

## Patient Education

# Readability, suitability and comprehensibility in patient education materials for Swedish patients with colorectal cancer undergoing elective surgery: A mixed method design



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## ARTICLE INFO

## Article history:

Received 25 February 2013

Received in revised form 20 August 2013

Accepted 26 October 2013

## Keywords:

Colorectal cancer

Patient education materials

Surgical care

ERAS

Readability assessment in material

Suitability assessment in material

Comprehensibility assessment in material

Language technology analysis

Focus groups

## ABSTRACT

**Objective:** To characterize education materials provided to patients undergoing colorectal cancer surgery to gain a better understanding of how to design readable, suitable, comprehensible materials.

**Method:** Mixed method design. Deductive quantitative analysis using a validated suitability and comprehensibility assessment instrument (SAM + CAM) was applied to patient education materials from 27 Swedish hospitals, supplemented by language technology analysis and deductive and inductive analysis of data from focus groups involving 15 former patients.

**Results:** Of 125 patient education materials used during the colorectal cancer surgery process, 13.6% were rated 'not suitable', 76.8% 'adequate' and 9.6% 'superior'. Professionally developed stoma care brochures were rated 'superior' and 44% of discharge brochures were 'not suitable'. Language technology analysis showed that up to 29% of materials were difficult to comprehend. Focus group analysis revealed additional areas that needed to be included in patient education materials: general and personal care, personal implications, internet, significant others, accessibility to healthcare, usability, trustworthiness and patient support groups.

**Conclusion:** Most of the patient education materials were rated 'adequate' but did not meet the information needs of patients entirely. Discharge brochures particularly require improvement.

**Practice implications:** Using patients' knowledge and integrating manual and automated methods could result in more appropriate patient education materials.

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## 1. Introduction

Printed patient education materials (PEM) are used to provide information, advice and/or counseling about procedures and activities linked to diagnosis and intended care. They are a complement to oral information [1]. An essential challenge for healthcare professionals is to satisfy the information needs of patients with colorectal cancer (CRC) throughout the cancer care

process, from diagnosis, surgery and postoperative care to recovery and follow-up [2–4]. Patients also need to understand and adhere to certain routines and procedures before and after CRC surgery to promote the best outcome [5,6].

Colorectal cancer is the third most common malignancy in Europe and the USA [7,8]. In Sweden, with a population of 9.5 million, almost 6000 people are diagnosed with CRC each year. The primary form of treatment is surgery complemented by adjuvant chemotherapy when necessary. The widely used [9–13] multi-modal care pathway for the surgical process, the enhanced recovery after surgery (ERAS) protocol, has proved to be best evidence-based practice during pre- and postoperative care [5,6]. Key components, such as dietary changes and structured mobilization, require greater patient involvement, even on the

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day of surgery. The outcomes are improved recovery, fewer complications and a reduced stay in hospital by 3–5 days [6].

Much of the responsibility for postoperative recovery is being shifted to patients and their families, taking place at home with less help and support from hospital staff [2,3]. Many patients experience a sense of desolation after discharge [2,3,14], and a feeling of ‘existential issues lurking in the background’ [3]. However, the literature [3,5,6] shows little evidence that the existential or psychological aspects of having cancer are addressed when informing patients before and after surgery. Furthermore, information needs across the cancer care process for patients with CRC are not described fully [4]. PEM are important as a source of supplementary information and support, from diagnosis to follow-up. However, the language used in printed CRC information is more complicated compared to other cancer diagnoses [15]. This makes it more difficult to understand, particularly for older people [16]. Acute psychosocial reactions to a cancer diagnosis could also be greater for less literate patients with a lower socioeconomic status and education level. [17]. Cancer generally is more common in people with lower literacy levels [7] and discrimination in CRC care has been reported in those with lower socioeconomic status [18]. Consideration must also be given to health literacy – the ability to acquire, understand and use information about health, including cognitive and social functions [1,19]. This concept could be considered dynamic, depending on internal and external factors, such as the level of stress in a new context [20]. A person with a high health literacy level might struggle to understand written information during certain periods in the cancer care process. The way information is presented is vital to all patients, regardless of background and level of education.

Although healthcare makes complex demands on patients, including self-management of their health and reading difficult texts [1], PEM are often produced internally by hospital staff [21] without sufficient consideration being given to their suitability for the intended reader [22]. Avoiding unknown vocabulary and difficult grammatical structures makes the information easier to read and comprehend [1,22–27]. Content, organization, layout, typography, illustrations and how the PEM stimulate patient learning and motivation must be taken into account [28]. More suitable PEM can help patients pose more informed questions to their caregiver and could reduce their anxiety [29].

Different methods and instruments are used to evaluate the readability, suitability, comprehensibility and content of the PEM [1,30–32]. Language technology methods for measuring the readability of text computationally [33] offer the advantage of measuring consistently and objectively linguistic factors that characterize PEM. Although these methods have been used extensively in the analysis of all types of medical content [34,35], they fall short on measuring complex dimensions, such as content, complexity, layout or familiarity with the subject, and additional methods are required. The PEM thus need to be evaluated for readability, suitability, comprehensibility and content [36] in relation to patients’ perceived information needs [4]. Account needs to be taken of how PEM can be better designed and delivered to become a valuable complement to oral information for patients with CRC.

### 1.1. Aim

The aim of the study was to characterize PEM provided to patients undergoing surgery for colorectal cancer to gain a better understanding of how to design readable, suitable and comprehensible PEM. The research questions were:

- What are the levels of readability, suitability and comprehensibility of PEM?

- How do patients perceive the suitability, comprehensibility and content of PEM?

## 2. Methods

A mixed method design [37] was used, i.e. the application of deductive quantitative analysis of PEM using a validated instrument, supplemented by language technology analysis, as well as deductive and inductive analysis of data from focus group meetings involving former CRC patients.

### 2.1. PEM collection, inclusion and classification

All patients diagnosed with CRC are entered into the Swedish colorectal cancer registers and the hospitals are divided into quartiles according to the number of registrations per year. Hospitals with more than 35 CRC registrations in 2008 were asked to send all the PEM used in 2010. The hospitals were contacted by e-mail and, if necessary, they received a follow-up telephone call and a reminder e-mail. Externally produced PEM from four stoma care companies used by most hospitals were also included (Fig. 1) resulting in 217 PEM items. PEM that provided information, advice or counseling about procedures and activities during the CRC surgery process were included for analysis ( $n = 125$ ), and classified as either brochures or leaflets. A brochure is printed matter comprising more than one page of information, usually folded or bound. A leaflet is a single-page handout. Excluded PEM were: welcome letter/notification letter, declaration of health, maps and directions, business cards, ERAS diary with no information, oncological treatment and other material not specifically related to CRC surgery ( $n = 92$ ). To our knowledge, none of the PEM were evaluated using specific validated instruments.

### 2.2. Manual analysis

The PEM were divided into six groups by the first author: information brochures about the surgery process, information

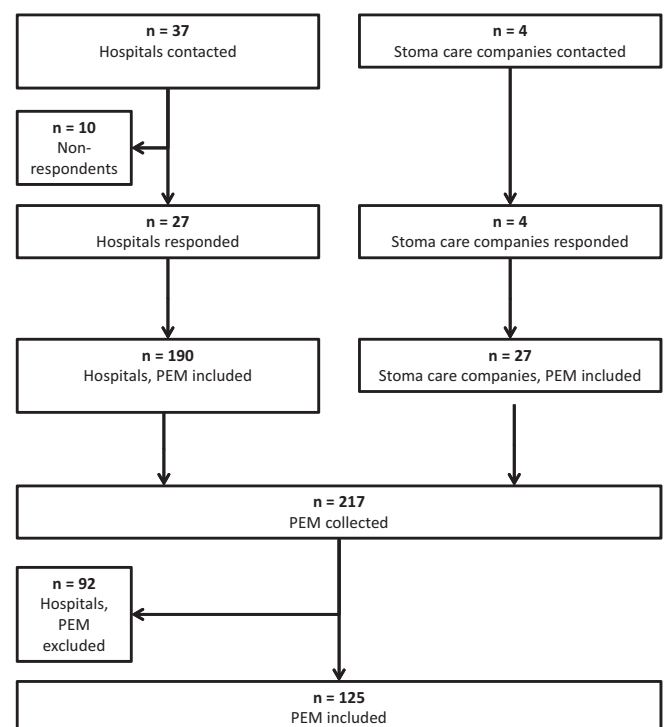


Fig. 1. Patient education materials (PEM) included.

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