XXX CICLO - Anno Accademico 2017/2018

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Titolo tesi: Self-care in ostomy patients and their caregivers: From the patients' experience to new tools for monitoring the outcome

ABSTRACT

Background

Stoma creation is a radical treatment with the loss of an important bodily function and an alteration of one's body image. It causes physical, psychological, and social changes in lifestyle through the acquisition of new skills for the management of the ostomy and the new condition. Ostomy self-care is considered essential to the maintenance of a certain socio-psychological stability, acceptance of the stoma, and adaptation to it. Research in this field may provide additional information about central elements when adapting to life with a stoma, especially on stoma care, stoma problems, and stoma education. There are currently no studies that adequately focus on the self-care of these patients and their caregivers, and despite the availability of a growing number of standardized tools, it seems there are no tools that measure this concept in particular. In addition, aspects related to the impact of self-care on the patient's quality of life, stomal complications, and hospital readmission are worthy of investigation. Riegel's self-care theory is a theory that best represents these patients. In fact, Riegel et al., define it as a naturalistic decision-making process that influences actions that maintain physiological stability, facilitate the perception of symptoms, and direct the management of those symptoms.

Objectives

The objectives of this doctoral program were (1) to explore the experiences of self-care of patients with a urostomy and identify the influencing factors of self-care, (2) to develop and validate two new tools to measure self-care in ostomy patients and their caregivers, and (3) to describe the levels of self-care in ostomy patients and their informal caregivers and the impact of self-care on quality of life, ostomy complications, and hospital readmissions.

Methods

In order to respond to the first aim, an interpretative phenomenological analysis was performed, as a qualitative method seemed ideal to explore patients' experiences. A purposive sample of eleven people living with urostomies took part in semi-structured interviews composed of eight open-ended questions about their self-care experience. The interviews were done four to six months after surgery. Collection of data stopped when data saturation was reached. Data were collected by an expert nurse who was not involved in the participants' care from March and September 2016. Data were analysed by two researchers independently in accordance with the principles of interpretative phenomenological analysis, and strategies were adopted in order to ensure trustworthiness. For the second aim, a multistep process was implemented, articulated along the following phases: instrument development, content validity, construct validity, criterion validity, and internal consistency. For the last aim, a study protocol describing a multicentre longitudinal study was developed. The study will be administered using a questionnaire given to a sample of patients with ostomies and their informal caregivers to collect data about this life-changing experience. Data will be collected at baseline (coinciding with access to the ostomy outpatient centre) and after six months from eight outpatient centres in Rome. Data collected will include sociodemographic and clinical data, including information about living conditions, family and work conditions, clinical information, and ostomy type. The Ostomy Self-Care Index

(OSCI) and the Caregiver Contribution to Self-Care in Ostomy Patient Index (CC-OSCI) will be used to collect data about self-care. The Stoma QoL and SF12 will be used to assess quality of life, while the PHQ-9, Mutuality Scale, Multidimensional Scale of Perceived Social Support, and Caregiver Preparedness Scale will assess psychosocial behaviour (e.g. depression, mutuality). Data analysis will include descriptive and correlational statistical techniques.

Results

The first study involved eleven participants, two women and nine men, with an age range from 59 to 83. Six themes and twelve subthemes emerged from the data analysis. The themes were surgery impact (life expectancy and fear of relapse, physical repercussions of surgery, quality of life), body image, daily and social activities (daily activities and hobbies, away-from-home management, job and stoma management), stoma and sexuality, managing stoma education (home stoma management and reference people, nurse's support, problem-management strategies, lack of information), and family and friends' support (emotional involvement and encouragement, feeling of pity). For the second aim, a multicentre validation study was conducted on a convenience sample of 468 ostomy patients and 227 caregivers. Two indexes were developed, building on the self-care theory of chronic illness: The Ostomy Self-Care Index (OSCI) and the Caregiver Contribution to Self-Care in Ostomy Patient Index (CC-OSCI). Tool validation was performed by testing content validity, construct validity, criterion validity, and internal consistency. For the OSCI, 32 items were developed and grouped into four 5-point Likert scales: maintenance, monitoring, management, and confidence. For the CC-OSCI, 22 items were developed and grouped into three 5-point Likert scales: maintenance, monitoring, and management. The content validity indexes for the OSCI and CC-OSCI were 95% and 93%, respectively. Exploratory factor analysis showed appropriate factor loadings (OSCI: min 0.395 to max 0.852; CC-OSCI: min 0.442 to max 0.841). Criterion validity was established through significant correlation between self-care and quality of life, complications, hospital readmissions in patients, and caregivers (Mann-Whitney U test; $p < 0.0001$ in all scales). Strong internal consistency was found for the overall indexes and within the scales (OSCI: $\alpha = 0.975$; CC-OSCI: $\alpha = 0.972$). Regarding the third aim, the study findings will have a theoretical impact on the study of ostomy patients and practical implications in planning interventions aimed at supporting patients and their caregivers.

Conclusion

This doctoral program has allowed for the study of self-care in a new population composed of ostomy patients and their caregivers. The results from this qualitative study showed that life can be complex for urostomy patients, since a urostomy brings changes in all aspects of their life, resulting in the need for a psychological and practical support system. For instance, not only are patients' adaptation skills important, but also their reactive skills, the care of their family, and an adequate level of self-care, all of which can play an important role in letting the patient return to pre-surgery work and social activities. Considering this, it is important to provide urostomy patients support and continuing education to foster a high level of self-care, a better quality of life, and respect for their needs. In addition, there should be further research to help urostomy patients to have the best possible level of self-care and help nurses address patients' needs through a personalized education program. The results of this study showed that the OSCI and CC-OSCI are valid and reliable indexes. Further studies specifically aimed at predicting the level of self-care are especially recommended. In addition, it is important to continue developing advanced psychometric tests to study in depth the properties and characteristics of these indexes. The protocol study proposed supports the importance of understanding how self-care influences ostomy patients and their caregivers. Self-care behaviours are a convenient way to ensure continuity of care, minimise complications, reduce hospital readmissions, and improve quality of life. Collected data about self-care helps nurses to personalise interventions for patients and their caregivers and prevent complications and readmissions. Caregivers' involvement can support and increase patients' level of self-care.
Keywords

Cancer, caregiver, hospital readmission, instrument development, interpretative phenomenological analysis, longitudinal study, ostomy patients, psychometric test, quality of life, research protocol, self-care, stoma complication