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Changing Perceptions in Head and Neck Cancer Management Caused by Quality of Life Issues

Sir Felix Semon was an outstanding clinician and exceptional laryngologist. The money raised by donations from his colleagues on his retirement in 1909 was used to establish the London University's Semon Lecture. Semon's Obituary in the BMJ, reads: "In Semon's own hands a lasting cure was obtained in over 80% of the cases he operated on for malignant laryngeal growths, and... his work has proved of immense and lasting benefit to humanity. Furthermore... by avoiding the necessity for more drastic and maiming operations... a large number of patients who have undergone a radical operation for laryngeal cancer are restored... to a useful and happy life."¹ Today's topic reflects these sentiments and is also reminiscent of the 1989 Semon Lecture, delivered by my mentor, Philip Stell, entitled 'Head and Neck Cancer: can we do any better?'

Points of tension between QoL and cure

The primary outcome of head and neck cancer (HNC) treatment is cure; treatment that gives the best chance of cure should be the preferred option and quality of life (QoL) issues will be secondary. But this does not necessarily equate to cure at any cost; the time trade-off technique has shown that there are people who would rather be dead than to continue as they are.

The so-called 'Andy Gump' deformity is an early, extreme example of QoL compromise in pursuit of cure. Such adverse QoL outcomes have driven the search for better reconstructive techniques. Now heroic surgery can be attempted – in the name of cure – and followed by prodigious reconstruction aimed at restoring form and function. Such spirited surgery has more recently been matched by equally belligerent

chemoradiotherapy, with the aim of preserving form and function rather than restoring it. This has led in turn to conservation ('organ preservation') surgery such as TLM (trans-oral laser microsurgery) and TORS (trans-oral robotic surgery).

Thus 'organ preservation' has become something of a surrogate for QoL. Sadly, organ preservation does not always mean organ function. Hoffman *et al.*² refer to this when discussing treatment of advanced laryngeal cancer, "Organ preservation should only be considered when survival and function (is) equivalent to total laryngectomy and postoperative radiotherapy..."

Demez *et al.*'s survey³ found that 75% of Belgian otolaryngologists would withhold curative treatment if it led to impaired QoL. About 40% considered oral diet limited to liquids to be unacceptable but only 25% considered gastrostomy feeding unacceptable. Clinical research suggests that patients do not carry the same values.

Personal research on QoL

My first paper on QoL appeared in 1984 while working with Stell in Liverpool; I reported a 39% incidence of depression in previously treated bucco-pharyngeal cancer patients.⁴ This study pre-dated free flaps and IMRT, and the patients were all struggling to cope with the effects of major surgical resections and radical RT. Added to that they were living in Liverpool after all, where the evidence of the Toxteth riots was a constant reminder of how things were.

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I was struck by the plight of these patients; I subsequently conducted a two-year observational study in Auckland patients; QoL scores two years after treatment were better than at the time of diagnosis.⁵

In Toronto, using the same QoL instrument, I found that patients of the same age, gender, tumour type and tumour stage, had a *worse* QoL than the Auckland patients, at the equivalent time after treatment, despite having virtually *identical* dysfunction and symptom scores.⁵ This comparative study reflects both the resilience of the New Zealand character and the good common sense of our nurses, who were advising the patients. As explained by Calman (1984): “*Quality of Life measures the difference, or the gap, ... between the hopes and expectations of the individual and that individual's present experiences*”⁶... which implies that Toronto patients had a generally higher expectation than the Auckland group, and were more dissatisfied even though they had comparable clinical outcomes.

Calman was a student of Immanuel Kant, who wrote: “*Our perception is shaped by our previous experiences.*” Kant also said: “*We see things not as they are, but as we are*” which may explain why clinicians rate patient quality of life differently from the patients. Using Calman's ‘gap’ approach, we can influence a person's QoL by:

1. Enhancement: optimise function and minimise symptoms wherever possible,
2. Modification: all members of the MDT should present the patient with a consistent picture of what to expect, and avoid unrealistic expectations,
3. Guidance: consider counselling or psychotherapy, to provide patients with the tools with which to cope with change.

When I repeated the QoL questionnaire on the 10 year survivors from my original QoL cohort, the earlier ‘good’ QoL scores had deteriorated materially.⁷ Most of the survivors originally had stage I and II tumours, and should have had relatively few symptoms. So, why the deterioration?

My hypothesis is that they were no longer the focus of attention. Everyone – the doctors, the nurses, and their family – had moved on. The patients were ‘locked in’ to a life that they hadn't prepared for. Most of them had not expected to survive this long, and the euphoria of having ‘beaten the disease’ had long gone.

This ‘time-since-treatment’ effect is not related to age, because at no time is age correlated with QoL.^{5,7,8}

I also hypothesised that QoL after treatment would be more important than QoL before treatment. Before treatment patients are full of hope and generally pleased that their tumour is being attended to. After 12 months, the therapeutic dust will have settled, and patients know what to expect. Our analysis showed that QoL was clearly the strongest determinant of subsequent survival.⁸ In 2005 a Swedish group reported QoL in 357 HNC patients using the EORTC QoL instrument.⁹ Five year survival was 54%, and the five year survivors reported better HRQoL at 12 months than those who died. There are four other relevant studies:

1. Goldstein *et al.* (2007)¹⁰ reviewed QoL scores in 479 patients of whom 60% survived three years or more. There was a consistent relationship between several quality of life domain scores and survival, especially in QoL scores at six and 12 months ($p < 0.001$). Only long-term survivors showed a positive slope between six and 12 months for all QoL domains and global QoL.
2. Nordgren *et al.* (2008)¹¹ studied 122 patients with oral cancer; the survival at five years was 52%. They found that the *change* at 12 months in some EORTC QoL items was significantly correlated with survival ($p < 0.001$). Unfortunately they did not study the *global* quality of life scores at 12 months.
3. Meyer *et al.* (2009)¹² studied 540 stage I and stage II cancers treated by radiotherapy. Survival was 75% at five years, the change between baseline and six months global QoL was significantly related to survival ($p = 0.00047$). The change in the EORTC Physical Functioning also carried very strong statistical significance ($p < 0.0000046$) and was an independent predictor of survival.
4. Oskam *et al.* (2009)¹³ is an unpublished Dutch study of 75 patients where a deterioration in quality of life at six months carried a HR of 5.08; this, and global QoL was the sole predictor of survival at six years.

Research shows that baseline ‘perceived physical self-efficacy’ is a strong correlate of six year survival.¹⁴ This is a clue to QoL dynamics. Physical self-efficacy refers to patients' ability to generate and test alternative forms of behaviour and strategies that possibly could influence

the course of the illness. Also, “*patients who expressed a higher intensity of negative feelings in regard to their illness... were more likely to survive... than those patients who were unable to express such feelings*”.¹⁴ An inability to express negative emotions is known to be related to the progression of cancers elsewhere in the body.

This begs the question: could we improve survival if we improve QoL after treatment? So far, this aspect of QoL in HNC remains in the research domain.

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QoL impact on HNC management

At large international meetings where there are several concurrent sessions, the audiences at QoL sessions tend to be very small; the ‘hands-on’ subjects seem to be more appealing. Nevertheless, surveys show that virtually all clinicians think QoL should be measured, but rather few of them actually do it. Many clinicians consider that QoL assessment does not affect HNC management, even though HNC treatment affects QoL. Presumably, those clinicians do not understand QoL measures or do not know how to use the results. Perhaps they don't have the resources to collect or analyse the data or they believe that they have sufficient information without a QoL enquiry. Even so, most *research*

funding bodies require – and professional bodies such as the British Association of Head & Neck Oncologists (BAHNO) recommend – that a quality of life component be included in the dataset for head and neck cancer.

Perceived role of QoL assessment

Authors reporting on QoL in HNC often do not define what they mean by QoL yet always define HNC. The net result is that the term ‘quality of life’ has come to be applied very loosely to all kinds of measures and observations.

Ferrans (2007)¹⁵ uses the Wilson-Cleary model to examine what added value may be obtained by measuring health-related QoL. There are both objective measures and patient-generated data. Factors external to the main health stream can contribute substantially to overall QoL which Ferrans calls ‘*the quintessential element of the model*’. While symptom scores and functional status are important (indeed, often these outcomes are of specific interest), they are really only components.

Some say that global QoL is too far ‘downstream’ to be sensitive to treatment-related symptoms and outcomes, and is anyway unrelated to the symptom functioning scores. This is true, but does not invalidate the value of measuring both. There are many examples where QoL has improved even when symptom scores have deteriorated, and it is well recognised that symptom severity scores are not reflected in patients’ symptom ‘importance’ ratings.

Irrespective of whether QoL is measured, one should in practice address patient expectations; inform and advise patients about what to expect not only at the time of diagnosis but also into the ‘on-going surveillance’ phase. In addition patients’ dysfunction and pain must be treated, to minimise symptoms.

The case of laryngeal cancer

Early glottic cancer

If we were to look for a classic tumour for which QoL is a core consideration it would be T1 glottic cancer. Just as QoL is a primary outcome in *palliative care* because survival is not the concern (as everyone dies at the end of treatment), so it is that if virtually everyone survives – as we expect with T1 glottic cancer – then QoL again should be a prime consideration.

A 2009 consensus statement on transoral laser assisted surgery for early glottic cancer, was focussed on local control,

which was 91-100%, and disease-specific survival which was 91-98%, irrespective of how the tumours were treated.¹⁶

I submit that if long-term QoL is not being examined in T1 glottic cancer care, then we are missing the point. The above consensus document states that “*there is no universally accepted functional measure to assess the impact of treatment on voice*”.¹⁶ That may be so, but we do have a way of assessing the impact of treatment on QoL. Even if voice outcomes differ between treatments, it is not clear how those differences might relate to QoL or patients’ perception of their treatment outcome.

Thus, cure rates do not change with treatment, but QoL outcomes might. If QoL proves to be no different, then personal preference – and maybe cost – becomes the issue. Currently, there is an increased awareness of QoL as an issue in T1 glottic cancer, but we cannot say if one treatment or another affects it materially.

Advanced laryngeal cancer

QoL in advanced laryngeal cancer is probably even more important than in early tumours. Alternate treatments for advanced laryngeal cancer exist: chemoradiotherapy or total laryngectomy, followed by radiotherapy. A review¹⁷ of treatment options for advanced laryngeal cancer shows survival outcomes to be effectively the same. On QoL outcomes, the authors state that: “*both chemoradiation and laryngectomy impact negatively on quality of life in different ways. Although differences in quality of life could be detected by functional and subscale analyses, the overall quality of life scores of both groups was similar*.” I came to the same conclusion in my analysis of Auckland laryngeal cancer patients.

A cautionary note comes from a study of the National Cancer Database (2006)² which reported that “*increase in use of chemoradiotherapy has paralleled increased mortality of patients with laryngeal cancer... the most notable decline in survival occurred among advanced glottic cancer*”. So there are questions being asked about the efficacy of chemoradiotherapy.

The quality of life paradox

Because QoL is a composite, complex integrated measure that is not generally reflected in symptom scores, there is a paradox: after treatment patients improve their QoL, even though they

have increased difficulty with (say) swallowing, breathing, speaking or with secretions. Patients seem to accept these symptoms as a trade-off for being alive.

Meanwhile, doctors perceive QoL outcomes differently from patients, very often focussing on one or other function and thinking of that as a *surrogate* for QoL. This kind of thinking must be discouraged.

QoL surrogacy; QoL utility

QoL is more than the sum of its parts, and no single item should be used as a surrogate for QoL. If we consider, say, swallow function to be the outcome of interest, when comparing different treatments, then we should call that outcome swallowing, and not ‘quality of life’. Hybrid terms are now creeping into the QoL taxonomy, such that we now read of ‘voice-related quality of life’ when in fact the subject of interest is voice, not QoL. This slippage in terminology is not helping.

Demez *et al*’s survey³ indicates that doctors are willing to consider offering a treatment that has a lower survival probability, to preserve patients’ QoL. However, Demez *et al*. state: “*in a majority of cases, physicians underestimate the quality of life of their patients*”, and ask: “*should the physician allow his choice of treatment to be influenced by his own perception of quality of life?*” This strikes at the very core of the subject of this lecture. The wealth of patient-generated QoL data in the literature has increased physician awareness of QoL outcomes. The problem is that the quality of much of the reporting is poor, which confuses the issue.

Routine use of QoL measures in the clinical setting continues to be questioned, presumably because functional outcome and symptom scores do not correlate with QoL. However, patient surveys in both Auckland and Liverpool suggest that at least patients find it useful as an *aide-memoire* prior to their consultation.¹⁸

Quality-adjusted survival is a focus of my current interest together with investigation of unmet needs and the role of psychological enquiry and intervention.

Summary

Overall, there is increased awareness of QoL as an outcome today, and there is increased expectation that QoL will be taken into account when planning treatment. However, most clinicians don’t collect or analyse QoL data.

Nevertheless, when reporting survival outcomes, increasingly more papers refer to QoL, even if the data are not available.¹⁹ Ultimately, some form of quality-adjusted survival may become the norm when assessing results of treatment for HNC.

A recent paper states that “*the evaluation of QoL... in cancer is critical to optimal patient care, comprehensive evaluation of treatment alternatives and the development of informed rehabilitation and patient education services*”.²⁰ I agree. The problem for many is that until we

have a unified and meaningful understanding of QoL, what comprises QoL domains, and how they could be measured, reported and interpreted, our perceptions of how HNC management is affected by QoL issues will remain disparate and confused. ■

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