

The use of health related quality of life data to produce information sheets for patients with head and neck cancer

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ABSTRACT

INTRODUCTION Health related quality of life information gives patients and carers an indication of how they will be affected following treatment. Such knowledge can promote realistic expectations and help patients come to terms with their outcome. The aim of this paper is to describe the background development of patient information sheets produced at our unit.

METHODS The data were compiled using a common head and neck cancer specific quality of life questionnaire (University of Washington Quality of Life [UW-QOL]). There are 12 domains comprising activity, appearance, anxiety, chewing, mood, pain, recreation, saliva, shoulder, speech, swallowing and taste. The data were collected over 19 years at our unit and focus on follow-up records at around 2 years as this gives a good indication of health related quality of life in survivorship. UW-QOL questionnaires were available from 1,511 patients treated following primary diagnosis of head and neck cancer, and there were 24 subgroups based on cancer site, stage and treatment. There were 2 other subgroups: 132 having transoral laser resection and 176 having laryngectomy.

RESULTS The patient and carer research forum helped to design the information sheets, which display overall quality of life, percentages with 'good' outcome and 'significant problem' by domain, and the most important domains. Three examples are included in this paper: early stage oral cancer treated by surgery alone, early laryngeal cancer treated by surgery alone, and late stage oropharyngeal cancer treated by surgery and postoperative radiotherapy. All 26 subgroup information sheets are available in booklet form and on the internet.

CONCLUSIONS How the surgical community best utilises this type of resource needs further research.

KEYWORDS

Health related quality of life – Head and neck cancer – University of Washington Quality of Life – Patient reported outcomes – Expectations – Information

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Patients and their carers need differing amounts of information, delivered in various ways and at various times.^{1–5} Too much information can result in reduced recall and anxiety whereas too little information can result in patients unable to reach understanding. Anxiety and supportive care needs are paramount during the diagnostic phase of the cancer journey.^{4,5} Anxiety and unmet needs are high prior to treatment, and poor information and lack of psychological support are related to emotional distress.^{5,6} Information provision needs to be tailored and should include material about illness, treatment, side effects, function, physical fitness, impact on functioning, duration of recovery time and impact on quality of life, support groups, where to find financial advice and long-term effects of treatment on ability to work.^{6,7}

Newell *et al* found that while most head and neck (H&N) cancer patients felt well informed about the surgical

procedure they were undergoing, many reported feeling unprepared for the long-term lifestyle changes that occurred.¹ Individuals who wanted to take an active role in decision making reported difficulties accessing information to enable them to do so. The exchange of information underpins both informed consent and shared decision making, and there is evidence that patients want detailed information on how treatment affects survival and quality of life.^{6,8}

There are several commonly used H&N cancer specific health related quality of life (QoL) questionnaires.⁹ There is no gold standard, and each has individual strengths and weaknesses. One of the more frequently reported questionnaires is the University of Washington Quality of Life (UW-QOL) questionnaire.¹⁰ It focuses on 12 domains comprising activity, appearance, anxiety, chewing, mood, pain, recreation, saliva, shoulder, speech, swallowing and taste. The categories for each domain are hierarchical and described

in words. These descriptions can help patients understand what the scores might mean in practical terms (eg for speech: 'being understood over the telephone'). The description of level of function is useful as it can help patients understand the level of deficit more clearly.

Previously, we pooled accumulating UW-QOL data to summarise patients' accounts of their outcome following primary surgery for untreated oral and oropharyngeal cancer.¹¹ The sample then consisted of 561 consecutive patients, and the report was limited to only 6 common groups based on clinical presentation and treatment. It showed big differences by tumour size, free flap surgery and adjuvant radiotherapy. The information was presented in tabular form.

As more data were collected, it was possible to divide the groups further into four clinically distinct tumour subsites in the oral cavity (buccal/retromolar, oral tongue, floor of mouth and other sites) split by stage and treatment (surgery alone or surgery and radiotherapy).¹² Data were again presented in tables, which was not an easily digestible format for discussing with patients and carers. More recently, for oral, oropharyngeal, laryngeal and other H&N sites, logistic regression was used to demonstrate outcome by stage, treatment, free flap, sex and age where these were key significant predictive factors.¹³

Although these data help inform clinicians and the wider multidisciplinary team about likely outcomes and they can be discussed with patients and carers, there is a need to present clinical outcomes data in a format that patients and carers can more easily understand, possibly by using graphical methods. Information graphics are visual representations of information, data or knowledge intended to present complex information quickly and clearly.¹⁴ Cognition can be improved by using graphics to enhance the human visual system's ability to see patterns and trends.¹⁵

H&N cancer information sheets have been developed in collaboration with patients and carers through the research forum and support group at the regional centre. The intention is to present health related QoL data in a format that is more easily interpreted by patients, carers and members of the wider team. The aim of this paper is to describe the background development of these information sheets and to demonstrate them using three examples: early stage oral cancer treated by surgery alone, early laryngeal cancer treated by surgery alone, and late stage oropharyngeal cancer treated by surgery and postoperative radiotherapy.

Methods

Twenty-six subgroups (Table 1) were considered as they reflect common patient treatment groups. Twenty-four of these groups were formed of consecutive patients diagnosed and treated for primary H&N squamous cell carcinomas in 1995–2010 at the regional maxillofacial unit at Aintree University Hospital, with 1995 being the year the regular surveying began of patients using the University of Washington Quality of Life questionnaire (UW-QOL). Patients with cutaneous and salivary gland malignancy, those treated with palliative intent and those with cognitive impairment or living overseas were excluded.

The data collection has been described and analysed elsewhere.^{11–13} Two additional cohorts of patients comprised all those undergoing transoral laser resection (TOLR) between July 2006 and April 2013, and all those having laryngectomy surgery between November 2003 and October 2011. These additional subgroups included some non-primary cases that had earlier been primary cases and were included in the 24 primary treatment subgroups. Mortality status was tracked via the Office for National Statistics up to 1 March 2014, enabling Kaplan–Meier estimates of overall 24-month survival to be obtained for each subgroup.

The UW-QOL questionnaire is well established.⁹ Version 4 consists of 12 single question domains, these having between 3 and 6 response options scaled evenly from 0 (worst) to 100 (best) according to response hierarchy.¹⁰ Another question asks patients to choose up to three domains that were the most important to them in the previous week. We also used criteria derived from earlier work¹⁶ to determine the domains in which patients had a 'significant problem', these criteria being based on a mix of domain scores and domain importance. For the single item overall QoL scale, patients were asked to consider not only physical and mental health but also other factors such as family, friends, spirituality and personal leisure activities important to their enjoyment of life.

UW-QOL records were selected for analysis from patients who had completed one or more UW-QOL questionnaires at least nine months after the time of primary treatment (or after TOLR/laryngectomy for patients in the additional two cohorts). Where there was a choice between two or more UW-QOL records, the record closest to two years was selected. Two years was selected as this reflects long-term health related QoL outcomes with a tendency for stability in patients' responses after that time point.¹⁷

The information sheets display outcome information at around two years into the cancer journey for several key indicators. They include a bar chart summary of the percentage of patients reporting the best two responses for each domain and of the percentage reporting a 'significant problem' for each domain, a word cloud featuring domain names with the prominence of names giving an approximation of how often they were considered one of the top three most important issues and the percentage of patients reporting a 'good' or better overall QoL. The information sheets were designed in collaboration with patients and carers. The layout and use of tables, graphs and pictograms was discussed. For example, there was a preference for using a smiley face to reflect overall QoL. The project was registered with the hospital audit department.

Results

The 24 primary case subgroups comprised 2,624 patients, of whom 2,315 were alive at the 9-month follow-up appointment. Two-thirds of these (1,511/2,315, 65%) completed one or more UW-QOL questionnaires after 9 months and the record closest to 2 years (median: 24 months, interquartile range [IQR]: 20–29 months) was selected for

analysis. The TOLR cohort comprised 152 patients, with 125 alive at 9 months and 95 (74%) of these completed UW-QOL questionnaires after 9 months (median: 24 months, IQR: 19–32 months). The laryngectomy cohort comprised 176 patients, with 149 alive at 9 months and 74 (50%) of these completed UW-QOL questionnaires after 9 months (median: 32 months, IQR: 25–59 months). Table 1 shows overall patient numbers, Kaplan–Meier overall 24-month survival estimates and numbers of UW-QOL records selected for analysis for each subgroup.

For indicative purposes, three examples are included in this paper: 601 cases of early stage oral cancer treated by surgery alone (subgroup 1; Table 1, Appendix 1 – available online), 149 cases of early laryngeal cancer treated by surgery alone (subgroup 3; Table 1, Appendix 2 – available online) and 197 cases of late stage pharyngeal cancer treated by surgery and postoperative radiotherapy (subgroup 18; Table 1, Appendix 3 – available online). Of the 601 oral cancer patients, 572 were alive at 9 months, with 425 (74%) having UW-QOL data. Of the 149 laryngeal cancer patients, 140 were alive at 9 months, with 92 (66%) having UW-QOL data. Of the 197 pharyngeal cancer patients, 185 were alive at 9 months, with 145 (78%) having UW-QOL data.

Of these three groups, those with late stage oropharyngeal cancer who were treated by a combination of surgery and radiotherapy scored significantly worse in terms of swallowing, chewing, taste, saliva and shoulder function (all $p < 0.001$, chi-squared test) than those with early stage oral or laryngeal cancer treated only by surgery, between which there were minimal differences. Despite the worse UW-QOL domain results for the late stage oropharyngeal patients, 73% reported having a ‘good’, ‘very good’ or ‘outstanding’ overall QoL, which was similar to the 77% reported by each of the other two groups.

Discussion

QoL data can help give patients and their carers an indication of how they will be affected following treatment. This information can promote realistic expectations, assist patients in coming to terms with their outcome and serve to reassure as patients often fear the worst. The importance of adequate information for patients (including those with H&N cancer) is well recognised^{1–8} but there is very little material available aimed specifically at patients and carers to inform them of possible health related QoL outcomes in survivorship. Publications have been focused on clinicians and members of the specialist team,^{11–15} and information sheets of this type are probably the first for H&N cancer.

Our aim was to produce information sheets illustrating post-treatment health related QoL outcomes in a patient friendly format. The QoL data have been collected over a series of surveys spanning 19 years. This has allowed stratification into 26 subgroups of H&N cancer treatments. However, it is acknowledged that the information sheets are limited to only one type of health related QoL questionnaire and that health related QoL outcomes are more complex. Furthermore, the data are pooled and so can only

give an indication of outcome. For some subgroups, the numbers were very small and appropriate caution should therefore be applied when discussing these outcome data with patients.

The data have been collected from one unit but it is likely that they apply to patients having similar treatment elsewhere. There are some treatments that are underrepresented, in part reflecting our unit’s treatment protocols and also changes in treatment strategies over time, for example more patients having chemoradiotherapy in recent years. As the UW-QOL is a commonly used questionnaire, it would be possible to add to the dataset by including data from other units that have collected data in a structured fashion.

The information sheets help patients and carers to imagine possible outcomes. One could construct sheets for various time points but to simplify the data presentation, two years was selected as this broadly reflects longer-term outcomes.¹⁷ The number of patients with data does allow further breakdown for the more common treatments by other clinical characteristics such as age or sex. In addition, one could focus on specific functions in more detail (eg speech and swallowing). In order to not produce such a large array of information sheets, an interactive search portal has been added on our H&N cancer website (<http://www.headand-neckcancer.co.uk/For+patients/What+will+I+be+like.aspx>). Patients can use this to gain more detailed information.

Despite this, it is very important to have paper versions of the information as around half of H&N cancer patients do not use the internet.¹⁸ The format of the current information sheets was chosen in collaboration with patients and carers but there are many ways these data could be presented. Through use of the information sheets in clinical practice, other suggestions about how best to present the data will be forthcoming, and these can be piloted and evaluated. Although the data on the one-page sheets are less detailed than the searchable web-based resource, it might be that the amount of information needs to be reduced for ease of understanding by new patients and their carers.

There are differences in the outcomes in the three groups reported in this paper. Not surprisingly, late stage pharyngeal cancers, treated by a combination of surgery and radiotherapy, scored notably worse in terms of swallowing, chewing, taste, saliva and shoulder function. On the positive side, however, 73% of patients reported a ‘good’, ‘very good’ or ‘outstanding’ quality of life and 93% agreed with one of the following statements: ‘My speech is the same as always’ or ‘I have difficulty saying some words but I can be understood over the phone’. One of the major deficits for H&N cancer patients concerns saliva and the detrimental impact of radiotherapy.

A similar approach could be used for other health related QoL questionnaires. Nevertheless, it should be noted that the use of words that describe the level of function or dysfunction might be easier for patients to relate to than the categorical scoring used in some questionnaires (eg ‘a lot’, ‘a little’) as this can be very subjective and patients might differ in what they view as ‘a lot’ or ‘a little’. How best to use data to inform patients of likely outcomes

Table 1 The 26 treatment subgroups

Subgroup	Stage	Site	Treatment	Patients	Kaplan–Meier survival estimate in % at 24 months	Patients with UW-QOL record	Median (IQR) follow-up in months of UW-QOL record
1	Early	Oral	Surgery only	601	87 (±1)	423	24 (20–29)
2	Early	Pharyngeal	Surgery only	108	88 (±3)	74	22 (18–28)
3	Early	Laryngeal	Surgery only	149	88 (±3)	92	25 (20–31)
4	Early	Other	Surgery only	7	86 (±13)	4	26*
5	Early	Oral	Surgery + RT	119	65 (±4)	69	23 (20–29)
6	Early	Pharyngeal	Surgery + RT	47	93 (±4)	36	23 (18–29)
7	Early	Laryngeal	Surgery + RT	31	87 (±6)	17	26 (21–33)
8	Early	Other	Surgery + RT	7	100 (–)	5	30*
9	Early	Oral	RT or CRT	35	40 (±8)	6	36*
10	Early	Pharyngeal	RT or CRT	38	63 (±8)	15	21 (17–32)
11	Early	Laryngeal	RT or CRT	115	88 (±3)	58	28 (20–43)
12	Early	Other	RT or CRT	11	73 (±13)	6	41*
13	Late	Oral	Surgery only	205	61 (±3)	111	24 (19–28)
14	Late	Pharyngeal	Surgery only	72	73 (±6)	40	21 (17–24)
15	Late	Laryngeal	Surgery only	34	76 (±7)	18	27 (19–45)
16	Late	Other	Surgery only	39	50 (±8)	12	26 (16–53)
17	Late	Oral	Surgery + RT	334	61 (±3)	182	24 (19–28)
18	Late	Pharyngeal	Surgery + RT	197	86 (±3)	145	23 (19–28)
19	Late	Laryngeal	Surgery + RT	68	73 (±5)	27	25 (21–32)
20	Late	Other	Surgery + RT	72	76 (±5)	45	25 (21–31)
21	Late	Oral	RT or CRT	68	21 (±5)	5	25*
22	Late	Pharyngeal	RT or CRT	184	62 (±4)	87	24 (20–29)
23	Late	Laryngeal	RT or CRT	42	46 (±8)	13	21 (14–25)
24	Late	Other	RT or CRT	41	57 (±8)	21	25 (18–30)
Total				2,624	74 (±1)	1,511	24 (20–29)
25			TOLR	132	89 (±3)	93	24 (19–32)
26			Laryngectomy	176	72 (±3)	74	32 (25–59)

UW-QOL = University of Washington Quality of Life; IQR = interquartile range; RT = radiotherapy; CRT = chemoradiotherapy; TOLR = transoral laser resection
*insufficient cases for computing interquartile range

needs further evaluation. At diagnosis, the priority for H&N cancer patients is survival but QoL data could support better informed decision making. How much information and when this is given needs individual patient consideration as patients can become overwhelmed.

With the prospect of more data becoming available in the future, further research is required to better understand how to integrate this into the information process and choice around treatment selection. It would be possible to include other outcomes in addition to health related QoL if patients and carers felt it helpful (eg gastrostomy dependency rates, return to work and complications).

The design of QoL information sheets and the use of interactive internet datasets would benefit from much wider consultation, beyond the patients and carers at one regional service. There might be scope for a national strategy so that even the most vulnerable and deprived patients have equal access to this type of resource.

Conclusions

There is huge scope to incorporate patient reported outcomes and health related QoL data in discussions around treatment outcomes with patients and their carers. How

the information is best presented and the benefit it makes to shared decision making, consent, realistic expectations and patient satisfaction all need further evaluation.

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Appendices

Three appendices summarising the survey results have been published online with this paper, and are available to view online at publishing.rcseng.ac.uk

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