What will I be like one year after head and neck cancer treatment?

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Scientific outline

Abstract: Consequences of treating head and neck cancer are reflected in health-related quality of life (HRQOL) patient-reported outcomes. HRQOL is an important outcome alongside survival and recurrence. However, relatively little HRQOL information is in a format that patients and oncology teams can easily interpret as a guide to likely outcomes following curative treatment.

The study aim is to collate University of Washington Quality of Life (UW-QOL) questionnaires collected in Head Neck 5000 with a view of summarizing the key clinical parameters of age, gender, site, stage and treatment on HRQOL outcomes at one years following diagnosis. We will then produce one-page summary tables for subsites based on the clinical parameters similar to those available for two-year outcome based from one centre in the UK. Also the data will be available on a online for a more individualised search.

The increasing amount of HRQOL data allows for quite detailed subgroup analysis, which can help patients and the clinical team to have a better understanding of likely HRQOL outcome one year following treatment. The data are sufficiently detailed to be used in discussions with patients about likely outcomes. They can help patients to make decisions about the type of treatment, provide a reference for realistic expectations, and enable them to be better informed when they give their consent. How the surgical community best utilises this type of resource needs further research.

Outline: Health related quality of life (HRQOL) 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. Recently HRQOL data has been collated and summarised by one unit in the UK to produce 'what will I be like' at two years following treatment (1,2,3).   UW-QOL questionnaires were available from 1,511 patients treated following primary diagnosis of head and neck cancer, and 24 subgroups were produced based on cancer site (oral, oropharyngeal, laryngeal, other sites) , stage (early or late) and treatment surgery (surgery alone, surgery plus radiotherapy, radiotherapy/chemotherapy). There were 2 other subgroups: 132 having

transoral laser resection and 176 having laryngectomy. One-page advice sheets were produced in collaboration with patients and carers. The sheets display overall quality of life, percentages with 'good' outcome and 'significant problem' by domain, and the most important domains. In addition an online resource has been made available (4.)

Even with 1,511 patients some subgroups have relatively small numbers. With more patients it would be possible to separate the groups further by the key clinical parameters of age, site, stage and treatments. The data thus far had to be pooled to those closest to two years, however with Head Neck 5000 there will be a large sample with one-year outcome. One-year data reflects long-term outcome.

The increasing amount of HRQOL data allows for quite detailed subgroup analysis, which can help give patients and the clinical team a better understanding of likely long-term HRQOL outcomes. The knowledge gap is that there is only relatively limited data at 2 years and it would be useful for patients, their family, and clinicians to have more information in a similar way about outcomes at one year.

Anonymous UW-QOL data collected at one year will be used. The aims are
1. Describe 'what will I be like' at 1 year
2. Produce fact sheets in a similar design to those reported at 2 years and also allow the data to be included in the online search tool
3. With larger patient numbers it will be possible to split clinical groups based on age, gender, site, stage and treatment.
4. Compare one year what will I be like to the existing data on two-year outcomes.

References

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