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Suboptimal health literacy in patients with lung cancer or head and neck cancer

Running title: Suboptimal health literacy in cancer

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Partial results presented at the 46th Annual Meeting of the American Society of Clinical Oncology, June 4-8 2010, Chicago, Illinois; and at the International Conference on Communication in Healthcare, 5-8 September 2010, Verona, Italy.

Full results presented at the Annual Scientific Meeting of the Clinical Oncological Society of Australia, November 15-17 2010, Melbourne, Victoria.

Abstract

Background

Health literacy is the capacity to seek, understand and utilise health information to make informed health decisions. Suboptimal health literacy has been linked to poor health outcomes. This study assessed health literacy in patients treated for head and neck or lung cancer, and associations between health literacy and demographic factors and distress levels.

Methods

Consecutive English-speaking patients were approached at Peter MacCallum Cancer Centre. Face-to-face interviews were conducted. Health literacy was assessed using the Shortened Test of Functional Health Literacy in Adults (S-TOFHLA) and Health Literacy Management Scale (HeLMS). Distress was assessed by the Distress Thermometer.

Results

Response rate was 73% (n=93). Using S-TOFHLA, prevalence of inadequate and marginal health literacy was 5.4% and 6.5% respectively, and both groups were associated with older age ($p=0.043$) and low education level ($p=0.009$). Specific assessment of S-TOFHLA revealed 70% could not interpret prescription labels. HeLMS reported 17% had health literacy difficulties. Low scores on domains of HeLMS were associated with lower education level ($p<0.05$) but younger age ($p<0.05$). Distress was not associated with S-

TOFHLA scores but related to low scores in two domains of HeLMS ($p<0.05$).

Conclusion

Using two different measures, a substantial proportion of patients have poor health literacy abilities and may experience difficulties accessing health services.

Keywords

Consumer health information; health communication; health literacy; neoplasms; patient education as topic; physician-patient relations.

Introduction

Health literacy is the capacity to obtain, process and understand health information and services to make sound health decisions [1]. This includes the ability to communicate, access health care and be involved in clinical care [2]. Patients are often required to make important health-related decisions in an increasingly complex health system [3]. In oncology, people need good health literacy skills to make informed decisions about prevention strategies, screening options, complex multimodal care and participation in clinical trials.

Previous research has revealed that 7%-50% of the Australian population may have limited health literacy, depending upon the measure used [4, 5]. Different instruments measure different aspects of health literacy [6]. One widely used instrument, the Test of Functional Health Literacy in Adults (TOFHLA), focuses on measuring understanding of health information [7], while a recently developed tool, the Health Literacy Management Scale (HeLMS) measures broader aspects of health literacy [2, 8].

Suboptimal health literacy is an independent risk factor for poorer health outcomes, including increased risk of hospitalisation [9, 10]. Cancer patients with poor health literacy may have more misconceptions about their disease and impaired communication with health professionals, potentially leading to suboptimal treatment or poor adherence to treatment plans [11-13]. Cancer patients who felt that they were inadequately informed were more likely to be

dissatisfied with their care, report reduced overall wellbeing, and increased depression and anxiety levels [14, 15].

There has been limited research into the prevalence of poor health literacy amongst cancer patients [12, 13, 16, 17]. No study has examined the relationship between health literacy and distress levels. Health literacy of people with lung cancer or head and neck cancer is under-researched. These patients are more likely to have a history of heavy smoking and smokers tend to have lower education compared with non-smokers [18-20]. Given the association between low education level and poor health literacy [5, 21], these patients may be disadvantaged by the complex health system.

The aims of this study were: 1) to determine the prevalence of poor health literacy in people with lung or head and neck cancer using the Shortened-TOFHLA (S-TOFHLA) and HeLMS; and 2) to examine the association between health literacy levels and patients' socio-demographic factors and clinical characteristics, including distress.

Methods

Setting

The study was conducted at Peter MacCallum Cancer Centre (Peter Mac), a specialist cancer centre in Victoria, Australia.

Design

Consecutive patients attending the lung cancer and the head and neck cancer clinical services were screened for eligibility.

Participants

The inclusion criteria were: age 18 years or older; histologic diagnosis of either lung cancer or head and neck cancer within the last month, and sufficient English to complete patient measures. Exclusion criteria were: serious cognitive or psychological difficulties; physically too unwell; a cancer diagnosis within the past week, or attending an initial pre-chemotherapy education session.

Procedure

Following confirmation of eligibility from the patient's clinician, a research assistant introduced the study and offered to read and explain a single-page information and consent form written in simple language to each patient (developed according to guidelines outlined by Jefford and Moore [22]). Patients who agreed to participate signed the consent form.

Ethics

The Peter Mac Human Research Ethics Committee approved the study. In discussions with patients, phrases like “health literacy” were avoided to minimise risk of embarrassment and potential recruitment bias [5, 23].

Measures

Demographics: marital status, residential postcode, employment situation, occupation, educational level, native language, country of birth, smoking and alcohol history were provided. Other information including patients’ age, sex, disease type and stage was obtained from the hospital records system.

Health literacy: S-TOFHLA, a 40-item instrument, has been widely used to assess levels of health literacy in various settings [7]. It assesses reading comprehension and numeracy skills related to health care issues in two sections. The numeracy section consists of four individual task assessments, requiring participants to interpret examples of prescription labels, an appointment card and laboratory results. The comprehension section comprises two passages, based on commonly used written information in hospitals, presented in a modified Cloze passage format, that is, every fifth to seventh word in each passage is omitted and four multiple choice options are provided for patients to choose the appropriate answer to fill in the blanks [7]. Minor adaptations were previously made to the questions to reflect the Australian context [5].

Scores from both numeracy and comprehension sections are added up and categorised into inadequate, marginal or adequate health literacy [24]. Patients with inadequate or marginal health literacy may have difficulty interpreting written health information [24]. Low scores have been independently correlated with poor health outcomes, supporting validity [24, 25]. Internal consistency of the numeracy items is modest (Cronbach's alpha 0.68), while the comprehension section is good (alpha= 0.97) [24].

HeLMS is a 29-item self-report questionnaire covering eight domains: 'receptivity to health improvements', 'understanding health information', 'support with utilising health care', 'economic barriers to care', 'accessing general practitioners' healthcare services', 'communication with health professionals', 'proactive about seeking alternative care' and 'utilising health information' [2, 8]. Response options include: 5-without any difficulty; 4-with little difficulty; 3-with some difficulty; 2-very difficult; 1-unable to do. It has been demonstrated to have robust psychometric properties including strong face, content and construct validity, all domains have high internal consistency (Cronbach alpha >0.82), and good to excellent test-retest reliability (Intraclass Correlation Coefficients =0.73-0.96) [2, 8].

Distress: Distress Thermometer (DT) is a single item screening tool, measuring global distress in cancer populations using a visual analogue scale, based on self-evaluated amount of distress on a 0 ("no distress") to 10 ("extreme

distress") scale, with scores of 4 or more indicating a significant level of distress [26].

Statistical Analysis

Sample size

A sample size of 82 patients was required to identify statistically significant correlations between health literacy levels and demographic factors, calculated using the point biserial model, based on a moderate effect size of approximately 0.30 (two-sided, 5% significance level and 80% power).

Data analysis

Data was analysed using the Statistical Package for the Social Sciences, Windows Version 17.0 (SPSS, Chicago, IL, USA).

Demographic variables with many response options were regrouped into two or three categories before analysis.

Patients' postcodes were converted to represent socioeconomic status based on the Australian Bureau of Statistics Socio-Economic Indexes for Areas, with a score below 1000 indicating an area of lower socioeconomic status [27].

The distribution of S-TOFHLA and HeLMS scores were significantly negatively skewed. Hence, non-parametric statistics were used to examine their relationships with demographic factors. The Mann-Whitney test and Kruskal-

Wallis test were used for categorical variables, while Spearman's rho test was used for continuous variables. A significance level of p=0.05 (two-tailed) was assumed in all relevant tests and no adjustment was made for multiple testing.

Results

Recruitment

Among the 128 patients approached, 60 patients with head and neck cancer and 33 patients with lung cancer completed the survey, yielding an overall response rate of 72.7% (head and neck cancer: 73.2%, lung cancer: 71.7%). Specific recruitment details are shown in Figure 1.

< Insert Figure 1 here >

Patients who declined participation were significantly older (M=68.3 years) than those who completed the study (M=61.7 years, p=0.015).

Demographic and Clinical Characteristics

Table 1 reports the demographic and clinical characteristics of all study participants. Among patients with lung cancer, 84.8% were former or current smokers, compared to 53.3% for patients with head and neck cancer (p=0.002). Patients with lung cancer reported a significantly higher mean distress score (M=4.91, SD=2.92), compared to patients with head and neck cancer (M=3.37 SD=2.40, p=0.007), with 45.0% of the latter and 60.6% of the former meeting the criteria for distress on DT. As there were no other differences, all participants were combined into one sample for further analysis.

< Insert Table 1 here >

Health Literacy

S-TOFHLA

In total, 11 patients (11.9%) had limited health literacy, with five patients having inadequate health literacy and six patients having marginal health literacy. The other 88.1% of patients had adequate health literacy. There was no significant difference between the mean scores for patients with head and neck cancer (M=83.50, SD=15.02) and patients with lung cancer (M=83.70, SD=15.40, p=0.95).

Individual task assessment revealed 65 patients (69.9%) struggled with interpreting a prescription label, while 28 patients (30.1%) were unable to understand a standard appointment card. Additionally, 19 patients (20.4%) could not follow instructions of having medicine before a meal, and 14 patients (15.1%) had difficulty interpreting a simple blood glucose test report.

Table 2 demonstrates the relationship between S-TOFHLA scores and patients' demographic and clinical characteristics. Older age and lower education level (non-university education) were significantly related to poor health literacy (rho=0.211, p=0.043 and U=583, p=0.009 respectively). Patients' distress levels and socio-economic scores were not associated with S-TOFHLA scores (rho=0.034, p=0.744 and rho=0.042, p=0.686 respectively).

< Insert Table 2 here >

HeLMS

Table 3 reports each domain of the HeLMS where the median score was >4.67 for all scales (range: 1-5). For each domain, there was no significant difference between patients from the two tumour groups ($p>0.05$ for all).

A total of 16 patients (17.2%) from both tumour groups scored three or below for one or more domain suggesting that they may require assistance in these areas.

< Insert Table 3 here >

Table 4 displays the relationship between each HeLMS domain and demographic and clinical characteristics. Older age was positively related to higher scores in most domains ($p<0.05$), except 'understanding health information' (rho=0.116, p=0.266) and 'support with utilising health care' (rho=0.083, p=0.426). There were also significant relationships between high distress levels and lower scores in 'receptivity to health improvements' (rho=0.276, p=0.007) and 'communication with health professionals' (rho=0.239, p=0.021). Patients with university education scored significantly better in 'economic barriers to care' (U=569, p=0.003). Low scores in 'receptivity to health improvements' (U=265, p=0.005) and 'economic barriers to care' (U=326, p=0.041) were significantly related to former and current smokers.

< Insert Table 4 here >

Discussion

This study assessed health literacy in a consecutive sample of patients with lung cancer or head and neck cancer using two different measures. Although the overall S-TOFHLA scores suggested 11.9% of patients had limited health literacy, a substantial percentage of patients appear to have difficulties with simple health tasks, like interpreting a prescription label.

Poor health literacy as measured by S-TOFHLA was significantly related to lower education level and older age, though not distress levels. In contrast, the HeLMS, identified a larger proportion (17.2%) of people with low health literacy, and in somewhat different subgroups compared with S-TOFHLA. Poor health literacy in particular domains of HeLMS were associated with *younger* age, high distress levels and low education level.

The reason underpinning these disparate findings is most likely that S-TOFHLA and HeLMS measure different aspects of health literacy using different methods. S-TOFHLA predominantly assesses comprehension and numeracy skills. While this information is important to ensure appropriate communication, it is not modifiable by the health professional. In contrast, HeLMS directly asks patients to rate their difficulty with a range of health-related tasks thereby allowing health professionals to address these explicitly.

The proportion of patients with limited health literacy as measured by S-TOFHLA (11.9%) was higher than that reported in an Australian population

study (6.8%) [5]. This could be attributed to the higher mean participant age of 61.8 years in this survery, compared to a mean of 53.7 years in the population study [5]. However, the prevalence of limited health literacy in this study was lower than other similar studies conducted in the US using TOFHLA or S-TOFHLA (20%-40%), likely because those studies primarily targeted older patients or African-Americans, who tend to have less education [28-31].

Consistent with previous literature, our study found that health literacy, as measured by S-TOFHLA was related to age and education [5, 7, 13, 21, 32]. Patients with lower education level might struggle understanding and using complicated health information and older patients may have difficulties due to deteriorating mental and physical abilities. As for HeLMS, patients without university education demonstrated significantly lower scores in the domain of 'economic barriers to care', which assessed affordability for medical-related expenses. Patients with lower education level may have lower income and may not be aware of available support services. In contrast to S-TOFHLA, older people tended to perform better in most domains of HeLMS. Older patients are likely to have had more encounters with the health system due to medical co-morbidities. Hence, they may be more confident when rating their ability to deal with the health system.

To our knowledge, this is the first study examining the relationship between health literacy and distress levels. Based on related studies, we hypothesised that poor health literacy may be associated with high distress. Although high

distress levels were not significantly related to health literacy, as measured by S-TOFHLA, they were related to lower scores in certain domains of HeLMS.

A recent study reported that satisfaction with clinical trial participation was correlated with subjective understanding rather than objective understanding of the trial [33, 34]. This suggests that poor subjective understanding of health information may contribute to patients' dissatisfaction and distress. This could explain the absence of an association between patients' distress levels and S-TOFHLA scores (an objective assessment tool), as well as the significant relationship with certain domains of HeLMS (a self-assessment tool).

A major strength of this study was the high response rate of 72.7%. In a recent systematic review of studies measuring prevalence of limited health literacy, only about half of the studies reported response rates, which ranged from 48%-100%, with a weighted mean of 63%[35]. This study also used a consecutive sampling method of recruitment, rather than convenience sampling, which was used in more than 75% of studies included in the systematic review[35]. Furthermore, our study used two measures of health literacy with published reliability and validity information [6, 8, 24].

A limitation of this study is that the study population may not represent all patients with these cancers. We conducted the study at a single cancer centre. Also, patients who refused to participate were significantly older than those who completed the survey (mean age=68.33 and 61.76 respectively), and thus may

have poorer health literacy as assessed by S-TOFHLA. Hence, results from this study may slightly underestimate the prevalence of limited health literacy. Furthermore, we did not evaluate health literacy in different subgroups of head and neck or lung cancer. For example, an increasing proportion of oropharyngeal cancer is associated with the human papilloma virus, rather than risk factors of tobacco and alcohol[36, 37]. This distinct entity is associated with younger age, better performance status, non-smoking history, white race and lower risk of other co-morbidities. There may also be differences in educational level and socio-economic status.

Results from this study are important as they highlight the extent and need for poor health literacy to be identified and managed within the cancer population. In particular, findings from the individual task assessment could have serious implications for patients' adherence to treatment plans and their follow-up care, impacting on health outcomes. Deficiency in the five areas of health literacy highlighted in HeLMS could interfere with patients' ability to understand about their medical conditions, navigate the health system and access social support services. The relationships between poor health literacy and demographic factors such as age and education level may provide some guidance to health professionals in identifying patients who could have difficulties understanding and utilising health information and services.

Conclusions

To our knowledge, this is the first study measuring prevalence of health literacy in cancer patients currently receiving treatment. A significant proportion of the patient population had poor health literacy and many had difficulty interpreting commonly used written health information. However, the prevalence of poor health literacy and its association with demographic factors vary with the use of different instruments. The relationship between health literacy and distress levels suggests that subjective understanding of health information plays an important role in patients' distress. Further research might include patients with other tumour groups to understand the overall prevalence of limited health literacy in cancer patients. To date, there has been limited research on interventions to assist patients with low health literacy, including use of simple language or decision aids and health literacy training for physicians [38, 39]. Additional research is required to develop interventions for people with differing levels of health literacy to ensure that everyone receives the necessary information and support to enable optimal health outcomes.

Conflict of interest statement

None declared for all authors.

References

1. Nielsen-Bohlman L, Panzer A, Kindig D (2004) Health literacy: A prescription to end confusion. The National Academies Press, Washington D.C.
2. Jordan JE, Buchbinder R, Osborne RH (2010) Conceptualising health literacy from the patient perspective. Patient Educ Couns 79:36-42
3. Laine C, Davidoff F (1996) Patient-centered medicine. A professional evolution. JAMA 275:152-156
4. Australian Bureau of Statistics (2006) Health Literacy, Australia cat. no. 4833.0. Australian Bureau of Statistics, Canberra.
5. Barber MN, Staples M, Osborne RH, Clerehan R, Elder C, Buchbinder R (2009) Up to a quarter of the Australian population may have suboptimal health literacy depending upon the measurement tool: results from a population-based survey. Health Promot Int 24:252-261
6. Jordan JE, Osborne RH, Buchbinder R (2011) Critical appraisal of health literacy indices revealed variable underlying constructs, narrow content and psychometric weaknesses. J Clin Epidemiol 64:366-379
7. Parker RM, Baker DW, Williams MV, Nurss JR (1995) The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. J Gen Intern Med 10:537-541
8. Jordan JE (2010) Understanding the role and impact of health literacy on patient health outcomes to facilitate effective health interventions (PhD thesis). University of Melbourne,
9. Baker DW, Gazmararian JA, Williams MV, Scott T, Parker RM, Green D, Ren J, Peel J (2002) Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. Am J Public Health 92:1278-1283
10. Baker DW, Parker RM, Williams MV, Clark WS (1998) Health literacy and the risk of hospital admission. J Gen Intern Med 13:791-798
11. Gansler T, Henley SJ, Stein K, Nehl EJ, Smigal C, Slaughter E (2005) Sociodemographic determinants of cancer treatment health literacy. Cancer 104:653-660
12. Brewer NT, Tzeng JP, Lillie SE, Edwards AS, Peppercorn JM, Rimer BK (2009) Health literacy and cancer risk perception: implications for genomic risk communication. Med Decis Making 29:157-166
13. Koay K, Schofield P, Jefford M (2012) Importance of health literacy in oncology. Asia Pac J Clin Oncol 8:14-23
14. Jefford M, Tattersall MH (2002) Informing and involving cancer patients in their own care. Lancet Oncol 3:629-637
15. Fallowfield LJ, Hall A, Maguire GP, Baum M (1990) Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. BMJ 301:575-580
16. Mohan R, Beydoun H, Barnes-Ely ML, Lee L, Davis JW, Lance R, Schellhammer P (2009) Patients' survival expectations before localized prostate cancer treatment by treatment status. J Am Board Fam Med 22:247-256
17. Lillie SE, Brewer NT, O'Neill SC, Morrill EF, Dees EC, Carey LA, Rimer BK (2007) Retention and use of breast cancer recurrence risk information from

genomic tests: the role of health literacy. Cancer Epidemiol Biomarkers Prev 16:249-255
18. Sturgis EM, Wei Q, Spitz MR (2004) Descriptive epidemiology and risk factors for head and neck cancer. Semin Oncol 31:726-733
19. Thun MJ, Lally CA, Flannery JT, Calle EE, Flanders WD, Heath CW,Jr (1997) Cigarette smoking and changes in the histopathology of lung cancer. J Natl Cancer Inst 89:1580-1586
20. Siminoff LA, Ravdin P, Colabianchi N, Sturm CM (2000) Doctor-patient communication patterns in breast cancer adjuvant therapy discussions. Health Expect 3:26-36
21. von Wagner C, Knight K, Steptoe A, Wardle J (2007) Functional health literacy and health-promoting behaviour in a national sample of British adults. J Epidemiol Community Health 61:1086-1090
22. Jefford M, Moore R (2008) Improvement of informed consent and the quality of consent documents. Lancet Oncol 9:485-493
23. Buchbinder R, Hall S, Youd JM (2006) Functional health literacy of patients with rheumatoid arthritis attending a community-based rheumatology practice. J Rheumatol 33:879-886
24. Baker DW, Williams MV, Parker RM, Gazmararian JA, Nurss J (1999) Development of a brief test to measure functional health literacy. Patient Educ Couns 38:33-42
25. Dewalt DA, Berkman ND, Sheridan S, Lohr KN, Pignone MP (2004) Literacy and health outcomes: a systematic review of the literature. J Gen Intern Med 19:1228-1239
26. National Comprehensive Cancer Network (2003) Distress management. Clinical practice guidelines. J Natl Compr Canc Netw 1:344-374
27. Australian Bureau of Statistics (2006) Socio-economic indexes for areas: introduction, use and future directions. Australian Bureau of Statistics, Canberra.
28. Williams MV, Parker RM, Baker DW, Parikh NS, Pitkin K, Coates WC, Nurss JR (1995) Inadequate functional health literacy among patients at two public hospitals. JAMA 274:1677-1682
29. Gazmararian JA, Baker DW, Williams MV, Parker RM, Scott TL, Green DC, Fehrenbach SN, Ren J, Koplan JP (1999) Health literacy among Medicare enrollees in a managed care organization. JAMA 281:545-551
30. Baker DW, Wolf MS, Feinglass J, Thompson JA, Gazmararian JA, Huang J (2007) Health literacy and mortality among elderly persons. Arch Intern Med 167:1503-1509
31. Gazmararian JA, Williams MV, Peel J, Baker DW (2003) Health literacy and knowledge of chronic disease. Patient Educ Couns 51:267-275
32. Donelle L, Arocha JF, Hoffman-Goetz L (2008) Health literacy and numeracy: key factors in cancer risk comprehension. Chronic Dis Can 29:1-8
33. Jefford M, Mileshkin L, Matthews J, Raunow H, O'Kane C, Cavicchiolo T, Brasier H, Anderson M, Reynolds J (2011) Satisfaction with the decision to participate in cancer clinical trials is high, but understanding is a problem. Support Care Cancer 19:371-379

34. Joffe S, Cook EF, Cleary PD, Clark JW, Weeks JC (2001) Quality of informed consent: a new measure of understanding among research subjects. J Natl Cancer Inst 93:139-147
35. Paasche-Orlow MK, Parker RM, Gazmararian JA, Nielsen-Bohlman LT, Rudd RR (2005) The prevalence of limited health literacy. J Gen Intern Med 20:175-184
36. Ang KK, Harris J, Wheeler R, Weber R, Rosenthal DI, Nguyen-Tan PF, Westra WH, Chung CH, Jordan RC, Lu C, Kim H, Axelrod R, Silverman CC, Redmond KP, Gillison ML (2010) Human papillomavirus and survival of patients with oropharyngeal cancer. N Engl J Med 363:24-35
37. Rischin D, Young RJ, Fisher R, Fox SB, Le QT, Peters LJ, Solomon B, Choi J, O'Sullivan B, Kenny LM, McArthur GA (2010) Prognostic significance of p16INK4A and human papillomavirus in patients with oropharyngeal cancer treated on TROG 02.02 phase III trial. J Clin Oncol 28:4142-4148
38. Davis TC, Williams MV, Marin E, Parker RM, Glass J (2002) Health literacy and cancer communication. CA Cancer J Clin 52:134-149
39. Ferreira MR, Dolan NC, Fitzgibbon ML, Davis TC, Gorby N, Ladewski L, Liu D, Rademaker AW, Medio F, Schmitt BP, Bennett CL (2005) Health care provider-directed intervention to increase colorectal cancer screening among veterans: results of a randomized controlled trial. J Clin Oncol 23:1548-1554

Table 1: Demographic and clinical characteristics

Demographic and clinical characteristics	Head and neck cancer, n	Lung cancer, n	Number of patients	Percentage (%)	p-value ^
Age					
Mean age	62.35	60.70			0.551
Age range	27 – 92	41 – 87			
Cancer type					
Head and neck			60	64.5	
Lung			33	35.5	
Sex					
Males	52	25	77	82.8	0.182
Females	8	8	16	17.2	
Socioeconomic status					
Above mean	34	15	49	52.7	0.135
Below mean	26	18	44	47.3	
Marital status					
Married/ defacto [+]	45	23	68	73.1	0.562
Separated/ divorced [+]	9	6	15	16.1	
Widowed [+]	2	0	2	2.2	
Never married	4	4	8	8.6	
Employment					
Full-time/ part-time	18	8	26	27.9	0.554
On sick leave [^]	13	5	18	19.3	
Not employed [^]	5	4	9	9.7	
Retired [^]	19	15	34	36.6	
Home duties [^]	4	1	5	5.4	
Studying [^]	1	0	1	1.1	
Education					
No formal schooling [#]	1	2	3	3.2	0.218
Primary schooling [#]	4	1	5	5.4	
Secondary schooling [#]	28	15	43	46.3	
Trade/ community/ TAFE (vocational training) [#]	7	8	15	16.1	
University: undergraduate [##]	10	6	16	17.2	
University: postgraduate [##]	10	1	11	11.8	
Language background					
English as first language	52	28	80	86.0	0.809
English as non-primary language	8	5	13	14.0	
Country of birth					
Australia	46	22	68	73.1	0.298
Other countries	14	11	25	26.9	
Smoking status					
Former or current smoker	32	28	60	64.5	**0.002***
Never smoked	28	5	33	35.5	
Alcohol consumption					
Never	15	5	20	21.5	0.072
Sometimes	27	13	50	53.8	
Everyday	18	5	23	24.7	

[+] collapsed into one category of 'married' for analysis
[^] collapsed into one category of 'not working' for analysis
[#] collapsed into one category of 'non-university education' for analysis
[##] collapsed into one category of 'university education' for analysis
^ p-value refers to statistical tests of difference between patients from the two tumour streams

Table 2: Statistics relevant to tests of differences (median, IQR, p-value) for S-TOFHLA scores

Patient characteristic	Median (IQR)	p-value
Sex		
Males	87.0 (80.5-93.0)	0.55
Females	88.0 (72.3-91.0)	
Marital status		
Never married	91.5 (61.5-97.5)	0.64
Married	87.0 (80.5-91.5)	
Employment		
Full time/ part time work	89.0 (84.0-94.0)	0.11
Not working	87.0 (79.0-91.0)	
Education level		
Non-university	85.5 (78.8-91.0)	0.009
University	93.0 (84.0-94.0)	
Language background		
English as first language	87.0 (82.0-92.8)	0.35
English as non-primary language	86.0 (64.0-92.5)	
Country of birth		
Australia	87.0 (80.5-91.8)	0.98
Other	87.0 (78.0-93.0)	
Smoking status		
Former or current smokers	88.0 (82.0-93.0)	0.21
Never smoked	84.0 (75.5-91.0)	
Alcohol consumption		
Never	81.5 (66.8-91.0)	0.15
Sometimes	89.0 (82.0-93.3)	
Everyday	86.0 (82.0-91.0)	

Table 3: Results breakdown of HeLMS

HeLMS Domains	Number of patients requiring assistance (%)	Median score (range: 1–5)
Receptivity to health improvements	1 (1.1)	4.75
Understanding health information	2 (2.2)	5.00
Support with utilising healthcare	0 (0.0)	5.00
Economic barriers to care	10 (10.8)	5.00
Accessing GP healthcare services	0 (0.0)	5.00
Communication with health professionals	1 (1.1)	5.00
Proactive about seeking alternative care	4 (4.3)	4.67
Utilising health information	0 (0.0)	5.00

Table 4: Statistics relevant to tests of association (Spearman's rho) and differences (median, IQR) for HeLMS domains

Patient characteristic	Receptivity	Understanding	Support	Economic barriers	Accessing GP	Communication	Proactive	Utilising
Age	**.28**	.12	.083	**.29**	**.30**	**.28**	**.26**	**.26**
Socioeconomic status	<.001	.15	.057	.090	.058	.022	.013	.11
Distress levels	**.28**	.15	.15	.20	.16	**.24**	.090	.19
Sex								
Male	4.8 (4.1-5.0)	5.0 (4.6-5.0)	5.0 (4.5-5.0)	5.0 (4.0-5.0)	5.0 (5.0-5.0)	5.0 (4.5-5.0)	4.7 (4.0-5.0)	5.0 (4.8-5.0)
Female	4.6 (3.8-5.0)	5.0 (4.6-5.0)	5.0 (4.5-5.0)	4.5 (3.3-5.0)	5.0 (4.5-5.0)	4.7 (4.2-5.0)	4.3 (3.8-5.0)	4.9 (4.6-5.0)
Martial status								
Married	4.9 (3.4-5.0)	4.9 (4.8-5.0)	5.0 (4.5-5.0)	5.0 (3.5-5.0)	5.0 (4.8-5.0)	5.0 (4.8-5.0)	4.7 (4.2-4.9)	5.0 (4.8-5.0)
Never married	4.8 (4.0-5.0)	5.0 (4.5-5.0)	5.0 (4.5-5.0)	5.0 (3.8-5.0)	5.0 (4.8-5.0)	5.0 (4.3-5.0)	4.7 (4.0-5.0)	5.0 (4.8-5.0)
Employment status								
Working (full- or part-time)	4.5 (3.9-5.0)	5.0 (4.7-5.0)	5.0 (4.5-5.0)	5.0 (4.3-5.0)	5.0 (4.5-5.0)	5.0 (4.3-5.0)	4.7 (3.7-5.0)	5.0 (4.5-5.0)
Not working	4.8 (4.3-5.0)	5.0 (4.5-5.0)	5.0 (4.5-5.0)	5.0 (3.3-5.0)	5.0 (5.0-5.0)	5.0 (4.7-5.0)	4.7 (4.0-5.0)	5.0 (4.8-5.0)
Education								
University	4.8 (4.3-5.0)	5.0 (4.8-5.0)	5.0 (4.5-5.0)	**5.0 (5.0-5.0)**	5.0 (5.0-5.0)	5.0 (4.7-5.0)	4.7 (4.0-5.0)	5.0 (4.8-5.0)
No university	4.6 (4.0-5.0)	5.0 (4.5-5.0)	5.0 (4.5-5.0)	**4.7 (3.3-5.0)**	5.0 (4.8-5.0)	5.0 (4.3-5.0)	4.8 (4.0-5.0)	5.0 (4.8-5.0)
Primary language								
English	4.6 (4.0-5.0)	5.0 (4.6-5.0)	5.0 (4.5-5.0)	5.0 (4.0-5.0)	5.0 (4.8-5.0)	5.0 (4.4-5.0)	4.7 (4.0-5.0)	5.0 (4.8-5.0)
Other	5.0 (4.0-5.0)	5.0 (4.6-5.0)	5.0 (4.5-5.0)	4.7 (3.3-5.0)	5.0 (4.6-5.0)	5.0 (4.5-5.0)	4.7 (3.8-5.0)	5.0 (4.5-5.0)
Country of birth								
Australia	4.6 (4.0-5.0)	5.0 (4.6-5.0)	5.0 (4.5-5.0)	5.0 (3.7-5.0)	5.0 (4.8-5.0)	5.0 (4.3-5.0)	4.7 (4.0-5.0)	5.0 (4.8-5.0)
Other	4.8 (4.0-5.0)	5.0 (4.6-5.0)	5.0 (4.5-5.0)	4.7 (4.0-5.0)	5.0 (4.9-5.0)	5.0 (4.8-5.0)	5.0 (4.2-5.0)	5.0 (5.0-5.0)
Smoking status								
Never smoked	**5.0 (4.6-5.0)**	5.0 (4.8-5.0)	5.0 (4.5-5.0)	**5.0 (4.8-5.0)**	5.0 (5.0-5.0)	5.0 (4.7-5.0)	5.0 (4.0-5.0)	5.0 (4.8-5.0)
Current / former smoker	**4.5 (4.0-5.0)**	5.0 (4.5-5.0)	5.0 (4.5-5.0)	**4.7 (3.4-5.0)**	5.0 (4.8-5.0)	5.0 (4.3-5.0)	4.7 (4.0-5.0)	5.0 (4.8-5.0)
Daily alcohol consumption								
Never	4.8 (4.1-5.0)	4.9 (4.6-5.0)	4.9 (4.1-5.0)	5.0 (4.4-5.0)	5.0 (5.0-5.0)	5.0 (4.3-5.0)	5.0 (4.4-5.0)	5.0 (4.8-5.0)
Sometimes	4.8 (4.0-5.0)	5.0 (4.5-5.0)	5.0 (4.8-5.0)	5.0 (3.3-5.0)	5.0 (4.7-5.0)	5.0 (4.7-5.0)	4.7 (4.0-5.0)	5.0 (4.8-5.0)
Daily	4.5 (4.0-5.0)	5.0 (4.8-5.0)	5.0 (4.5-5.0)	5.0 (4.0-5.0)	5.0 (5.0-5.0)	5.0 (4.3-5.0)	4.3 (4.0-5.0)	5.0 (4.5-5.0)

Notes:
HeLMS subscales include Receptivity (Receptivity to health improvements), Understand (Understanding health information), Support (Support with utilising healthcare), Economic barriers (Economic barriers to care), Accessing GP (Accessing GP healthcare services), Communication (Communication with health professionals), Proactive (Proactive about seeking alternative care) and Utilising (Utilising health information).
Associations for age, socioeconomic status and distress assessed using Spearman's rho. Differences for sex, marital status, employment status, education, primary language, country of birth and smoking status assessed using Mann-Whitney U. Differences for daily alcohol consumption assessed using Kruskal-Wallis oneway ANOVA.
Significant associations / differences in bold for emphasis.

Figure 1: Recruitment details