‘Who are our patients?’ A Socio-Demographic Profile of Head and Neck Cancer Patients

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ABSTRACT

The purpose of this study was to address a significant need for baseline local, Australian specific socio-demographic data at the time of diagnosis for people presenting with head and neck cancer. The findings provide fresh insights that challenge the assumption with regards to the socio-economically challenged profile of head and neck patients. Also of significance, the socio-demographic profile deepens our understanding of the psychosocial impact of the disease on work and employment, especially for those of working age. All data was obtained through patient medical chart audit and retrospective analysis of psychosocial and demographic assessment interview practitioner notes on all new service users who completed that assessment (n=301) at or just prior to the point of first presentation at the Princess Alexandra Hospital, Brisbane, Australia Head and Neck Clinic in the calendar year 2008. Defined codes were developed through initial thematic analysis, team consensus and informed by current psychosocial health literature and health professionals working within the Clinic. Coded data was entered into SPSS to provide descriptive statistics such as frequency and percentage to provide a basis for analysis.

Key words: Employment; Head and neck cancer; Socio-demographics; Supportive care.
With the exception of age and gender distribution, all other variables such as accommodation type, work and income, marital/partnered status and Indigenous representation reflected the Australian norm. Such comparisons were made across all subgroups (Advanced oral, pharyngeal, laryngeal cancer; other advanced cancer; non-advanced cancer; non-cancer) and metropolitan/regional home address. The findings indicate the potential for psychosocial distress associated with a change in work and financial situation before treatment commences for many of those aged 64 years and under; an age group that constitutes 50.2% of the total cohort. Services need to be tailored towards persons who may be vulnerable to psychosocial distress and available in a form and at a time which suits their specific needs.

INTRODUCTION

A knowledge of the socio-demographic profile of people presenting at diagnosis with a new head and neck cancer can help the treating team assist and provide services for these people in an appropriate and timely manner as they face the many challenges associated with the disease and treatment. Most will present with advanced disease, and will likely quickly transition into treatment. At the point of diagnosis, disease may already affect vital functions and communication ability and the individual is likely to have varying levels of emotional distress. However, there is evidence of head and neck cancer patients under-reporting psychosocial concerns with the consequence that treating teams can have difficulty in identifying patient need for psychosocial assistance.

The considerable health-related quality of life research literature on head and neck cancer patients focuses predominantly on the period of treatment to survivorship. However, as the present socio-demographic findings indicate, there is also need to understand the situation of these patients during the period of diagnosis to treatment, a period of considerable challenge and vulnerability. Socio-demographic indices for this diagnostic group influencing patient outcome have been shown to be age, marital status, emotional status, income and employment. The likely median age at diagnosis is early 60s, with a possible trend towards younger patient age. Such a trend would increase the relevance of work and income support mechanisms (for those of working age who are unable to work) in understanding the magnitude of challenges people face as they transition into treatment. Anecdotally, head and neck cancer patients have been regarded as disproportionately socio-economically challenged. In the literature, research indicating a socio-economically challenging profile for head and neck cancer patients is documented in regional and ethnic minority studies, case-control studies and a recent large population study showing decreasing incidence with increasing social advantage using indices such as income, work and housing.

The majority of research originates in the United States of America and Europe and consequently does not address regional-specific issues including differences in cultural norms, distance and relocation for treatment, hospital and government support and primary care support. The purpose of this study is to address a significant need for baseline local, Australian specific socio-demographic data at the time of diagnosis on a range of variables including age, gender, marital/partnered status, accommodation type, income (which for working age involves work or alternatives). The findings provide fresh insights that challenge the assumption with regards to the socio-economically challenged profile of head and neck patients. Also of significance, the socio-demographic profile deepens our understanding of the psychosocial impact of the disease on work and employment, especially for those of working age.

THE RESEARCH

This research represents collaboration between the Social Work Department, Princess Alexandra Hospital (PAH) and the International Program of Psycho-Social Practitioner Research (IPR) Scheme. The IPR Scheme enables health professionals interested in research to undertake research on a topic of direct relevance to their professional practice with the support and mentorship of experienced researchers. In this case, the first author for the paper, who was a social worker working with head and neck cancer patients at the hospital, participated in the IPR Scheme to conduct a socio-demographic profile of head and neck cancer patients from the clinical notes available through her work at the head and neck clinic. The Social Work Department provided in-kind support by some approved dedicated research time. The IPR program provided assistance through mentoring, access to technical resources, office space from which to work, expertise in research methodology, provision of training in use of research programs such as SPSS and support
for conference attendance and publication activities for dissemination of research findings. The project was initiated during the IPR’s employment at the hospital and completed during her retirement. A full report detailing the findings was completed and presented to the Social Work Department at PAH.

METHODOLOGY

All data was obtained through patient medical chart audit and retrospective analysis of psychosocial and demographic assessment interview practitioner notes on all known new service users (n=301) who completed that assessment at or just prior to the point of patient first presentation at the Princess Alexandra Hospital (PAH), Brisbane, Australia Head and Neck Clinic in the calendar year 2008. The Clinic was seeing approximately 300 new presentations each year at the time of data collection. Ethics Committees’ approval was obtained.

Some assessments were not completed due to late referral, late arrival at the Clinic or human resource issues. All data was de-identified and defined codes developed through initial thematic analysis, team consensus and informed by current psychosocial health literature and health professionals working within the Clinic. Coded data was entered into SPSS to provide descriptive statistics such as frequency and percentage to provide a basis for analysis of data.

Whilst best effort has been made to ensure data integrity and accuracy, all data presented has a variability factor of +/- 2%. Data that was not available was deemed 'systems missing' and was not included in analysis or presentation of descriptive statistics. Advanced cancer was defined to include all people classified by the Clinic team as having TIII or TIV disease20 and all people treated with more than one treatment modality.1,2 Source of income was sought and recorded. Education information was not sought or recorded. Indigenous identity data was gathered from medical records and assessment data. It is the person’s discretion as to whether they identify themselves as indigenous. Regionality was defined by patient’s home address being more than 55 kilometres from Princess Alexandra Hospital which approximates the definition used in the Queensland Department of Health’s Patient Travel Subsidy Scheme.

A Report provides an overview including further information on work and income, support, lifestyle factors and relocation issues.21 This paper presents the findings from the study that challenges anecdotal comment and research literature indicating low socio-economic status for individuals diagnosed with head and neck cancer

FINDINGS

Disease and treatment

There were four sub-groups identified by the study, including Advanced Oral, Pharyngeal or Laryngeal Cancer 48% (n=145), Advanced Cancer (Other) 25% (n=75), Non-Advanced Cancer 22% (n=65) and Non-Cancer (presented with a medical condition which was diagnosed as non-cancer) 5% (n=16). Primary tumour sites identified were hypopharynx (n=17), larynx (n=37), nasopharynx (n=13), oropharynx (n=33), occult primary (n=20), oral (n=65), salivary (n=29), sino-nasal (n=15), skin and face (n=41), thyroid (n=4), unquantifiable nerve sheaths (n=4), and some miscellaneous (n=3). Of the total group, 73.1% (n=220) presented at diagnosis with advanced cancer.

Socio-demographics

Age, gender, marital status, accommodation type and geographical location data is shown in Table 1. Slightly more regional than metropolitan people lived in their own home. Average age was 63 years (S.D. 15). Of the 301 patients, 67.4% (n=203) lived with a spouse or partner, with family or in a residential care facility and indicated they had some form of in-home support. This is consistent with the figure of 67.4% for family households shown by Australian Bureau of Statistics 2006.21

Four people (1% of total group) identified as Indigenous. This compares to 2.4% of general population.21-24

Work and finances

Sources of income for working age (aged 64 years and under, and 50.2% (n=151) of the total cohort), and non-working age (65 years and over, and 49.8% (n=150) are shown in Table 2. One person was below the legally defined working age of 15 years. Data of working age people in work at diagnosis by identified subgroups is...
shown in Table 1.

With regards to paid leave status such as sick leave, recreation leave, long service leave, seventy-five individuals of working age indicated what leave they understood they were entitled to receive to assist them through treatment. Of these 56% said they had no paid leave available with more regional than metropolitan people finding themselves without leave.

With regards to financial commitments relating to accommodation, of those of working age and in employment (n=81), 61.7% lived in their own home or unit and 20% of these lived alone or provided the sole income for the household. 27.2% (n=22) lived in a home or unit in the private rental market and 68.2% of this rental group lived alone or provided the sole income for the household.

Table 1

<table>
<thead>
<tr>
<th>Demographic Categories</th>
<th>Non Cancer</th>
<th>Adv OPL Cancer</th>
<th>Adv ca (Other)</th>
<th>Non-Adv Cancer</th>
<th>Total Cohort n=301</th>
<th>General Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>44 years and under</td>
<td>50.0(8)</td>
<td>6.9(10)</td>
<td>7.0(5)</td>
<td>6.2(4)</td>
<td>9.0(27)</td>
<td>62.0(13,552,966)</td>
</tr>
<tr>
<td>45 to 54 years</td>
<td>63.1(12)</td>
<td>20.7(30)</td>
<td>16.0(12)</td>
<td>20.0(13)</td>
<td>19.0(56)</td>
<td>14.0(3,011,597)</td>
</tr>
<tr>
<td>55 to 64 years</td>
<td>12.5(2)</td>
<td>26.9(39)</td>
<td>19.0(14)</td>
<td>20.0(13)</td>
<td>23.0(68)</td>
<td>11.0(2,475,791)</td>
</tr>
<tr>
<td>65 to 74 years</td>
<td>12.5(2)</td>
<td>25.5(37)</td>
<td>23.0(17)</td>
<td>23.1(15)</td>
<td>24.0(71)</td>
<td>7.0(1,554,361)</td>
</tr>
<tr>
<td>75 to 84 years</td>
<td>18.8(3)</td>
<td>18.6(27)</td>
<td>25.0(19)</td>
<td>21.5(14)</td>
<td>21.0(63)</td>
<td>4.0(981,009)</td>
</tr>
<tr>
<td>85 years and over</td>
<td>0.0(0)</td>
<td>1.4(2)</td>
<td>11.0(8)</td>
<td>9.2(6)</td>
<td>5.0(16)</td>
<td>2.0(379,442)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>43.8(7)</td>
<td>76.6(114)</td>
<td>76.0(57)</td>
<td>81.5(53)</td>
<td>76.7(231)</td>
<td>49.9(10,931,694)</td>
</tr>
<tr>
<td>Female</td>
<td>56.3(9)</td>
<td>21.4(31)</td>
<td>24.0(18)</td>
<td>18.5(12)</td>
<td>23.3(70)</td>
<td>50.1(11,023,562)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/partnered</td>
<td>62.5(10)</td>
<td>55.9(81)</td>
<td>55.0(41)</td>
<td>56.9(37)</td>
<td>56.0(169)</td>
<td>61.0(27,28)(N/A)</td>
</tr>
<tr>
<td>Other</td>
<td>37.5(6)</td>
<td>40.0(58)</td>
<td>41.0(31)</td>
<td>41.5(27)</td>
<td>41.0(122)</td>
<td>N/A</td>
</tr>
<tr>
<td>Systems missing</td>
<td>0.0(0)</td>
<td>4.1(6)</td>
<td>4.0(3)</td>
<td>1.5(1)</td>
<td>3.0(10)</td>
<td></td>
</tr>
<tr>
<td>Accommodation type</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Own home or unit</td>
<td>43.8(7)</td>
<td>60.0(87)</td>
<td>64.0(48)</td>
<td>72.3(47)</td>
<td>63.0(189)</td>
<td>68.0(27,28)(N/A)</td>
</tr>
<tr>
<td>House/unit (priv. rent)</td>
<td>37.5(6)</td>
<td>22.1(32)</td>
<td>17.0(13)</td>
<td>15.4(10)</td>
<td>20.0(61)</td>
<td>24.0(27,28)(N/A)</td>
</tr>
<tr>
<td>House owned by family</td>
<td>18.8(3)</td>
<td>9.7(14)</td>
<td>12.0(9)</td>
<td>3.1(2)</td>
<td>9.0(28)</td>
<td>2.0(27,28)(N/A)</td>
</tr>
<tr>
<td>Gov’t rental house/unit</td>
<td>0.0(0)</td>
<td>6.9(10)</td>
<td>5.0(4)</td>
<td>9.2(6)</td>
<td>7.0(20)</td>
<td>5.0(27,28)(N/A)</td>
</tr>
<tr>
<td>Systems missing</td>
<td>0.0(0)</td>
<td>1.3(2)</td>
<td>1.0(1)</td>
<td>0.0(0)</td>
<td>1.0(3)</td>
<td></td>
</tr>
<tr>
<td>Geographical location</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metrop. home address</td>
<td>75.0(12)</td>
<td>53.1(77)</td>
<td>53.0(40)</td>
<td>53.8(35)</td>
<td>54.5(164)</td>
<td>45.5(2,004,262)</td>
</tr>
<tr>
<td>Regional area ““</td>
<td>25.0(4)</td>
<td>46.9(68)</td>
<td>47.0(35)</td>
<td>46.2(30)</td>
<td>45.5(137)</td>
<td>55.5(2,447,841)</td>
</tr>
<tr>
<td>Working age in work</td>
<td>81.8(9)</td>
<td>51.0(40)</td>
<td>45.0(14)</td>
<td>60.0(18)</td>
<td>53.6(81)</td>
<td>65.4(9,712,645)</td>
</tr>
</tbody>
</table>

(Total working age population n=14,851)

Note on definitions: Adv OPL – Advanced Oral, Pharyngeal or Laryngeal. Adv – Advanced. Ca – Cancer. Own home or unit - Living in own home or unit which may or may not be owned outright. House/unit. (priv. rent) – House or unit rented in private rental market. Gov’t rental house/unit – Government owns house or unit and rents to eligible people. Metrop – Metropolitan. N/A – Not available.
DISCUSSION

The research literature on head and neck cancer emphasises the difference to the public norm with such patients profiled as predominantly socio-economically challenged. The present findings concur with difference in relation to age and gender distributions when compared to that of the general population.\(^1\) There appears a trend towards younger age\(^{32,12,1}\) with half of the total cohort of 301 people being of working age (64 years and under). However, a significant finding that challenges both research and anecdotal understanding is the fact that on many variables the socio-demographic profile is similar to a cross section of the general Australian community.

The pattern for accommodation type fitted the Australian norm with most living in their own home or unit. The percentage living with spouse or partner and those living in a house owned by a family member is slightly different to that of the general population but not unusual given the high percentage of head and neck cancer people aged 75 years and over compared to similar age in the Australian general population. Nevertheless, despite this socio-demographic normality, there is potential for vulnerability for those with head and neck cancer who are without in-home family support.\(^{11,34}\)

The range of income categories for working age people fitted the Australian norm. Several factors are relevant when comparing working age people in work with that of the general population. Overall half of those with advanced cancer were aged 64 years and under. With major functional problems for many with advanced cancer such as hoarseness, pain, swallowing difficulties and feeling ill,\(^{3,33,6}\) and pain linked to work-related disability,\(^{33}\) it is understandable that half of those of working age still in work who gave information on their paid leave status at diagnosis had no paid leave available. Poirer\(^35\) found a similar situation at the beginning of treatment. Lack of paid leave and the nature of the Australian government income support system\(^30\) would account for many working age people being 'self funded, having 'no income' as well as some as well as some already being on Centrelink Allowance.\(^30\) Lack of work-related income can involve working age people being reduced to subsistence income or no income with implications also for their disposable assets.\(^30\) For the approximately 45% of working age people aged 55 to 64 years however

### Table 2 Employment and income categories by working/non-working age and 10 year age cohorts

<table>
<thead>
<tr>
<th>Employment &amp; Income</th>
<th>Pxs Working Age</th>
<th>Pxs Non-Working Age</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&gt;44</td>
<td>45-54</td>
</tr>
<tr>
<td>Employed</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Centrelink Allowances</td>
<td>11</td>
<td>7</td>
</tr>
<tr>
<td>No Income</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Self funded</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Government pension</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Gov’t pension &amp; other</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Systems missing</td>
<td>(0)</td>
<td>(1)</td>
</tr>
</tbody>
</table>

Notes on definitions: Pxs – Patients. Employed – Paid or self employment or combination (for comparison purposes average adult full-time ordinary earnings were $1,256.30 per week\(^29\). Self funding – includes all forms of incomes which are not government-related or through employment (assets and investments, spousal or family income, superannuation, insurance). No income – Patient was not currently receiving any income from any employment and not receiving any Government income support payments\(^30\). Centre link Allowances\(^30\) – government income support payment for working age people; eligibility included less than 2 years incapacity for work and passing income and asset tests (For comparison purposes - for single person living in their own home: allowable disposable assets such as savings, investments, insurance of less than $5,500 with payment at approximately one-quarter of the above work figure. Government pension\(^30\) – Veterans Affairs Pension, and government income support payment following upon assessed incapacity to work for an extended period with both income and asset tests. (For comparison purposes – For single person as above: allowable disposable assets of under $178,000 with assessment and payment criteria differing to Centrelink Allowance\(^30\). Government pension\(^30\) and other income – includes some form of government pension and working or self-funded income. Gov’t – Government.)
the data indicates some have more income options available to them particularly for those able to transition into early retirement.

For those aged 65 years and over the income pattern ranged from the well off (self funding in retirement) to government pension and is consistent with that of the general Australian community. Although some of these people's income may be of subsistence level, the income options for those aged 65 years and over generally provided a stable income throughout treatment and post-treatment, and therefore potentially this removed income transition issues and associated stresses when adjusting to a cancer diagnosis.

In addition to the purely functional problems associated with advanced disease at diagnosis, the findings illustrate that working age people can face challenges which can include adjusting lifestyle commitments and responsibilities to a changed financial situation which can cause considerable economic distress. Examples of such economic distress can variously relate to costs for such basic items as accommodation, household requisites including food, utilities bills, and transport. As noted by McGrath, the self-employed are particularly vulnerable when confronting the financial distress associated with cancer treatment. These challenges can also include having to leave work without the security which paid leave affords and with uncertainty about work prospects once treatment ends. Additionally, with the large percentage of the total cohort having a rural residential address, there is also the challenge for many of all ages of preparing to relocate for treatment to likely an unfamiliar hospital environment with or without a supportive person accompanying them. Relocation for treatment has potential for psychosocial stress as well as financial stress related to additional financial costs involved in this relocation for the patient as well as their spouse/partner. These challenges occur in the context of many coping with advanced cancer diagnosis and facing impending treatment which for most, but not all, will be of curative intent. There are supportive care issues for these people, particularly younger age people, associated with emotional distress, lack of in-home support in the form of a spouse or partner, and work and income difficulties which have been shown to influence treatment outcome.

CONCLUSION

The relative lack of socio-demographic data specifically at the time of diagnosis can lead to minimising the challenges these people face as they transition into becoming patients who will be mostly facing lengthy and debilitating treatment. The data indicates that, socio-demographically, at the time of diagnosis they represent a cross-section of the Australian community with the exception of age and gender. The findings do not support anecdotal commentary and research literature that these people are disproportionately socio-economically challenged. The findings do however indicate a change in work and financial situation occurring even before treatment commences for many of those aged 64 years and under through a combination of disease, socio-demographic factors such as lack of paid leave and the nature of the Australian government’s income support system, as well the challenge of additional costs involved for those having to relocate for treatment. A change in financial situation can have flow-on effects on basic lifestyle commitments and responsibilities. Examples of such economic distress can variously relate to costs for such basic items as accommodation, household requisites including food, utilities bills, and transport. As noted by McGrath, the self-employed are particularly vulnerable when confronting the financial distress associated with cancer treatment. These challenges can also include having to leave work without the security which paid leave affords and with uncertainty about work prospects once treatment ends. Additionally, with the large percentage of the total cohort having a rural residential address, there is also the challenge for many of all ages of preparing to relocate for treatment to likely an unfamiliar hospital environment with or without a supportive person accompanying them. Relocation for treatment has potential for psychosocial stress as well as financial stress related to additional financial costs involved in this relocation for the patient as well as their spouse/partner. These challenges occur in the context of many coping with advanced cancer diagnosis and facing impending treatment which for most, but not all, will be of curative intent. There are supportive care issues for these people, particularly younger age people, associated with emotional distress, lack of in-home support in the form of a spouse or partner, and work and income difficulties which have been shown to influence treatment outcome.

REFERENCES


