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British Journal of Oral and Maxillofacial Surgery 53 (2015) 1015-1020

# Where do patients treated for oral cancer die? A 20-year cohort study 1992-2011

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Accepted 4 October 2015 Available online 1 November 2015

#### Abstract

Of 1290 consecutive patients treated between 1992 and 2011 for primary squamous cell carcinoma of the oral cavity at a regional centre, 750 had died by August 2013. About half of them (n = 373) died in hospital, 113 (15%) in a hospice, 180 (24%) at home, 57 (8%) in a care home, and 22 (3%) elsewhere. Cancer was the underlying cause of death in 64%, and of them, 56% were oral cancers. The place of death was strongly associated with the age at death and cancer being the underlying cause. The percentage of people who died from cancer at home or in a hospice rose over time across all age groups and, from 2010, accounted for two-thirds. In contrast, less than 1 in 5 who did not die from cancer, died at home or in a hospice ranged from 32%-38% and 20%-29%, respectively, across age groups. An increase in the number of deaths from cancer in care homes in those aged 75 years and over was mirrored by fewer at home. Most of those who did not die from cancer, died in hospital, two-thirds were under 65 years, 85% were aged 65-84, and 56% were older. This was mirrored by fewer deaths at home in those under 85 and more in care homes in those over 75. In conclusion, our findings suggest that patients' preferences not to die in hospital are being realised. However, at the end of their lives, patients and their carers need more support at home, and more research is required. © 2015 The British Association of Oral and Maxillofacial Surgeons. Published by Elsevier Ltd. All rights reserved.

Keywords: Head and neck cancer; Oral cancer; Place of death; Survival

## Introduction

Every year around 8 million people die of cancer worldwide and the number is projected to rise.<sup>1</sup> Given the choice, patients tend to prefer to die at home,<sup>2</sup> but various studies have found that most patients dying of cancer do so in hospital.<sup>2–4</sup>

Catriona.Mayland@aintree.nhs.uk (C. Mayland), jackb@edgehill.ac.uk (B. Jack), astraglobeltd@btconnect.com (D. Lowe), snrogers.aintree@gmail.com (S.N. Rogers). Gao et al<sup>4</sup> analysed all deaths from cancer in England between 1993 and 2010 and concluded that between 2005 and 2010, there was a steady downward trend in the number that died in hospital and that the pattern was mirrored by an increasing trend towards deaths at home. The authors highlighted marital status, age, deprivation, and type of cancer, as important risk factors for more deaths in hospital, as well as regional variations. In the North West, patients dying of cancer had the second highest chance of being at home or in a hospice.

The National End of Life Care Programme launched in England in 2004, aimed to reduce the number of patients who died in hospital by promoting good end of life care that included better access to facilities that would enable them to choose where to die. Studies have shown that patients

http://dx.doi.org/10.1016/j.bjoms.2015.10.003

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with cancer who die in hospital have a poorer quality of life than those who die at home.<sup>5</sup> Marie Curie Cancer Research showed that end of life care in hospital is 3-times more costly than that in the community.<sup>6</sup>

We know of only a few studies that report the place of death in patients with head and neck cancer, and none has focused specifically on oral cancer. Ethunandan et al<sup>7</sup> reported that 63% died in hospital and 16% at home, while Ledeboer et al<sup>8</sup> reported that 23% died in hospital and most died at home. Of 65 patients with oral cancer who were treated with palliative intent,<sup>9</sup> 22 died in hospital, 14 in a hospice, 14 in their own home, and 14 in a care home. In June 2014, Public Health England published statistics on deaths from cancer of the head and neck in England for 2003- 2012 using details on death certificates.<sup>10</sup> Their latest (2012) incidence figures show that 11 725 patients were diagnosed with cancer of the head and neck, and it was mentioned on 3718 death certificates, which is about one-third of all cases. From their figures of average annual deaths (2003-2012), patients who died from cancers of the lip, tongue, and oral cavity comprised 30% (830/2726) of all those who died from cancer of the head and neck, and of the 30%, 36% died in hospital, 28% at home, 24% in a hospice, 11% in a care home, and 2% elsewhere.

Our study reports the place of death for a group of patients treated for primary squamous cell carcinomas at the Aintree Maxillofacial Unit in the North-West region over a 20-year period (1992-2011). Our aim was to analyse the influence of clinical and demographic characteristics on the place of death, and to explore how it has changed over time. An understanding of this will inform best practice concerning the support of patients and their carers at the end of life.

## Patients and methods

The head and neck database at the Aintree Regional Maxillofacial Unit was used to identify patients treated curatively for primary squamous cell oral carcinomas between 1992 and 2011. Deaths were tracked through the Office for National Statistics with certification details to 31 August 2013. Details on the death certificate enabled the place of death to be categorised: at home, in a care home (nursing or residential), hospital, hospice, or elsewhere. These categories were chosen to match as closely as possible with previous published work.

For purposes of analysis, the underlying cause of death on the death certificate was categorised as being cancer or otherwise. The age at death and sex were also included as having a possible association with place of death, as were clinical characteristics at the time of primary diagnosis (site and stage of the tumour, and mode of treatment).

Kaplan-Meier methods were used to estimate cumulative survival. The chi square test was used to compare personal and clinical characteristics in regards to the place of death. Logistic regression methods were used to estimate the associations of factors with deaths at home or in a hospice compared

| Table 1               |     |
|-----------------------|-----|
| Cancer as cause of de | ath |

|  | No. (%)<br>(n=476) |
|--|--------------------|
| Oral   | 265 (56)           |
| Head and neck not including oral                     | 58(12)             |
| Bronchus/lung  | 56(12)             |
| Head and neck, and bronchus or lung                  | 12(3)              |
| Oesophagus   | 12 (3)             |
| Stomach/gastric                                      | 9 (2)              |
| Colon/rectal   | 9 (2)              |
| Prostate   | 5(1)               |
| Others, including carcinomatosis and site not stated | 50 (11)            |

with those elsewhere. This outcome was chosen in light of the work by Gao et al.<sup>4</sup> Factors considered as predictors are shown in Table 1. Age at death is also considered as a numerical variable. Missing data were categorised as such within all analyses.

#### Results

The 20-year study group (1992-2011) comprised 1290 patients, mean (SD) age 63 (13) years, of whom 788 (61%) were male. Sites of tumour were the tongue (n = 430, 33%), floor of the mouth (n = 399, 31%), retromolar (n = 126, 10%), buccal (n = 110, 9%), and elsewhere (n = 225, 17%). Overall clinical staging was early (0 - 2) in 682 (53%), late (3 or 4) in 573 (44%), and unknown in 35. Primary treatment was operation alone (n = 754, 58%), operation with adjuvant radiotherapy (n = 424, 33%), and radiotherapy or chemoradiotherapy (n = 112, 9%). Kaplan-Meier survival (SD) from diagnosis was 81.5% (1.1%) at 12 months, 70.3% (1.3%) at 24 months, and 54.1% (1.4%) at 60 months. As at 31 August 2013, 750 patients had died, median (IQR) 23 (9-60) months from diagnosis, and details about where they had died were available for 745: 373 (50%) had died in hospital, 113 (15%) in a hospice, 180 (24%) at home, 57 (8%) in a care home, and 22 (3%) elsewhere.

A total of 476/745 (64%) died from cancer, and of them, 265 (56%) died from oral cancers (36% of all the deaths from cancer). Table 1 shows the other sites.

Cancer was not the underlying cause of death in 269 of the 745 (36%). The causes are shown in Table 2. In part 2 of the certificate, cancer was mentioned in 97 of the 269 cases (36%), of which 67 (69%) were oral cancers, and 7 (7%) were at other sites in the head and neck.

Factors most strongly associated with the place of death were age at death and whether cancer was the underlying cause (Table 3). Results stratified by these factors (Table 4) show that for deaths from cancer the percentage that died in hospital was similar across age groups (range 32%-38%) with no notable trend with age; it was similar for those who died in a hospice (range 20%-29%). The percentage of those who died in a care home increased, however, in those aged 75 years and over, and this was mirrored by fewer deaths at

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