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Regional Centre for Maxillofacial Surgery
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Liverpool

**Thursday 8th
& Friday 9th
November 2012**

Contact person:
Leanne Gorvett
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Professor SN Rogers

Edge Hill
University

Aintree University Hospital NHS
NHS Foundation Trust

Where quality matters

8th International
Quality of Life Conference,
Liverpool

http://www.harddaysnighthotel.com
The Hard Days Night Hotel, Liverpool

Course Organiser, Professor Simon Rogers Liverpool

PROGRAMME

12 CPD points

EPRC

Thursday 8th
November

Quality of Life in Head & Neck Cancer
8th International Conference

Morning

An update in Head and Neck since the last conference
Chair: Professor Simon Rogers

8:30 Refreshments

9:00 Introduction and summary, Professor Rogers

9:30 Keynote speaker, Dr Mary Wells
Addressing the consequences of head and neck cancer treatment

10:30 Refreshments

11:00 Free papers

Kate Reid: Health Related Quality of Life Questionnaires – Are they fit for purpose?

Jennifer Doss: Longitudinal HRQOL of Oral Cancer Patients Undergoing Surgical treatment and Other Treatment Modalities

Margereth Bjorklund: Ideas for Using Bottom Up Communication to Integrate Health Promotion and Empowerment for Patients Living with Head & Neck Cancer

Barry Scott: Introduction of the Head & Neck Patient Concern Inventory Into a Consultant Clinic – Observational Study

12:30 Lunch

Thursday 8th
November

Quality of Life in Head & Neck Cancer
8th International Conference

Afternoon

Functional Outcomes (appearance, dental, nutrition/PEG, speech, swallowing)
Chair:: Professor Hisham Mehanna

13:30 Keynote speaker, Dr Joanne Patterson
Swallowing Outcomes In Head & Neck Cancer

14:30 Free papers

Diane Goff: Pre Treatment Information Regarding Dysphagia - Exploring The Views of Head & Neck Cancer Patients

Sam Harding: The Impact of Disfigurement Following Treatment for Head & Neck Cancer

Sobia Bilal: Cross Cultural Adaptation of the Facit H&N v.4.0 in Urdu Language for a Pakistani Clinical Setting

Professor Hans Aarstad: Distress Scores Predict Uniquely Subsequent Survival in Successfully treated Head & Neck Cancer Patients – A Prospective Study

15:30 Refreshments

16:00 Free papers

Emma Hogg: "What will I Be like?" – Patient Reported Health Related Quality of Life Outcomes Following Head & Neck Cancer Treatments.

Yeur-Hur Lai: Examine Head & Neck Cancer Patients Neck and Extremities Muscle Functions, Mouth Opening and Speaking Ability – Are these factors related to patients employment status?

Aileen Timmons: Post-treatment Support Needs of Survivors of Head & Neck Cancer – View and Experiences of Survivors and Health Professionals

Sami Moubayed: Tumour p16 Status Does Not Influence the Quality of Life and Depression Outcomes in Oral and Oropharyngeal Squamous Cell Carcinoma

Cherith Semple: Plans to transform a head and neck cancer clinic in South Easter HSC (Belfast)

17:15 Discussion and Close

18:00 – 19:00 Informal Survivorship, North of England Psychology Meeting – Taking place in the bar area

19:00 Course Dinner, Blakes Restaurant, Hard Days Night Hotel

Friday 9th
November

Quality of Life in Head & Neck Cancer
8th International Conference

Morning

Psychological Aspects, Communication
Chair: Professor Gerry Humphris

8:30	Refreshments
9:00	Introduction and summary, Professor Humphris
9:15	Keynote speaker, Professor Peter Salmon Empowerment and Vulnerability: Contrasting Perspectives on Cancer Care
10:00	Up Skill Staff in 4 Tier Model, Dr Elspeth Desert
10:30	Refreshments
11:00	Fear of Recurrence Update, Professor Gerry Humphris
11:30	Fears of Cancer Recurrence: A Qualitative Account of Similarities, Differences and Conflict, Dr Gozde Ozakinci
12:00	Self management and a Way Forward in Head & Neck Cancer, Sharon Collins
12:30	Lunch

Friday 9th
November

Quality of Life in Head & Neck Cancer
8th International Conference

Afternoon

The Patient and Carer Perspective
Chair: Professor Steve Thomas

13:30	Steve Thomas: Update on the NCRI Survivorship Group Activity
13:45	Keynote speaker, Dr Andrea Waylen Healthtalkonline and its Potential for Head & Neck Cancer Services
14:30	Free papers
	Brendan Noonan: The Impact of Total Laryngectomy
	Kate O Brien/Brenda Roe: An Exploration Into the Perceived Changes in Intimacy of Patients Relationships Following Head & Neck Cancer
	Sam Harding: the Impact of treatment for Head & Neck Cancer On Post Traumatic Growth
	David Laraway: Quality of Life in Elderly Oral Cancer Patients
	Sarah Dodd: Mode of Death in Head & Neck Cancer – A Prospective Audit
	Aileen Timmins: Post-Treatment Supportive Care Needs in Head & Neck Cancer – What about the care givers?
16:00	Closing remarks, refreshments & depart

Welcome

'The long and winding road'

I have chosen this opening phrase as it the one used for the Liverpool marathon. As a participant last year I have a personal experience. I can certainly relate to the long run up Parliament Hill and the winding paths in Sefton Park. I expect many of our cancer patients and their carers can also connect to their experience of cancer in terms of *'the long and winding road'*.

As I take this opportunity to extend another warm welcome to Liverpool, has it really been two years since our last meeting? I think we can say 'yes' as it might feel that there has been a period of considerable change, with a new landscape within the NHS driven through the need for financial belt tightening. It has never been more necessary for us to have a collective vision for what is best cancer care and support. We need to focus resources and ensure that we all work together to make excellence as our standard.

The conference brings together an international selection of presentations with wide experience in the field. Contributions from a variety of backgrounds and disciplines will help to consolidate a wide spectrum of viewpoints and provide a unique opportunity for coherent dialogue. I am very grateful for your participation as I appreciate that the purse strings on study leave budgets are tight and that we all have demanding clinical and family commitments.

I am excited about the exchange of ideas and views that will aired over the next two days. There will be diverse opinion and no right or wrong answers. Your clinical experience will add to the meeting, so please may I encourage you to participate and make your views known. Feedback from last time was that there was not enough time for discussion so this year the number of more free papers has been reduced. Please may I ask all speakers to keep to time and allow 5 minutes or so at the end of their talks for questions. In the 15 minute free papers ideally the presentations should be for 10 minutes to allow 5 minutes debate.

This year for the first time we are based in a hotel. This should provide a more convivial atmosphere and space to breakout. The lecture facilities might not be as good so it is uncharted waters so I really hope you enjoy the meeting, At worst ,we are very close to Liverpool One - so you have an excuse to get out and take in the atmosphere.

You will see from the programme that the workshop has been roughly divided into four sections and there has been an attempt to fit the free papers around these themes:

i. Thursday morning we will address general issues
ii. Thursday afternoon emphasis is more towards function
iii. Friday morning we will consider psychological aspects
iv. Friday afternoon there is slightly more patient and carer focus

Please do not hesitate to let me know if there are any problems during the conference and I will do my best to deal with them for you. Also please take the opportunity to complete the course evaluation forms, as this will help shape the next meeting planned for November 2014.

Finally ,I wish to express my sincere thanks to Leanne Gorvett for her tremendous administrative support which have been in addition to her day to day NHS job ! We owe her a huge debt of gratitude as there is so much to arrange and she needs the patience of a saint having to work along side me!

Quality of Life in Head & Neck Cancer: 8th International Conference - Meet the Chairs

Chairpersons

Thursday Morning

Professor Simon Rogers

BDS, MBChB (Hons), FSD RCS (Eng), FRCS (Eng), FRCS (Max), MD

Simon was appointed Consultant Oral and Maxillofacial Surgeon at the Aintree University Hospital on 1st January 1999.. He has an interest is in health related quality of life and in 2000 was awarded his MD from the University of Birmingham. In 2002 he was awarded a Hunterian Professorship from the Royal College of Surgeons of England for his research into the relationship between function and quality of life following primary surgery for oral and oropharyngeal cancer. In November 2006 he joined Edge Hill University, Faculty of Health and has a Chair in the Evidence based Practice Research Centre (www.edgehill.ac.uk/eprc). He is very active in the field of outcomes research and has published widely on this topic . He has published over 200 peer review journal articles, 8 book chapters and 1 book. In 2009 he gave the Nunn Lecture at the annual scientific meeting of the British Association of Head and Neck Oncologists.

Thursday Afternoon

Professor Hisham Mehanna:

PhD, BMedSc (hons), MBChB (hons), FRCS, FRCS (ORL-HNS)

Director, Institute of Head and Neck Studies and Education,
Chair of Head and Neck Surgery, University of Birmingham
Consultant head neck and thyroid surgeon

Hisham Mehanna is the Chair of Head and Neck Surgery, University of Birmingham and a consultant head and neck and thyroid surgeon, at the University Hospitals Birmingham and Heart of England Hospital, Birmingham. He is also the Director of the Institute of Head and Neck Studies and Education (www.InHANSE.org).

He received his PhD from the University of Erasmus, Rotterdam. He holds Royal College Fellowships in General Surgery and Otolaryngology-Head Neck Surgery and is on the Specialist Register in the UK.

His clinical interests are oral cancer and reconstructive microvascular surgery for head neck cancer and thyroid and minimal access parathyroid surgery.

Hisham has a keen interest in clinical research, heading a research team of 15 researchers, and holding approximately £5.5m in research grants. He has published over 50 articles and book chapters, and has given numerous presentations and invited lectures.

He is the Chair of the UK's National Cancer Research Institute head and neck group. He is also on the Council of the British Association of Head Neck Oncologists, the Council of the Royal Society of Medicine - Laryngology section, and the Council of the International Association of Oral Oncology. He was also the past Secretary of the Otorhinolaryngological Research Society.

Quality of Life in Head & Neck Cancer: 8th International Conference - Meet the Chairs

Chairpersons cont'd

Friday Morning

Professor Gerry Humphris

Gerry Humphris studied Psychology at Reading University (1973-76) before going to Guy's Hospital to complete a PhD (1983). He gained his clinical psychology qualification at Liverpool (1986) and after 10 years teaching of undergraduate dentists and medics (Director of Communication Skills) moved to University of Manchester as Reader in the Clinical Psychology Department (2001) before taking up the post of Chair in Health Psychology at Medical School, University of St Andrews (Nov 2003).

His main interest is understanding the communication processes between clinician and patient in particular conditions. He is a member of the Verona Network on Sequence Analysis.

Friday Afternoon

Professor Steve Thomas

BDS(Lond), MB,BCh(Wales), PhD(Q'ld), FDSRCS, FRCS(Eng), FRCS(OMFF)
Professor in Oral and Maxillofacial Surgery

Steve is leading the Head and Neck 5000 initiative. The Head and Neck 5000 study is a collaborative projects between both researchers and clinicians across the United Kingdom. The study is funded by the National Institute for Health Research, UK.

Steve is currently Chair of the NCRI Head and Neck Clinical Studies Group (H&N CSG) Survivorship Sub-group.

Quality of Life in Head & Neck Cancer: 8th International Conference - Meet the Faculty

Keynote speakers

Mary Wells
PhD MSc BSc RGN

Mary trained in London and began a career in cancer nursing in 1988, first working with head and neck cancer patients undergoing major surgery. As a ward sister in radiotherapy/oncology, she developed an interest in rehabilitation following cancer treatment. She then held a variety of clinical, educational, managerial and research posts in London and Oxford before moving to Scotland in 1997. Since then, she has led both qualitative and quantitative research studies of patients' experiences / nurse-led interventions in cancer care. She completed a PhD in 2007 and has published widely in peer-reviewed journals and books, including co-authoring the leading textbook 'Supportive Care in Radiotherapy'. Her long-standing interest in the supportive care and recovery of patients with head and neck cancer led to a grant from Macmillan Cancer Support for a programme of work into the consequences of cancer treatment, as part of the UK National Cancer Survivorship Initiative. Mary is a member of the Consequences of Cancer Treatment Collaborative www.cancerconsequences.org.uk and an Executive Board member of EONS (European Oncology Nursing Society) www.cancernurse.eu She is currently a Senior Lecturer in Cancer Nursing at the University of Dundee.

Dr Joanne Patterson

Dr. Jo Patterson has a combined clinical and academic post. She is a Macmillan Speech & Language Therapist at Sunderland Royal Hospital, specialising in head and neck cancer dysphagia and an Associate Clinical Researcher at the Institute for Health & Society, Newcastle University. She was awarded a NIHR Doctoral fellowship in 2005. Her PhD reported on swallowing outcomes from a clinical, patient and carer perspective. She is currently involved in a number of research projects identifying swallowing outcomes for specific treatments as well as developing interventions for patients with dysphagia.

Professor Peter Salmon

Peter Salmon is Professor of Clinical Psychology at University of Liverpool, where his research focuses on communication between practitioners and patients, particularly in cancer care. He is also Hon Consultant Psychologist at Royal Liverpool & Broadgreen Hospitals NHS Trust where he established the Liverpool Psychology Service for Cancer.

Elspeth Desert

Elspeth Desert is a Clinical and Health Psychologist, working as the Clinical lead for Health Psychology in Cumbria. Her clinical interests are head and neck cancer, pain and long term conditions. Elspeth has been developing a network of new posts to promote:
Psychological care and skills among non mental health staff
Integration with Primary care and Long term conditions teams

Quality of Life in Head & Neck Cancer: 8th International Conference - Meet the Faculty

Keynote speakers – cont’d

Gozde Ozakinci

Graduating from Bogazici University (Istanbul) with a BA (Hons) degree in Psychology, Gozde Ozakinci did MSc in Health Psychology at University College London in 1998. He was awarded a PhD in Psychology in 2004 for studies in genetic counselling and testing for BRCA 1/2 from Rutgers, The State University of New Jersey, USA. His current research interests are in the area of health-related behaviour interventions for clinical (e.g. smoking cessation in cancer patients) and non-clinical populations (e.g. medical students) and emotional regulation interventions for patients who have completed cancer treatment. He is currently a lecturer in health psychology at the University of St Andrews and also has an honorary contract with Edinburgh Cancer Centre to hold psycho-oncology clinics.

Sharon Collins

Sharon Collins is a Macmillan Clinical Psychologist working in the Head and Neck Survivorship Project in Bradford. She has extensive experience of working in cancer service and palliative care as well as with chronic and long term conditions, and in mental health. She is also a Cognitive Analytic Practitioner (CAT) and has an interest in applying CAT to help teams work more effectively and to understand complex systems.

Andrea Waylen

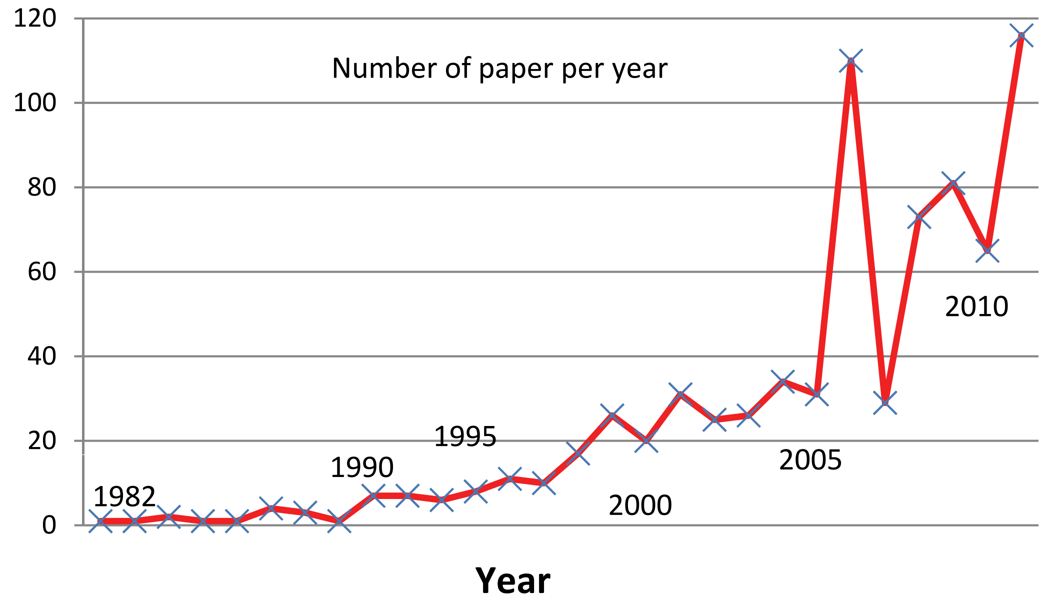
Andrea Waylen is the lecturer in Psychology at Bristol Dental School and teaches social science and communication skills to dental undergraduates. She undertook her first degree in Psychology at the University of Reading and her PhD in risky behaviour was completed there in 2002.

Her research interests include dento-facial appearance and quality of life (particularly related to cleft lip and palate and head and neck cancer) and the effects of relationships and communication on health outcomes and health-related behaviour.

Presentation – Simon Rogers

Author/Affiliations: Rogers SN, Heseltine N, Flexen J, Hevican C, Cole-Hawkins H

Between 1992 and 2011 there have been around 754 peer review articles that have used questionnaires to report 'quality of life' / 'health related quality of life' outcomes following head and neck cancer. This represents a huge amount of literature that helps shape our current understanding of the concept of HRQOL and the main determinants related to patient reported outcomes. Of the five broad themes i. predictors, ii. functional, iii. questionnaire development /validation, iv. randomised controlled trials or a control trials, and v. reviews and editorials, the majority of papers have focused on predictors of HRQOL outcomes or the functional consequences. There have been a diverse range of issues covered over this time frame and it some of the less frequently reported issued that are perhaps the most challenging to us as we explore ways to improve patient derived outcomes. Examples would include the role of support groups, carers, telemedicine intervention, de-escalation of treatment as a trade of between cure, treatment burden and HRQOL. Indeed perhaps we are left to reflect on some newer treatments that seem to confer a very modest improvement in cure rates yet can have significant delayed impacts on certain aspects of HRQOL and function. Hopefully as more data emerges patients will be able to make better informed choice in treatment selection, have improved understanding of the short-term and late consequences of treatment, and enhanced access to support throughout their cancer journey based on their patient reported outcomes and multidisciplinary team working.



Abstract Submission – Mary Wells

Title: Addressing the consequences of head and neck cancer treatment

Author/Affiliations: Mary Wells, University of Dundee

Background:
An increasing number of people are living with the consequences of head and neck cancer (HNC) treatment, and current models of care are unlikely to be sufficient to meet future needs. Post-treatment follow-up is largely aimed at detecting recurrence, and rehabilitation services are patchy. The rise in HPV-related HNC also means that we are increasingly dealing with two potentially distinct groups of survivors, with very different needs.

Aims:
This paper explores the challenges of survivorship care in HNC, within a UK policy context. Results from a cross-sectional survey of the priorities and needs of survivors up to six years after diagnosis, and from a data linkage project to explore socio-demographic and clinical outcomes in a cohort of over 400 patients, will be used to illustrate the key issues facing clinical teams as they consider how best to develop services to support people living with and beyond head and neck cancer.

Method:
A postal survey of patients in 3 Health Boards was conducted, including demographics, the Quality of Life in Adult Cancer Survivors Scale (QLACS), the Distress Thermometer, PCI and a PCI-Help questionnaire to assess unmet needs. Anonymised clinical and socio-economic data were linked with retrospective case note review data from a five-year cohort. Data were analysed in SPSS using descriptive statistics, correlation and regression.

Results:
Survey results illustrate the persistent concerns and priorities for help reported by HNC survivors, as well as the ways in which quality of life is compromised and enhanced by the experience of cancer. Regression analysis shows that certain groups are more likely to score poorly in terms of cancer specific quality of life. Data linkage provides additional insight into patterns of morbidity and mortality within the first five years.

Conclusions:
New models of care are required to address the long-term consequences of HNC treatment. These must be targeted according to individual needs and characteristics.

Abstract Submission – Kate Reid

Title: Health Related Quality of Life Questionnaires –Are they fir for Purpose ?

Author/Affiliations: Kate Reid University Hospital Birmingham NHSFT
Professor Carolyn Hicks; Dr Derek Farrell; Professor Carol Dealey University of Birmingham

Background ;
Despite the call from the research community that HRQoL questionnaires should be used with H&NC patients this is not translated into the clinical setting. There is also a limited understanding as to how other salient factors such as personality, coping strategies and complications during treatment interact for the patient. Given the complex and multiple interactions it is of no surprise that the relationship between HRQoL and survival for H&NC patients has been described as neither strong nor proven (Mehanna et al., 2008).

Aims;
To establish if H&NC-specific HRQoL measures reflect the literature on patient experience and the experiences of H&NC that patients report themselves.

Method:
A qualitative methodology was used. Three different sources of information were explored to identify themes:
a) The three HRQoL questionnaires most commonly as identified by Rogers et al., 2007
b) Themes emerging from a review of the literature on H&NC patient's experience of the treatment and sequaelae;
c) Themes from semi-structured interviews -six H&NC patients.

Results;
Six global themes were evident; four from all three sources: day-to-day physical-comfort, emotional well-being, place in society and own mortality; one from the literature and semi-structured interviews: quality of care; and one global theme from the semi-structured interviews: reality.

Conclusion:
The focus of HRQoL is narrow and it is important to build a context in which the HRQoL variables are a part rather than the whole. The questionnaires cannot capture the wealth of data available. Clinically it is valuable to invite patients to discuss, the individual impact of the disease and the treatment. The purpose of this would be to facilitate a deeper understanding of the individual experience so that specialist teams can support patients. As clinicians working with patients closely and regularly there is potential and scope for this to happen.

Abstract Submission – Jennifer Doss

Title: Longitudinal HRQOL of oral cancer patients undergoing surgical and other treatment modalities

Author/Affiliations: J.G. DOSS. W.M. THOMSON, and B.K. DRUMMOND, Faculty of Dentistry, University of Malaya, Kuala Lumpur, Malaysia, Oral Sciences, University of Otago, Dunedin, New Zealand

Background:
Information on HRQOL impacts of oral cancer patients at different intervals of life especially upon diagnosis, and after commencing treatment are relevant foe specialists managing this condition. Current efforts to assess such impacts in Malaysia using HRQOL instruments are still in its infancy.

Aims:
To assess the impact of oral cancer and related treatment modalities on patients' health-related quality of life.

Method:
A longitudinal study of a cohort of newly diagnosed adult oral cancer patients followed over a period of three months. HRQOL data was collected for each patient upon diagnosis (baseline), one month after commencing treatment (first follow-up) and after three months (second follow-up) using a Malay-translated FACT-H&N (v 4.0), a global question, and a supplementary set of eight questions (maq; obtained after cross-cultural adaptation of the instrument). The FACT-H&N (v 4.0) is a 39-item head-and-neck-cancer-specific instrument which assesses patients' physical (7 items), social (7 items), emotional (6 items), functional (7 items) well-being and head/neck concerns (12 items). FACT-G, FACT-H&N Total Outcome Index (TOI) and FACT-H&N symptom index (FHNSI) scores, which are FACT-H&N derivatives, were also calculated. Paired t-tests were used to test the statistical significance of score changes.

Results:
Of the 76 patients recruited at baseline, 42 (55.3%) were followed from baseline to the end of the study. Their HRQOL worsened from baseline (FACT-H&N score= 94.1±17.6) to first follow-up (score=87±20.0; $p<0.05$) and then improved by the second follow-up (score=91.4±20.9) although not all returned to pre-treatment levels. Worsening by first follow-up was reflected in significant deterioration of combined physical and functional well-being and increased head and neck concerns (FACT-H&N-TOI baseline score=58.4±13.9; first follow-up score=50.1±15.6; $p<0.05$). Patients' emotional well-being significantly improved from baseline (FACT ewb score=15.6±4.1) to second follow-up (FACTewb score=18.1; $p<0.05$). Those undergoing surgical interventions experienced a higher HRQOL improvement by the second follow-up (FACT-H&N=98.5; FACT-G=78.5; FACT-H&N TOI=60.0)than those who received other treatment types (FACT-H&N=83.0; FACT-G=65.5; FACT-H&N TOI=45.0; $p<0.05$).

Conclusion:
Oral cancer patients experience substantial worsening in HRQOL once treatment commences, but this improves with time, especially among those treated surgically.

Abstract Submission – Margereth Bjorklund

Title: Ideas for using bottom-up communication to integrate health promotion and empowerment for patients living with head and neck cancer

Author/Affiliations: Margereth Björklund, Department of Health and Sciences, Kristianstad University

Background:
Patients with head and neck cancer can experience a sense of being exposed and vulnerable when interacting with and communicating their needs to health professionals. In particular, they find it difficult to make initial contact with professional caregivers. Often these patients experience complex communication problems, with limited speech or no voice, which further complicates life and contact with health professionals.

Aim:
To explore whether a bottom- up communication strategy can be used to integrate health promotion with a sense of empowerment for patients living with head and neck cancer.

Method:
Thirty-five participants (21 men aged 38-83 years, and 14 women aged 59-81 years) participated. Each was interviewed up to four times. Qualitative, interpretative and descriptive analyses were used to analyse the data.

Results:
The patients expressed a need for easy access, coordination, continuity, and support from trained professionals in a patients-centred organisation. Positive human encounters helped counter-balance the patients´ unequal position in health care and strengthen their health, activity, participation, co-operation, and ability to communicate. Electronic health information helped minimise problem.

Conclusion:
If health professionals could focus on individually tailored communication, based on patients' activity and requests of what to discuss, it could help the individual to find strength and promote health. This could empower the patient and humanise care, ultimately empowering the individual and lowering his/her vulnerability when communicating with health professionals.

Abstract Submission – Barry Scott

Title: Introduction of the Head and Neck Cancer Patient Concerns Inventory into a Consultants Clinic: An Observational Study

Author/Affiliations: Ghazali N, Kanatas A, Rogers SN, Scott B, Bekiroglu F, Lowe D

Background:
The Patients Concerns Inventory (PCI) is a tool to help identify potential unmet needs of patients attending a head and neck cancer follow-up clinic.

Aims:
To assess the impact of the PCI and to evaluate its use with a consultant previously not experienced in the use of the PCI.

Methods:
A total of 106 patients were included, 52 before and 54 after the introduction of the PCI. Data collection included observational data made during the consultation about which issues were discussed and which multidisciplinary health professionals were referred to.

Results*:*
'Cancer treatment' was the issue most discussed in 60-70% of consultations. After the introduction of the PCI, with the notable exceptions of 'cancer treatment' and 'fears of recurrence' (FOR), the rates of discussion of other concerns/issues occurring within consultation were broadly similar to levels selected by patients themselves when completing the PCI just before seeing the consultant. There was poor overall agreement between items specifically raised on the PCI by patients and those being discussed in consultation. The distribution of referrals arranged for the 25 patients after the introduction of the PCI bore little relationship to the distribution of MDT members that these patients had selected when completing the PCI prior to consultation.

Conclusions:
This pilot study provides a window into the possible implementation of a simple holistic needs assessment tool in clinics for post-treatment survivors; further evaluation should be undertaken to quantify its impact on patients and the supportive care they receive.

Presentation – Jo Patterson

Title: Swallowing outcomes in head and neck cancer

Author/Affiliations: Jo Patterson

Swallowing ability is a priority issue for head and neck cancer patients as well as being a serious medical concern associated with malnutrition and possibly pneumonia. Evidence suggests that patients are more likely to rate their swallowing symptoms more severely than do clinicians and so the impact of this side effect can be under-estimated.

An understanding of how the disease and its treatment affects swallowing is crucial, so that we can give accurate patient information, gauge the outcome of different treatments and evaluate dysphagia interventions. Swallowing can be assessed in a number of different ways, reflecting its complexity and multi-dimensional nature.

Outcomes include clinical performance measures, instrumental tests, questionnaires and surrogate indicators such as the presence of a feeding tube. There is no standardised agreement on which measures should be employed.

From a research perspective, this variety creates difficulties for cross comparisons and meta-analysis, further compounded by various time points for data collection. From a clinical perspective, finding a tool that is practical as well as being meaningful for patient and clinician is problematic. This presentation will review dysphagia outcome measures in head and neck cancer and will consider issues of selection and implementation.

Abstract Submission – Diane Goff

Title: Pre-treatment information regarding dysphagia: exploring the views of head and neck cancer patients

Author/Affiliations: Goff, D; Brockbank, S; Owen, S; Miller, N; Patterson, J.

Background:
National guidelines state that head and neck cancer patients should receive a pre-treatment assessment from a speech and language therapist (SALT). The purpose is to prepare patients for potential changes to eating and drinking during and following treatment. Chemoradiation can result in severe and chronic dysphagia, with some patients remaining permanently dependent on feeding tubes, whereas others return to a near-normal diet. There is little guidance on what information to give, when and in what format. A service evaluation was conducted to assess current provision.

Aims:
To explore patients' views on pre-chemoradiotherapy information regarding potential changes to eating, drinking and swallowing function.

Method:
This evaluation was conducted across two North East England hospitals using a qualitative approach. Patients had completed primary chemoradiotherapy within two years and were disease free. Ninety-one patients were identified from clinical databases and were approached consecutively. Two focus groups and semi-structured interviews were audio-recorded and transcribed verbatim. Data were analysed thematically, using open coding and themes which were organised into a final framework.

Results:
Twenty four patients participated, and were 2-20 months post-treatment. 49% had moderate-severe dysphagia. 87% had received a pre-treatment SALT assessment. Three main themes emerged: expectations about treatment outcomes (onset, severity and longevity), presentation of information (delivery, detail and timing), absorption (remaining positive, retention). Each theme is discussed in-depth showing some polarity in opinion though in general, consensus was seen.

Conclusion:
Results suggest that patients found pre-treatment swallowing information valuable, preparing them for side effects, thus reducing anxiety. They wanted specific, paced and accurate information. There were individual differences in the level of detail required. Retaining information was difficult in the context of a cancer diagnosis. Further work is indicated in how to identify and tailor personal information needs and how to meet these in the pre-treatment period.

Abstract Submission – Sam Harding

Title: The impact of disfigurement following treatment for head and neck cancer

Author/Affiliations: S. HARDING, T. MOSS, University of the West of England

Background:
Head and Neck Cancer (HNC) is a relatively uncommon disease but carries a high level of morbidity and mortality. Treatments, especially surgical operations for HNCs can be mutilating, and disfigurement is often an issue for patients. Patients must cope not only with loss of structure and function as a result of the treatment, but also with the consequences of the treatment on social aspects of life and altered body image.

Aims:
Much of the existing HNC research has focused on functioning and has overlooked appearance distress. This research aimed to address this oversight.

Method:
Responses on the Short Form 12 (SF-12), University of Washington Scale (UoW) and Derriford Appearance Scale 24 (DAS24), were collected on 167 patients to investigate appearance distress and dysfunction.

Results:
Women showed a significantly higher DAS24 total score than men. DAS24 correlated with a number of the medical and demographic data including age at time of diagnosis, age at time of questionnaire completion, all of the UoW QoL sub-scales excluding pain and saliva and Mental Component Summary of the SF12. ANOVA showed no association with tumour location, or tumour staging with the DAS24. ANOVA with the UoW revealed an association with tumour staging (higher staging equals' greater appearance concerns). Linear regression analysis indicated that Mental Component Summary and Age at time of diagnosis are predictive of DAS24.

Conclusion:
In conclusion more awareness of appearance concerns is needed, particularly for women, those diagnosed at a younger age, and people coping poorly. The DAS24 reveals greater insight into the psychosocial impact of HNC and how it effects patients.

Abstract Submission – Sobia Bilal

Title: CROSS-CULTURAL ADAPTATION OF THE FACIT-H&N v.4.0 IN URDU LANGUAGE FOR A PAKISTANI CLINICAL SETTING.

Author/Affiliations: Sobia Bilal, PHD Student, Department of Community Dentistry, University of Malay, Malaysia; Jennifer Doss, Oral Cancer Research and Co-ordinating Centre, Department of Community Dentistry, University of Malay, Malaysia

Background:
Quality of life (QOL) measures have now become an essential part of health outcomes. In the last decade there has been an increasing awareness about QOL of cancer survivors in developing countries.

Aim:
The study aimed to achieve cross-cultural adaptation of the FACIT –H&N (v 4.0) in Urdu language for the Pakistani head and neck cancer patients.

Methods:
In this study the ‘same language adaptation method’ was used. Cognitive debriefing through in-depth interviews of 25 Pakistani H&N cancer patients for the purpose of assessing semantic, operational and conceptual equivalence was carried out. The validation phase included 50 patients to evaluate internal consistency (Cronbach’s alpha), convergent and discriminant validity, known group validity and dimensionality through factor analysis.

Results:
The translated FACIT-H&N (v4) was found to be easy to understand (100%). A few minor disparagements were noted and adjusted accordingly. A set of nine Pakistani questions was extracted and pilot tested along with FACIT-H&N on 50 patients, mostly aged 46-60 years (44%) and predominantly males (68.0%). Mostly, oral cavity tumors (68.0%) with a high proportion of late stage presentation (68.0%) were noted. Cronbach's alpha for FACIT-G subscales ranged from 0.726 - 0.969. The head and neck subscale and Pakistani questions subscale showed low internal consistency (0.426 and 0.541 respectively). All the FACIT summary scores and most of subscales demonstrated known-group validity in differentiating patients of different clinical stages, treatment status and tumor sites ($p<0.05$). Most FACIT summary scales correlated strongly with each other ($r>0.75$) and showed convergent validity ($r>0.90$), with little discriminant validity. Factor analysis on the 48 items revealed 6 factors, analysis explained 85.173% of the total variance. The Kaiser-Meyer-Olkin measure of sampling was very good (>0.8) with Bartlett's Test of Sphericity highly significant ($p<0.001$) for all the subscales.

Conclusions:
The cross-culturally adapted FACIT-H&N into Urdu language showed adequate reliability and validity to be incorporated in Pakistani clinical setting for head and neck cancer patients.

Abstract Submission – Hans J Aarstad

Title: GHQ scores predict uniquely subsequent survival in successfully treated head and neck cancer patients: a prospective cohort study

Author/Affiliations: Hans J. Aarstad[1,2], Arild A Osthus[1], Jan Olofsson[1,2], Anne K.H. Aarstad[2,3]
[1]Department of Surgical Sciences, Faculty of Medicine, University of Bergen, N-5021 Bergen, Norway.
.[2]Department of Otolaryngology/Head and Neck Surgery, Haukeland University Hospital, 5021 Bergen, Norway.
[3]Faculty of Health and Social Sciences, Bergen University College, Bergen.

Introduction:
Health-related QoL (HRQoL) scores predict survival in successfully treated head and neck squamous cell carcinoma (HNSCC) patients. This raises the possibility that distress levels may do the same. Present co-morbidity is both related to HRQoL scores and predict survival. To what extent any distress survival prediction is secondary to HRQoL and co-morbidity scores remains not determined.

Objective:
To examine the survival prediction of distress by general health questionnaire (GHQ) scores, HRQoL by the EORTC H&N35 Quality of Life questionnaire (QLQ) and present co-morbidities among successfully treated and cognitive functioning HNSCC patients.

Material and methods:
Through structured interviews, self-reported questionnaires were given to 139 successfully treated HNSCC patients, 67±32 months following diagnosis. GHQ-scores, self-reported levels of neuroticism, avoidance focused coping, coping by suppression of competing activity, alcohol consumption, smoking status, and co-morbidities, as well as gender, age, TNM-stage, and tumour site were determined. Co-morbidities were determined by a self reported questionnaire. The mean observation period was 75±4 months among the survivors. Twenty-four deaths were observed.

Results:
GHQ sum score, including a dichotomized version (HR 2.9), was predictive of survival, both directly and after adjustment for TNM stage and the above mentioned psychosocial variables. The dichotomized GHQ sum score compared the 4th upper quartile to the three lower quartiles. Analyses demonstrated that a high risk group with 33% mortality may include only one quarter of the patient population as opposed to 12.5% mortality among the other patients. Cox multivariate survival analysis showed a unique survival prediction of GHQ and HRQoL H&N35 sum score if adjusted by gender, age and reported level of neuroticism.

Conclusion:
Our findings indicate a unique survival prediction from GHQ sum scores in successfully treated HNSCC patients. GHQ and H&N35 HRQoL uniquely predict survival if adjusted by neuroticism levels. Furthermore, GHQ- and HRQoL scores may be a screening tool for identifying patients with high mortality risk.

Abstract Submission – Emma Hogg

Title: “What will I be like?” Patient reported health-related quality of life outcomes following head and neck cancer treatment.

Author/Affiliations: Rogers SN, Hogg ES, Cheung W, Lai LKL, Jassal P, Lowe D
Presented by: Emma S Hogg

Background:
The prevalence of undesirable side effects following the treatment of head and neck cancer has established health-related quality of life (HRQoL) as an important outcome of treatment along with survival and cancer recurrence rates. During consultations with their oncologist, head and neck cancer patients frequently ask “What will I be like?” following treatment. To enable oncologists to provide this information, they need sufficient evidence of the statistical likelihood and degree of impact of specific side effects to allow predictions to be made without ambiguity. In 2007 the Merseyside Regional Head and Neck Cancer Centre created the website: www.headandneckcancer.co.uk which aimed to provide this information using its unique search facility: “What will I be like?”. However, the internet was not readily accessible to almost half (46%) of patients in 2010.

Aims:
The aim of this cross-sectional study was to determine the post-treatment HRQoL in head and neck cancer patients using the University of Washington Quality of Life questionnaire version 4. In addition, ways of presenting this data in a patient-friendly manner were subsequently proposed.

Method:
A University of Washington Quality of Life questionnaire version 4 was sent to 866 eligible head and neck cancer patients who were at least 13 months post-treatment.

Results/Discussion:
Of the 866 patients in the cohort, x% completed and returned their questionnaire, producing a response rate of y%. There was no obvious response bias when comparing the demographics of the respondents and the non-respondents. In addition to updating the “What will I be like?” section of www.headandneckcancer.co.uk this study also proposed that two separate booklets could be used to present the HRQoL data: one for the clinician and one for the patient. The clinicians’ booklet would consist of the raw data in a tabulated format, whereas the patients’ data would be summarised and presented using diagrams. This booklet would be available in large print, Braille, audio tape and several languages to meet NHS standards in differentiation.

Conclusion:
Part of the informed consent process involves making outcomes clear to the patient. In order for the Merseyside Regional Head and Neck Cancer Centre to facilitate this it is looking towards producing “What will I be like?” booklets. Hence, the authors of this study should be most interested to determine how delegates currently answer requests for such information at their own centres as well as seeking opinions on the layouts that have been proposed, whether delegates would consider adopting such a system, and if they could offer methods on how to adapt and possibly improve it. Feedback can then be collated and assessed for validity, appropriateness and currency, before the proposed method is amended and made available for review by patient support groups and focus groups as the final stage in achieving our goal of producing booklets that are implemented in routine clinical practice.

Abstract Submission - Yeur-Hur Lai

Title: Examine Head and Neck Cancer Patients’ Neck and Extremities Muscle Functions, Mouth-Opening and Speaking Ability – Are These Factors Related to Patients’ Employment Status?

Author/Affiliations: Yeur-Hur Lai, PhD, Professor. College of Medicine & Hospital, National Taiwan University, Taipei, Taiwan

Background:
Due to disease or treatment related complications, head and neck cancer (HNC) patients might suffer from long-term complications, particularly, upper body muscle functions and restricted communication abilities. Limited information has been reported in this area.
Aims (1) examine HNC survivors’ neck, extremity muscle functions, mouth-opening and speaking abilities and employment status; and (2) identify factors related to survivors’ employment status.

Method:
This cross-sectional study is part of a major HNC survivorship research project in Taiwan. Eligible subjects were HNC patients who had completed surgery for more than 3 months. Patients were recruited from a medical center in Northern Taiwan by several trained clinical trial nurses. Patients were assessed of their neck functions (angles measures about flexion, extension, R’t & L’t sides bending) and extremity muscle power (measuring grip strength in hands and measuring muscle power in legs/bilateral hip flexor by Micro FET2), mouth-open ability, speaking ability, symptom severity, depression status, stages and current employment status (employment or non-employment due to cancers).

Results:
A total of 179 subjects were recruited. There were about 45% of patients lost or retired from their job due to cancers and only one third of patients still kept jobs. The logistic regression analysis by entering all factors (as independent variables) to predict the employment vs. non-employment status revealed that patient with less aggressive cancer stages, higher education level, better mouth-opening ability, less speaking and chewing restricted ability, better dominant hand muscle power and less depression reported to have more promising employment status after HNC diagnosis.

Conclusion:
The results suggest the future direction of studies as well as clinical services should emphasize more on enhancing HNC patients’ physical function and skills trainings (neck, extremities muscle power, mouth opening, speaking) to help them back to job.

Abstract Submission – Aileen Timmons

Title: Post-treatment support needs of survivors of head & neck cancer? Views and experiences of survivors and health professionals.

Author/Affiliations: Aileen Timmons[1], R. Gooberman-Hill[2], E. O'Sullivan[3], P. Butow[4], L. Sharp[1]
[1]Research, National Cancer Registry Ireland, Cork, Ireland, [2]Department of Social Medicine, University of Bristol, Bristol, UK, [3]Oral surgery, Cork Dental School and Hospital, Cork, Ireland, [4]Medical Psychology Research Unit, University of Sydney, Sydney, NSW, Australia

Background:
Although many cancer survivors eventually adjust well to their new status, significant numbers may experience significant morbidity resulting in ongoing needs for support. It is unclear whether these needs are being met by current services.

Aims:
We used qualitative methods to explore: the post-treatment support needs of head & neck cancer (HNC) survivors in Ireland; and the experiences of health professionals caring for them.

Method:
Two sets of face-to-face, semi-structured, interviews were conducted with (1) health professionals involved in head and neck cancer care (consultants, clinical nurse specialists, and allied health professionals) and (2) head and neck cancer survivors who were at least one-year post diagnosis. Health professionals were asked about survivors' support needs post-treatment, if needs were being met, any barriers, and additional supports/services needed. Survivors were asked about their experiences post-treatment, available support, support(s) used, and any additional supports/services needed. Interviews were audio-recorded and transcribed verbatim. The two sets were analysed separately using a content analysis approach.

Results:
31 health professionals and 17 survivors were interviewed. Support needs were identified in a range of areas including: information, emotional and psychological issues, medical matters, financial and social issues. Support needs can arise across the full survivorship trajectory, including long after initial treatment ends. Gaps in existing services, barriers to meeting HNC survivors' support needs faced by health professionals, and factors influencing survivor's willingness to use support services were highlighted. Survivors felt supportive care should be available post-treatment for those who need it.

Conclusion:
The findings suggest that head and neck cancer survivor's support needs often go unmet, in part due to gaps in services. Identification of the barriers to meeting head & neck cancer survivors support needs as well as recommendations/suggestions from health professionals and survivors could help improve existing supportive care services.

Abstract Submission – Sami Moubayed

Title: Tumor p16 status does not influence quality of life and depression outcomes in oral and oropharyngeal squamous cell carcinoma

Author/Affiliations: SP Moubayed MD (1), OE Gologan MD (2), JS Sampalis PhD (3), T Ayad MD (1), A Christopoulos MD MSc (1)
(1) Otolaryngology Head and Neck Surgery Service, Notre-Dame Hospital; (2) Department of Pathology, Notre-Dame Hospital; (3) Division of Experimental Surgery, McGill University; Montreal, Canada

Background
Quality of life (QOL) studies have shown that patients with oral or oropharyngeal squamous cell carcinoma (OSCC) often have the poorest outcomes among all head and neck cancer patients. Human papillomavirus (HPV) infection is recognized as a favourable prognostic factor in head and neck cancer. Tumor p16 status is a commonly used surrogate marker for HPV infection.

Aims
We aim to evaluate the prognostic value of p16 status on long-term QOL and depression in OSCC patients. We hypothesize that these patients may have a more favorable QOL and depression trajectory.

Method
A cross-sectional study was conducted on 87 OSCC patients at least 12 months after diagnosis. We administered the EORTC QLQ-C30, QLQ-H&N35, and HADS questionnaires. Demographic, biochemical, tumor, and treatment data was collected for all patients. p16 status was evaluated using immunohistochemistry on paraffin-embedded samples. Bivariate analyses (t-test, chi-square) were used to examine the predictive value of p16 status on questionnaire scores.

Results
Our sample included 60 males and 27 females with a mean age of 58.9 years and a median follow-up of 33.1 months. We encountered 61 oral cavity primaries and 26 oropharyngeal primaries. Advanced tumors (T3 and T4) represented 32% of our population (28 patients). A total of 29 patients (33.3%) were treated with curative-intent radiation therapy. 71 patients receive any form of surgery (81.6%), and 33 patients received chemotherapy (37.9%). 40 patients were p16+ and 47 were p16-. No statistically significant difference between p16+ and p16- groups was found on all subscales of the EORTC QLQ-C30 and QLQ-H&N35 ($p>0.05$). There was no statistically significant difference between groups on HADS subscale results ($p>0.05$).

Conclusion
In the current state of science, p16 status does not predict QOL or depression outcomes in oral and oropharyngeal cancer patients. As treatment de-intensification protocols emerge, this type of study methodology might produce different outcomes in the future.

Presentation – Peter Salmon

Title: Empowerment and Vulnerability: Contrasting Perspectives on Cancer Care

Author/Affiliations: Peter Salmon

Research and guidance about psychological aspects of cancer care reflect an overriding emphasis on supporting patients' autonomy. From this perspective, patients need information to support decision-making, and they need explicit emotional support to remove emotional distress. This emphasis on autonomy provides an incomplete, and sometimes misleading, picture of patients' needs. From a perspective of patients as inherently vulnerable and dependent, a more complex picture emerges whereby they also need information to help trust their practitioners and feel hopeful and they sometimes need to avoid explicit emotional support.

Presentation– Elspeth Desert

Title: Promoting psychological skills in Multidisciplinary Teams

Author/Affiliations: Elspeth Desert, Consultant Clinical Psychologist
Cumbria Partnership Trust and North Cumbria University Hospitals

Presentation:
Since 2004 NICE guidance on Supportive and Palliative care, which identified unmet need for psychological care for cancer patients, there has been a drive to improve psychological skills among all staff working with oncology patients. Peer review now specifies that all Core MDT members must have completed Advanced communication skills training and that each team must have a level 2 practitioner, with further training and access to a name Level 4 practitioner.

This presentation will consider, with specific emphasis on Head and Neck Cancer:
The importance of identifying patients psychological needs
The four tier model of psychological skills
Current training programmes to increase psychological skills in site specific MDT staff
The outcome of training for patients and staff

Presentation – Gerry Humphris

Title: Fear of recurrence update

Author/Affiliations: Gerry Humphris

The literature on fear of recurrence has expanded dramatically in the field of cancer including in the specialty of head and neck cancer. The number of assessments of recurrence fears has expanded and attempts to predict and understand its behaviour has begun to produce some important empirical data. Theoretical models have yet to be strongly developed to assist with these investigations and the formulation by Lee-Jones et al provides a starting point for researchers and practitioners wishing to seek assistance in how to explicate patients concerns and fears about the return of their cancer. This presentation will review some of the findings that are recognised with this specific psychological problem associated with cancer, announce the first major review of the phenomenon which has been submitted for peer review and provide details of a licensing agreement for users of the AFTER intervention. A recent case will be presented to illustrate some of the issues that patients will present and the type of approaches that can be utilised to manage and assist such patients.

Presentation – Gozde Ozakinci

Title: Fears of cancer recurrence: A qualitative account of similarities, differences and conflict

Author/Affiliations: Gozde Ozakinci[1], Evelyn Watson[1], Michael Sharpe[2], Gerry Humphris[1]
[1]University of St Andrews, UK
[2]University of Oxford, UK

Background:
Fear of recurrence (FoR) is often the most frequently ranked concern for people treated with various types of cancer and has been related to emotional distress, intrusive thinking, and lower vigour. It has also been shown to be associated with lower quality of life of family members.

Aims:
In this study, we aimed to capture an in-depth account of FoR in people who have been treated for breast or colorectal cancer through focus group discussions (FGDs) guided by Leventhal's Self-regulation model.

Method:
Participants were randomly selected from a cohort of participants (from a previous study). We conducted 6 separate FGDs (3 for breast and 3 for colorectal) with 18 people classified having either low, moderate, or high FoR (12 women; aged 49 and over; time since diagnosis 1-12 years) in community settings. They were led by one of two field investigators and audio-recorded and anonymised after transcription. Participants were first asked to talk about their cancer history with regard to events leading up to diagnosis, previous experiences of cancer in family and friends, treatment experiences, and impact on family and work. This led to discussion of triggers of recurrence fears and their methods of managing these as well as how their view of their future is affected by their cancer experience and the possibility of cancer coming back. A constant comparative technique was utilised to analyse the data.

Results:
Similar themes emerged in both cancer site groups in relation to the importance of symptom-related triggers (e.g., general aches and pains, annual appointments) and ways of dealing with FoR (e.g., distraction, trust in health care team). Participants described a conflict between looking to the future and moving on and having to manage the reminders of cancer. This was evident when exploring issues that arose between low FoR and high FoR groups. FoRs were expressed irrespective of time elapsed since end of treatment. Differences emerged in events leading up to diagnosis, treatment experience and follow-up time-line between breast and colorectal cancer groups.

Conclusion:
The findings speak to the similarities in the experience of people who have been treated for cancer and can be transferred to other illnesses that involve uncertainty about future. Qualitative work is important in bringing out the most pertinent themes in people's cancer experiences in order to develop interventions to address these worries. This work has illuminated the significance of assessing people's FoR following completion of treatment and symptom-related triggers for FoR.

Presentation – Sharon Collins

Title: Self management and a way forward in Head and Neck Cancer

Author/Affiliations: Sharon Collins, Macmillan Clinical Psychologist, Richard Keen, Patient/User Representative

Background

Macmillan have funded a 3 year project to create a working model of self-management to include risk stratification for Head and Neck patients. We are reporting on the first 9 months: from conception almost to birth.

Aims

- To clarify what 'self management' means and can mean in Head and Neck cancer
- To explore what that means to the patient and to the MDT: why is this relevant?

Method

- Bringing in the research evidence to discover best practise
- Finding out what the gaps were
- Pushing where it moves! Valuing what works already
- Asking patients views about self management and what it means to them: Focus group feedback
- Setting out intervention packages and what patients need

Results

- Some tips: Brownie points and raspberries
- Proposals and where we are with them

Conclusion

- Managing a change project in the current NHS climate : how?
- What next?

Presentation – Andrea Waylen

Title: Healthtalkonline and its potential for head and neck cancer services

Author/Affiliations: Waylen, A[1]., Rogers, S[2]., Ness, A[1]. & Thomas, S[1].
[1] University of Bristol [2]Aintree University Hospitals

Background:

In the UK, around 8000 patients per year are newly diagnosed with head and neck cancer. Taken in conjunction with improving cure rates, this figure means an increasing number of people survive, and learn to live with, this cancer and its treatment. However, there is low public awareness of head and neck cancer and relatively few resources that patients can access for information and support. Indeed, some patients, family members and carers report that, due to limited clinic time, they feel they have received inadequate information and support from their specialist team.

Aims:

In order to improve resources available for patients diagnosed with this condition we plan to develop an online website consisting of video, audio and occasionally written extracts that describe "real life" aspects of being diagnosed and living with head and neck cancer.

Method:

We will apply for funding to carry out around 40-45 qualitative interviews with a range of patients recently diagnosed with head and neck cancer and develop a freely available online resource following the protocol for the development of healthtalkonline websites. The resource will be formatted for iPad or tablet technology so it can be accessed in clinic time when health care professionals are available to discuss concerns and questions that arise from diagnosis and treatment.

Results:

This presentation will compare healthtalkonline websites with other online resources and discuss its potential benefits for people with head and neck cancer. We will consider how it can add to other studies currently ongoing in Bristol and elsewhere.

Conclusion:

We will discuss ways to evaluate the project in order to see whether access to appropriate and comprehensive "real life" information about their condition helps people make properly informed decisions about their treatment, improve their adherence to treatment regimes and facilitate a more positive quality of life.

Abstract Submission – Brendan Noonan

Title: The Impact of Total Laryngectomy: The Patient's Perspective

Author/Affiliations: Mr. Brendan Noonan Lecturer Practitioner and Professor Josephine Hegarty Catherine McAuley School of Nursing and Midwifery, University College Cork, Ireland.

Background:
Worldwide, approximately 450,000 new cases of head and neck cancer are diagnosed each year, with a high incidence of laryngeal cancer in southern and eastern Europe, Latin America, and western Asia (Donnelly et al. 2009). Patients whose tumours are not eradicated by radiation are generally subjected to surgery to control the disease. Total laryngectomy is believed to be more emotionally traumatic than any other type of cancer surgery because of the resultant psychological and functional impairment. The majority of the research studies published investigating the impact of total laryngectomy use fixed quality of life categories, which may not capture the individuality of patients' experiences and are therefore at risk of omitting important symptoms patients might express in another way.

Aims:
The aim of this study was to develop an insight into the experiences of total laryngectomy patients. The objective was to describe these experiences as accurately as possible from the patient's perspective.

Method:
In a descriptive qualitative study, 10 total laryngectomy patients took part in audio-taped semi-structured interviews in the participants' homes or investigator's hospital office, using an interview topic guide built on the framework of the literature review. Informed written consent was obtained. Data was analysed using descriptive content analysis. Trustworthiness of the study was enhanced through the use of verbatim quotations, audible data analysis trail and a reflexive approach.

Results:
Patients who have undergone a total laryngectomy report difficulties and concerns that are largely functional and psychological. The functional difficulties reported included descriptions of altered swallow, excess phlegm, speech difficulties, weak neck muscles, and altered energy levels. The psychological concerns reported include descriptions of depression, regrets, and personal resolve.

Conclusion:
As a group, patients experience a broad range of problems well after completion of treatment, reinforcing the need for rehabilitation management, not just from the initial postoperative period but for prolonged periods after surgery.

Abstract Submission – Kate O'Brien and Brenda Roe

Title:
An exploration of the perceived changes in intimacy of patients' relationships following head and neck cancer.

Author/Affiliations:
Miss Kathryn O'Brien, Professor Brenda Roe, Professor Simon Rogers, Mr Chris Low, Mrs Lorraine Deyn

Background :
A diagnosis of head and neck cancer, subsequent surgical treatment and radiotherapy can lead to an altered quality of life. Whilst important developments have been made to improve the quality of life for this patient group from a functional perspective, psychosocial perspectives are much less understood

Aims :
This presentation is based on a study that reports the experiences of former patients who have undergone a range of head and neck cancer treatments and their perceptions of the changes in intimacy experienced.

Method :
A qualitative approach was used to explore the experiences of former patients and their perceptions of the changes in intimacy experienced, as an individual and through their relationships with partners, family and friends. In 2007, postal questionnaires were sent to all patients
treated for head and neck cancer as identified from the University Hospital Aintree Head and Neck database revealing that 110 people had experienced difficulties with intimacy following treatment. In principle 99 participants agreed to be interviewed. A purposive quota sample of 16 patients representing two head and neck categories (ENT/MFU) were recruited. The final sample was established in relation to head and neck category, age group and personal intimacy score.

Results :
Analysis of the data produced three broad themes. These were: the person as an individual and their perceived changes to self esteem and image. The perception of their position in society and the impact this has on their willingness to re-engage, and the degree to which treatment can alter an individual's ability to resume former intimate relationships with family and partners.

Conclusion :
Patients' definitions of intimacy are multifaceted and related directly to the type of relationship that existed prior to treatment. The concerns and challenges faced by patients need to be addressed and support opportunities considered as part of the rehabilitation process. The presentation gives insight for healthcare professionals who are expected to provide effective emotional and therapeutic support for this patient group.

Abstract Submission – Sam Harding

Title: The impact of treatment for head and neck cancer on posttraumatic growth

Author/Affiliations: S. HARDING, T. MOSS, University of the West of England

Background:
Head and Neck Cancer (HNC) is a relatively uncommon disease but carries a high level of morbidity and mortality. So why would anyone find having such a disease a positive event? The adversity hypothesis of “what doesn’t kill you makes you stronger” suggests people can use adversity, trauma and setback to grow.

Aims:
Posttraumatic growth (PTG) has not been investigates in HNC or its relationship to Health Related Quality of Life (HRQoL).

Method:
Responses on the Silver Lining Questionnaire (SLQ), University of Washington Scale (UoW) and Short-Form 12 (SF12) were collected on 164 patients.

Results:
Comparative data on the SLQ and UoW indicates that the greater the disease threat to life the greater the PTG. Younger patients and those with lower pain or functional difficulties had higher levels of PTG. In relation to HRQoL the study data shows poorer Physical HRQoL and Mental HRQoL than an age matched normative population. Additionally the study group had significant poorer Mental HRQoL than normative cancer data. We suggest that some in HNC survivors PTG facilitates healthier coping.

Conclusion:
If we are able to predict the veracity of specific mechanisms to individual survivors we could enhance and promote resilience in this vulnerable group. Further research would aid in the identification of personality, social, and medical factors that may influence or predict correlations between coping mechanism and PTG. Understanding the specific triggers and differentiators will enable us to develop interventions which enhance and promote resilience in this vulnerable group.

Abstract Submission – David Laraway

Title: Quality of Life in Elderly Oral Cancer Patients

Author/Affiliations: Lakshmiah R, Laraway DC, Lowe D, Rogers SN

There is an ever increasing elderly population presenting with, and surviving, oral cancer. Treatment decision making is complex and is influenced in part by prognosis and expected health related quality of life (HRQOL) outcomes. The aim of this paper was to compare the HRQOL in patients by age to identify any HRQOL differences between the different age groups.

The HRQOL was measured by the University of Washington Head and Neck Quality of Life Scale (UWQOL) at a time closest to one year. Survival analysis was facilitated through data from the Office of National Statistics.

A consecutive series of 1091 patients treated curatively for oral squamous cell carcinoma at the Regional Maxillofacial Unit of Aintree University Hospital between 1992 and 2009 were included in the main analysis. UWQOL data for 638 was available from about 1 year post treatment. Older patients (65 years or more) reported better physical and emotional function notably in regard to appearance, speech, saliva (75 years and over), pain, shoulder, mood and anxiety.

In conclusion, elderly patients seem to cope and adjust well to treatment and this is reflected in their HRQOL outcome. Their treatment needs to reflect a decision made on an individual patient basis and should not be based on age alone.

Abstract Submission – Sarah Dodd & Rachel Glascott

Title: Mode of death in head and neck cancer: a prospective audit

Author/Affiliations: Dr S.L. Dodd, R.E. Glascott, Dr V.L. Keeley, Department of Palliative Medicine, Derby Hospitals NHS Foundation Trust, Uttoxeter Road, Derby DE22 3NE

Background and aims:
In patients with progressive, incurable head and neck disease, the site of the primary tumours and their proximity to large blood vessels and airways mean a greater risk of catastrophic haemorrhage and acute airway obstruction. This is an outcome feared by patients, their families and health professionals. This audit describes and quantifies mode and place of death for this group of patients, from the medical death certificate data and data collection forms designed by the team.

Design:
Prospective audit, data collection sheets completed by members of the Head and Neck MDT between July 2006 – July 2011.
Setting: Derby Burton Cancer Network, covering to a population of 800,000.
Study group: All patients with head and neck cancer known to the MDT who have died in a 5 year period, (n=241) at our Cancer Centre.

Results:
Over half of patients dying from head and neck cancer followed a “typical” cancer trajectory of gradual deterioration. A large proportion of those deteriorating rapidly died from a chest infection. 3.1% died from haemorrhage, 3.6% died from acute airway obstruction. Fewer patients with head and neck cancer die at home compared with those dying from other cancers, with more dying on an acute hospital ward.

Conclusion:
While a small but significant minority of patients die from catastrophic haemorrhage or acute airway obstruction the majority follow a “typical” cancer trajectory or have a chest infection. The place of death of patients with head and neck cancer may reflect the complexity of this condition.

Abstract Submission – Aileen Timmons

Title: Post-treatment supportive care needs in head and neck cancer: what about the caregivers?

Author/Affiliations: Aileen Timmons[1], R. Gooberman-Hill[2], E. O'Sullivan[3], P. Butow[4], L. Sharp[1]

[1]Research, National Cancer Registry Ireland, Cork, Ireland, [2]Department of Social Medicine, University of Bristol, Bristol, UK, [3]Oral surgery, Cork Dental School and Hospital, Cork, Ireland, [4]Medical Psychology Research Unit, University of Sydney, Sydney, NSW, Australia

Background:
Cancer survivors may experience significant morbidity resulting in ongoing needs for support post-treatment. Evidence from various healthcare systems suggest that these needs are not always adequately met by existing services, and that family members often step in to fill this gap.. Studies of other cancers suggest that the burden of providing support and care means that caregivers themselves may have significant support needs.

Aims:
As part of a qualitative study of post-treatment supportive care in head and neck cancer (HNC), we described: (1) the role of informal carers and (2) carers’ support needs.

Methods:
In-depth, semi-structured, interviews were conducted with health professionals involved in head and neck cancer care in Ireland (consultants, clinical nurse specialists, and allied health professionals). Interviewees were asked about survivors' support needs post-treatment, if needs were being met, any barriers to meeting needs, and additional supports/services needed. They were also invited to discuss any other issues relating to post-treatment care which they considered important. The interviews were analysed using a content analysis approach.

Results:
31 health professionals were interviewed. Health care professionals reported that much of the support for HNC patients/survivors is provided by family members in the community. Family members are the main providers of psychological support. They also often have to help with medical care (e.g. dealing with feeding tubes). Informal carers of HNC survivors can themselves experience significant unmet support needs in a number of areas including: medical, psychological, information, social and financial. Health care professionals considered that there may even be greater unmet needs for support among family caregivers than among patients/survivors of HNC. Health professionals made some suggestions about how to better support informal carers.

Conclusions:
Given the health services’ reliance on the informal support/care provided by family/friends, these findings suggest HNC services should provide more supportive services for carers.

Regional Centre for Maxillofacial Surgery
UNIVERSITY HOSPITAL AINTREE
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Where quality matters

Pre-Conference Workshop

8th Head and Neck Quality of life Conference
8th and 9th November 2012

The Patient Concerns Inventory (PCI)

Wednesday November 7th 2012 Afternoon

Clinical Science's Centre, University Hospital Aintree, Liverpool L9 7AL

Workshop Timetable

13.00:	Introductions and refreshments
13.15	*Assessment and Care planning* *Noeline Young*
	The pilot e-HNA project and next steps *Amanda Watson*
14.00:	Our experience following the introduction of the PCI-H&N *Barry Scott*
14:45:	Further evaluation of the PCI across H&N clinics *Naseem Ghazali*
15.30:	Afternoon tea and demonstration of PCI-H&N
16:00:	The Dundee Perspective of using and developing the PCI-H&N *Mary Wells*
16:45:	Taking the PCI-H&N forward- group discussion *Simon Rogers*
17.30:	*Depart for refreshments*

http://www.patient-concerns-inventory.co.uk/PCI/Home.html

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