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REVIEW ARTICLE

The use of quality of life measures in oral medicine: a review of the literature

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OBJECTIVES: To explore the use of patient reported quality of life measures in oral medicine, to highlight the importance of use of these measures in oral medicine practice and to provide guidance for the selection of such measures in the future.

METHODS: A detailed literature review was undertaken to investigate the use of quality of life measures in oral medicine. The databases searched were MEDLINE (through PubMed), EMBASE, CINDHL, Web of Science Citation Index and the Cochrane Database of Systematic Reviews and randomised controlled trials.

RESULTS: The initial literature search yielded a total of 5310 citations; however, only 63 of these fulfilled the inclusion criteria. Twenty-two articles were regarding oral mucosal conditions, 14 related to orofacial pain disorders and 27 were regarding salivary gland-related conditions.

CONCLUSIONS: The evaluation of quality of life in oral medicine has a broad applicability, providing information in treatment-based studies and population-based studies. A predominance of generic and oral health specific quality of life measures are being used to a limited extent in oral medicine practice. A scarcity of reports of the development, validation or use of disease specific measures is evident.

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Introduction

An outcome measure in healthcare has been defined as 'a change in current or future health status that can be attributed to the antecedent intervention'. Outcome measures are becoming increasingly important because of the current trend towards the evaluation of healthcare in terms of patient reported benefits. Patients-centred outcomes commonly include psychosocial changes, such as changes in health status, ability to function and satisfaction with the care provided.

In the last number of years the use of patient-centred outcome measures in general medicine has increased substantially (Ware, 1993). These have focused mainly on the patients' own perceptions of the impact of their health on their quality of life (Bowling, 1995). The World Health Organisation recognises Quality of Life (QofL) not only as the absence of disease or infirmity but also the ability of a person to lead a productive and enjoyable life (WHO). QofL is therefore acknowledged as a multidimensional concept which includes the domains of physical health and functioning, mental health, social functioning, satisfaction with treatment, concerns about their future and general well-being (El Achhab *et al*, 2008). An appreciation of the importance in measuring the real-world impact of a condition on patients, through formal assessment of QofL, has grown significantly since the early 1990s. QofL represents the effect of an illness on a patient, as perceived by the patient, and can result in additional information in commonly recorded medical or epidemiological data. In fact QofL is becoming increasingly accepted as one of the most important outcome measures in the evaluation of any treatment or health-related intervention (Skevington, 1998).

Hegarty *et al* (2002c) highlighted the need to establish the effect of oral mucosal diseases upon quality of life. Conditions affecting the oral mucosa and conditions commonly managed in an oral medicine clinical setting are often chronic in nature or recurrent, painful disorders. Some of these conditions can predispose to or lead to the development of life-threatening conditions (Hegarty *et al*, 2002c). Not only can these chronic conditions have an impact on quality of life but also many of the treatment options available for these conditions and their side effects can also affect the QofL of a patient.

The aims of this review were to explore the use of patient reported quality of life measures in oral medicine, to highlight the importance of the use of these measures in oral medicine practice and to provide guidance for the selection of such measures in the future.

Materials and methods

Search strategy

Search strategies for this review were designed to retrieve references relating to the use of patient reported

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quality of life measures in an oral medicine setting, a detailed search of the literature was then performed. The databases searched were MEDLINE (through PubMed), EMBASE, CINDHL, Web of Science Citation Index and the Cochrane Database of Systematic Reviews and randomised controlled trials. The following MeSH terms were used: 'quality of life', 'health related quality of life', 'patient centred', 'outcome measurement', 'patient defined' and 'oral medicine', 'burning mouth syndrome', 'glossodynia', 'dysguesia', 'stomatodynia', 'glossopyrosis', 'sore tongue', 'oral lichen planus', 'recurrent aphthous stomatitis', 'pemphigoid', 'pemphigus', 'orofacial granulomatosis', 'Melkersson Rosenthal Syndrome', 'Cheilitis Granulomatosa', 'Granulomatous cheilitis', 'Behçet's disease', 'temporomandibular disorder (TMD)', 'trigeminal neuralgia', 'tic doloreaux', 'atypical facial pain', 'atypical odontalgia', 'xerostomia' and 'Sjögren's syndrome'. The decision to use condition specific subheadings in addition to 'oral medicine' was to ensure completeness in the search strategy.

Inclusion and exclusion criteria for the review

Papers were included in the review if they fulfilled the following criteria:

Publication in the English language, published in a peer reviewed journal and if the paper included a report on the use of a validated quality of life measure to assess the impact of a condition on the quality of life of a patient.

Papers were excluded from this review: if they were based solely on author opinion, literature reviews, editorials and letters, if the articles mentioned a change in quality of life but this outcome was not in fact measured if the treatments discussed in the articles were outside the scope of oral medicine practice and if the papers were relating to malignant disease and or its management. Although malignant disease and its management fall under the remit of oral medicine practice we decided to exclude this literature as a number of reviews of this individual area of practice have been published in the last number of years, with at least five articles comprehensively reviewing quality of life in head and neck cancer published since 1999 (Rogers *et al*, 1999, 2007; Ringash and Bezjak, 2001; Chandu *et al*, 2006; Pusic *et al*, 2007).

If there was any uncertainty as to the suitability of a paper for the review then a copy of the complete paper was consulted.

Data extraction

Copies of the papers obtained were thoroughly reviewed by the two researchers to identify articles suitable for inclusion. A study specific data extraction form was used, allowing reviewers to standardise the manner in which the papers were being reviewed. Recorded items included study aims and objectives; study type (population-based studies, questionnaire- properties-, development- and validation-based studies, treatment-based studies); patient reported outcome measures used and study outcome. The articles were then tabulated according to condition (oral mucosal conditions, chronic orofacial pain disorders and salivary gland related conditions) as shown in Tables 1–3.

Results

Search results

The initial literature search yielded a total of 5310 citations, these included duplicates and spurious references. Following a review of the titles and abstracts of these citations, 80 abstracts were selected, the articles sourced and then reviewed. Having reviewed these 80 articles 63 were deemed suitable for inclusion in this literature review.

Population-based studies

A total of 25 articles reported on the quality of life of a population of patients with varying conditions. Thirteen of these articles were regarding salivary gland conditions, for example, a number of authors investigated the quality of life of patients with Sjögren's syndrome (McMillan *et al*, 2004; Stewart *et al*, 2008) whereas others looked at the QofL of patients with xerostomia both in older adults (Matear *et al*, 2006) and in a young adult population (Thomson *et al*, 2006). Other conditions studied included pemphigus (Tabolli *et al*, 2008; Paradisi *et al*, 2009) Behçet's disease (Bodur *et al*, 2006; Gur *et al*, 2006) TMD (John *et al*, 2007; Barros Vde *et al*, 2009) and human immunodeficiency virus (HIV) (Mulligan *et al*, 2008; Yengopal and Naidoo, 2008).

Another 14 population-based studies compared quality of life in two or more populations of patients with certain conditions or with normal healthy subjects. Again a number of these studies looked at patients with salivary gland disease (Sutcliffe *et al*, 1998; Strombeck *et al*, 2000) whereas others reported on patients with burning mouth syndrome (Lopez-Jornet *et al*, 2008), Behcet's disease (Moses Alder *et al*, 2008) and TMD (Reißmann *et al*, 2007).

Questionnaire properties, development and validation-based studies

In two articles regarding oral lichen planus Hegarty *et al* (2002d) and McGrath *et al* (2003a) investigated the reliability, validity and sensitivity to treatment of two oral health related quality of life measures, OHIP-14 and OHQoL.

Gilworth *et al* (2004) described the development and validation of a disease specific quality of life questionnaire for Behçet's disease (BD-QoL) which was subsequently adapted for use in Korea by Yi *et al* (2008). Mumcu *et al* (2006) investigated the quality of life of Turkish patients with Behçet's disease and also examined the performance of OHIP-14 and OHQoL in the same population. The multidimensional properties of OHIP-14 were statistically tested by Mumcu *et al* (2007a) in patients with both Behçet's disease and recurrent aphthous stomatitis.

The validity of OHIP-14 and OIDP was investigated by Baker *et al* (2006) in patients with xerostomia with a further xerostomia related article looking at Wilson and

Table 1 Oral mucosal conditions

Reference	*Condition*	*Study type*	*Aims and objectives*	*Quality of life measure used*	*Study outcomes*
Hegarty *et al* (2002c)	Oral lichen planus	Questionnaire	To evaluate the performance of patient-centred outcome measures in the oral medicine setting in patients with oral lichen planus	OHQoL, OHIP-14	Both measures had good validity and internal reliability
Hegarty *et al* (2002b)	Oral lichen planus	Treatment	To investigate the acceptability and efficacy of topical fluticasone propionate spray (FP) and betamethasone sodium phosphate mouthrinse (BSP) upon the signs and symptoms of OLP, assessing patient quality of life changes as a consequence of these therapies	OHQoL, OHIP-14	Both drugs results in a significant improvement in OHIP and OHQoL.
Kaliakatsou *et al* (2002)	Oral lichen planus	Treatment	To investigate the efficacy and safety of 0.1% topical tacrolimus in erosive or ulcerative oral lichen planus	OHIP	54.7% reduction in OHIP group score
Llewellyn and Warnakulasuriya (2003)	Stomatological disease	Population	To test whether patients attending an outpatient oral medicine clinic would have worse oral health related quality of life (OHR-QoL) compared with the general population. To assess whether anxiety or depression could be predicted by OHR-QoL and to explore the relationship between clinical diagnoses, OHR-QoL and anxiety/depression	OHIP-14	Patients reported significantly lower overall OHIP-14 score and in all domains
McGrath *et al* (2003b)	Oral lichen planus	Questionnaire	To evaluate the sensitivity of two patient-centred outcome measures to the topical application of a corticosteroid (betamethasone) in the treatment of oral lichen planus (OLP)	OHIP-14, OHQoL	Both measures are sensitive to the clinical effects of topical betamethasone in the treatment of oral lichen planus
Gilworth *et al* (2004)	Behçet's disease	Questionnaire	To develop a disease-specific measure of quality of life for Behçet's disease	BD-QoL	BD-QoL provides a simple, reliable and valid tool for assessing the influence of interventions
Bodur *et al* (2006)	Behçet's disease	Population	To investigate quality of life (QoL) and life satisfaction (LS) in patients with Behçet's disease (BD) and determine the relationship with disease activity	NHP, LSI	Poor QoL and diminished LS in patients with BD
Gur *et al* (2006)	Behçet's disease	Population	To determine arthritis frequency, quality of life (QoL), anxiety and depression levels in Behçet's disease (BD) and thereby the effect of joint involvement on QoL, anxiety and depression	NHP, HAQ	Arthritis in BD considerably decreases QoL in patients
Mumcu *et al* (2006)	Behçet's disease	Questionnaire/ Population	To investigate oral and general health related quality of life (QoL) in patients with Behçet's disease (BD) and to assess the performance of Turkish versions of oral health related quality questionnaires	OHIP-14 SF-36	Turkish versions of OHIP-14 and SF-36 were valid and reliable. Oral and general QoL were impaired in BD.
Gorouhi *et al* (2007)	Oral lichen planus	Treatment	To compare the efficacy and safety of pimecrolimus 1% cream with triamcinolone acetonide 0.1% paste in treating OLP	OHIP	No significant differences between changes in VAS score, OHIP score of either drug at the end of 2 months
Heffernan *et al* (2007)	Oral erosive lichen planus	Treatment	To evaluate the efficacy of efalizumab in the treatment of oral erosive lichen planus	OHIP-14	Mean improvement of 69.3% in OHIP-14
Mumcu *et al* (2007b)	Behçet's disease and recurrent aphthous stomatitis	Questionnaire	To test multidimensional properties of oral health impact profile-14 (OHIP-14) in Behçet's disease and recurrent aphthous stomatitis patients with active oral ulcers	OHIP-14	OHIP-14 was reliable and sensitive to clinical parameters and treatment modalities

Table 1 (Continued)

Reference	*Condition*	*Study type*	*Aims and objectives*	*Quality of life measure used*	*Study outcomes*
Uguz *et al* (2007)	Behçet's disease	Population	To investigate the impact of major depression (MD) on the quality of life of patients with Behçet's Disease	WHOQoL-BREF	MD has a negative impact on QoL of BD patients
Moses Alder *et al* (2008)	Behçet's disease	Population	To examine various outcome measures using the multi-dimensional Health Assessment Questionnaire (MDHAQ) and compared them between Behçet's syndrome (BS) patients with and without arthritis. We also compared the results to those for patients with rheumatoid arthritis (RA), the disease in relation to which the MDHAQ has been most thoroughly studied	MDHAQ	BS patients have higher levels of functional disability and fatigue than RA patients
Mulligan *et al* (2008)	HIV and at risk women	Population	To compare the oral health-related quality of life (OHRQOL) between a group of HIV-infected women and a similar group of at-risk HIV-uninfected women and to investigate the role of potential confounding clinical oral health and behavioural factors	OHIP-14	HIV-infected women had on average 10% poorer OHRQOL than HIV-uninfected women
Tabolli *et al* (2008)	Pemphigus Vulgaris and Pemphigus Foliaceus	Population	To assess the impact of disease on the health status of patients with Pemphigus	SF-36	Patients with pemphigus vulgaris with mucocutaneous lesions had significantly lower scores than all the other subgroups
Yengopal and Naidoo (2008)	Oral lesions associated with HIV	Population	To assess the impact of oral lesions on quality of life (QOL) in HIV-positive (HIV+) individuals using the oral health impact profile (OHIP)	OHIP	Patients with oral manifestations of HIV had significantly lower OHIP scores
Yi *et al* (2008)	Behçet's disease	Questionnaire	To adapt the Behçet's disease quality of life questionnaire (BD-QoL) for use in Korea	BD-QoL	The Korean version of BD-QoL is reliable and valid
Babaee *et al* (2009)	Recurrent aphthous stomatitis	Treatment	To evaluate the clinical efficacy of a novel paste containing Myrtus communis (Myrtle) in the treatment of recurrent aphthous stomatitis	OHIP	Myrtle was effective in improving the quality of life in patients with RAS
Mumcu *et al* (2009)	Behçet's disease	Population	To evaluate and compare oral health-related quality of life (oral QoL) in patients from UK and Turkey with Behçet's disease (BD)	OHIP-14	Oral QoL was similar in BD patients from UK and Turkey with active oral ulcers
Paradisi *et al* (2009)	Pemphigus	Population	To achieve an exhaustive description of health status in a large sample of patients with pemphigus, assess the impact on quality of life (QoL) and define a minimum set of QoL tools for clinical practice	SF-36, Skindex 29, GH 12	Patients with pemphigus showed a markedly impaired overall QoL in comparison to healthy subjects
Tabolli *et al* (2009)	Oral mucosal disease	Population	To evaluate oral health-related quality of life (OHRQoL) and the burden of disease of dermatological patients with oral mucosal diseases	OHIP-14, SF-12. GHQ-12	High OHIP-14 scores were observed in RAS, OLP and BMS patients

Table 2 Orofacial pain disorders

Reference	*Condition*	*Study type*	*Aims and objectives*	*Quality of life measure used*	*Study outcomes*
Turner *et al* (2005)	Temporomandibular Disorder	Treatment	To evaluate a brief cognitive-behavioural treatment (CBT) for chronic temporomandibular disorder (TMD) pain	GCPS	Brief CBT increased perceived control over pain, improved activity interference and jaw use limitations for a subgroup of patients
Turner *et al* (2006)	Temporomandibular disorder	Treatment	To evaluated the short- and long-term efficacy of a brief cognitive-behavioral therapy (CBT) for chronic temporomandibular disorder (TMD) pain	GCPS	Brief CBT improved one-year clinical outcomes of TMD
Jedel *et al* (2007)	Temporomandibular disorder	Population	To compare health related quality of life, pain threshold (PT) and range of motion (ROM) in child patients with temporomandibular disorder (TMD) pain and an age and gender matched control group	CHQ-CF87	Child patients with TMD pain more than once a week reported significantly lower scores in CHQ-CF87 when compared with a control group
John *et al* (2007)	Temporomandibular disorder	Population	To characterise the level of impairment of oral health-related quality of life (OHRQoL) in a temporomandibular disorder (TMD) patient population	OHIP	OHRQoL was markedly impaired in TMD patients
List *et al* (2007)	Atypical odontalgia	Population	To provide a systematic description of clinical findings and psychosocial factors in patients suffering from atypical odontalgia (AO)	SF-36	Every domain measured by the SF-36 group demonstrated a greater impact on AO patients
Luo *et al* (2007)	Orofacial pain	Population	To determine orofacial pain (OFP) characteristics, associated disability and effect on quality of life in elderly community-dwelling Chinese people	OHIP-14 GHQ-12	OFP had a substantial detrimental impact quality of life in Chinese elders with mean OHIP-14 summary scores significantly higher in OFP subjects
Reißmann *et al* (2007)	Temporomandibular disorder	Population	To comparing the level of impaired oral health-related quality of life in patients with a specific temporomandibular disorder (TMD) diagnosis to general population subjects unaffected by TMD to derive the unique functional and psychosocial impact because of TMD	OHIP	TMD has a significant impact on OHRQoL. Subjects with pain-associated conditions present higher scores than those without pain.
Fischer *et al* (2008)	Complex regional pain syndrome	Treatment	To assess the effectiveness of occlusal splint (OS) therapy on self-reported measures of pain in patients with chronic complex regional pain syndrome (CRPS) as compared with a non-treatment group	SF-36	There were no differences in the changes of SF-36 scores between groups. The use of OS improved signs and symptoms of TMD but had no impact on CRPS-related pain.
Lemos *et al* (2008)	Trigeminal neuralgia	Treatment	To evaluated the clinical efficacy of associating Gabapentin (GBP) with ropivacain (ROP) analgesic block of facial trigger points in trigeminal neuralgia patients	SIP	GBP and ROP resulted in improved functional health status, as measured by SIP, of TN patients when compared with GBP alone
Lopez-Jornet *et al* (2008)	Burning mouth syndrome	Population	To compare BMS patients with healthy controls and to compare subgroups of BMS patients on the type of therapy received	SF-36 OHIP-49	BMS patients had poorer scores on both QoL measures used compared to healthy controls
Naikmasur *et al* (2008)	Myofacial pain dysfunction syndrome	Treatment	To evaluate the efficacy of occlusal splint therapy and compare it with pharmacotherapy (using analgesics and muscle relaxants) in the management of myofascial pain dysfunction syndrome	GPI	Gradual decrease in GPI scores in patients on occlusal splint therapy during the follow-up period as compared to the pharmacotherapy group
Rener-Sitar *et al* (2008)	Craniomandibular disorders	Population	To determine the impact of craniomandibular disorders (CMD) to the self-perceived oral health related quality of life (OHRQoL) and to compare the OHRQoL with a control group.	OHIP	Significantly higher OHIP summary scores and OHIP subscores were obtained in the CMD patients when compared with the control group

Table 2 (Continued)

Reference	*Condition*	*Study type*	*Aims and objectives*	*Quality of life measure used*	*Study outcomes*
Schierz *et al* (2008)	Temporomandibular disorder	Population	To compare patients' perceived impact from temporomandibular disorders (TMD) and from dental anxiety on oral health using item profiles contained within the Oral Health Impact Profile (OHIP)	OHIP	Dental anxiety patients demonstrated the highest mean OHIP summary scores and indicated problems more frequently than TMD patients in the OHIP domains of psychological discomfort and psychological disability
Barros *et al* (2009)	Temporomandibular disorder	Population	To evaluate the relationships between gender, diagnosis and severity of temporomandibular disorders (TMD) with self-reports of the impact of TMD on the quality of life	OHIP-14	No group difference between genders was evident. The presence of muscular disorders and osteoarthritis was related to greater impact on quality of life and correlation between severity of TMD and impact on quality of life observed

Cleary's (Wilson and Cleary, 1995) conceptual model of pathways between clinical and non-clinical variables in relation to the oral health-related quality of life (OHRQoL) of patients with xerostomia. (Baker, 2007). Medical Outcomes Study Short Form-36 (SF-36) and The World Health Organisation Quality of Life-BREF (WHOQOL-BREF) were used in the development of the Sjögren's systemic clinical activity index (SCAI) for the measurement of systemic disease activity in patients with primary Sjögren's syndrome (PSS) (Bowman *et al*, 2007).

Treatment-based studies

Eleven of the treatment-based studies were randomised controlled trials (RCTs). Some of these RCTs were single blinded (Gorouhi *et al*, 2007) whereas others were double blinded (Babaee *et al*, 2009). Naiskmasur *et al* (2008) compared two treatment modalities, muscles relaxants and analgesics with soft occlusal splint therapy, in the management of MPDS with a number of other studies using a placebo for comparative purposes (Mariette *et al*, 2004; Dass *et al*, 2008).

Randomised crossover study design was used by Hegarty *et al* (2002a) and Leung *et al* (2008). Hegarty *et al* compared the use of Fluticasone spray with the use of Betamethasone mouthwash in the management of oral lichen planus and Leung *et al* conducted a double blinded placebo controlled study of the management of Sjögren's syndrome with cevimeline hydrochloride.

Kaliakatsou *et al* (2002) and Heffernan *et al* (2007) carried out two open label studies regarding the management with oral lichen planus.

Instruments used

Table 4 represents a summary of all the instruments used in these articles and their frequency of use. The most commonly used instruments were Medical Outcome Survey Short Form 36 Health Survey (SF-36) and OHIP-14. Developed by Ware and Sherbourne (1992) in the early 1990s the Short Form 36 Health Survey (SF-36) was designed to assess general health concepts that are not age, disease nor treatment group specific. The instrument consists of 36 items encompassing eight health concepts: bodily pain, physical functioning, role limitations because of physical problems, mental health, vitality, social functioning, role limitations because of emotional problems and general health. The format for responses to these items is yes or no or in a three-to-six response scale. For each health concept questions scores are coded, summed and transformed on a scale from 0 (worst health) to 100 (best health).

Oral Health Impact Profile (OHIP-14) is a 14-item questionnaire, derived from a 49-item questionnaire (Slade and Spencer, 1994), designed to measure the frequency of difficulties patients experience associated with the mouth, teeth, or dentures in the recent past on seven domains; functional limitation, pain, psychological discomfort, physical disability, psychological disability, social disability and handicap. Patients are asked to rate each question on a five-point Likert's type scale from 0 (never) to 4 (very often). Two measures can be

Table 3 Salivary gland-related conditions

Reference	*Condition*	*Study type*	*Aims and objectives*	*Quality of life measure used*	*Study outcomes*
Sutcliffe *et al* (1998)	Sjögren's syndrome, Systemic lupus erythematous and Primary Sjögren's syndrome	Population	To determine the accumulated end organ damage and health status in patients with Sjögren's syndrome and to compare with patients with SLE	SF-20	Patients in all three groups had reduced quality of life with respect to all aspects of functional status and well being
Thomas *et al* (1998)	Sjögren's syndrome	Population	To report the prevalence estimates of Sjögren's syndrome from a general population and present the first population data to assess the impact of the syndrome	SF-36	Patients diagnosed with SS were more impaired for all dimensions of the SF-36 than those without a diagnosis
Strombeck *et al* (2000)	Primary Sjögren's syndrome, rheumatoid arthritis and fibromyalgia	Population	To investigate the health-related quality of life in women with primary Sjögren's syndrome (PSS) and compare with normative data and the health-related quality of life in women with rheumatoid arthritis and women with fibromyalgia	SF-36	PSS patients experienced a higher quality of life level with regard to physical function than the women with RA and fibromyalgia. Psychological dimensions the quality of life level were comparable in all groups
Valtysdottir *et al* (2000b)	Primary sjögren's syndrome	Population	To examine the degree of anxiety and depression and to assess well being and general symptoms in patients with primary Sjögren's syndrome	GQOL	Patients with PSS had poor quality of life than those with controls
Valtysdottir *et al* (2000a)	Primary Sjögren's syndrome	Population	To evaluate quality of life and psychological symptoms in patients with primary Sjögren's (PSS) syndrome and to compare this with patients with rheumatoid arthritis	PGWB	Patients with PSS have a reduced quality of life than patients with RA
Hay *et al* (2001)	Sjögren's syndrome with xerostomia	Population	To investigate whether a New Zealand population of people with Sjögren's Syndrome and xerostomia was malnourished	GHQ-12	Xerostomia was not a significant determinant of overall QoL
Rostron *et al* (2002)	Primary sjögren's syndrome and xerostomia	Population	To compare the health status of groups of Primary Sjögren's (PSS) and Xerostomia patients, using the Medical Outcomes Short Form 36 (SF-36)	SF-36	SF-36 was unable to detect significant differences between subjects with PSS and Xerostomia
Bowman *et al* (2004)	Primary Sjögren's syndrome	Population/ questionnaire	To compare existing instruments and a new tool for measuring fatigue and general discomfort in PSS, with systemic lupus erythematosus (SLE), rheumatoid arthritis (RA) and healthy controls	SF-36, WHOQoL-BREF and NEW	New questionnaire was more sensitive than the SF-36, WHOQOL-BREF at distinguishing the three rheumatic disorders from controls
Mariette *et al* (2004)	Sjögren's syndrome	Treatment	To evaluate the effect of infliximab in primary Sjögren's syndrome (PSS)	SF-36	No evidence of the efficacy of infliximab in PSS
McMillan *et al* (2004)	Sjögren's syndrome	Population	To investigate oral health-related quality of life (OHRQOL) among southern Chinese people with Sjögren's syndrome	SF-36	Oral symptoms of SS had a negative effect on OHRQOL. Health-related quality of life in general was also impaired in SS sufferers. The OHIP did not appear to discriminate oral problems of concern to SS sufferers.
Belenguer *et al* (2005)	Sjögren's syndrome	Population	To evaluate health-related quality of life (HR-QoL) in patients with primary SS (PSS) patients using the SF-36 questionnaire and to analyse the association between the main clinical features and the SF-36 scales	SF-36	Patients with PSS had clearly lower HR-QoL scores than the healthy population with significantly lower scores in all SF-36 scales
Gerdin *et al* (2005)	Dry mouth conditions	Population	To evaluate the impact of dry mouth conditions on oral health-related quality of life in frail old people, residents at community care Centres	OHIP-14	Significant associations were found between both objective and subjective dry mouth and oral health-related quality of life
Robinson *et al* (2005)	Xerostomia	Treatment	To assess the effect of a reservoir biteguard for artificial saliva on the oral health-related quality of life of patients with erostomia	OIDP	Reservoir biteguards improved the quality of life of people with xerostomia by reducing the number of impacts on daily life

Table 3 (Continued)

Reference	*Condition*	*Study type*	*Aims and objectives*	*Quality of life measure used*	*Study outcomes*
Baker *et al* (2006)	Xerostomia	Questionnaire	To compare the validity of the short form of the Oral Health Impact Profile (OHIP) and Oral Impacts on Daily Performance (OIDP) as measures of oral health-related quality of life in patients with xerostomia in the UK	OHIP-14, OIDP	Both OHIP14 and OIDP displayed good psychometric properties and appeared to be useful measures of OHRQoL in xerostomia. OHIP14 performed better than OIDP
Champey *et al* (2006)	Sjögren's syndrome	Population	To compare pain, fatigue and sicca symptoms; quality of life; and psychological status between patients with primary Sjögren's syndrome (PSS) and those with sicca symptoms but no autoimmune features [sicca asthenia polyalgia syndrome (SAPS)] and to determine whether a psychological pattern can be detected in patients with SAPS, which could suggest psychological distress as the cause	SF-36	Patients with PSS and SAPS do not differ in quality of life
Matear *et al* (2006)	Xerostomia	Population	To report on the severity of xerostomia in the elderly population and investigate the relationship with other aspects of perceived health	OHIP-14, GOHAI	Xerostomia has a significant and negative impact on the quality of life of elderly individuals
Thomson *et al* (2006)	Xerostomia	Population	To examine the association between xerostomia and oral-health-related quality of life among young adults while controlling for clinical oral health status and other potential confounding factors	OHIP-14	There was a strong association between xerostomia and OHRQoL in all OHIP-14 domains
Baker *et al* (2007)	Xerostomia	Questionnaire	To systematically test Wilson and Cleary's conceptual model of the direct and mediated pathways between clinical and non-clinical variables in relation to the oral health-related quality of life (OHRQoL) of patients with xerostomia	OHIP-14	The results support Wilson and Cleary's conceptual model of patient outcomes as applied to a chronic oral health condition
Bowman *et al* (2007)	Primary Sjögren's syndrome	Questionnaire	The development of the Sjogren's systemic clinical activity index (SCAI) for the measurement of systemic disease activity in patients with primary Sjogren's syndrome (PSS)	SF-36 WHOQoL-BREF	Initial results support the potential for the SCAI as a tool for systemic activity assessment in patients with PSS
Ikebe *et al* (2007)	Dry mouth and hyposalivation	Population	To determine the association of hyposalivation and the perception of dry mouth with oral health-related quality of life for independently living elderly	OHIP-14	Poor OHIP-14 scores were related to fewer residual teeth, perception of dry mouth on eating and hyposalivation
Ship *et al* (2007)	Xerostomia	Treatment	To evaluate the safety and efficacy of a group of topical dry mouth products (toothpaste, mouth rinse, mouth spray and gel) containing olive oil, betaine and xylitol		Use of the novel topical dry mouth products improved xerostomia-associated quality of life
Strombeck *et al* (2007)	Primary Sjögren's syndrome	Treatment	To investigate the effect of a moderate to high intensive exercise programme on two primary outcomes (aerobic capacity, fatigue) and three secondary outcomes (anxiety, depression and health-related quality of life) in women with primary Sjögren's syndrome	SF-36	There was no difference in HRQoL with exercise in women with PSS
Dass *et al* (2008)	Sjögren's syndrome	Treatment	To investigate the efficacy of rituximab in reducing fatigue in primary Sjogren syndrome	SF-36	There was a significant difference at 6 months in the social functioning score of SF-36 and a trend to significant difference in the mental health domain score of SF-36
Leung *et al* (2008)	Sjögren's syndrome	Treatment	To evaluate the effects of cevimeline on health-related quality of life and oral health status in patients with Sjögren's syndrome	SF-36, GOHAI	There was a significant improvement in GOHAI scores. SS patients had lower SF-36 scores, but these did not improve after treatment with cevimeline.
Lopez-Jornet and Camacho-Alonso (2008)	Sjögren's syndrome	Population	To investigate the general and oral quality of life in patients with Sjögren's syndrome (SS) and sicca complex	SF-36 OHIP-49	Patients with primary SS present lower scores for both oral and general quality of life

Table 3 (Continued)

Reference	*Condition*	*Study type*	*Aims and objectives*	*Quality of life measure used*	*Study outcomes*
Stewart *et al* (2008)	Sjögren's syndrome	Population	To characterise the relationship between both generic and oral health-related QOL and clinical measures of disease status in a sample of patients with SS and to assess the unique contribution of oral health to more general measures of health and well-being	OHIP-14 SF-36	Both generic and oral health-related QOL were poor in patients with SS
Segal *et al* (2009)	Primary Sjögren's syndrome	Population	To assess the health related quality of life of patients with primary Sjögren's syndrome (PSS) in a large US sample	SF-36	The impact of SS on health related quality of life was substantial with patients with a confirmed diagnosis of SS reported significant reductions in all eight domains of the SF-36

Table 4 Quality of life instruments used and the frequency of use

Frequency of use	*Quality of life instruments*	*Abbreviation*
27	Oral Health Impact Profile 14 and 49	OHIP-14, OHIP
23	Medical Outcome Survey Short Form 12, 20 and 36	SF12, SF20, SF36
3	General Health Questionnaire 12	GHQ12, GH12
	Oral Health Related Quality of Life-UK	OHQoL-UK
	World Health Organisation Quality of Life-BREF	WHOQoL, BREF
2	The Behçets Disease Quality of Life	BDQoL
	Nottingham Health Profile	NHP
	Graded Chronic Pain Scale	GCPS
	Oral Impact on Daily Performance	OIDP
	Geriatric Oral Health Assessment Index	GOHAI
1	Life Satisfaction Index	LSI
	Health Assessment Questionnaire	HAQ
	Multidimensional Health Assessment Questionnaire	MDHAQ
	Skindex-29	Skindex-29
	Child Health Questionnaire	CHQ-CF87
	Sickness Impact Profile	SIP
	Psychological General Well-Being	PGWB
	Gothenburg Quality of Life Instrument	GQOL

created from the OHIP-14, an unweighted additive measure (0–56) and a weighted impact measure (0–14).

Discussion

A number of citations originally included were then deemed unsuitable following a review of the article in full as they purported to evaluate QofL and in fact did not do so (Sepici-Dincel *et al*, 2006; Samet *et al*, 2007). These authors associated a reduction in clinical signs and symptoms and a decrease in pain with an improvement in QofL, therefore, failing to acknowledge the multidimensionality of QofL. Each individual's interpretation of QofL varies hence the need for carefully developed and validated measures of this concept. Ahmed (2001) used a five-point Likert's scale to assess quality of life avoiding quality of life questionnaires as the author concluded that elderly patients may find it difficult to respond spontaneously to such complex questions. However, the use of a simple Liker't scale to quantify changes in QofL cannot be considered a viable assessment of QofL in an individual. The measure of QofL as an outcome in clinical trials or in population studies can certainly add to the information available to physicians in the management of conditions but these data are only of use if appropriately assessed.

Generic QofL instruments like SF-36 have been developed for the general population, not only do they allow measurement of quality of life but they also allow comparisons to be made across a number of diseases (Strombeck *et al*, 2000; Valtysdottir *et al*, 2000a,b). These generic instruments are however unlikely to detect small, clinically important changes as can be assessed by disease specific measures. Gilworth *et al* (2004) report the development of a disease specific measure for Behçet's disease. This questionnaire was further adapted for use in Korea by Yi *et al* (2008). Bearing in mind the vast number of disease specific quality of life questionnaires that have been developed for other autoimmune conditions (Boyer and Earp, 1997; Bradley *et al*, 1999), it is surprising that no other articles could be found regarding the development of disease specific instruments in the field of oral medicine. When used in conjunction with a generic questionnaire, a disease-specific questionnaire can create a more complete picture of the impact of a condition on a patient's daily life. Hegarty *et al* (2002d) and McGrath *et al* (2003a) investigated the validity, reliability and sensitivity to treatment of oral health related quality of life questionnaires, OHIP-14 and OHQoL. The authors found both questionnaires to be valid, reliable and sensitive to treatment in patients with oral lichen planus (OLP). In an article by Escudier *et al* (2007) the authors recommended a tripartite approach to the assessment of OLP, including the assessment of quality of life. The aforementioned articles by Hegarty *et al* (2002d) and McGrath *et al* (2003a) could give practical direction to clinicians and researchers alike as to which oral health related quality of life measures to use in the assessment of OLP and interventions used in this condition. While there is a paucity of disease specific measures in oral medicine, researchers should be encouraged to consider using both a generic and oral health related quality of life questionnaire when assessing quality of life in clinical trials in an oral medicine setting.

A number of articles have been published regarding the evaluation of QofL in temporomandibular disorder, evaluating the merits of cognitive behavioural therapy (Turner *et al*, 2005), comparing TMD patients with healthy subjects and investigating the relationship between gender, diagnosis and severity of the condition (Barros Vde *et al*, 2009), giving a good deal of both generic and oral health specific quality of life data concerning TMD. Only one article, however, was found concerning trigeminal neuralgia (Lemos *et al*, 2008). It is surprising that no papers have been published evaluating either QofL or OHQofL in TN patients. Such studies could provide valuable information to both physicians and patients alike regarding the condition.

Although a considerable number (n = 19) of the articles reviewed concerned the impact of Sjögren's syndrome on quality of life only two of these studies measured the impact of the disease on oral health related quality of life (Lopez-Jornet and Camacho-Alonso, 2008; Stewart *et al*, 2008). This is surprising as the number of oral symptoms experienced by patients with SS can be quite extensive. Not only do patients experience a reduction in salivary flow changes but changes can also occur in the composition of saliva that increase susceptibility to dental caries, increased the incidence of oral candidiasis and ulceration (Lundstrom and Lindstrom, 1995). Alteration in taste and problems with wearing dentures, with chewing and swallowing food and difficulty with speech can also be experienced, all of which can impact greatly on daily life (Binon and Fowler, 1993).

In conclusion, a predominance of generic and oral health specific quality of life measures, most commonly SF-36 and OHIP, are being used to a limited extent in oral medicine practice. A scarcity of reports of the development, validation or use of disease specific measures is evident. The evaluation of quality of life in oral medicine has a broad applicability, providing information in treatment-based studies such as clinical trials and population-based studies, investigating the impact of conditions on certain populations or comparing groups from different geographic locations.

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