# Evidence summary: what do we know from qualitative research about people's care-seeking about oral health?

Developed from the original question submitted by Steve Simmons, June 2010
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**KEY TERMS**

- **Care-seeking:** patients trying to obtain care/advice/treatment from a health professional/service.
- **Patient acceptance of healthcare:** the seeking and acceptance by patients of health services.
- **Qualitative research:** research that derives data from observation, interviews, or verbal interactions and focuses on meanings and interpretations of the participants.
- **Oral health:** the optimal state of the mouth and normal functioning of the organs of the mouth without evidence of disease.

RESEARCH

Since August 2009, members of the Primary Care Dentistry Research Forum (www.dentistryresearch.org) have taken part in an online vote to identify questions in day-to-day practice that they felt most needed to be answered with conclusive research. The question which receives the most votes each month forms the subject of a critical appraisal of the relevant literature. Each month a new round of voting takes place to decide which further questions will be reviewed. Dental practitioners and dental care professionals are encouraged to take part in the voting and submit their own questions to be included in the vote by joining the website.

The paper below details a summary of the findings of the ninth critical appraisal. In conclusion, the critical appraisal showed a wide range of factors that influence care-seeking about oral health. These included both barriers and triggers to care-seeking. Only five papers were found that provided relevant data, and their data collection settings varied widely. Further research into care-seeking about oral health would be useful for both policy makers and practitioners in understanding patients' needs.

## BACKGROUND

Within medical and nursing literature, both quantitative and qualitative data collection methods have been used to describe people's care-seeking or help-seeking behaviour.[1–5] Healthcare policy and service redesign may be informed by use of this evidence that places an understanding of the individual patient at the core.[6]

In oral health, what is understood about people's perceptions towards care-seeking? There is literature that mainly derives from use of (semi-)quantitative research methods, including the Adult Dental Health Survey.[7–11] However, exploration of the subjective factors influencing people's care-seeking behaviour using qualitative research methods may reveal additional insights.

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Sponsored by
the Shirley Glasstone Hughes Trust

DOI: 10.1038/sj.bdj.2010.796

## AIM

This review aimed to identify and summarise UK primary research studies which have adopted qualitative research data collection methods using open questions to explore people's care-seeking or help-seeking about oral health.

## REVIEW METHOD

An initial search was made of Ovid MEDLINE® (1950 to week 3, May 2010) using search terms 'patient acceptance of health care'; health knowledge, attitudes, practice; choice behaviour; and decision making. One hundred and fifty-one titles were identified, 18 of which were relevant to the UK. Four papers were retrieved as full text and examined; one title was rejected.

Further searches included:

- Ovid MEDLINE® (1950 to week 4, May 2010) using the search terms patient acceptance of health care; motivation; dental 'seeking strategies'; UK. One hundred and fifty-two titles were identified and four papers retrieved as full text and examined. All four titles were rejected
- Ovid MEDLINE® (1950 to week 4, May 2010) using the search terms patient acceptance of health care; narration (relating the particular and the personal in an individual's life story); attitude to health; UK. Sixty-one were titles identified and all 61 titles rejected

In addition, CEBD, Cochrane Oral Health Group, ADA, TRIP database, social sciences databases (Science Direct, ASSIA (CSA), Web of Science, EBSCO, SwetsWise), and individual journal searches including *Evidence-Based Dentistry*, *Journal of Evidence-Based Dental Practice*, and *Journal of the American Dental Association*. Ten titles were identified and retrieved as full text and examined. Eight titles were rejected.

## FINDINGS

Three hundred and seventy-four titles and abstracts arising from the web-based searches were screened. Eighteen potentially relevant papers were retrieved as full text and reviewed. Five of these 18 papers provided relevant findings, having used open questions as part of a qualitative method to develop insight into

patients' care-seeking about oral health.

The studies' authors' interpretations of patients' subjective perceptions of oral health-related care-seeking are simply listed in Table 1, structured under the headings of barriers or triggers to care-seeking. These interpretations are further summarised in Figures 1 and 2.

We could find very few qualitative research studies that had used open questions to elucidate UK people's care-seeking about oral health. Of the five papers located, there was considerable diversity in the setting of the data collection, for example emergency dental care hospital, cancer care centre, people's homes. In addition, the reason for care-seeking varied, such as retrospective accounts of patients with oral cancer diagnosis, patients seeking emergency dental care, and others who gave accounts of factors that may influence their care-seeking for the protection of their oral health. As such, no synthesis of the findings was attempted. However, despite the range of people and places, it is apparent that there was considerable commonality of factors that are barriers and triggers to seeking care from a dentist.

## ADVANCING THE QUALITATIVE REVIEW

In-depth analysis of the findings of the presented qualitative studies may be

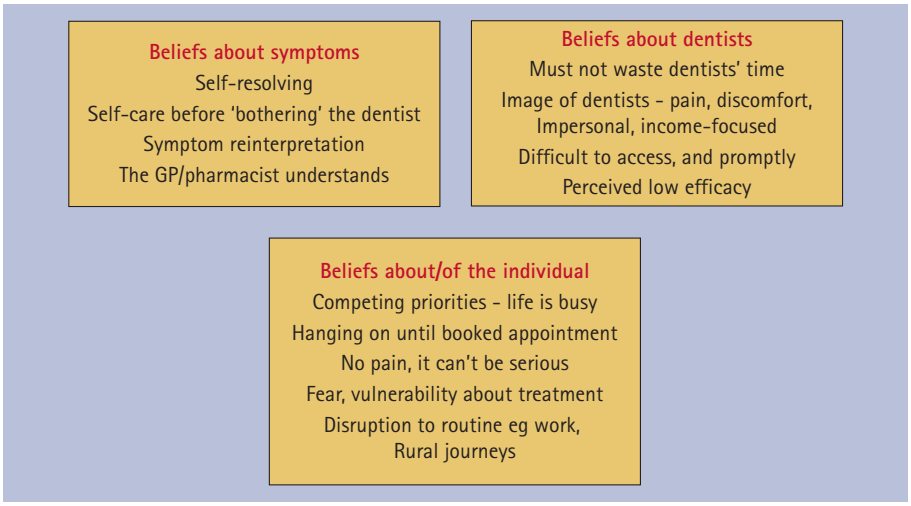


**Fig. 1 Researchers' interpretations of patients' perceived barriers to care-seeking**

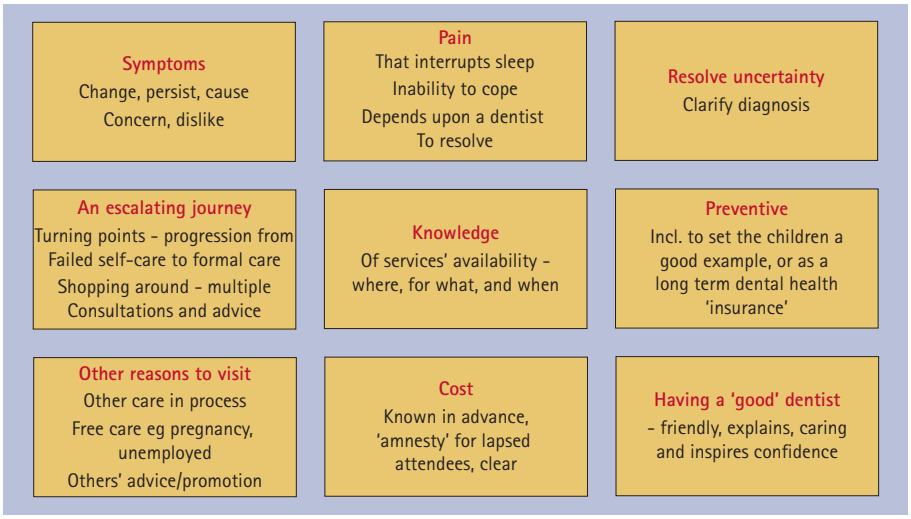


**Fig. 2 Researchers' interpretations of patients' perceived triggers to care-seeking**

**Table 1 Details of studies and researchers' interpretations of people's subjective perceptions about oral health-related care-seeking**

| Studies and interpretations | Scott et al.[13] | Grant et al.[14] | Pau et al.[15] | Anderson & Thomas[16] | Finch et al.[17] |
|---|---|---|---|---|---|
| Study sample | 57 newly-referred (by GDP/GP) adult patients with potentially malignant oral mucosal symptoms. 2000* | 15 patients under 45 years old, resident in Scotland, previously diagnosed with oral or oropharyngeal cancer. 2006* | 35 adults emergency-presenting with toothache, swelling or abscess. 2008* | 44 consecutive weekend emergency dental patients (including children)/ patients' representatives. 1999* | 108 dentate residents, aged 16-59 years, selected upon initial screening for gender, age, social class and dental attendance pattern. 1987* |
| Study data collection | Semi-structured, 15-30 minute tape-recorded telephone interviews (interviewer unidentified). | Semi-structured, 20-40 minute face-to-face interviews with an NHS Liaison Counsellor. | Unstructured (with topic guide), 15-90 minute, in depth face-to-face interviews with a dentist. | Semi-structured, 2-5 minute face-to-face interviews with a Cardiff dental school researcher. | Eight, approx. 1.5 hour semi-structured group discussions (n = 68). SCPR‡ interviewer. Also 40 semi-structured in-depth interviews (interviewer unidentified). |
| Study setting | Oral Medicine Department and Head & Neck Service at a London hospital. | Maggie's (cancer care) Centres, Scotland, or at patient's own home. | A UK dental teaching hospital emergency clinic. | Cardiff Dental Hospital and the emergency dental clinic at Pontypridd Health Centre. | Respondents' own homes, or local centres, in Nottingham, Sunderland, Guildford and Somerset. |

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* Year of study, or publication.
‡ SCPR – Social and Community Planning Research
§ Pathways to care – the chronology of places and people (professional/lay) from which patients seek care prior to visiting the emergency dental service.
Empty cells – no relevant information in this paper about the specific care-seeking factor.

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| Studies and interpretations | Scott et al.[13] | Grant et al.[14] | Pau et al.[15] | Anderson & Thomas[16] | Finch et al.[17] |
|---|---|---|---|---|---|
| **Study objective** | To explore how patients arrive at their decision to seek help for potentially malignant oral symptoms. | To identify and understand the views of younger oral cancer patients relating to emerging symptoms, routes into and time taken for specialist referral and diagnosis. | To explore the subjective experience of the toothache phenomenon. | To understand the types of dental problems which present at weekends. Also to gather data ('toothache stories') on the care-seeking behaviour of emergency dental patients, including:<br>i. Triggers for seeking formal care<br>ii. Pathways to care.[§] | To explore the range of factors which inhibit people from seeking dental treatment. Also to generate ideas on ways by which barriers to seeking dental treatment might be overcome. |
| **I. Researchers' interpretations of people's subjective perceptions: barrier(s) to seeking help** | | | | | |
| **Beliefs about symptoms** | 1. Patients viewed their symptoms as transient, minor and self-resolving<br>2. Self-care and coping with symptoms was considered to be desirable before seeking help. | 1. Self-treatment (for up to two months) provided from a pharmacy (some with pharmacist advice)<br>2. Re-interpretation of symptoms without seeking professional help<br>3. Most participants had prior knowledge of oral cancer. Most did not recognise their symptom(s) were serious at least until referred for further tests. | 1. Patients also consult with doctors and pharmacists to exclude other causes of symptoms. | 1. Symptoms (pain) 'not that great'<br>2. Assumption the problem is temporary/self-limiting – particularly postoperative pain<br>3. By omission – no patients referred to their problem as 'being an emergency'. | |
| **Beliefs about the healthcare professional** | 1. A belief that patients must not waste healthcare professionals' (HCPs') time with minor health problems<br>2. A view that professional attention should not be sought as soon as illness starts<br>3. Real/perceived issues with access to a HCP, eg distance to travel, the 'hassle' of visiting a HCP, the cost of consultation, inconvenient surgery opening times<br>4. Negative perceptions of HCPs, eg due to previous experiences, apprehension of consultation, low belief in the professional's efficacy. | Patients' concern about wasting HCPs' time, or appearing to be a hypochondriac. | Perceived difficulty in accessing emergency dental care other than at the dental hospital emergency clinic. | 1. Low expectations or uncertainty of prompt in-hours appointment (especially for unregistered)<br>2. Perceived lack of formal services at weekends<br>3. Seeking care from (non-dental) health professionals or services that were unable to help<br>4. Seeking care from dental services when not entitled (unregistered). | 1. Reception and waiting procedures, also the atmosphere and the environment at dental surgeries, may either reinforce or reassure existing anxieties about attendance<br>2. Patients' perceptions of dentists:<br>i. An image associated with potential for pain, hurt, discomfort, whether or not actually experienced<br>ii. Impersonal, pre-occupied with the physical or mechanical techniques of dentistry<br>iii. As highly paid – so wanting to treat patients as much, and as fast as possible to achieve this income<br>3. Enduring recall of negative childhood experiences with the school dentist. |

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**Table 1 Details of studies and researchers' interpretations of people's subjective perceptions about oral health-related care-seeking**

| Studies and interpretations | Scott et al.[13] | Grant et al.[14] | Pau et al.[15] | Anderson & Thomas[16] | Finch et al.[17] |
|---|---|---|---|---|---|
| **Beliefs of/about an individual/ individual's circumstances** | Relative priority of competing demands/ circumstances and time available to seek help, eg childcare, holidays, co-morbidities. | 1. 'Patient delay' in seeking HCP advice. The causes included waiting to consult at an already booked appointment and, for most, an assumption that lack of pain meant the symptom was not serious<br>2. Patients usually knew the links between alcohol and smoking with oral cancer risk<br>3. A few patients had heard of oral cancer, but it did not 'mean anything' to them (ie cancer happens elsewhere in the body)<br>4. None thought that oral cancer 'would happen to them'. | | 1. Ability to function normally, especially with self-care, for example painkillers<br>2. Functioning normally as a form of self-care ('keeping busy')<br>3. 'Hanging on' for an appointment already planned<br>4. Physically unable to care-seek, for example on holiday, away from own dentist, lorry driver on road. | 1. Fear: of pain, of a specific treatment, of possible reprimand, or other potential embarrassment/ discomfort<br>2. Vulnerability: a relinquishing of control in the sensitive area of the mouth<br>3. Perception of cost of dental care may postpone a dental visit, especially following a lapse in attendance. Confusion, suspicion and ignorance about the system of charging for care<br>4. The journey to visit the dentist, including time and cost, were significant in rural areas, and also impacted upon selection of dentist<br>5. Disruption to working peoples' routine to organise and attend appointments<br>6. Disruption to a pattern of dental attendance upon leaving school, due to apathy and inertia, also competing time and affordability priorities. |
| **II. Researchers' interpretations of people's subjective perceptions: trigger(s) to seeking help** | | | | | |
| **Change in symptoms** | Patients' perceived change/ worsening, increased number of symptoms. | | | Change in intensity, frequency, quality, location or visibility of symptoms. | |
| **Persistence of symptoms** | Longevity was considered indicative of something being 'wrong'. | | Management of toothache can be complex and lengthy – diagnosis and resolution. | | |
| **Worry/concern about symptoms** | When patients became worried – to alleviate both the symptoms and the worry. | | | Fear that the symptoms are indicative of 'something serious'. Aligned with a perceived urgency of need for care. | |
| **Dislike of symptoms** | Care sought if the appearance, nature, or interference of symptoms were considered to be unpleasant, annoying or irritating. | | | | |

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| **Pain** | Where there was a need to relieve pain. | | 1. A need for, and dependency upon, a dentist/other to alleviate pain<br>2. Expression of perceived inability to cope with toothache pain to access care: when patients do not know what to do/do anything, ie helplessness, disempowerment, incapacitation. Also loss of control, despair and isolation. Potential complex impact upon patient-dentist relationship. | 1. Pain strong enough to prevent or interrupt sleep is a key trigger to urgently seeking formal care.<br>2. Inability to function, for example eat. | |
| **Presence of another reason for visiting a healthcare professional** | Problem raised 'in passing' when visiting the HCP for other reasons – either because an appointment was already booked, or because they would not have made a specific appointment about the oral health symptoms. | A pre-existing condition meant a patient was already receiving regular dental check-ups. | | | 1. Pregnancy in women (free care); parenthood (setting a good example); becoming unemployed (free care); middle-aged persons' fear of becoming edentulous<br>2. Effect of an urgent or very obvious need for dental treatment can convert a patient into being a regular attender. |
| **Desire early diagnosis** | To seek help 'better sooner than later' to avoid worsening outcomes. | | | | |
| **Need to resolve uncertainty** | To receive a diagnosis, provide understanding and clarity about their symptoms. | | | Uncertainty about perceived cause. | |
| **Certainty of perceived cause – self-diagnosis** | | | | Self-diagnosis and consequent strongly perceived need for dental treatment. | |
| **Advice of significant others** | Friends and family advised patients to seek help. | A regional TV cancer awareness campaign prompted a few patients to make an initial appointment with an HCP to investigate their symptoms. | | Patients told to seek dental care by another HCP or service. | |
| **Progression/ escalation of care-seeking** | | | 'Shopping around': multiple visits (by patients dissatisfied with the care received) to the same or different dentist(s) for emergency care before being directed to/presenting to emergency dental care clinic. | 1. 'Turning points': changing from a coping (but failed) self-care phase to an active, multi-stage process of seeking formal care<br>2. Distinction made between 'having problems' with teeth or gums and 'having a dental problem', one that needs a dentist to resolve (including if attributed to failed dental treatments, if a recurrence of a problem previously treated by a dentist, on GP/ pharmacist recommendation, or family/friends made a lay diagnosis). | 1. The barriers to care of anxiety and cost could generally be overcome where there was a need for attendance.<br>2. Need for attendance was generally a low priority to the young. An increased perception of need could be instrumental in (re-) establishing a regular attendance pattern. |

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| Knowledge of, and provision of, dental care services | | | | Knowledge that a local emergency dental care service exists and how to contact it. | Availability of extended surgery opening hours, knowledge of location of surgeries, mobile dentists, 'open surgeries' (no appointment). |
| As a preventative measure | | | | | 1. Regular dental attendance as 'an insurance policy' to safeguard against dental ill health. For some, a positive way to actively promote dental health in general; for others, perceived to be reactive to fears about the potential effects of not attending<br>2. Some regular attenders sought care out of habit, or to set an example to their children. A few associated dental attendance with class – it is the 'done thing' amongst the 'higher' or 'aspiring higher' classes. |
| Level of cost | | | | | 1. Reduced level of dental charges, or free treatment<br>2. A clear charging system<br>3. Access to an estimate of costs prior to commitment to dental care<br>4. An 'amnesty period' of no cost for the long-term non-attender. |
| Having a 'good' dentist | | | | | People perceived a 'good' dentist to be able to reduce anxiety/apprehension for patients. Dentists should be seen to have an approach that is friendly, have a personal touch, explain what is being done, be caring/gentle/reassuring, and inspire confidence. |

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| **III. Researchers' overall interpretations of the findings of peoples' subjective perceptions** | | | | | |
| **Researchers' overall interpretations of findings (per study)** | There are both barriers and triggers to seeking help. The main barriers related to beliefs about symptoms, the HCP and an individual's circumstances. The main triggers to seeking help included symptomatology and the presence of another reason for visiting an HCP. | The culture of not consulting a GDP/GP unless a health issue is perceived to be serious is a barrier to timely/appropriate care-seeking. The public's gaps in awareness and understanding of oral cancer lead to self-management and delay in seeking professional help. Overall, there are unclear links between advance awareness of oral cancer, considering the symptom may be serious, and deciding to visit an HCP. | Care-seeking for toothache may be associated with toothache pain intensity, the clinical conditions that present as toothache, treatment quality and emergency dental care need management. Perceived inability to cope with toothache may also be associated with these factors. | The effects of, and meanings attached to, acute dental symptoms are complex. Along with poor awareness of emergency dental services, patients' pathways to care are also complicated and incorporate non-physiological triggers. 'Perceived inability to cope' (either with symptoms or uncertainty) is a central organising concept. | Individuals' oral healthcare-seeking is seldom explained in terms of one factor. People tend to present these factors as 'barriers' to dental attendance, expressed in emotions, beliefs, perceptions and practicalities about the individual, or the external factors of service provision. Some of these barriers may be reinforced by certain factors, others diluted by them. The main barriers relate to: i. Anxiety/ fear/ apprehension in relation to a dental visit ii. Factors associated with the cost of a dental visit. |

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undertaken, although there are no 'gold' standard methods amongst the various existing methods for conducting syntheses of qualitative research. One possible approach, meta-ethnography, synthesises qualitative data across studies to permit identification of concept relationships, translation and synthesis into one another.[12] Such synthesis is beyond the scope of a rapid review.

## CONCLUSIONS

It appears that relatively few studies using qualitative research methods have been undertaken in the UK to understand people's care-seeking about oral health. The current findings indicate that a wide range of factors influence care-seeking about oral health, either as a trigger or barrier to care.

Further research into people's care-seeking about oral health would provide a useful addition to policymakers' and practitioners' understanding of their needs.


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