THE CHALLENGE OF HEAD AND NECK CANCER

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Bristol-Myers Squibb

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Patient case studies have been provided by the following charities:
INTRODUCTION

The Challenge of Head and Neck Cancer has been produced by Bristol-Myers Squibb (BMS) to highlight the issues facing patients and the services they need in a disease area that many know little about.

With the support of The Swallows and the Mouth Cancer Foundation, this report seeks to:

• Outline what head and neck cancer is,
• Highlight who it affects and how,
• Understand the quality and breadth of services that are currently available to patients with the disease in the UK,
• Make recommendations about service provision for head and neck cancer patients in the UK.

WHAT IS HEAD AND NECK CANCER?

Head and neck cancer is an umbrella term covering a number of different tumour types in the head and throat. Despite around 10,000 new patients in the UK being diagnosed every year (according to 2015 data), many patients do not understand the signs and symptoms of having the disease. It is also associated with emotional trauma and poor quality of life.

A number of challenges exist in this disease area which negatively impact upon patients and their ability to access the services they need. Head and neck cancer is marked by its complexity, with many different specialists and services involved in delivering good patient care.

Significant variation exists across the UK in terms of access to and quality of services for patients, meaning that inconsistent care is being given to head and neck cancer patients in the UK. This report highlights this variation. It also, crucially, provides an insight into the lives of people with head and neck cancer through a series of patient case studies which illustrate the impact of the disease and the care they receive on patients’ quality of life, and the need for all patients to have access to appropriate treatment and services no matter where in the UK they live.

RECOMMENDATIONS

The recommendations below set out a series of essential steps that could improve the care received by head and neck cancer patients in the UK. Our recommendations are based on the issues highlighted in the report, including variation in the quality of services provided for patients identified by the National Head and Neck Cancer Audit (2014) and concerns raised by patients about their own experiences with this disease.

1. All patients across the country should have access to a Clinical Nurse Specialist as a matter of course, from diagnosis and post discharge. The decline in the number of patients being able to access these specialists, as revealed in the National Clinical Audit for Head and Neck Cancer, should be reversed.

2. The next National Clinical Audit for Head and Neck Cancer should provide details on variation in all of the six Key Elements of Care (discussed further on page 8). In particular, it should identify where patients are not able to receive support that is crucial to their quality of life – including dietary support, speech and language therapy, and dental care. Where a significant lack of access for patients to dietary support, dental care and speech and language therapy is identified, this should be rectified and the NHS should assess how best to include these professionals in the work of multi-disciplinary teams for head and neck cancer.

3. To reduce the amount of variation in services and care across the UK, a clinical audit to understand patient care should be conducted in Scotland and Northern Ireland in addition to existing audits in England and Wales.

4. Data on one-year and five-year survival for head and neck cancer should be routinely and robustly collected. This should include details of outcomes by stage of disease progression.

5. NHS England should consider how to encourage Strategic Clinical Networks and Hospital Trusts in areas with high performing services to share best practice with lower performing areas. If necessary, NHS England should update the service specification for head and neck cancer to ensure all patients receive the six Key Elements of Care identified by the Audit. The six elements should also be imbedded in planning at both a local and regional level in order to ensure appropriate resources are available to deliver them to all patients.
WHAT IS HEAD AND NECK CANCER?

“Head and Neck Cancer” is a relatively uncommon type of cancer, which can develop in more than 30 areas around the mouth and throat. The most prominent of these are:

- The mouth and lips;
- The voice box (the larynx);
- The throat (the pharynx);
- The salivary glands;
- The nose and sinuses, and;
- The area at the back of the nose and mouth, known as the nasopharynx.

Around 10,000 new cases of head and neck cancer are diagnosed in the UK each year.

Oral (mouth) cancer is the most commonly diagnosed type, with 7,591 new cases diagnosed in the UK in 2013. Laryngeal cancer is the second most common, with 2,315 new cases diagnosed in UK in the same year. Other types of head and neck cancer affect a much smaller number of patients; just 457 patients are diagnosed with salivary gland cancer on average each year in England, with even fewer people diagnosed with nasal, paranasal sinus cancer and nasopharyngeal cancer.

Oral cancer is the 14th most common cancer in the UK (2013 data), accounting for 2% of all new cases of cancer, but it is a growing problem – incidence rates have increased by 92% in Great Britain since the late 1970s, and by 39% in the UK in the last decade alone.

Despite 91% of cases being thought to be preventable, many people diagnosed with head and neck cancer die from the disease. In 2014, 2,386 people died as a result of oral cancer in the UK. Laryngeal cancer was responsible for 839 deaths in the same year. A remarkable 93% of those deaths were classed as preventable.

Long-term survival

There is considerable variation in the long-term survival prospects for patients with different types of head and neck cancer. According to the most recent Head and Neck Cancer Audit, patients with laryngeal cancer have a four-year survival rate of 61% and people with oral cavity cancer have a survival rate of 57% (2009/10 data). For those with cancer of the hypopharynx (bottom of the throat), survival prospects are even less positive; only 33% of patients with this type of tumour survive for four years after diagnosis (2009/10 data).

According to Cancer Research UK, long term (5-year) survival for some types of mouth cancer can vary from as much as 40% to 90%. However, there is very little data to draw on and it is hard to tell how survival outcomes differ depending on how advanced a patients’ tumour is at the time of diagnosis.
On average there are 12.9 cases of oral cancer for every 100,000 people in the UK (age-standardised figures); however, there is variation in incidence rates in and between each of the four nations. While the largest number of patients are found in England, its incidence rate is below average for the UK with 12.4 cases of oral cancer per 100,000 people.

Incidence rates for head and neck cancer are higher in Scotland and Wales. In 2013, 859 cases of oral cancer were diagnosed in Scotland, which means there are 16.8 cases for every 100,000 people. Wales also has an above average incidence rate, with 14.1 cases of oral cancer per 100,000 people. Patient outcomes are also worse in Scotland and Northern Ireland, with more deaths from the disease in these countries than in England or Wales in 2014. All figures are age standardised.
The same is true for people with laryngeal cancer. Across the UK, 4 people in every 100,000 develop laryngeal cancer, but that figure is 5.7 in 100,000 in Scotland and rates are higher than average in Wales and Northern Ireland as well. As with oral cancer, patients were much more likely to die from a tumour in the larynx in Scotland or Northern Ireland in 2014 than elsewhere in the UK.

Within England there is considerable variation in the incidence of oral or laryngeal cancer, people living in London, the North East, the North West and the Midlands having a greater risk of being diagnosed with oral cavity cancer than the national average. In London, the North East, the North West and Yorkshire and The Humber, there is a much greater chance of developing laryngeal cancer than in the rest of England.

The reasons for this regional variation are unclear. Some variation in incidence may be explained by the likelihood of infection with HPV-A (a strain of the HPV virus) in different parts of England. Links between head and neck cancer and alcohol consumption and smoking mean that areas with traditionally higher rates of these behaviours tend to have higher prevalence of the disease. Incidence has also been traditionally higher in areas of the country that have a lower socio-economic status.

HEAD AND NECK CANCER – THE RISK FACTORS

There are a number of risk factors for the development of head and neck cancer. These include:

- Smoking tobacco, or chewing tobacco or betel quid;
- Alcohol consumption;
- Human Papilloma Virus (HPV) infection;
- Diet, including diets that are high in animal fats and low in fresh fruit and vegetables, and diets with large quantities of certain types of salty fish;
- Exposure to certain types of dust and workplace chemicals, including hardwood dust, leather dust and formaldehyde;
- A family history of head and neck cancer, or having certain pre-existing health conditions.

CARING FOR PATIENTS

Diagnosing, treating and caring for people with head and neck cancer is an immensely complex enterprise, with a large number of different types of health professionals involved in the management of these conditions. According to NHS England, a specialist multi-disciplinary team for head and neck cancer should include:

- Surgeons, including ear nose and throat (ENT), maxillofacial or plastic surgery specialists;
- Clinical oncologists;
- Dentists;
- Radiologists;
- Clinical Nurse Specialists;
- Speech and Language Therapists; and,
- An extended team made up of a broad range of professionals including clinical psychologists, pain management specialists, neurosurgeons and doctors specialising in palliative (end of life) care.

There are a number of possible treatments for head and neck cancer depending on the type a patient has and how advanced it is. Patients may be treated surgically, using radiotherapy or drug treatments, or a combination of these options may be used.

Treatment for head and neck cancer can impact dramatically on the lives of patients, including causing significant changes to a patient’s physical appearance, impacting how they speak, eat and affecting their hearing.

Patients with laryngeal cancer may have to have a full laryngectomy, where the entire voice box is removed, or require a breathing stoma – a hole in the neck created to allow a patient to breath after surgery on the voice box. These changes can be life-changing and distressing for head and neck cancer survivors.

According to Macmillan Cancer Support, head and neck cancer patients need ongoing support following discharge. This can include support with eating, breathing and speaking as well as to overcome emotional barriers associated with this cancer. Patients with head and neck cancer have also been found to have higher levels of emotional distress caused by their disease and treatment than patients with other cancer types. Despite this, only 56% of patients who required care reported that they had adequate support after they were discharged from hospital.
PATIENT CASE STUDIES

STUART CAPLAN

(Case Study provided by the Mouth Cancer Foundation)

Stuart lives in Marylebone with his wife Susan. He is a business consultant at St. James’s Place Wealth Management. He was diagnosed with tongue cancer in May 2012 after suffering with a number of symptoms for a year; which four of the doctors he consulted failed to diagnose as cancer. His dentist also failed to pick up on his condition.

At that time he was told that surgery was not an option, and so he commenced chemotherapy in June 2012 followed by radiotherapy. An attempt to install a radiologically inserted gastronomy (RIG) feeding tube failed so the procedure was attempted a second time. This was abandoned when the radiologist realised that due to his anatomy it would have been impossible to successfully insert the tube. All attempts to complete this procedure were abandoned. This meant that Stuart had to struggle through the radiotherapy which destroyed his ability to eat and drink. The first chemotherapy drug he was given combined with the fluid in his abdomen caused by the failed RIG tube insertion lead to renal failure. This could have meant that Stuart faced dialysis for life or required a kidney transplant. The side effects from Stuart’s radiotherapy included severe nausea and various infections, one of which attacked his eyes and devoured the skin on his neck and chest. All this meant that he was hospitalised for most of the second half of 2012.

The post-treatment PET/CT scan at four months showed that, although the cancer had not spread, the combined chemotherapy and radiotherapy had failed to destroy it. At this point he was offered surgery, a glossotomy which could potentially have had a devastating impact on his life. He was therefore referred to a psychiatrist to assess his suitability for this procedure. Prior to surgery Stuart married Susan, his partner of eighteen years. Following a short honeymoon in Paris he had a PEG feeding tube fitted followed by the surgery on 19 February 2013. The ENT surgeon removed two-thirds of his tongue and the maxillofacial surgeon built a tongue flap with tissue taken from Stuart’s thigh. A neck dissection was also performed to remove lymph nodes.

Over a year post-surgery Stuart is active, speaking, eating and drinking. This has involved a lot of hard work and focus but shows his determination to overcome obstacles which is typical of him. Life is slowly returning to normal, and in addition to his professional career he also does voluntary work for Mouth Cancer Foundation, The Rarer Cancers Foundation, Macmillan, Cancer Voices and as a Patient Representative at London Cancer. He is also piloting a Skype-based buddying and mentoring project.

He understands that he has had cancer but cancer hasn’t got him. Or to put it another way, in prizefighting there is an expression: “Everyone has a plan until they’ve been hit.” Well my friend, you’ve just been hit. The getting up is up to you.”

CHRIS CURTIS

(Case Study provided by The Swallows – Head and Neck Cancer Support Charity)

“I was diagnosed on Friday 13th May 2011 at 11am with throat cancer. My world fell apart! Talk about information overload. I went in to shock mode. Thank God for my very special wife Sharon, without her it would have been a different outcome I am sure!

My treatment plan: 46 days of intense Radiotherapy, 6 weeks of Chemotherapy, 2 Neck Dissections, Feeding Peg and a Mask fitted that pinned you to a table. I needed lots and lots of recovery time and dealing with all the short and long-term side effects of the treatment plan.

In March 2012 I became aware of a small group of people that met in a local pub to talk about issues they were going through so I went along. It helped me but I soon realised this could become a lot more. I started to work with my Clinical Nurse Specialist about my ideas, not realising at the time this was actually helping me deal with my cancer - there I said it! My depression started to retract, I started to be positive and the outcome was that, in November 2012, I successfully obtained full charity status for the group and it is now known as The Swallows Head & Neck Cancer Support Charity.

Over the last 4 years the charity has helped patients and carers all over the UK, and it also reaches out to other parts of the world. The Charity holds regular monthly meetings for patients and carers to come together. They also reach out via Social Media and the internet.

Awareness of Head & Neck cancer forms a big part of the activity, plus supporting Head & Neck cancer units in hospitals – our biggest achievement was a £31,000 purchase of a scanner for Blackpool Victoria Hospital.”
Over the last decade, the NHS has conducted a substantial clinical audit of head and neck cancer services, which brings together data from thousands of patients in England and Wales. This allows us to assess not only the survival outcomes of care, but also the quality and variation in services provided for head and neck cancer patients across the country. The audit does not cover Scotland or Northern Ireland, and therefore data is not available for those nations.

The findings of the most recent audit, which was the tenth in a series of annual reports, are concerning. Despite consecutive audits reporting considerable variation between services and multi-disciplinary teams across the country, there is still a notable gap in the quality of care received by patients—much of which is avoidable.

According to the Audit, there are six “key elements of care” that all patients should receive, encompassing the whole pathway from diagnosis to treatment. The average patient is only assured access to 3.3 of these key elements, and just 8% of patients are able to access all six. This means that more than 90% of patients are unable to access the best quality care for head and neck cancer.

Nationally, there are some major areas of concern. Only 63% of patients had access to a Clinical Nurse Specialist (4,337 patients out of a possible 6,895 covered by the Audit), slightly fewer than in the previous year. Access to radiotherapy services is also an issue, with a quarter of patients (out of a total of 1,052) having to wait 54 days or longer to begin treatment after being diagnosed.

HPV is also seen as a major risk factor for certain types of head and neck cancer, including oropharyngeal cancer. Despite this, just under half of patients with this cancer type are still not tested for HPV. More positively, almost every patient in England and Wales has their case discussed by an MDT.

Despite the impact that head and neck cancer treatment can have on a patient’s ability to perform basic functions, such as eating and speaking, very few patients in England and Wales have access to the support necessary to deal with these issues. Only 34% of patients (2,334 people) have a pre-treatment nutritional assessment, 35% of Trusts met the Key Element of Care requirement for dental assessment, and 29% of patients met the speech and language therapy assessment element according to 2013-14 data.

“I want to finish on variation, and why this persists despite the evidence presented here. There are parts of the country where outcomes are good, services are timely and the experience of care is positive. We need to understand what underpins variation and tackle it head on. The parts of the country where they have good outcomes need to help those that have less good outcomes. This will mean networking and collaboration using patient outcomes as the basis of discussion. Clinical networks have a role in not only helping health economies internally, but also being able to reach out across NHS England to facilitate change.”

Sean Duffy, Former National Clinical Director for Cancer, writing in the Tenth Annual Head and Neck Cancer Audit Report 2014

KEY ELEMENTS OF CARE

- Pre-treatment seen by Clinical Nurse Specialist (CNS)
- Pre-treatment nutritional assessment
- Pre-treatment speech and language therapy (SALT) assessment
- Pre-treatment dental assessment
- Pre-treatment chest CT/chest X-ray (CXR)
- Discussed at multi-disciplinary team (MDT)
- Resective pathology discussed at MDT (additional seventh key element of care for patients receiving surgical treatment only)
Within England and Wales, there is also a considerable variation in the quality of services across different regions. As the Audit shows, these areas often have below average achievement rates against Key Elements of Care for head and neck cancer patients.

The Audit provides some data for the performance of Strategic Clinical Networks (SCNs) against some of the Key Elements of Care. As the table below indicates, some regions are falling below average on a number of different standards. However, there is a paucity of data provided on certain Key Elements of Care, such as access to speech and language therapy, making it difficult to determine which areas might be underperforming against the national average.
<table>
<thead>
<tr>
<th>Key Element of Care</th>
<th>Regions falling below the England / Wales average</th>
</tr>
</thead>
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| Discussion of Resective Pathology                            | London Cancer*  
West Midlands  
London Cancer Alliance*  
Greater Manchester, Lancashire and South Cumbria                                                            |
| Access to a Clinical Nurse Specialist pre-treatment           | Cheshire and Merseyside  
London Cancer  
East of England  
Yorkshire and the Humber  
Greater Manchester, Lancashire and South Cumbria  
London Cancer Alliance  
East Midlands                                                     |
| A Clinical Nurse Specialist being available when bad news is broken | Cheshire and Merseyside  
South East Coast  
London Cancer Alliance  
Greater Manchester, Lancashire and South Cumbria  
London Cancer  
Yorkshire and the Humber  
East Midlands                                                         |
| Pre-treatment nutritional assessment                          | East Midlands                                                                                               |
| Pre-treatment chest scanning                                 | London Cancer  
Greater Manchester, Lancashire and South Cumbria  
Yorkshire and the Humber  
North Wales  
East Midlands                                                    |
| *N.B. There are two SCNs in London – London Cancer, and the London Cancer Alliance iii                             |

**PATIENT ACCESS**

The Audit also reveals that there are issues for patients trying to access different kinds of treatment for head and neck cancer. Only two areas in England or Wales satisfied the recommended maximum time between a patient having surgery and then receiving post-operative radiotherapy which is deeply concerning.iii Many areas of the country are shown by the Audit to be doing well. Wessex, Thames Valley and the East of England consistently appear to perform well against the standards laid out in the Audit.iii However, more should be done to ensure there is less variation in the care received by head and neck cancer patients across the country, and to ensure that the best practice demonstrated in some parts of the country is shared elsewhere. As responsibility for conducting the audit process moves away from the NHS, and is taken over by Saving Faces – The Facial Surgery Research Foundation, it is also essential that any variation in those measures that potentially relate to a patient’s quality of life – including access to dieticians, speech and language therapists and others, is adequately captured so that issues can be addressed.
CONCLUSIONS

Head and neck cancers affect thousands of people across the UK but are rarely spoken about. Patients with these tumours can experience different standards of care depending on where they live, and depending on what kind of head and neck tumour they have. While in some cases up to 65% of patients can survive for four years, the availability of appropriate treatment and care can significantly impact upon their lives. Addressing patients’ problems, including complications they may have with eating, speaking and breathing, as well as changes to their appearance, is crucial to improving outcomes and experiences of care.

In order to help secure the best possible outcomes for patients, it is important that services are designed in the most effective and efficient ways to support treatments which are available now and could become available for head and neck cancer patients in the coming years.

It is imperative that high quality services are made nationally available across the UK in order to ensure that all patients can benefit equally.

REFERENCES


iii. Health and Social Care Information Centre, National Head and Neck Cancer Audit 2014


xix. Case Study provided by the Mouth Cancer Foundation

xx. Case Study provided by The Swallows