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Is routine holistic assessment with a prompt list feasible during consultations after treatment for oral cancer?

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Abstract

The head and neck cancer Patient Concerns Inventory (PCI-HN) is a holistic, self-reported list of items that can help patients to disclose their needs and concerns during routine follow-up consultations. The aim of this study was to report how often it was used during the first three years of follow up after treatment for oral cancer, and the range of issues that were raised. The sample comprised consecutive patients treated over a three-year period with curative intent. All clinic attendances were reviewed until October 2015 or until patients had a recurrence, a subsequent primary, metastases, or were discharged home or to follow up at a peripheral hospital, or started palliative care. We identified 92 patients and data were available for 88 of them. The median (IQR) age at the time of treatment was 65 (57–76) years, and 48 (55%) were men. Reviews alternated between the surgeon and oncologist, and typically there were 4.4 surgical reviews in year one, 2.8 in year two, and 1.6 in year three. The inventory was completed 157 times; at least once by 71% (55/77) during year one, 57% (29/51) during year two, and 37% (13/35) during year three. Of those who completed none, nearly half (7/17) died within 12 months, and another six were over 80 years of age. In conclusion, the diversity of concerns raised by patients highlights the need for holistic assessment during follow up, and integration of the inventory into routine consultations will mean that we can repeat it.

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Keywords: Patient Concerns Inventory; holistic needs assessment; oral cancer; follow up

Introduction

After treatment for oral cancer it can be difficult in clinics to elicit patients' concerns about physical, functional, social, and psychological problems¹ because of a lack of time, resources, expectation, or training.² Addressing these concerns is part of individual, patient-centred care, and is a philosophy that is bound up in the concept of assessment of holistic needs, which should be part of the care of every patient.³ Various tools are available to support this, and the

Patient Concerns Inventory is one that is specific to cancer of the head and neck (PCI-HN).⁴

There is a body of evidence to support the benefit to patients of a condition-specific prompt list in clinical consultations.⁵ The PCI-HN, a self-reported 56-item list that is designed to help patients disclose their needs and concerns,⁶ comprises physical and functional, social, treatment-related, and emotional and spiritual domains. Its use, combined with the University of Washington Quality of Life head and neck cancer-specific questionnaire version 4 (UW-QoLv4), can help to focus the consultation and provide a holistic assessment of need. The identification and discussion of potentially unmet needs, which together form

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a clinical intervention, can lead to referral to other members of the multiprofessional team.⁷

Review after treatment is an essential component of care. There are recommendations about frequency, but in practice (allowing for events such as cancelled clinics) most patients are seen about six times in year one, three times in year two, twice each in years three and four, once or twice in year five, and then annually.⁸ These consultations enable clinicians to check for recurrence, give advice about lifestyle, and address concerns in a holistic framework. Inclusion of the PCI-HN has not appreciably increased consultation times, and the possible benefit of its use as a repeated intervention has led to a randomised trial powered at just over 400 patients. The primary outcome is the proportion of participants with a less-than-good overall quality of life at the final one-year clinic as measured by the single UW-QoLv4 question, and secondary outcomes are the mean social-emotional subscale score (UW-QoLv4), and the proportion with a Distress Thermometer score of four or more.⁹

Although patients have appreciated use of the PCI,¹⁰ to the best of our knowledge the number of times it is completed as part of routine follow up has not been investigated. The aim of this study therefore was to follow a consecutive group of patients treated for oral cancer, to report how often it was used in the first three years of follow up, and the range of issues raised.

Methods

The study group comprised patients treated curatively for oral cancer between January 2008 and December 2011, inclusive, at Aintree Regional Oral and Maxillofacial Centre within one consultant's practice (SNR). Patients were identified retrospectively from the hospital's cancer database. All clinic attendances and subsequent letters to general practitioners (GP) and to other members of the multiprofessional team were reviewed until October 2015 or until patients had a recurrence, a subsequent primary, metastases, or were discharged home or to follow up at a peripheral hospital, or started palliative care. Each clinic date was recorded, as were comments relating to the reason for the clinic and the outcome so that routine and non-routine appointments could be identified.

Two items (dry mouth and sore mouth) were added to the PCI¹¹ in the middle of 2012; otherwise most date from 2007, with a few from March 2008. We searched clinic letters for any mention of the PCI, and for its use by the patient. As touch-screen technology was not available between November 2011 and June 2012, completion of the inventory was not possible.

For surgical patients, results from the first year of follow up were taken as those one year after operation. Results for the second and third years followed on from the first year. We recorded the total number of clinics/patient/year of follow up for each patient and the total number of rou-

Table 1
Reasons why follow up did not continue.

Reason	No. of patients (n = 88)
Death	15
Discharge	28
Recurrence or second primary	22
Referral elsewhere	4
End of follow up reached (October 2015)	5
No further clinic records	8
Palliative treatment	4
Other	1
Not known	1

tine clinics/patient. Non-routine clinics were typically those soon after operation to check healing, and for dressings. Appointments within 30 days of operation were considered non-routine, as were those after 30 days if the time lag from the previous clinic was less than 28 days.

The data, which had been collected as part of a service audit rather than for research, met the criteria of the local Clinical Governance Department for service evaluation.

Results

A total of 92 patients had attended clinics between January 2008 and December 2011, and data were available for 88 of them. The median (IQR) age at treatment was 65 (57-76) years, and 48 (55%) were male. The sites of the primary tumour were anterior two-thirds of the tongue (n = 38), floor of the mouth (n = 18), buccal mucosa (n = 16), lower gum (n = 13), and other (n = 3). The overall clinical stage was 1-2 for 58, and 3-4 for 30. Treatment comprised operation alone (n = 54), operation with adjuvant radiotherapy (n = 32), or chemoradiotherapy without operation (n = 2). Free flaps were used in 49/86 operations (37 soft and 12 composite flaps). Table 1 shows the reasons why follow up ended.

Table 2 shows the total number of clinics attended during the first three years after operation by the 86 surgical patients, the number of routine clinics, and the number of those at which patients completed the PCI. There were 501 attendances during year one, of which 308 were routine appointments. This equates to 7.1 clinics/year/patient, of which 4.4 were routine appointments. For year two the corresponding figures were 3.5 and 2.8, respectively, and for year three 2.1 and 1.6.

A total of 69/86 patients (80%) completed at least one inventory at routine clinics during the three-year follow-up period. Results from the first one, completed at a median (IQR) of 114 (41-227) days after operation, are shown in Fig. 1. Nearly half (7/17) of those who did not complete an inventory died within 12 months compared with 6/69 who did. The median (IQR) age of the 17 who failed to complete one was 80 (65-83) years, and six of the 10 who did not complete one and who were alive at 12 months, were aged over 80 years. Kaplan-Meier estimates of overall survival for

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