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Understanding the reasons why patients delay seeking treatment for oral cancer symptoms from a primary health care professional: An integrative literature review



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A B S T R A C T

Keywords:

Patient delay
Diagnostic delay
Treatment delay
Delayed presentation

Purpose: The purpose of this integrative literature review was to investigate existing research on the reasons why patients delay in seeking treatment for oral cancer symptoms from a primary health care professional.

Method: The systematic approach developed by Cooper (1984) was the guiding framework for this integrative review. Cooper (1984) identifies the process of conducting an integrative review as encompassing the following five stages: (a) problem formulation, (b) data collection, (c) evaluation of data points, (d) data analysis and interpretation, and (e) public presentation of results.

Results: Despite different research designs employed and sample sizes ranging from 15 to 559, three major themes emerged from the 16 studies included in the review, all of which are directly related to the reasons why people delay seeking treatment for oral cancer symptoms: Patient Sociodemographic Characteristics; Health Related Behaviours, and Psychosocial Factors.

Conclusions: Overall, this integrative review demonstrates the complexity surrounding the reasons why patients delay in seeking help for oral cancer treatment. The association between knowledge and patient delay has implications for information provision about cancer to those at risk of developing the disease. The relationship between socioeconomic status and patient delay behaviour warrants further investigation as this has been shown to be an influential factor in the study of patient delay. The meaning of many of the investigated psychosocial factors (e.g. an individuals' symptom interpretation/attribution, disclosure of symptoms to significant others, social priorities), have not been discussed in detail and the research is not theory driven.

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Introduction

Oral cancer is the sixth most common cancer worldwide with 575,000 new cases each year and 200,000 deaths annually (O'Sullivan, 2009). Around 5 out of every 10 patients with oral cancer present with advanced stage disease (Scott et al., 2005; Rogers et al., 2007, 2009). The majority of the delay is in the time taken for the patient to present rather than professional delay (Rogers et al., 2007, 2010). Late presentation is an important issue in oral cancer as advanced disease requires more radical treatment and is associated with poorer prognosis (Rogers et al., 2009). Radical treatments are linked to additional treatment burden, patient and carer distress and with worse health related quality of life

outcomes (Rogers et al., 2007). Furthermore, detecting oral cancer at an early stage (when lesions are small and localised) is believed to be the most effective means to reduce death, morbidity and disfigurement from this disease, along with reducing hospital cost, duration of treatment and professional fees (Rogers et al., 2002).

A systematic review of patient delay in oral cancer undertaken by Scott et al. (2006) clearly identified that a significant proportion of patients delay seeking the help of a health care professional after self-discovery of symptoms of oral cancer. More recent research suggests that one of the reasons that patients may delay is that public awareness of oral cancer tends to be poor (O'Connor et al., 2010; Rogers et al., 2010).

Aim

The aim of this integrative literature review is to investigate existing research on the reasons why patients delay in seeking

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treatment for oral cancer symptoms from a primary health care professional. Typically the primary health care provider acts as the principal point of consultation for patients within a health care system and coordinates other specialists that the individual may need. Such a professional can be a primary care physician such as general practitioner or family physician or depending on the locality, health system organisation, and patient's discretion, they may visit a dentist, pharmacist, nurse practitioner, a clinical officer (such as in parts of Africa) or an Ayurvedic or other traditional medicine professional (such as in parts of Asia). Depending on the nature of the health condition patients may then be referred for secondary or tertiary care.

Method

Recent evidence-based practice initiatives have increased the need for and the production of literature reviews (Whitmore and Knalf, 2005). The increase of all types of research reviews (systematic reviews, integrative reviews, meta-analyses, and qualitative reviews) during the last ten years has contributed to more systematic and rigorous methods. Concern has been raised however that review methods such as systematic reviews and meta-analyses approaches, while important for evidence-based practice, over-emphasise the randomised controlled trial and hierarchies of evidence (Kirkevold, 1997; Evans and Pearson, 2001). An integrative review of the literature is an approach that allows for the inclusion of diverse methodologies and has the potential to play a greater role in evidence-based practice for nursing (Whitmore and Knalf, 2005).

The systematic approach developed by Cooper (1984) was the guiding framework for this integrative review. Cooper (1984) identifies the process of conducting an integrative review as encompassing the following five stages: (a) problem formulation, (b) data collection, (c) evaluation of data points, (d) data analysis and interpretation, and (e) public presentation of results.

Problem formulation

Inclusion criteria and a plan for data extraction were developed prior to conducting the integrative review. Only studies which investigated the reasons/factors why patients delayed seeking treatment for oral cancer symptoms from a primary health care professional were included in the review. Primary data papers were included if the sample only included patients with malignancies of the oral cavity. If a study covered a set of malignancies and reported separate information for oral cavity cancers, it was included in the review. However, if a study covered a set of malignancies (including oral cancer) but did not report separate data on the oral cavity subset, it was not included in the review. Only papers that provided a clear definition of patient delay were included. 'Duration of symptoms' was not considered to be a sufficient definition unless it was clarified to be the duration of symptoms until the first visit to a primary health care professional for those symptoms. Delay is the term commonly used to describe the waiting time in the diagnostic process, and is usually divided into patient and provider delay. In this integrative review, the focus is on patient delay which is defined as the period from onset of symptoms to the first medical consultation.

Data collection

Databases included in the search for relevant literature were PubMed, CINAHL, and ISI Web of Knowledge. Search terms included: delay, delayed presentation, delay in oral cancer/carcinoma/neoplasms, mouth cancer, lip cancer, oral symptoms,

malignant oral symptoms, head and neck squamous cell carcinoma, neck cancer, tongue neoplasms and oropharyngeal cancer. To further focus the search the following limits were applied: English; human; publication years 2000–2011. The search process yielded 15 articles which met the specific inclusion criteria. Search strategy and results are presented in Table 1. Ancestry searches of the reference lists of all articles included in the review were also conducted and relevant studies extracted. This produced a further 6 studies for potential inclusion. Further reasons for exclusion of papers were those studies not published in English; unrelated to the topic of interest; and investigated perspectives of practitioners rather than patients.

Evaluation of data points

Data were evaluated based on the significance and overall quality of the research to include studies that presented primary research, published in peer-reviewed journals and completed in the last 11 years. Furthermore, the quality of all studies identified, were assessed using the criteria adapted from previously published systematic reviews (Bee et al., 2008; Curran and Brooker, 2007) which enabled the author to assess papers based on methods of research design, sampling and conclusions (Table 2). When uncertainties occurred regarding whether the publication met the criteria, the author consulted with a clinical academic colleague in the field of head and neck cancer, where a final decision was made after both the author and colleague read the full content of the publication independently and then together.

Data analysis and interpretation

Studies that reported factors associated with patient delay and oral cancer were transcribed into table format for ease of reader interpretation. Following content analyses of each study, it became obvious that common themes were identified throughout. The studies will be presented under the identified themes accordingly.

Presentation of results

Studies that purported to explore the reasons for delay in treatment for oral cancer but instead identified and quantified delays in diagnosis and treatment were discarded. A total therefore of 16 studies were included in the review (7 quantitative, 4 mixed

Table 1
Search strategy and results.

	CINAHL Citations	ISI web of knowledge Citations	PubMed Citations
Search #1			
'Patient delay', 'diagnostic delay', 'treatment delay' 'delayed presentation'	9323	25,112	15,422
Search #2			
'oral cancer/carcinoma/neoplasm/ tumours', 'mouth cancer/carcinoma/ neoplasm/tumours', 'oropharyngeal cancer', 'tongue cancer', 'head and neck cancer', 'oral squamous cell carcinoma', 'malignant oral symptoms'	1150	68,409	24,308
#1 and #2			
Combined results	13	233	174
Abstracts reviewed following removal of duplicates and irrelevant material	0	27	7
Relevant articles meeting inclusion criteria	0	11	4

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