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Development and validation of the preparedness for Colorectal Cancer Surgery Questionnaire: PCSQ-pre 24

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ABSTRACT

Purpose: The aims of the study were to develop and psychometrically evaluate a patient-reported outcome instrument for the measurement of preoperative preparedness in patients undergoing surgery for colorectal cancer.
Methods: This study was conducted in two stages: a) instrument development (item generation, construction of items and domains), empirical verification and b) instrument evaluation. A questionnaire with 28 items measuring preparedness for surgery was developed covering four domains and was tested for content validity with an expert panel and with patients. Psychometric testing of the questionnaire was conducted on 240 patients undergoing elective surgery for colorectal cancer.
Results: The scale content validity index of the preparedness items was 0.97. The final version consisted of 24 items measuring 4 subscales: Searching for and making use of information, Understanding and involvement in the care process, Making sense of the recovery process and Support and access to medical care. Confirmatory factor analysis revealed good model fit with standardized factor loadings ranging from 0.58 to 0.97. A well-fitting second-order factor model provided support for a total preparedness score with second-order factor loadings ranging from 0.75 to 0.93. The ordinal alpha values of the four latent factors ranged from 0.92 to 0.96, indicating good internal consistency. The polyserial correlations with the total score were 0.64 ($p < 0.01$) for the overall preparedness question and 0.37 ($p < 0.01$) for overall well-being.
Conclusion: The Swedish Preparedness for Colorectal Cancer Surgery Questionnaire for use in the preoperative phase demonstrated good psychometric properties based on a sound conceptualization of preparedness.

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1. Introduction

Preoperative teaching is an interactive process in which patients are provided with information and explanations to enable their understanding about the surgical process (Bernier et al., 2003). Psychosocial support that helps to promote patients' postoperative recovery is highlighted. An integrative review (Suhonen and Leino-Kilpi, 2006) identified the following important areas of preoperative information needs for surgical patients: symptoms, pain management, wound care, activity, postoperative self-care and psychological issues. Consideration of all these factors points to the need to prepare the patient for pre- and post-operative phases. As highlighted by Kenton et al (Kenton et al., 2007) patient preparedness is an important predictor for surgical outcome, and how the patient takes action to become an active partner is of particular importance for the evaluation of person-centred care (Olsson et al., 2013). The patient's sense of preparedness before surgery and

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during recovery is thus important to take into account. A particular challenge in colorectal cancer (CRC) care, the third most common malignancy in Europe (van de Velde et al., 2014) and the USA (Jemal et al., 2008), is to meet patient information needs over time throughout the care process from diagnosis, surgery, postoperative care and recovery (Allvin et al., 2008; Norlyk and Harder, 2009). Since surgery is the primary treatment, the surgical phase is of significance for patient learning – a phase where knowledge exchange often takes place within a short period of time. In the last decade, the enhanced recovery after surgery (ERAS) protocol (Eskicioglu et al., 2009; Kehlet, 1997) has been positively evaluated and proven to be best evidence-based practice during pre- and postoperative CRC care, reducing morbidity, mortality and length of stay in hospital. An important part of the protocol is to coach the patient throughout the hospital stay to improve recovery (Eskicioglu et al., 2009). Even though ERAS has impact on the patient's participation in improving his or her recovery, it is mainly evaluated on the basis of bio-medical variables (Norlyk and Harder, 2009). The evidence-based treatments included in the ERAS protocol have increased over the years. Some of the key components are preoperative carbohydrate loading, no overnight fasting and immediate postoperative diet, no nasogastric-tubing and avoidance of drainage and early removal of urinary catheter, early postoperative structured mobilisation and pain control (Gustafsson et al., 2013; Nygren et al., 2013). However, since patients must be prepared for surgery and recovery, not only bio-medically, but also emotionally and cognitively, there is a need to develop measures for the evaluation of patients' preparedness for surgery and subsequent recovery.

1.1. Questionnaires measuring preparedness

Only a few validated questionnaires for measuring preparedness were found. Most measured family caregivers' (Archbold et al., 1990) or professionals' perspectives (Todaro-Franceschi, 2013; Van Riesenbeck et al., 2015). The "Preparedness for Caregiving Scale" (Archbold et al., 1990) measures the perceived readiness to provide care. Over the years, this measure has been successfully operationalized into useful (Grant et al., 2013; Hendrix et al., 2015; Henriksson et al., 2013; Hudson et al., 2013; Stone, 2014) and valid measurement instruments (Henriksson et al., 2015; Hudson and Hayman-White, 2006). Preparedness is here related to readiness for the tasks and demands of the care-giving role. In the study by Stone (Stone, 2014) "The Preparedness for Caregiver Scale" developed by Zwicker (Zwicker, 2010) was used to measure caregivers preparation to provide care following a patient's discharge from inpatient rehabilitation. In Todaro-Franceschi's (Todaro-Franceschi, 2013) questionnaire "Perceptions of preparedness and ability to care for dying patients in intensive care" (PPACD scale) the focus is on perceived competence in talking and listening to patients. Wheatley-Price et al (Wheatley-Price et al., 2010) developed a questionnaire (not validated) to measure physicians' preparedness in discussing diagnoses with lung cancer patients to help physicians be more comfortable in delivering a serious diagnosis.

Validated questionnaires for measuring patients' preparedness were found in connection with recovery from breast cancer treatment (Jones et al., 2013), mammography (Wang et al., 2015) and oncological clinical trials (Manne et al., 2014). In Jones et al.'s study (Jones et al., 2013), "Perceived Preparedness for re-entry scale" was used to measure what to expect physically and emotionally during recovery from breast cancer treatment, how to make healthy eating choices and how to be connected to community services. Wang et al (Wang et al., 2015) used the "Mammography Preparedness Measure" (MPM) to study knowledge and preparedness for mammography in women with intellectual disabilities. In the study by Manne et al. (Manne et al., 2014), cancer patients' preparedness for participating in oncological clinical trials was measured by the Ottawa Preparation for Decision making scale.

Kenton et al (Kenton et al., 2007) studied the influence of readiness for reconstructive pelvic surgery on surgical outcomes. A "Preoperative preparedness questionnaire" was developed for measuring knowledge and understanding related to alternatives, purpose, risks and complications of surgery pre- and postoperatively. The participants were considered 'prepared' if they strongly agreed with the statement, "Overall I feel prepared for my surgery". Brubaker et al (Brubaker et al., 2014) also used the "Preoperative preparedness scale" in a study of stress urinary incontinence surgery. Higher preoperative preparedness was associated with higher postoperative satisfaction. Kenton's questionnaire (Kenton et al., 2007) is not psychometrically validated and was too focused on the surgical outcome, which was regarded as limited. Our review revealed that the term preparedness is seldom clearly defined, nor is the literal meaning described or problematized, with the exception of Hebert (Hebert et al., 2006, 2009). Notably, preparedness is often used in combination with other terms, such as readiness (Hudson and Hayman-White, 2006; Kenton et al., 2007) and knowledge or understanding (Wang et al., 2015).

A few single-item questionnaires measuring patient preparedness were found (e.g., (Hauksdottir et al., 2010; Hebert et al., 2006; Steginga et al., 2005)). One illustrative example of a single item is "How prepared were you for your wife's death" (Hauksdottir et al., 2010). Here, preparedness is described as a forewarning.

No validated questionnaires involving the concept of preparedness in relation to the pre- and post-surgical phase associated with CRC were found.

1.2. Conceptualization of preparedness

As a basis for operationalizing preparedness there is a need to position the concept semantically and theoretically. Preparedness is a future or forward directed noun and derived from the adjective "prepared" which means to be capable of achieving something (Friberg, 2001). The verb "preparing" means to create a favourable situation by taking action in advance. The person is prepared for something, a notion also revealed in the literature search for available instruments. Theoretically, the construct of preoperative preparedness is informed by patients' knowledge-seeking, concerns and sense-making of illness (Radley, 1994), treatment, signs and symptoms in relation to surgery.

We assume that the construct of preparedness is multidimensional, including cognitive: I know, emotional: I feel, and activity: I can, aspects (Friberg et al., 2007; Hebert et al., 2006, 2009). Preparedness could be characterized as building capabilities to handle possible future problems and challenges (Eriksson, 2008) in an ongoing process of realizing, adjusting and anticipating what to be prepared for (Holm et al., 2015), as well as awareness that the process might involve transitions (Janze and Henriksson, 2014; Jones et al., 2013). We position preparedness in a view of the patient as a person (Ricoeur, 1992; Smith, 2010) with biography, expectations, responsibilities and capabilities. Thus, preparedness indicates a shift from seeing patient education as explained by behaviour to seeing that person seeking knowledge for "acting", which here points to something conscious and voluntary in comparison to the more reactive and reflexively laden term "behaviour" (Cf. (Schutz, 1967)).

In summary, patient preparedness presumes some kind of knowledge-seeking activities. Most often, this occurs in relation to professionals' intentions to support and involve the patient in care and decisions. Consequently, preparedness is always situational and thus contextualized as recovery following CRC surgery is

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