handover process. In such cases, the patients can participate in handovers through exchange of information about their self-management, care and treatment in the present encounter, the next encounter and the handover between those. Organizational factors contribute to healthcare professionals' patient-centeredness, and patient-centeredness seems to increase patients' participation in handovers. The interactive aspects should be encouraged, an organization providing allocated time and resources, and a following patient-centered attitude of the healthcare professionals could benefit all involved stakeholders resulting in patient-centered handovers with participating patients.

ISBN: 978-91-7549-413-5