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Cognitive and emotional processes influencing patient presentation or non-presentation of oral Cancer symptoms to healthcare professionals

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ABSTRACT

Objective: Greater time that patients take to present symptoms to health care providers (HCPs) increases the likelihood of later stage cancer, which increases mortality and morbidity in symptomatic cancers. The common-sense model (CSM) is used to understand time to first consultation with a healthcare provider, but inconsistencies exisy between its current use and important empirical findings.
Method: To resolve inconsistencies, we conducted a qualitative examination to determine how the CSM could be revised to better account for these findings. We conducted in-depth interviews of a consecutive sample of 38 recently diagnosed patients who described events from first noticing symptoms to first consultation. Framework analysis was used to develop a theoretical model of processes leading to presentation or non-presentation.
Results: Patients reported median presentation times of 3–4 weeks. Early presentation was facilitated by pre-symptomatic perceptions of vulnerability to serious illnesses and beliefs that early intervention could mitigate illness. These patients rarely tried to identify symptoms. They responded inductively, seeking help because symptoms were unusual. Where patients did not describe pre-symptom perceptions of vulnerability, many deductively tried to identify symptoms but misattributed them to minor conditions. Pre-symptomatic perceptions of vulnerability could also prolong presentation. When vulnerability was characterized by intense fears of cancer and cancer treatment, patients tended to avoid thinking about symptoms which extended presentation time.
Conclusion: Risk perception theories explain how participants' pre-symptomatic perceptions of vulnerability and potential treatment outcomes influence presentation time. Incorporating risk perception perspectives into the CSM can improve its ability explain responses to ambiguous symptoms.

1. Introduction

During 2014, total UK cancer incidence was 356,860 cases, with ten-year survival of about 50% [1]. Later stage cancers are associated with higher mortality and morbidity. A key modifiable cause of later stage cancers is time to commence treatment [2], with time mostly taken between patients first detecting symptoms and first presenting to a health care professional (HCP) [3]. Oral squamous cell carcinoma (OSCC) is a symptomatic cancer that has doubled in UK incidence over 10 years [4] to a 2012 incidence of 7300 and 48% five-year mortality [5]. Time to treatment of three months or more increases the probability of late stage OSCC by 4.5 times [6, [7]]. 20–30% of patients first consult HCPs more than three months after detecting symptoms [3].

Most cancer cases occur outside monitored populations [8]. Interventions to reduce time to presentation cannot solely be directed toward 'at risk' individuals but should target large populations [9]. Theoretically-grounded population interventions can facilitate presentation of cancer symptoms in populations [10]. The common-sense model (CSM) [11] has been extensively and successfully used to understand events during symptom appraisal and decisions about help-seeking. We argue that conceptual problems exist in the application CSM, and aim to resolve these.

1.1. Theoretical background

The CSM posits that individuals recognize specific illnesses because they perceive symmetry between symptoms and their implicit and explicit mental representations of those illnesses [11]. Representations are underpinned by prototypes; long-term understandings of normal health states and specific illnesses, that are formed through personal experience and social and cultural understandings. Self-prototypes pertain to physical and psychological attributes associated with normal

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functioning. Illness prototypes refer to understandings of specific illnesses organized in terms of symptoms, expected duration of the illness, implications for morbidity, cause and likely outcomes of actions to mitigate illness. The detection of symptoms that deviate from self-prototypes stimulates the formation of symptom representations. People access illness prototypes that are similar to observed symptoms, and deductively use prototype information to populate their representations [12]. Symptom presentation is associated representations that are associated with serious illnesses [13].

Studies on presentation time in OSCC [6,14,15] and other cancers [16] conclude that longer presentation times occur because deductive processes fail. Patients do not link OSCC symptoms to cancer because symptoms are inconsistent with cancer prototypes and better resemble minor oral conditions [14]. Presentation later becomes triggered if symptoms persist or deteriorate, making initial attributions untenable. The implication is that interventions should seek to stimulate symptom recognition through the development of illness prototypes [17].

Conceptual and empirical gaps exist in the application of the CSM. First, the CSM is usually applied to patients with diagnosed conditions where illness prototypes are defined and elaborate. There is less understanding of what happens when prototypes are poorly elaborated or multiple prototypes compete to explain symptoms. Studies show that many patients experience uncertainty in attributing OSCC or other cancer symptoms to specific conditions, and consider multiple causes [15]. It is important to understand why patients do not simply consult a HCP as a 'safe option'. Second, misattributions of OSCC symptoms favor transient conditions. The CSM proposes that symptom persistence should trigger reappraisal, yet, patients frequently maintain misattributions over six to twelve months and it is not clear why [15,18]. Lastly, many patients report not consulting HCPs because they fear cancer or other serious illness [16,19]. This is inconsistent with a symptom misattribution account.

1.2. Current study

In view of the above concerns, our aim was to identify whether and how the CSM can be revised to better explain presentation time or alternative approaches are needed. We interviewed a consecutive sample of OSCC patients to identify the reasons for presentation or non-presentation. In the absence of firm theoretical guidance to address our concerns, we took an inductive approach and used qualitative methods.

2. Method

2.1. Patient sample

Approval was obtained from the UK National Research Ethics Service (North West); Ref 13/NW/0056. From July 2014 to September 2015, we recruited a consecutive series of patients with recently diagnosed OSCC in a large Head and Neck Cancer service. Patients were introduced to the study by their clinical team. Interested patients were referred to JB who provided a written explanation of the study aims, and obtained informed consent to organize a face-to-face interview. Patients consented in writing before the interview.

2.2. Procedure

Patients were interviewed by JB after diagnosis but before surgical treatment. Retrospective accounts can be inaccurate or have omissions [20,21,22]. Patients may forget or inadvertently construct interpretations in the light of subsequent events [23], particularly for subtle and complex appraisals [24]. Cognitive interviewing [25] uses three techniques to improve recall of complex and emotionally distressing events. 1) Focused meditation combines relaxation with an induced attentional focus on current experience [26]. 2) Context reinstatement creates contextual overlap between encoding and retrieval by asking interviewees to reconstruct event-relevant contextual, emotional, physical, and cognitive states [27]. 3) 'Report everything' reduces self-editing by asking patients to report all event-relevant thoughts and feelings [25]. Interview recordings were reviewed by a cognitive interviewing practitioner.

2.3. Interview content

A request to 'report everything' was made at the start of the interview, and prompts to do so given within interviews. Context reinstatement was used throughout the interview by asking for contextual details of key events. The first objective was to develop a timeline of key events during presentation time, defined as the interval between initial symptom detection and first presentation to a HCP. These were discovering symptoms, changes or persistence of the symptoms, reappraisals of symptoms, decisions to present or not present to HCPs, and when patients presented. We encouraged patients to remember details such as day of the week, activities on that day and temporal proximity to holidays, birthdays or other events that they could accurately date.

The second objective was to gain a detailed understanding of patient's thoughts and emotions. Before interviewing patients about symptoms we gave a brief pre-scripted focused meditation exercise, if they consented to it. Open-ended interview questions were generally used. The interviewer reflected, prompted, summarized, and probed where necessary. Questions explored the nature of symptoms, perceptions and interpretations of symptoms, courses of action considered, how and why courses of action were chosen, and why they were or were not followed. Where patients had not considered cancer, they were asked why not. Patients were asked about past or current oral conditions and how they felt HCPs would respond if they reported trivial symptoms. Interviews lasted a median time of about 40 min.

2.4. Data analysis

We used framework analysis [28] to examine themes across and within individuals, and how themes were associated with presentation time. Whilst alert to CRM processes, we wanted to capture and understand unexpected phenomena. Thus, whilst focusing on symptom appraisals, we did not explicitly use the model to frame the analysis. Each interview was read by two of the analysis team. JB used open coding to create initial codes and she and SLB created an analytic framework from descriptive summaries of initial cases. From this a theoretical analysis was developed and agreed by the group and recorded using a Microsoft Excel spreadsheet for codes and a Word document to record case summaries and development of the interpretation. The analysis was continually tested and refined through constant comparison with new data and cycling back to previous cases. Recognizing the potential for justifications and rationalizations, as well as unmotivated inaccuracies, we particularly focused the theoretical analysis on inconsistencies or contradictions within and between transcripts.

Themes were refined by searching for confirming and disconfirming evidence. Standards by which the analysis was assessed included theoretical and catalytic validity [29], by which we mean that findings should have the potential to add to existing theory and inform practice. Key findings are illustrated by italicized quotes, with ellipses (…) indicating omitted text and explanatory comments in square brackets.

3. Results

3.1. Description of sample

All 66 patients given OSCC diagnoses during data collection were approached. 19 refused, with the main reason that the interview may contribute to trauma or fatigue. Four could not participate for medical reasons. Consequently, less severely ill patients probably participated in