Patient Education Materials from a person-centred perspective

Coping and co-design in colorectal cancer care

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av

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I. Smith, F., Öhlén, J., Persson, L-O., Carlsson, E.
Daily Assessment of Coping in early postoperative recovery after colorectal cancer surgery
Manuscript, 2016

II. Smith, F., Carlsson, E., Kokkinakis, D., Forsberg, M., Kodeda, K., Sawatzky, R., Friberg, F., Öhlén, J.
Readability, suitability and comprehensibility in patient education materials for Swedish patients with colorectal cancer undergoing elective surgery: A mixed method design
Patient Education & Counselling 2014; 94(2): 202–209

III. Smith, F., Wallengren Gustafsson, C., Öhlén, J.
Participatory design in education materials in a healthcare context
Accepted for publication in Action Research, 2016

IV. Smith, F., Carlsson, E., Wallengren Gustafsson, C., Öhlén, J.
Principles on how to design and develop patient education materials to function as tools in person-centered care – a synthesis of Action Research and Person philosophy
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Abstract

To cope with possible stressful events after colorectal cancer surgery, patients need to be prepared for the early postoperative phase. Complementary written information is often used, but requires improvement. The overall aim for this thesis was to describe patient reported stressful events and coping strategies and with a person-centred approach characterize existing and co-design new patient education materials for patients undergoing colorectal cancer surgery.

Situational coping reported by 105 patients 4-6 weeks after colorectal cancer surgery were described in study I by using the Daily coping assessment instrument. Self reported stressful events along with coping strategies used and if considered helpful or not were analysed from 523 diary entries. In study II, 125 Patient Education Materials from 27 hospitals in Sweden were examined for readability, suitability and comprehensibility with a mixed method design. Using a validated instrument revealed that 44 % of the discharge information was not suitable. Language technology measures showed that up to 29 % of materials were difficult to understand. Analysis of five focus groups with 15 patients revealed additional areas to be included in new materials. A new Patient Education Material was developed with stakeholders (patients, professionals and researchers) using a participatory methodology design. In study III, negotiations derived by areas of tensions were reflected on and presented. Main tensions were related to power structures. Parallel to this, in study IV, principles on how to design Patient Education Materials by combining the dimensions of 1st, 2nd and 3rd person described in Action research as voice and in Ricoeur´s philosophy as self were developed from a theoretical analysis.

As a whole, the thesis is built upon the principles of first, second and third person perspective used as a philosophical and theoretical basis to present a workable example in a practical setting. The results can benefit both patients and other relevant stakeholders in the healthcare system in developing written patient education materials..

Keywords: Person-centred care, colorectal cancer, coping, written information, patient education materials, participatory co-design

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