



# Time from first symptom experience to help seeking for colorectal cancer patients: Associations with cognitive and emotional symptom representations



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## ABSTRACT

**Objectives:** The aim was to assess the association between cognitive and emotional symptom representations prior to diagnosis and the length of the patient interval (i.e. the time from the first symptom is experienced until healthcare is sought) for colorectal cancer patients.

**Method:** The study population included 436 newly diagnosed colorectal cancer patients. Questionnaire data were collected using the Danish Revised Illness Perception Questionnaire (IPQ-R), including cognitive and emotional symptom representations and information on the patient interval.

**Results:** High score in treatment control was associated with short patient interval (PR=0.52, 95% CI: 0.31–0.89) and high score on the timeline cyclical dimension was associated with long patient interval (PR=2.14, 95% CI: 1.29–3.57). Hence, patients with negative beliefs about the treatability of their symptoms and patients with strong beliefs about the cyclical nature of their symptoms were more likely to have a long patient interval. Assigning *blood in stool* as the most important symptom significantly interacted in the association between the patient interval and the two cognitive symptom representations *consequence* and *personal control*.

**Conclusion:** The results indicate that aspects of symptom representations were associated with the patient's help-seeking.

**Practical implications:** These findings may help clinicians and public health planners shorten patient intervals.

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## 1. Background

Colorectal cancer is one of the most commonly experienced types of cancer in Denmark [1]. For Danish colorectal cancer patients diagnosed during 2000–2002, the age-standardised relative 5-year survival was estimated to be 51.7%, which was significantly lower than in comparable countries, such as Sweden, Canada and Australia [2]. In Denmark, 25% of colorectal cancer patients are treated in stage IV in the tumour, node, metastasis

(TNM) system, while only 16% are treated in TNM stage I [3]. In addition, Denmark has a less favourable stage distribution than other countries [4]. Later diagnosis is thus believed to be a potential explanation for the poorer prognosis among cancer patients in Denmark compared with other countries [2,5]. This may occur as a result of longer patient intervals sometimes referred to as patient delay (i.e. the time from the first symptom is experienced until healthcare is sought) [6]. In Denmark, population screening for colorectal cancer using immunochemical faecal occult blood test (iFOBT) has been introduced in 2014 to reduce colorectal mortality through early detection [7]. Nevertheless, it is estimated that approximately 75% of colorectal cancer patients will still be detected through symptomatic presentation [8], making the patient interval essential.

If we are able to identify factors that influence the patient interval, this knowledge may inform health workers and policy

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makers in their efforts to reduce the length of the interval and as Torring et al. [9,10] have made clear, time matters for the cancer outcome. Leventhal's common-sense model (CSM) is a theoretical model that has been suggested as a useful tool to identify factors related to the patient interval after self-discovery of a cancer symptom [11]. The CSM provides a framework to explain how people interpret and cope with health problems [12], and it builds on the proposition that individuals create their own *common sense* representations of a health problem to guide their coping efforts [13]. These representations involve the creation of cognitive perceptions of *identity*, *timeline*, *consequences*, *control/cure* and *causes* of the health problem and also the creation of an *emotional* representation of the health problem [14].

In relation to the components *identity* and *consequences*, several studies have found that patients who do not attribute their symptom to cancer or do not perceive their symptom as serious have a longer patient interval than patients who perceive their symptoms as serious or specifically as cancer [15–19]. Conversely, Pedersen et al. [20] found that experiencing the alarm symptom, rectal bleeding, was associated with long patient intervals in colorectal cancer patients although many of these patients reported to have wondered if their symptom could be attributable to cancer. The *timeline* component of the CSM [14] is also relevant as patients who perceive their symptoms as temporary rather than permanent have been found to have a longer patient interval [15]. Thus, previous studies have used components comparable to those from the CSM, but have not explicitly been based on Leventhal's theoretical framework. However, several researchers have called for theoretically based studies on the patient interval [21–23] and Leventhal's CSM has been suggested as a useful tool in this connection [23]. In this study we have used the revised Illness Perception Questionnaire (IPQ-R) [24] to assess the representations of the CSM, which is also considered the measure of choice in other studies using Leventhal's theoretical framework [25,26].

The aim of this study was to investigate the association between the patient interval and cognitive and emotional symptom representations prior to colorectal cancer diagnosis. A further aim was to examine whether experiencing *blood in stool* (ranked as the most important symptom) was a potential effect modifier for the association between symptom representation and the length of the patient interval.

## 2. Methods

### 2.1. Study population

The study population consisted of patients who had been registered with histologically confirmed colorectal cancer in the Danish Pathology Data Bank (DPDB) between 1 January and 1 May 2010. The DPDB is a nationwide online database containing detailed information on all pathology specimen analysed in Denmark [27]. The database is updated automatically when a pathology analysis is completed at one of the Danish hospitals [28] and for this study data were retrieved using the Danish version of the Systemized Nomenclature of Medicine (SNOMED) codes for colorectal cancer: T67\*3, T68\*3 and T73970.

The data collection took place in the period from 12 July to 26 August 2010. In total, 1105 patients were identified in the DPDB (study base). In this present study, 206 (18.6%) were excluded because of death, unknown address or research protection (i.e. residents holding publicly recorded protection from research participation). The remaining 899 patients received a questionnaire; non-respondents received a reminder, including a new copy of the questionnaire, three weeks later. A total of 577 completed questionnaires were received during the data collection period (response rate: 64.2%).

The following groups of respondents were excluded from the analyses: 47 respondents (8.1%) were excluded because they indicated that they did not have any preceding symptoms of cancer before contacting a general practitioner (GP), 52 respondents (9.0%) because they had not stated which of their symptoms they perceived as their most important and 42 respondents (7.3%) were excluded as more than 50% of their responses were missing. Hence, a total of 436 respondents were included in the statistical analyses.

### 2.2. The IPQ-R

The revised Illness Perception Questionnaire (IPQ-R) [24], a quantitative measure derived from the CSM, was used to measure cancer patients' representations of their symptoms prior to diagnosis. The IPQ-R consists of nine subscales, including *identity* (perceptions of the symptoms associated with the health problem), *timeline acute/chronic dimension* (perception of the chronicity of the health problem), *consequences* (anticipated and experienced consequences of the health problem), *personal control* (perceptions of own ability to control the health problem), *treatment control* (perceptions regarding treatment for controlling the health problem), *coherence* (understanding of the health problem), *timeline cyclical dimension* (perceptions about the stability or changeability of the health problem), *emotional representation* (emotional responses to the health problem) and *cause* (perceived cause of the health problem) [24].

We adapted the IPQ-R to measure symptom representations among patients with colorectal cancer symptoms and validated the instrument in this setting [29]. In this modified IPQ-R, the *identity* subscale comprised 13 commonly experienced symptoms among colon and rectal cancer patients. Before answering the modified IPQ-R, patients were asked to think back on the time before contacting their GP. First patients were asked to rate whether they had experienced each symptom and then whether they believed that the symptom was related to their cancer. The patients were then asked to state which symptom they perceived as the most important and to think of this symptom when assessing the remaining questionnaire. Following the *identity* subscale, the cognitive representations were listed (*timeline acute/chronic dimension*, *consequences*, *personal control*, *treatment control*, *coherence*, *timeline cyclical dimension* and *emotional representations*) and included 32 statements. All statements were rated on a 5-point Likert scale: strongly disagree, disagree, neither agree nor disagree, agree and strongly agree. The scores of each subscale were calculated as stated by Moss-Morris [30].

### 2.3. Dependent variables

The patient interval was calculated from the dates entered in the questionnaire by the patients. Thus, the number of days between the date of the first symptom experience and the date of the first symptom-related contact to the GP was computed for each patient and subsequently dichotomised using the 75th percentile as the cut-off value, which was 88 days on average for all colorectal cancer patients.

### 2.4. The IPQ-R subscales

Based on whether the patients believed that any of their symptoms were related to cancer before their GP contact, the *identity* subscale was divided into patients who 'considered cancer' and patients who 'did not consider cancer'. The subscale ratings on the *timeline acute/chronic dimension*, *consequences*, *personal control*, *treatment control*, *coherence*, *timeline cyclical dimension* and *emotional representation* were divided into three groups, i.e. low, middle and high scores, using the 25th and 75th

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