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Review

Patient's delay in oral cancer: a systematic review

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Abstract – Detecting oral cancer at an early stage is the most effective means of improving survival and reducing morbidity from this disease, yet a significant proportion of patients delay seeking help after the self-discovery of symptoms of oral cancer. The literature on factors associated with patient delay was searched systematically to access relevant data published between 1975 and 2005. Eight studies met the inclusion criteria for the review. In these studies, most clinical/tumour factors, sociodemographic variables, and patient health-related behaviours were not related to the duration of patient delay. Healthcare factors and psychosocial factors may play a role but the research in this area is sparse, atheoretical and of poor quality. Patient delay is a problem in oral cancer and yet at present the reasons for such delays are poorly understood and under-researched. Systematic, high-quality and theory-driven research in this area is urgently required.

Key words: oral squamous cell carcinoma; patient delay; systematic review

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With approximately 389 000 new cases of oral cancer per annum, oral cancer is the 11th most common cancer in the world (1). Oral cancer has a low 5-year survival rate, with rates of 50% or less (2). Treating oral cancer at an early stage (when lesions are small and localized) is believed to be the most effective means to reduce death, morbidity and disfigurement from this disease (3). However, numerous reports suggest that up to 50% of patients present with advanced-stage disease (4). The silent nature of oral lesions and delay in the diagnosis are believed to be responsible for this high incidence of advanced-stage oral cancer (4). 'Patient delay' (the time between the initial discovery of symptoms and the first medical consultation for those symptoms) constitutes the largest proportion of the total delay period (5) and thus is the focus of this review. Estimates indicate that approximately 30% of patients delay seeking help for more than 3 months following the self-discovery of symptoms of oral cancer (6). A recent paper (7) which analysed delays in the diagnosis of six cancer types, concluded that interventions aimed at reducing patient delay need to be developed to improve morbidity, mortality and psychological outcomes. To develop an effective intervention to reduce the extent of patient delay one must identify factors associated with delay in oral cancer. This article presents a systematic review of empirical journal articles relating to patient delay in oral cancer in order to collate and evaluate the existing knowledge of factors that influence patient delay.

Methods

Literature search

Computerized databases 'Allied and complementary medicine (AMED)', 'CANCERLIT', 'CINAHL', 'EMBASE', 'MEDLINE', 'MEDLINE(R)' and 'PSYCHINFO' were searched to access relevant articles published between 1975 and November 2005 (see Fig. 1 for the search terms). The abstracts of the articles identified by the database search were screened to exclude irrelevant studies. This screening was required because as the search terms necessarily included 'oral', 'cancer' and 'delay' many studies concerned with the timing of orally

1. Exp oral neoplasms/
2. (oral and (cancer$ or malignan$ or tumor$ or tumour$)).mp.
3. (mouth and (cancer$ or malignan$ or tumor$ or tumour$)).mp.
4. (head and (cancer$ or malignan$ or tumor$ or tumour$)).mp.
5. 1 or 2 or 3 or 4
6. ((late or later) adj10 (diagnos$ or present$ or detect$)).ti.
7. (symptom$ adj10 (detect$ or duration or onset)).ti,ab,sh.
8. ((seek or sought) adj5 (diagnosis or treatment or help)).mp.
9. (helpseeking or wait).mp.
10. (denial or denies).mp. or deny.ti,ab,sh.
11. (referral and consultation).mp.
12. consult$.ti,ab,sh.
13. delay$.ti,ab,sh.
14. 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13
15. 5 and 14
16. limit 15 to human

[mp=title, abstract, cas registry/ec number word, mesh subject heading]
[ti.= title]
[ab. = abstract]
[sh= subject heading]

Fig. 1. Terms used to search the computerized databases.

administered medication for patients with cancer were accessed but were obviously not relevant to this review. To identify any further articles, researchers known to be involved in this area of study were contacted and bibliographic references were manually searched. Articles with relevant abstracts were read in full to determine if they fitted the inclusion criteria for the review.

Inclusion criteria

Primary data papers were included in the review if they met the following criteria:

(a) *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 and used the separate data provided. 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.

(b) *The research reported data for which at least 90% of the patients had a histological diagnosis of squamous cell carcinoma*. This restriction was enforced to ensure that each study reported a representative sample of patients with oral cancer as there may be differences in growth rate, symptomatology or appearance for malignancies of different histology, which may in turn influence the duration of patient delay.

(c) *The research reported data on factors investigated for statistical association with the duration of patient delay*. This criterion required the study to include a clear definition of patient delay. '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 healthcare professional for those symptoms.

(d) *The paper was written in English*.

Results

In total, 4387 articles were accessed. The initial screening of abstracts resulted in the identification of 148 relevant studies, which were read in full. Eight of the 148 met the inclusion criteria for this systematic review (see Fig. 2). A meta-analysis was not possible because of the small number of studies with good methodology and the variability in the factors examined. Details of the studies selected for review are provided in Table 1.

Factors associated with patient delay

Table 2 outlines the factors investigated for their association with patient delay and demonstrates that the majority have not been found to be related to the duration of patient delay.

Kerdpon and Sriplung (8) found that use of traditional herbal medication prior to seeking a professional consultation was a significant independent predictor of patient delay in Thailand. Those who received traditional herbal medication before their healthcare professional consultation had a longer patient delay [hazard ratio = 0.46, 95% confidence interval (CI) = 0.28–0.76; $P < 0.05$]. Four studies (6, 8–10) found no significant association between patient delay and stage of disease at diagnosis, yet in contrast a recent study (11) reported patients with advanced-stage disease to have exhibited significantly more delay than those with early-stage disease (odds ratio = 2.1, 95% CI = 1.0–4.2; $P < 0.05$). Kumar et al. (12) also reported an association between stage of disease and patient delay (G-test = 6.3; $P < 0.05$) although the direction of this association is unclear as the report did not match the presented statistics. While three studies (5, 8–9) reported the size of the malignant lesion to be unrelated to the duration of patient delay, Brouha et al. (11) reported that those with larger lesions were more likely to have experienced prolonged patient delay (odds ratio = 3.2, 95% CI = 1.4–6.9).

The univariate analyses reported by Kumar et al. (12) indicated the presence of an association between regular doctor attendance and patient delay and patients' socioeconomic status and patient delay. However, no information was given as to the direction or size of these associations.

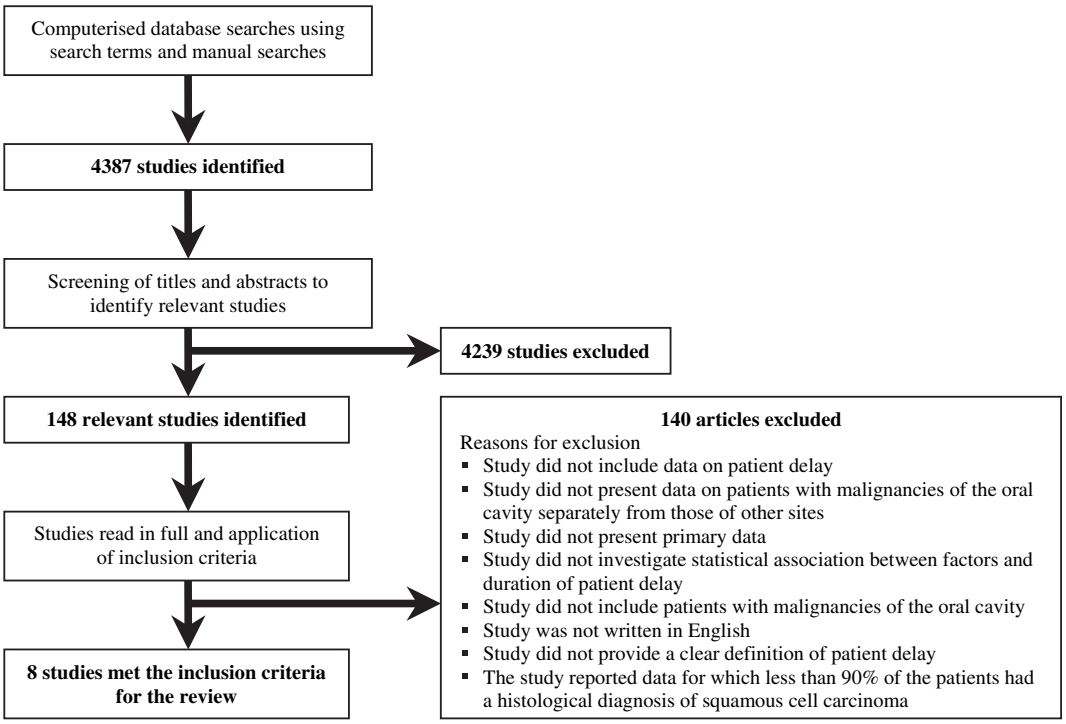

Fig. 2. A flow diagram depicting the identification of studies included in the review.

Kumar et al. (12) also found that patient beliefs of 'ill-fated to have cancer', 'cancer can develop if tobacco is used', that there would be 'family tension due to long treatment', the availability of transport and being escorted by someone were factors that were related to the duration of patient delay. Again, however, these variables often lacked clear definitions, details of measurement or direction of association and thus the results of this study are difficult to interpret.

Discussion

This systematic review collated the empirical research on the factors related to patient delay for oral cancer. A significant proportion of patients delay seeking the advice of a healthcare professional after self-discovery of symptoms of oral cancer, yet the current empirical research is unable to provide clear reasons for this delay. The only robust correlate of patient delay was the use of herbal medication before professional consultation, which was found to be an independent predictor of prolonged patient delay.

Although research into patient delay at other cancer sites has suggested psychosocial factors (e.g. an individuals' symptom interpretation/attribution, disclosure of symptoms to significant others, social priorities) play an important role in the decision to seek help (14), the study of psychosocial factors in relation to patient delay for symptoms of oral cancer is sparse and has not been conducted using reliable methods. The meaning of many of the investigated psychosocial factors has not been discussed in detail, the research is not theory-driven and many of the findings are unclear. Theoretical models that may help understanding of patient delay in oral cancer include Anderson et al.'s (15) model of total patient delay which provides an outline of the stages involved in receiving medical care following the self-discovery of unexplained signs or symptoms and Leventhal et al.'s (16) Self-Regulatory Model which proposes the information-processing mechanisms involved in the ways people perceive and respond to health threats. Support for application of these models to patient delay in oral cancer comes from recent exploratory interviews with newly diagnosed patients with oral cancer which indicated that an individual's interpretation of oral cancer symptoms can be misguided and thus can lead to inappropriate behavioural responses which may adversely affect help-seeking behaviour (17).

Particular methodological issues for research into patient delay for oral cancer include the inclusion/exclusion of patients with cancerous lesions found incidentally, rare use of multivariate

Table 1. Details of the reviewed studies

Study	Country	Aim of study	Period of data collection	Sample size for patient delay data	Source of patient delay data	Time of data collection	Extent of patient delay (months)			Type of patient delay data
							Range	Mean	Median	
Wildt et al. (9)	Denmark	To assess and describe the importance of different elements of delay and to investigate the possible correlation between the delay and some tumour and patient factors	1986–1990	167	Standard questionnaire	Before treatment	0.0–20.0	3.5	2.4	Continuous
Allison et al. (6)	Canada	To test the hypothesis that patient, professional and/or total diagnostic delays are associated with stage of disease	1995–1997	76	20–30 min interview using standard questionnaire; hospital records	Between initial consultation with treating specialist and initiation of cancer therapy	N/S	N/S	N/S	Categorical (< 1 month 1–3 months > 3 months)
Hollows et al. (13)	England	To investigate delays in referral and treatment of patients with oral cancer	1993–1998	92	N/S[a]	N/S	0.0–130.0	5.6	N/S	Continuous
Kerdpon et al. (8)	Thailand	To identify the factors related to patient and professional delay in diagnosis of oral squamous cell carcinoma	1996–1998	161	Interviews using structured questionnaire; hospital records	N/S	0.0–24.0	3.0	N/S	Categorical (< 1 month 1–3 months > 3 months)
Kantola et al. (10)	Finland	To study the process of detecting tongue cancer patients in primary care	1974–1994	75	Patient files of primary health centres; hospital records	N/S	0.0–46.0	N/S	1.0	Continuous
Kumar et al. (12)	India	To determine the predictors of delay using a well constructed detailed instrument structured on a health risk taking behavioural model	N/S	79	Questionnaire administered by a trained social scientist	N/S	0.1–36.0	N/S	N/S	Continuous
Onizawa et al. (5)	Japan	To elucidate variables related to delay in diagnosis of oral cancer	1991–2000	147	Hospital records; referral letters	N/S	0.0–60.0	N/S	1.6	Dichotomous (< median > median)
Brouha et al. (11)	Holland	To determine whether the difference stages of patient delay are related to different tumour stages and to examine the factors related to patient delay in patients with pharyngeal and oral cancer	2000–2002	128	Interview with patient and verified by a questionnaire sent to a close relative and doctor or dentist	Before treatment or during first chemotherapy/radiotherapy session	N/S	N/S	N/S	Dichotomous (< 30 days ≥ 30 days)

[a]N/S = Not stated.

Table 2. Factors investigated for their association with patient delay

Factors investigated	Study							
	Wildt et al. (9)	Allison et al. (6)	Hollows et al. (13)	Kerdpon et al. (8)	Kantola et al. (10)	Kumar et al. (12)†	Onizawa et al. (5)	Brouha et al. (11)
Clinical/tumour factors								
Tumour size	x[a]	.	.	□[b]	.	.	x	✔[c]
History of malignant disease	.	.	.	.	.	.	x	.
Initial symptom	.	.	.	□	.	.	x	.
Site	x	.	.	□	.	.	x	.
Histological score	x	.	.	.	.	.	.	.
Stage at diagnosis	x	x	.	□	x	✔	.	✔
Lymph node metastases	.	.	.	□	.	.	x	x
Visibility	.	.	.	□	.	.	.	x
Patient sociodemographics								
Sex	x	.	.	□	x	.	x	x
Age	x	.	.	□	x	.	x	x
Marital status	.	.	.	□	.	.	.	x
Area of residence	.	.	.	□	x	.	.	x
Occupation and income	.	.	.	□	x	.	.	.
Religion	.	.	.	□	.	.	.	.
Employment	.	.	.	.	.	.	x	.
Living arrangements	.	.	.	.	.	.	x	x
Education	.	.	.	.	.	.	.	x
Socioeconomic status	.	.	.	.	.	✔	.	.
Health-related behaviours								
Smoking	.	.	x	□	.	.	x	x
Alcohol	.	.	x	□	.	.	x	x
Betel quid use	.	.	.	□	.	.	.	.
Herbal medication before consultation	.	.	.	○[d]	.	.	.	.
Treatment-seeking before consultation	.	.	.	□	.	x	.	.
Regular dentist visits	x	.	.	.	.	.	.	.
Regular doctor visits	.	.	.	.	.	✔	.	.
Use of daily medication	.	.	.	.	.	.	x	.
Healthcare factors								
Healthcare professional consulted	x	.	.	□	.	.	.	.
Transport/finance	.	.	.	.	.	✔	.	.
Psychosocial factors								
Belief of fate	.	.	.	.	.	✔	.	.
Family tension due to long treatment	.	.	.	.	.	✔	.	.
Escorted by someone	.	.	.	.	.	✔	.	.
Cancer can develop if tobacco is used	.	.	.	.	.	✔	.	.
God's destiny	.	.	.	.	.	x	.	.
Necessity of consulting a doctor for mouth ulcers for those who use tobacco	.	.	.	.	.	x	.	.
Visit a doctor for early detection of cancer	.	.	.	.	.	x	.	.
Relative/friend had cancer	.	.	.	.	.	x	.	.
Tired of treatment	.	.	.	.	.	x	.	.

†Even though Kumar et al. (12) performed multivariate analyses, only univariate findings are reported here as the significance for variables in the multivariate analyses were not clearly reported.
[a]x = Results indicate there is no significant association between this factor and patient delay (univariate analyses).
[b]□ = Results indicate there is no significant association between this factor and patient delay (multivariate analyses).
[c]✔ = Results indicate there is a significant association between this factor and patient delay (univariate analyses).
[d]○ = Results indicate there is a significant association between this factor and patient delay (multivariate analyses).

analyses and measurement of patient delay. Including patients with cancerous lesions found incidentally in the assessment of patient delay will distort results. Although it seems logical to indicate that there was no delay by these patients, this is not an accurate reflection of the situation. Patients with lesions found incidentally have no opportunity to delay seeking help or to seek help immediately and in turn should be removed from analyses of patients help-seeking behaviour.

As the measurement of patient delay is based on retrospective recall, and is therefore subject to recall bias and error (18), the timing of data collection is extremely important in the study of patient delay. This should be reported and be as close as possible to the time at which the patients first sought medical help for their symptoms. In the analyses of factors related to patient delay, some studies defined 'delay' as a categorical variable (5–6, 8, 11) but as Facione (19) notes, operational definitions of patient delay (such as 'more than 3 months') remain largely arbitrary. Using median splits, choosing a clinically relevant definition of patient delay, or leaving patient delay as a continuous variable would be more appropriate. Furthermore, as a minority of cases with an extremely long duration of patient delay often skew the mean value of patient delay, using the median duration of patient delay would provide a more accurate and robust estimation of the extent of patient delay. Finally, it should be recognized that the term 'patient delay' should not be interpreted pejoratively [i.e. patient delays may not be due to patients but instead 'system' factors such as access, availability and affordability (6)].

There are several limitations associated with this review. First, the inclusion criteria limited papers to those written in English, thus research published in other languages is absent from the review. However, the 10 potentially relevant studies that were not written in English (20–29) did not appear to have patient delay as the primary focus of the study and therefore the selection bias does not seem to have been to such an extent to greatly influence the findings of this review. Secondly, some studies on patient delay in head and neck cancer (30–32) which have included patients with oral cancer were excluded from this review because separate data on the oral cancer subsample were unavailable. Furthermore, there is an increasing movement towards including cancer of the oropharynx in addition to those of the oral cavity in studies of oral cancer. As such, data that may be potentially relevant have not been included this review. However, only a few studies have investigated predictors of patient delay for oral cancer using this definition. Guggenheimer et al. (32) found the length of patient delay to be unrelated to patients' age, gender, history of alcohol consumption or amount of education. Llewellyn et al. (31) did find education to be important however, with those who had no further education (beyond high school education) experiencing more patient delay. Llewellyn et al. (31) also found those who smoked lower amounts of tobacco and those who reported lifestyle stress prior to diagnosis to have longer patient delay. Lower occupational social class was found to be associated with longer patient delay in the univariate analyses but was not an independent predictor of patient delay. The study by Llewellyn et al. (31) was concerned with investigating patient delay in patients under 45 years old (constituting <10% of oral cancers in the UK) and thus these variables require investigation in a more representative sample. In particular, the relationship between socioeconomic status and patient delay behaviour warrants further investigation as this has been shown to be an influential factor in many health-related areas (33).

Conclusion

This systematic review has highlighted the dearth of knowledge and its inadequacy in explaining patient delay in oral cancer. Furthermore, the need for systematic, good-quality and theory-driven research into the determinants of patient delay is apparent. Such research has the potential to inform targeted interventions aimed at promoting appropriate behavioural responses to potentially malignant oral symptoms.

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