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Head and neck cancer patients recollection of their clinical characteristics

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Abstract:	Patient reported outcomes (PRO) are an important component of treatment evaluation. Typically, PROs are completed by patients on paper, however through advances in technology, such as mobile phone apps and websites, there is great opportunity for electronic completion. It can be challenging particularly at a regional or national level to maintain accurate core clinical head and neck cancer (HNC) records; baseline, recurrence, second primary, and further treatments. These will influence PRO and outcomes reporting. In addition, with data security and confidentiality, there is merit in undertaking anonymous surveys but in this approach, there is a reliance on patient recall. The aim of this study was to compare updated hospital records with details completed by patients. In January 2019, 395 HNC patients treated in 2015 and 2016 were sent a survey. They were asked to recall clinical variables of gender, age at diagnosis, tumour site, tumour stage and primary treatment and these were analysed for agreement with hospital records. The Kappa statistic (KP) was used to measure strength of agreement for categorical variables. There were 146 responders with one patient correctly stating they did not have cancer. Five patients indicated further disease rather than primary cancer within the selection cohort of 2015-16. Agreement between hospital record and patient recall was excellent for gender (KP=0.97) and age-group (KP=0.92), very good for treatment (KP=0.79), good for site of cancer (KP=0.61) but poor for stage of cancer (KP=0.18). Conclusion: In general patients give accurate accounts of these HNC details apart from tumour staging.

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Abstract

Patient reported outcomes (PRO) are an important component of treatment evaluation. Typically, PROs are completed by patients on paper, however through advances in technology, such as mobile phone apps and websites, there is great opportunity for electronic completion. It can be challenging particularly at a regional or national level to maintain accurate core clinical head and neck cancer (HNC) records; baseline, recurrence, second primary, and further treatments. These will influence PRO and outcomes reporting. In addition, with data security and confidentiality, there is merit in undertaking anonymous surveys but in this approach, there is a reliance on patient recall. The aim of this study was to compare updated hospital records with details completed by patients. In January 2019, 395 HNC patients treated in 2015 and 2016 were sent a survey. They were asked to recall clinical variables of gender, age at diagnosis, tumour site, tumour stage and primary treatment and these were analysed for agreement with hospital records. The Kappa statistic (KP) was used to measure strength of agreement for categorical variables. There were 146 responders with one patient correctly stating they did not have cancer. Five patients indicated further disease rather than primary cancer within the selection cohort of 2015-16. Agreement between hospital record and patient recall was excellent for gender (KP=0.97) and age-group (KP=0.92), very good for treatment (KP=0.79), good for site of cancer (KP=0.61) but poor for stage of cancer (KP=0.18). Conclusion: In general patients give accurate accounts of these HNC details apart from tumour staging.

Introduction

Accurate data is essential when reporting treatment outcomes. For some countries large datasets exist; for example German-Austrian-Swiss Cooperative Group on Tumours of the Maxillofacial Region (DÖSAK),[1] Danish Head and Neck Cancer Group (DAHANCA),[2] National Cancer Database,[3] US population using Surveillance, Epidemiology, and End

Results (SEER),[4] whilst other centres collect regional data related to their unit such as Copenhagen,[5] and Liverpool.[6] Accurate data is more difficult to maintain for regional centres as they have a wider geographic referral base into the centre and follow-up tends to be in the patients locality. Good data relies on the flow of information especially when subsequent follow-up is at a distant unit. It is time consuming and relatively expensive to maintain accurate data. Potential inaccuracy occurs when amalgamating different sources of data and agreeing any discrepancies can be time consuming. Also, there is workload associated with manually extracting data from clinical records.

Patient reported outcomes (PRO) augment head and neck cancer (HNC) survival outcomes, and are important for case mix adjustment.[7] PRO are usually completed by the patient using paper or electronic devices and it gives their perspective of function and dysfunction.[8] Collating the clinical characteristics and linking these to individual patients in an 'audit' setting rather than dedicated trials research funded projects can be challenging.

Although the core clinical characteristics might be recorded at tumour board / multi professional team meeting, it is possible that the treatment decision of the MDT is not ultimately delivered. Failure to update the treatment record can be a source of error particularly if the oncology and surgical departments provide treatment at different sites and do not share the same patient record system. It can also be hard to update patients records in respect to events such as recurrence, second primaries, significant comorbidity, and further treatments.

If patients can accurately report their core clinical characteristics, this would be useful in anonymous surveys where the patient is not linked to any existing dataset. Anonymous data supports General Data Protection Regulation (GPD) as the use of personal data apart from patient identification is minimised. Although patients and carers are given a lot of information at the time of diagnosis and treatment planning and generally appear to be satisfied, there is still considerable variability in how the information is understood [9] and little evidence in the literature of how well this is retained over time. Key patient characteristics in the management of HNC include gender, age, year of diagnosis, site of cancer, stage of cancer, treatment, recurrence, and second primary.

The aim of this paper was to compare patient characteristics as derived from the clinical record with patient data derived from a postal survey. The intention was to measure agreement and to explore in greater depth any discrepancies. It was hoped to indicate which patient derived data can be trusted as being accurate from a postal survey. This has implications for research projects to alleviate the workload in manually extracting data from clinical records and also data submitted by patients via online internet surveys.

Method

For this study we identified patients treated for primary head and neck squamous cell carcinomas in the Aintree Regional Maxillofacial Unit between January 2015 and December 2016 and who were alive in January 2019. These patients were surveyed in early 2019 on the topic of loneliness and this is reported elsewhere.[10] Patients with cutaneous and salivary gland malignancy, treated with palliative intent, with cognitive impairment or living overseas were excluded. Clinical and demographic data, comprising gender, age at diagnosis, tumour site, tumour stage and primary treatment were collected from the clinical record. In the postal survey patients were asked in what year they were born (free text), to which gender they most identified (male, female, prefer not to say), the year of their first diagnosis (free text), the site of the cancer when first diagnosed (oral [mouth], laryngeal [voice box], oropharyngeal [throat-tonsil, soft palate, base of tongue]) , the stage of cancer (early [stage 1 or 2], advanced [Stage 3 or 4]), the treatments received (surgery, radiotherapy, chemotherapy).

The Kappa coefficient of agreement was used to measure the total sample level of agreement between categorical patient derived and clinical record data. The McNemar test (2 categories) and McNemar-Bowker test (more than 2 categories) were used to test for systematic disagreement between the two sources of information.

Aintree University Hospital Clinical Audit Department approved this study.

Results

There were 146 responders to the survey from a denominator of 395 known survivors, a response rate of 37%. Five patients indicated that their primary cancer treatment was earlier (1998, 2003, 2004, 2010, 2011) than the 2015-2016 cohort selected for the survey using

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clinical records and they indicated further disease within the selected cohort. One patient stated there was no diagnosis of cancer and indicated a non-cancer diagnosis in 2010.

Regarding patient gender the agreement was excellent (Kappa statistic 0.97), with just two discrepancies, though on further inspection the database was correct. Patient age at diagnosis was derived from clinical records using date of diagnosis and date of birth, whereas the survey asked for year of diagnosis and year of birth. There was agreement within one year of age for 90% (131/146) of patients; of the 15 patient age discrepancies, 5 stated a primary diagnosis before 2015, 1 stated a non-cancer diagnosis in 2010, 6 had age discrepancies of less than 2 years and 3 had discrepancies of 2.2, 2.3 and 20 years. Regarding patient age group (<55, 55-64, 65-74, ≥75) at diagnosis (Table 1) there was excellent overall agreement (Kappa statistic 0.92), with eight discrepancies between categories of which 3 were patients stating a primary diagnosis before 2015 and 1 with a non-cancer diagnosis in 2010.

Patients were asked to categorise the site of their cancer when first diagnosed as oral (mouth), laryngeal (voice box), oropharyngeal (throat-tonsil, soft palate, base of tongue), other site, unsure (Table 2). Three patients were unsure and did not state a site while three selected more than one category. The overall kappa statistic of 0.61 represents a good level of agreement with the clinical record; the exclusion of the six 'out of cohort' patients gave a kappa statistic of 0.62. However, there were 39 discrepancies in all, including 13 between oral and oropharynx and 8 between larynx and oropharynx.

Patients were asked to categorise the stage of their cancer when first diagnosed as early (stage 1 or 2), advanced (stage 3 or 4) or unsure (Table 3). In categorising the clinical record into early and late staging priority was given to pathology data when available over clinical staging. The overall kappa statistic of 0.18 represents a poor level of agreement and the significant McNemar-Bowker test (p<0.001) indicates systematic differences between clinically derived patient survey data. The predominant discrepancy (38 patients) was for the clinically derived staging to be advanced and for the patient to regard it as early; the discrepancy the other way round (clinical early, patient advanced) was seen for only three patients. There were 81 discrepancies in all.

Patients were asked to indicate what treatments (surgery, radiotherapy, chemotherapy) they received when first diagnosed with cancer (Table 4). The overall kappa statistic of 0.79

borders on a very good level of agreement; the exclusion of the six 'out of cohort' patients gave a kappa statistic of 0.81. There were 20 discrepancies in all.

Discussion

Maintaining correct HNC data over time is a challenge. However, with the wider use of smart phone technology and electronic patient records it is possible in future for patients themselves to help validate accuracy. For patient surveys, in terms of data confidentiality, there is merit in anonymous data collection. This relies on patient recall and understanding of their clinical characteristics. The findings might be different in other centres and countries. Unfortunately, the response rate was less than ideal but sufficient to gain an overall impression. As the survey was designed in the context of 'audit' no reminders were sent. The study was part of another survey on loneliness and quality of life [10] so perhaps the number of questionnaires and topic deterred patients from responding. Caution needs to be applied when interpreting and generalising these data since the responders perhaps were more knowledgeable about their clinical characteristics than those choosing not to respond. The awareness of patient cancer characteristics might be related to educational level and this was not recorded. It is not possible to know exactly what these patients were told at diagnosis, their understanding, and to what extent there was loss of recall over time. A larger study over a longer period would be required in order to comment on patient accuracy in regard to recurrence and second primaries.

The study would suggest that patient response to a paper survey was sufficiently accurate for age, gender, and treatment. The survey revealed clerical errors in the departmental dataset, particularly in regard to distinguishing between new cancers and previous disease. Despite attempts to be vigilant about recording all HNC patients it is possible also that some eligible patients might have been missed. In regard to gender, the two survey discrepancies were found to reflect patient error, which highlights mistakes that can occur either by ticking the wrong box or transcribing from questionnaire to database. Regarding age, to avoid patient identifiers the survey only asked for year of birth and the year of diagnosis; hospital records contained full date of birth and diagnosis. Consequently, there were minor discrepancies between age at diagnosis between hospital and survey data, most of which were consistent with this difference in precision. In a small number of cases some patients were placed within different age groups if they were close to age cut-offs. Further investigation of the patient with a 20 year discrepancy indicated the hospital database to be correct, the error occurring

because of illegibility of the year of birth on the survey form. There was some disagreement in relation to site and this tended to relate to when anatomical site touched or overlapped such as oral to oropharynx, oropharynx to larynx. There was relatively poor agreement in respect to stage with patients tending to consider themselves having earlier disease, and we are not sure why this was the case; further qualitative research would be helpful. There was complete agreement regarding those patients having single modality treatment, i.e. surgery alone or non-surgical treatment alone. For those with multi modal treatments it can be difficult to maintain accuracy because some patients will be selected for post-operative radiotherapy following surgery but for a variety of reasons have surgery alone; other patients might consider a tumour biopsy as being part of a surgical intervention even though they were managed non-surgically.

In order to have confidence in patient recollection of characteristics further research is required. It would be useful to ask about HPV status given its prognostic importance, though discussion around HPV can be awkward.[11] It is incumbent on those responsible for patient data to explore ways to allow patients themselves to contribute to the reliability of their data. This might be improved through careful explanations of stage, site or the use of diagrams with patients having an individualised summary of their cancer characteristics for their own record.

In conclusion, patients can help to validate their HNC data and any discrepancies clarified. Anonymous data would allow large patient cohorts for the purpose of patient reported outcomes; however, there is a need to have stronger evidence of accurate patient recall before this approach can be used reliably.

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Table 1. Agreement in patient age group

		Patient survey				
		<55	55-64	65-74	75+	Total
Clinical	<55	27	-	-	-	27
record	55-64	1	50	1	-	52
	65-74	1	-	43	2	46
	75+	-	1	2	18	21
	Total	29	51	46	20	146

Kappa statistic 0.924 (SE 0.026). McNemar-Bowker test p=0.78

Table 2. Agreement in site of cancer

		Patient survey						
						More than one category selected	Not stated	Total
		Oral	Laryngeal	Oropharyngeal	Other			
Clinical	Oral	38	-	8	3	2	-	51
record	Laryngeal	1	9	8	1	-	2	21
	Oropharyngeal	5	-	51	2	1	-	59
	Other	3	1	1	9	-	1	15
	Total	47	10	68	15	3	3	146

Overall: Kappa statistic 0.607 (SE 0.051)

For patients selecting one category only: Kappa statistic 0.643 (SE 0.053). McNemar-Bowker test p=0.12

Table 3. Agreement in Stage of cancer

		Patient survey			
		Early	Advanced	Not stated	Total
Clinical	Early	46	3	8	57
record	Advanced	38	18	32	88
	Total	84	21	40	145

One patient who said there was no cancer diagnosis did not answer this question.

Overall: Kappa statistic 0.184 (SE 0.041)

When patient stated Early or Advanced: Kappa statistic 0.249 (SE 0.071). McNemar test p<0.001

Table 4. Agreement in Primary treatment

		Patient survey			
		Surgery only	CT/RT only	Surgery + CT/RT	Total
Clinical	Surgery only	49*	-	6	55
record	CT/RT only	-	36	3	39
	Surgery + CT/RT	6	5	41	52
	Total	55	41	50	146

Overall: Kappa statistic 0.793 (SE 0.043). McNemar-Bowker test p=0.78

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Author contribution

Manuscript Title Head and neck cancer patients recollection of their clinical characteristics

Please provide details in the table below of each author(s) contribution to the submitted manuscript

AUTHORS	Conception and design of study/review/case series	Acquisition of data: laboratory or clinical/literature search	Analysis and interpretation of data collected	Drafting of article and/or critical revision	Final approval and guarantor of manuscript
Rogers	Yes	Yes	Yes	Yes	Yes
Al-Nakisbandi		Yes		Yes	
Dahill				Yes	
Lowe		Yes	Yes	Yes	

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Conflict of interest statement

We have no conflicts of interest.

Ethics statement/confirmation of patient's permission

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.