



Regional Centre for Maxillofacial Surgery
UNIVERSITY HOSPITAL AINTREE
Liverpool



Getting it right
for every patient
every time

10th International Quality of Life Conference Liverpool



Liverpool Medical Institute, Liverpool

Thursday 10th
& Friday 11th
November 2016

Course Organiser: Professor Simon Rogers

PROGRAMME 2016

CPD 12.25 hours

Contact person:
Rachel Wilson
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Professor SN Rogers

EPRC

Edge Hill University

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Thursday 10th
November
Morning

QOL in H&N Cancer: 10th International Conference

Chair: Professor Simon Rogers

- 08.30 Refreshments**
- 09:00** Introduction and summary: Professor Rogers
- 09:05 Keynote Speaker: Dr Catherine Oakley**
'National Chemotherapy Board Good Practice Guideline: Promoting Early Identification of Systemic Anti-Cancer Therapies Side Effects: Two Approaches. '
- 10.00** Mid Yorkshire's Macmillan Head and Neck Team: Delivering holistic, multidisciplinary, patient-centred care and service redesign including Cancer Follow up,
Ross L, Chadwick H, Corfield N, George C
- 10:15** Can swallowing therapy be combined with psychological therapy to improve dysphagia outcomes following head and neck cancer treatment? A feasibility study
Patterson J, McColl E., Wilson JA, Deary V.
- 10:30 Discussion**
- 10.40 Refreshments**
- 11:10** Redesign of a surgical head and neck cancer follow-up clinic using touchscreen technology to focus the post-treatment consultation
Semple CJ, Lannon DA, Qudairat E, McCormac R & McCaughan E.
- 11.25** Longitudinal assessment of Brazilian head and neck cancer patients concerns and relationship between expectations fulfillment and quality of life.
Jungerman I, Toyota J, Damascena A, Vartanian JG, Kowalski LP,
- 11.40** The impact of holistic needs assessment in outpatient cancer care: preliminary findings
Young J, Snowden A, McMahon J, Schipani S
- 11.55** Sexuality in Head and Neck cancer patients- Addressing the issues
Hoole J, Kanatas A, Mitchell DA
- 12.10 Discussion**
- 12.30 Lunch**

Thursday 10th
November
AFTERNOON

QOL in H&N Cancer: 10th International Conference

Chair: Dr Cherith Semple

- 13.30** **Keynote speaker: Professor Barbara Murphy**
- 14.20** **Discussion**
- 14.30** An Exploration through Interview & Drawings of the Experiences of Patients diagnosed with Oral Cancer across their Cancer Trajectory
Noonan, B
- 14.45** Does early feeding via a prophylactic gastrostomy improve quality of life in patients with head and neck mucosal SCC (HNSCC)?
Brown T, Banks,M, Brett G, Hughes M, Lin C, Kenny LM, Bauer J.
- 15.00** Randomised Pilot Study of Therabite versus Wooden spatula in the Amelioration of Trismus in Head and Neck Cancer Patients
Lee R, Rogers SN, Caress AL, Molassiotis A, Edwards R, Ryder D, Sanghera P, Lunt C, Yeo T, Slevin N.
- 15.15** **Afternoon Tea**
- 15.45** **Posters blog.-** 7 posters 3 minutes each and discussion
- 16.15** “Head and Neck 5000 – now and the future “- **Professor Steve Thomas**
- 16.30** “You save my life, I live it: QOL flux in HNC patients”- **Ros Dowse**
- 16.45** **Patient Conference Update-** Chris Curtis
- 17.00** **Discussion**
- 17.30** **Depart to Philharmonic Dining Rooms**

Conference Dinner at 19.30 at Everyman Theatre- 19.00- drinks

Patient Concerns Inventory RCT Steering Group Meeting 17.00 to 18.00

Friday 11th
November

Morning

QOL in H&N Cancer: 10th International Conference

Chair: Mr Anastasios Kanatas

- 08.30 Refreshments**
- 09:00 Keynote Speaker: Prof David Conway**
'Social inequalities across the head and neck cancer continuum'
- 09.50 Discussion**
- 10.00** 'Meaning of work and the process of returning after Head and Neck Cancer'
Tiblom Ehrsson Y, Isaksson j, Wilms T, Laurell G, Fransson P
- 10.15** 'Does disease stage and treatment complexity affect expressing fear of recurrence in head and neck cancer patients?'
Meyerhoff TJ, Humphries GM, Yuefang Z, Rogers SN
- 10:30 Discussion**
- 10.40 Refreshments**
- 11:10** 'Communication and quality of life' - Prof Gerald Humphris
- 11.40 Discussion**
- 11.45** 'Relationships between Self-management and Quality of Life in Post-Primary Treatment Head and Neck Cancer Survivors.'
Cullen C, Coffey L, Dunne S, O'Connor J, Desmond D, Sharp L, Timmons A, O'Sullivan E, Keogh I, Sheahan P, Timon C, Gallagher P
- 12.00** 'The psychosocial impact of a diagnosis of HPV-related head and neck cancer on patients and their partners.'
Dodd R, Marlow L, Forster A, Waller, J
- 12.15** 'How men with HNC experience appearance and functional change in the first 12 months following diagnosis'.
Rennie C
- 12.30 Lunch**

Friday 11th
November
Afternoon

QOL in H&N Cancer: 10th International Conference

Chair: Prof Gerry Humphris

- 13.30** 'Activity that creates experiences of flow for persons suffering of head and neck cancer'
Björklund M
- 13.45** 'The role of occupational therapy in Head and Neck Cancer rehabilitation'
Schuitemaker E , Rijpkema C, Passchier E, van den Brekel MWM, Martin Klop W, Stuiver MM
- 14.00** 'Does socioeconomic status influence doctor-patient communication in head and neck oncology clinics'
Allen S, Rogers SN, Harris RV, Brown S, Humphris G, Zhou Y.
- 14.15** 'Wilson Evaluation of a MDT facilitated Psychosocial Group for Head and Neck Cancer'
Wilson S, Raby L
- 14.30**
Discussion
- 14.40** 'Pre-operative counselling of patients undergoing total laryngectomy surgery in Ireland; analysing three differing perspectives'
Fitzgerald E, Perry A
- 14.55** 'Head and neck cancer survivors' experiences of self-managing their condition following primary treatment.'
Dunne S, Coffey L, Sharp L, Timmons A, Desmond D, Gooberman-Hill R, O'Sullivan E, Keogh I, Timon C, Gallagher P
- 15.10** 'Assessing the validity of EQ-5D-5L in for people with Head & Neck Cancer'
Davies, A, Waylen A, Thomas S, Leary S, Ness A
- 15.25** 'Discharge from hospital on the laryngectomy enhanced recovery pathway: A patient experience study'
White A
- 15.40**
Discussion
- 15.50**
Reflections- Simon N Rogers
- 16.00**
Afternoon Tea and break out groups
- 17.00**
Depart

QOL in H&N Cancer: 10th International Conference

Welcome

Well, everybody hurts sometimes

Everybody cries

Everybody hurts

Take comfort in your friends

No, no, no, you are not alone

R.E.M

Michael Stipe has mentioned in interviews that “Everybody Hurts” was meant to be a genuine message to the band’s teenage fans that, no matter how bad your life may seem, to please keep hoping for a brighter day.

Welcome to the 10th Head and Neck Quality of Life conference. How time has flown by since the first one in 1999. The format has remained much the same. The conference has been planned with four components in mind reflect the health related quality of life construct; i. overview, ii. function iii. psychological, iv. social/patient interaction. Each year the Faculty has been amazing but a special mention to Cherith Semple, Gerry Humphris and Tas Kanatas. Over the years we have some incredible keynote speakers, and just to mention a few; Kristin Bjordal, Bevan Yueh, Irma Verdonck-de Leeuw, Gerry Funk, Douglas Chepeha, Marcy List, Bill Lydiatt, Paul Allison, Pat Bradley, John Ellershaw, Galina Velikova, Vin Paleri, Elspeth Desert, Sheila Fisher, Mary Wells, Hisham Mehanna, Chris Nutting, Rob deLeeuw, Joanne Patterson, Derek C Stewart (OBE), Jamie Rae. This year we are really fortunate to have Catherine Oakley, Barbara Murphy, David Conway and Ros Dowse. Such an illustrious list is also joined by the many national and international delegates who have presented on a varied array of challenging and informative topics at each of the conferences.

It has been a journey. In 1999 we explored the issue of ‘what is quality of life’. In 2001, we considered the types of questionnaires available. At the 2002 meeting we looked at predictors of health-related quality of life. In 2004 we explored organ preservation and function, and psychological distress. In 2006 we focused on how to use ‘quality of life’ outcomes to enhance clinical practice and patient and carer support. At the 2008 meeting we looked at information based on HRQOL and brought in more formally the patient and carer focal point on Friday afternoon. At the 7th conference in 2010, we considered patient reported outcomes in practice and the 2012 meeting we addressed the consequences of head and neck cancer treatment in a patient focused and holistic model. At the last conference in 2014 we touched on clinical trials and interventions. This year the new aspect is the Patient and Carer Conference held in parallel on the Friday. As we plan our future meeting, we can think about how best to integrate the contributions from patient and professional. This really enhances our learning experience and also results in a more powerful drive to change clinical practice both in our own individual units but also nationally.

Please make the most of your time in Liverpool, at the meeting, at the social gatherings, and the city itself. Make the most of making new contacts and be inspired. The two days are going to be hectic and tiring but for most of us we will have the weekend to recharge the batteries before another week. If you don’t feel exhausted by the end of Friday you are superhuman!

Finally I wish to express my thanks to Rachel Wilson for all her hard work on top of the day job to make the conference happen. During the conference please do not hesitate to let us know if there are any problems, however trivial, and we will do our best to address them.

Chairpersons

Thursday Morning

Simon Rogers

Simon is getting ever closer to retirement. Simon qualified from Sheffield University Dental School 32 years ago. He became a Fellow of the Dental Faculty of the Royal College of Surgeons England in 1988 and qualified with honours from Birmingham University Medical School in 1990. In 1994 he passed his general surgical fellowship from the Royal College of Surgeons England and in 1997 won the gold medal in the Intercollegiate Oral and Maxillofacial exit examination. In 2000 he 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. In November 2006 he joined Edge Hill University, Faculty of Health and has a Chair in the Evidence based Practice Research Centre. In 2009 he gave the Nunn Lecture at the annual scientific meeting of the British Association of Head and Neck Oncologists.

In January 1999 Simon was appointed Consultant Maxillofacial Surgeon at Aintree University Hospital with special interest in oncology and reconstruction. He has been Clinical Director of the Regional Oral and Maxillofacial Unit, and more recently has been the Clinical Head of the Business Unit for Breast, Dermatology, ENT, Ophthalmology and Maxillofacial.

He has published widely on the subject of patient reported outcome and quality of life. His current focus of clinical innovation and outcomes research is the Patient Concerns Inventory.

Simon has been extremely fortunate to work with some most exceptional individuals. These collaborations have not only been exciting, enjoyable and truly humbling, but perhaps they have made a difference in how we care for patients and their families. There is still much work to do of course.

Websites

1. Patient Concerns Inventory
<http://www.patient-concerns-inventory.co.uk/PCI/Home.html>
2. What will I be like
<http://www.headandneckcancer.co.uk/For+patients/What+will+I+be+like>
3. Handle on QOL
<http://www.handle-on-qol.com>
4. Faculty of Health and Social Care, Edge Hill University
<http://www.edgehill.ac.uk/profiles/simon-rogers>

Chairpersons continued

Thursday Afternoon

Dr Cherith Semple

Macmillan Clinical Nurse Specialist

Cherith Semple completed her BSc (Hons) Nursing at the University of Ulster (Northern Ireland) in 1995. Having worked as a staff nurse at the Regional Plastic and Maxillofacial Unit in Ulster Hospital (Northern Ireland) she was appointed the Macmillan Clinical Nurse Specialist in Head and Neck Cancer in 1999. She completed her PhD in 2006 which explored the post-treatment needs of patients with head and neck cancer and development of a psychosocial intervention. She has published 13 peer reviewed papers, two Cochrane reviews; one entitled 'Effectiveness of psychosocial intervention for patients with head and neck cancer' and co-authored two book chapters. Her research interests include 'the impact of parental cancer when you have young children' and grant funding has been secured to provide training for oncology professionals' to increase their awareness of the potential challenges for families when a parent has cancer and implementation of a psychosocial intervention for children (aged 5 -12) whose parent has cancer in five acute oncology settings in Northern Ireland.

Friday Morning

Mr Anastasios Kanatas

BSc (Hons), BDS, MBChB (Hons), MFDSRCS, MRCSRCS, FRCS (Max Fac), PhD, MD, PGC

Anastasios is an Oral and Maxillofacial Surgeon with special interests in Head and Neck Oncology, reconstruction and clinical education. He received his training in the UK (Liverpool and Leeds), USA, Germany and France. He is the author of 110 publications in international peer-reviewed journals, book chapters and is working in collaboration with research groups in the UK, Germany, Austria and the USA. He is a Section Editor of the British Journal of Oral and Maxillofacial Surgery and the Associate Editor of the Journal of Solid Tumours. In addition, he is a member of the Faculty of the Patient Concerns Inventory and QOL Workshops in Liverpool, and he is the Chairman of the Bochum Flap / Microvascular Course in Germany.

Chairpersons continued

Friday Afternoon

Professor Gerry Humphris

The University of St Andrews

Gerry Humphris studied Psychology at Reading University (1973-76) before going to Guy's Hospital to complete a PhD (1983). He qualified in clinical psychology 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 long-term conditions. He has received notable EU funding for research projects with DG Justice, European Commission (e.g. ORION Project lead). His current interest is the development and dissemination of new complex psychological interventions. He holds an Honorary Consultant Clinical Psychology contract with NHS Lothian in the Edinburgh Cancer Centre, Western General Hospital, Scotland. He is a member of the Verona Network on Sequence Analysis (European Association of Communication in Healthcare-EACH). He is currently the Chair of the Research Committee for EACH. He is Co-Director of the WHO Collaborating Centre for International Child and Adolescent Health Policy at St Andrews Medical School.

QOL in H&N Cancer: 1th International Conference – Meet the Keynote Speakers

Keynote Speakers

Catherine Oakley- Chemotherapy Nurse Consultant

I have worked in cancer care for over 20 years. I am currently the chemotherapy nurse consultant at GSTT. I have particular knowledge about chemotherapy services, home support, symptom reporting and oral chemotherapy. I was awarded (with my colleague, Jo Johnson) the 2008 European Oncology Nursing Society prize for excellence in patient education materials and the 2009 Nursing Standard award for best practice in medication administration for our work developing a patient oral chemotherapy diary. This diary appears to improve patient confidence in reporting chemotherapy symptoms and taking chemotherapy tablets correctly. I have collaborated with my pharmacy colleagues to establish nursing and pharmacist led chemotherapy clinics that include non-medical prescribing. I represented cancer nurses and AHP's on the Cancer Taskforce. I am the current President of the UK Oncology Nursing Society (UKONS) and led on the development of the UKONS position statement on oral chemotherapy. I recently completed and was awarded two prizes for my PhD that explored how the risks of neutropenic sepsis are conveyed to patients. An output from my PhD has been local pre-treatment consultation communications skills training for chemotherapy nurses. The impact of the training appears to be reflected in the 2015 National Cancer Patient Survey which shows high patient satisfaction for possible side effects explained in an understandable way. My PhD also informed the 2016 National Chemotherapy Board good practice guideline for promoting early identification of chemotherapy side effects.

In terms of my professional background, I qualified as a Registered General Nurse in 1987 at St George's Hospital (SGH) in London and continued working there on a medical and surgical oncology ward. I underwent cancer nurse training at the Royal Marsden hospital and returned to SGH in 1993 to work as a chemotherapy clinical nurse specialist, where I set up one of the first home chemotherapy services in the UK. In 1999 I worked at the Princess Royal University Hospital in Kent as the Lead Nurse and Manager for Cancer Services. I returned to SGH in 2003 where I took up the Macmillan Lead Cancer Nurse position and more laterally the General Manager post for Oncology, Haematology and Palliative Care. In 2008 I took up my current post as the Chemotherapy Nurse Consultant at Guys and St Thomas' NHS Foundation Trust. My academic qualifications include: an NIHR funded doctorate (Philosophy in Nursing Research); Advanced Communication Skills; Non Medical Prescribing; Advanced Assessment Skills; PIS 313 Clinical Application & Management of Cancer Chemotherapy and ENB A11 Breast Care Nursing.

Keynote Speakers continued

Professor Barbara Murphy- MD Professor of Medicine in the Division of Haematology/ Oncology

Dr. Murphy serves as the Leader of the Head and Neck Research Team and the Director of the Pain and Symptom Management Program (PSMP) at the Vanderbilt Ingram Cancer Center. The dual role allows her to pursue her personal area of research interest: the early and late sequella of treatment for head and neck cancer patients. Dr. Murphy chairs the PSMP Research Team, a multi-disciplinary group of investigators representing numerous schools, divisions and departments within Vanderbilt University Medical Centre. In addition she serves as the Clinical Leader for the Head and Neck Team. Dr. Murphy has extensive experience in the development, implementation and management of clinical trials, supportive care studies and grants. She has a significant body of work representing investigator initiate trials. Through the collaborative effort of team members, the following issues in head and neck cancer patients are currently being investigated: 1) measurement of symptom burden associated with cancer therapy, 2) swallowing, nutritional and metabolic changes in head and neck cancer patients undergoing chemoradiation, 3) neuropsychiatric issues associated with treatment, 4) lymphedema and fibrosis: measurement and impact, 5) musculoskeletal impairment: impact on function, 6) oral complications of radiation therapy, 7) caregiver burden and 8) body image issues. Dr Murphy's second area of interest is systems approaches to improving pain control.

Professor David Conway - Professor of Dental Public Health / Honorary Consultant in Dental Public Health University of Glasgow Dental School / NHS National Services Scotland.

David graduated from University of Glasgow BDS in 1996. Following brief periods in general dental practice, hospital dentistry in Bristol and Edinburgh, and SHO posts in oral and maxillofacial surgery at St John's in Livingston, he attained FDS RCS (England) in 1999. He returned to Glasgow in 2000 for a clinical lectureship in dental public health combined with a specialist registrar training post based in NHS Lanarkshire and NHS Argyll and Clyde Health Boards. He completed the MPH at University of Glasgow in 2002 and attained the certificate of completion of specialist training in dental public health in 2005 (FDS DPH RCS, and FFPH). He was awarded a PhD in 2008 for research on the epidemiology of oral cancer from a socioeconomic perspective.

In 2015 David was appointed Professor of Dental Public Health at the University of Glasgow. Since 2005 David has held the position of Honorary Consultant in Dental Public Health with NHS National Services Scotland Information Services Division where he is the dental clinical lead and research strategy lead.

David's main research interests are in socioeconomic inequalities in health and oral health, cancer epidemiology, big data and data-linkage of administrative databases, health improvement programme development and evaluation, and systematic reviews / meta-analysis. He is the lead of the head and neck cancer epidemiology research theme in Glasgow Dental School, and has over 50 peer-reviewed publications in this area. The main focus of this research is in relation to socioeconomic inequalities and increasingly oral HPV - spanning the head and neck cancer continuum from investigating burden and risk, to screening and prevention, and to clinical outcomes and survival.

Abstracts: Thursday 10th November, Morning Session

MidYorkshire's Macmillan Head and Neck Team: Delivering holistic, multidisciplinary, patient-centred care and service redesign including Cancer Follow up

Ross, L; Chadwick, H; Corfield, N & George, C.

The MYHT Macmillan Head and Neck Team have redesigned their care pathway to provide consistent, holistic management of patients along their journey through the cancer care pathway. Project funding of £480,000 from Macmillan; the support of consultant colleagues; the determination and dedication of the clinical nurse specialists (CNS) and allied health professionals (AHP) involved and five years of perseverance have each contributed to this achievement. The processes and outcomes are now available to inform others to emulate this model which meets IOG; NCSI and NICE recommendations/guidance for standards of care, whilst being responsive to the changing climate of current delivery of healthcare.

The project brought together a CNS/AHP team comprising a CNS project lead and team manager; two further CNSs, all three being non-medical prescribers; a dietitian and a speech therapist, both whole time equivalent posts dedicated to and managed within H&N; an alcohol and wellbeing CNS, managed within a partnered community enterprise and a benefits advisor. Dependent on individual needs, all H&N patients now have access to the personnel required in a timely manner, improving experience and outcomes.

The highly specialised nature of this Head and Neck team has enabled redesign of this service even further:- extended CNS/AHP roles to provide the cancer follow-up of a risk stratified subgroup of H&N patients, namely those with oropharynx squamous cell carcinomas, one year post-completion of treatment; laryngectomees, upon completion of treatment and potentially oral cavity cancers.

Following revision of anatomy and physiology and successful completion of flexible endoscopy training, consultant approved competencies were devised. Various logistical difficulties resulted in a protracted timeframe, but all team members, having started the venture in October 2012, achieved these by February 2014. CNS/AHP cancer follow up clinics were then commenced, alongside the existing consultant clinic. Consultant review of assessment for the first year demonstrated competence and safety of all team members (n=126 (35 patients)) and a second year of independent, peer-assessed clinics (n=214 (50 patients)) have now been delivered. Audit also demonstrated that during both years any recurrences were successfully detected and appropriate investigations requested to rule out others. The service redesign is now established clinical practice and plans are being made to resume oral cavity cancer follow-ups.

Abstracts: Thursday 10th November, Morning Session

Can swallowing therapy be combined with psychological therapy to improve dysphagia outcomes following head and neck cancer treatment? A feasibility study

Patterson J, McColl E., Wilson JA., Deary V.

Background

Head and neck cancer (HNC) dysphagia is strongly associated with psychological distress, social isolation and a poorer quality of life. Patients with anxiety and/or depression can be difficult to engage and retain in swallowing rehabilitation. Research has largely focused on remediation of dysphagia through exercises, manoeuvres and dietary modification.

Aim

To explore the feasibility of an intervention which simultaneously uses a psychological therapy approach combined with evidence-based swallowing rehabilitation.

Methods

This is a prospective single cohort mixed-methods study, recruiting post-treatment HNC patients with dysphagia, from two institutions in NE England. The intervention combined Cognitive Behavioural Therapy with swallowing therapy (CB-EST), was individually tailored and delivered by a SLT. Feasibility measures included recruitment and retention rates. The primary outcome measure was a swallowing questionnaire (MDADI), recorded pre-, post-CB-EST with a three month follow-up. Secondary measures included feeding tube use, diet scores and questionnaires. An independent researcher conducted interviews to explore patients' experiences of CB-EST.

Results

A total of 30/43 (70%) eligible patients agreed to participate. The main reason for non-participation was difficulty with regular attendance. Five participants dropped out during the study. 84% of the sample were male, mean age 59yrs. Patients were between 1-60 months (median 4) post-cancer treatment. All participants had advanced stage disease, treated with surgery and radiotherapy (38%) or primary chemoradiotherapy (62%). Number of CB-EST sessions ranged from 2-10. Preliminary analysis found mean MDADI scores increased from pre-CB-EST 54.6 (S.D.14.9) to 61.6 (S.D.14.9)($p=0.015$) post-CB-EST. Feeding tube dependence reduced from 56% to 12% post-CB-EST. Additional data on diet, questionnaires and interviews will be presented.

Clinical implications

CB-EST is a novel, feasible treatment, addressing the emotional, behavioural and cognitive components of dysphagia alongside physical impairment. This is a complex, individualised intervention, taking a broader perspective to dysphagia rehabilitation. Further research is required to evaluate efficacy and effectiveness.

Abstracts: Thursday 10th November, Morning Session

Redesign of a surgical head and neck cancer follow-up clinic using touchscreen technology to focus the post-treatment consultation

Semple CJ, Lannon DA, Qudairat E, McCormac R & McCaughan E.

Southern Eastern Health & Social Care Trust & Ulster University, NI.

ABSTRACT

Background

The efficacy of traditional oncology follow-up care is being challenged, as cancer survivors supportive and psychological care needs are often neither identified, nor addressed.

Methods

A surgical follow-up clinic for oral and oropharyngeal cancer patients was redesigned, were participants completed a disease-specific HRQOL tool (UWQOLv4) and holistic prompt list (PCI) on a touchscreen computer (iPad). This information was used to focus the consultation. Patients were also educated on signs and symptoms of recurrence.

Using a prospective non-randomized, pre-test posttest design, this new model of follow-up was evaluated to ascertain if more topics/issues were discussed during the consultation and whether patient enablement was improved. Feasibility was explored from a patients' perspective (satisfaction survey) and clinicians' perspective (qualitative interview).

Results

Forty-four consecutive patients were recruited. Findings demonstrating that four of the eight topics (overall QOL, emotions, side-effects of treatment, chronic non-specific) on the Patient Content Checklist were discussed more frequently, but these changes were not statistically significant. The Patient Enablement Index (PEI) highlighted a trend towards perceived improvement on three items, with 'able to help yourself' reaching statistical significance (t-score -2.074, p=0.44). Using a touchscreen computer to aid communication during routine follow-up was reported as both feasible and beneficial from the clinician's and patient's perspective.

Conclusion

Post-treatment follow-up should move beyond merely focusing on recurrence detection. Enabling a patient-focused consultation can facilitate the capture of unmet needs, permitting timely and appropriate intervention being initiated.

Abstracts: Thursday 10th November, Morning Session

Longitudinal assessment of Brazilian head and neck cancer patients concerns and relationship between expectations fulfilment and quality of life.

Ivy Jungerman¹; Julia Toyota²; Aline Damascena³; José G. Vartanian²; Luiz P. Kowalski²

¹ University of Sao Paulo, Department of Radiology and Oncology

² AC Camargo Cancer Center, Head and Neck Surgery and Otorhinolaryngology Department

³ AC Camargo Cancer Center, Bioinformatics and Biostatistics Department

Background:

The impact of cancer diagnosis and the consequences of the treatment have a major impact on the quality of life of these patients.

Aims:

Characterize, at pre-treatment and 6 and 12 months after diagnosis, the patients concerns, their expectations (pre-treatment), the extent to which expectations were met (post-treatment) and to determine associations between the extent to which expectations were met and quality of life.

Methods:

Prospective, longitudinal study. All participants completed the validated Portuguese version of the Patient Concerns Inventory (PCI-H&N), the University of Washington Quality of Life Questionnaire (UW-QOL), the Expectations Assessment Protocol (at pre-treatment) and the Meeting Expectations Protocol (at 6 and 12 months post-treatment).

Results:

The samples comprised 104 patients (pre-treatment), 80 patients (6 months) and 62 patients (12 months), respectively. The main patient concerns and professionals selected were: chewing/eating, cancer treatment, speech/voice/being understood, swallowing; speech-therapist, nutritionist and oncologist/radiotherapist. In general, patient expectations at pre-treatment were good. Patient expectations for food-related items - chewing/eating, dry mouth, swallowing, taste and weight loss - were the least met after treatment. A number of significant associations were found between global quality of life of patients and extent to which various expectations were met at 6 and 12 months after diagnosis.

Conclusions:

The Patient Concerns Inventory was shown to be appropriate and psychometrically valid for use in Brazilian head and neck cancer patients at all stages of treatment. During one year after diagnosis, these patients tended to have predominantly physical/functional concerns, associated with fear of disease recurrence and prioritized contact with the physicians responsible for treatment and rehabilitation of treatment sequelae, had general expectations met (except food-related aspects), and the extent to which expectations were met impacted global quality of life. Patients concerns and expectations should be properly and constantly addressed by the clinicians, improving their quality of life.

Abstracts: Thursday 10th November, Morning Session

The impact of holistic needs assessment in outpatient cancer care: preliminary findings

Jenny Young, Austyn Snowden, Jeremy McMahon, Stefano Schipani

Background

Holistic needs assessment (HNA) entails a structured discussion of needs identified by the patient. HNA should facilitate more patient involvement within the consultation and this in turn should facilitate shared decision-making, resulting in improved self-efficacy.

Aims

This study explores how:

HNA affects the type of conversation that goes on during a clinical consultation, and
How these changes impact on shared decision-making and self-efficacy.

Methods

Patients had completed treatment and were attending their first follow up appointment. They were randomised to use HNA within their consultations or receive a routine consultation. All consultations were audio-recorded and analysed using MEDICODE, a method of breaking down elements of conversation according to whether it consists of monologue, dyad, or dialogue. Post-consultation the participant completed the Lorig self-efficacy scale and CollaboRATE (a measure of shared decision making).

Results

61 participants attended head and neck and seven a colorectal outpatient clinic. 33 were randomised to the experimental group, 35 to control. Mean (sd) age was 60 (12) years. 24 were female, 44 male. An average of 7 concerns was discussed per person per consultation, with 89% of these relating to physical issues. Average percentage of monologue was higher in control group (con= 65%: exp =38%) whereas dialogue was higher in experimental group (exp= 31%: con 19%). There were no significant differences in CollaboRATE (exp = 25.95: con = 25.15) scores. Lorig scores were significantly higher in experimental group (exp=8.3; con= 7.4 (p=0.045).

Clinical Implications

Although preliminary, results suggest that the HNA process facilitates more discussion between the clinician and patient. Having concerns addressed and supported in this manner appears to be associated with an increase in self-efficacy, which can be associated with a greater likelihood of self-management.

Abstracts: Thursday 10th November, Morning Session

Sexuality in Head and Neck cancer patients- Addressing the issues

J Hoole, A Kanatas and DA Mitchell

Abstract

Head and neck cancer shares features with chronic disease. Advances in its management resulted in improved survival. Although clinical teams are now much better in collecting quality of life data, the problems with intimacy and sex are often overlooked. The aim of our work was the development of an intimacy checklist that may be used and integrated into existing quality of life assessments in order to identify unmet needs and improve care.

Method

Item generation of head and neck specific intimacy related items - from the perspective of the literature, clinical specialists and patients. Six focus group discussions and semi-structured interviews with clinicians.

Results

After evaluating 2563 papers, we identified 20 that satisfied our inclusion criteria (English language instruments developed for patients with cancer). From the literature review we identified 227 potential items that were included in these 20 papers. Following a detailed process of refinement and exclusion of irrelevant items a preliminary checklist was produced that included a male and a female section and with a list of common items. Following the input from the focus groups (64 patients) and clinical specialists (20), the development of a preliminary checklist has been completed.

Conclusions

Following the development of this preliminary tool, refinement and validation will be the subsequent steps. A cross sectional survey of head and neck patients will gain an indication of relative frequency of individual items and compare clinical characteristics with the tool's items such as age, stage, treatment, time since treatment, and an established Head and Neck health related quality of life (HRQOL) measure.

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Abstracts: Thursday 10th November, Afternoon Session

Title: An Exploration through Interview & Drawings of the Experiences of Patients diagnosed with Oral Cancer across their Cancer Trajectory

Noonan B. O'Mahony, M. Hegarty, J. University College Cork, Cork, Ireland

Background:

The treatment of oral cancer is complex and lengthy. Curative treatment implies a combination of surgery, radiotherapy and chemotherapy. The main goal of treatment is to guarantee long-term tumour free survival with as little functional and cosmetic damage. Despite progress in developing these strategies, cancers of the oral cavity continue to have high mortality rates that have not improved dramatically over the past ten years.

Aim:

The aim of this study was to uniquely explore the dynamic changes in the physical, psychological, social and existential experiences of newly diagnosed patients with oral cancer at two points across their cancer illness trajectory i.e. at the time of diagnosis and at the end of treatment.

Methodology:

A qualitative prospective longitudinal design was employed. Non-probability purposive sampling allowed the recruitment of 15 participants. The principal data collection method used was a digital audio taped semi-structured interview along with drawings produced by the participants.

Analysis:

Data was analysed using latent content analyses.

Summary:

Three 'dynamic' themes, physical, psychosocial and existential experiences were revealed that interact and influence each other in a complex and compound whole. These experiences are present at different degrees and throughout the entire trajectory of care. Patients have a number of specific concerns and challenges that cannot be compartmentalised into unitary or discrete aspects of their daily lives.

Conclusion & Implications:

An understanding of the patient's experience of their illness at all stages of the disease trajectory, is essential to inform service providers' decision making if the delivery of care is to be client centred. Dynamic and fluctuating changes in the patient's personal experience of the cancer journey require dynamic, energetic and timely input from health care professionals.

Abstracts: Thursday 10th November, Afternoon Session

Does early feeding via a prophylactic gastrostomy improve quality of life in patients with head and neck mucosal SCC (HNSCC)?

Teresa Brown^{1,2}, Merrilyn Banks², Brett G. M. Hughes^{3,4}, Charles Lin^{3,4}, Lizbeth Moira Kenny^{3,4}, Judith D. Bauer¹

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Background

Patients with HNSCC are at high risk of malnutrition and weight loss which is associated with reduced quality of life. Enteral tube feeding is often required, however even with prophylactic gastrostomy placement significant weight loss still occurs.

Aim

The aim of this study was to improve nutrition outcomes utilising an early feeding approach via the prophylactic gastrostomy and thus improve quality of life.

Patients and Methods

Patients with HNSCC were eligible if identified for prophylactic gastrostomy prior to treatment and randomly allocated to the intervention (n=61) or usual care (n=70). The intervention recommended gastrostomy feeding immediately post placement to supplement oral intake. Usual care commenced gastrostomy feeding when clinically indicated. Key outcome measures were percentage weight loss and quality of life (EORTC-QLQ30 and EORTC-HN35) at three months post treatment.

Results

Patients were predominantly male (88%), mean age 60±10.1, with oropharyngeal tumours (76%), receiving chemoradiotherapy (82%). Adherence to the early intervention was poor (51%). There were no significant baseline differences for demographics, clinical or nutritional status variables, but a reduced quality of life in the usual care group. Weight loss outcomes were no different in each group (10.9% usual vs 10.8% intervention, p=0.930). Following adjustment of baseline differences in quality of life no statistical differences were observed for functional or symptom scales. The intervention group had a clinically important decline in social functioning (p=0.065). Both groups had clinically important deteriorations in; fatigue, appetite, senses, dry mouth, sticky saliva and social eating.

Clinical Implications

Symptoms impacting on quality of life persist post treatment and highlight the role of allied health support. There were no improvements in nutrition or quality of life measures following the early feeding approach. Poor adherence was explained by several clinical, environmental and psychosocial barriers which can be addressed to improve clinical practice, patient adherence and future outcomes.

Abstracts: Friday 11th November, Morning Session

Randomised Pilot Study of Therabite versus Wooden spatula in the Amelioration of Trismus in Head and Neck Cancer Patients

R. Lee, S.N. Rogers, A.L. Caress, A. Molassiotis, R. Edwards, D. Ryder, P. Sanghera, C. Lunt, T. Yeo, N. Slevin

Background

'Trismus' can be described as any restriction to mouth opening, including restrictions caused by cancer, surgery or radiation treatment. This restriction in mouth opening can cause serious functional impairment for the patient including eating problems, difficulty with speech and compromised oral hygiene.

Aims

To evaluate the feasibility of conducting a RCT comparing exercises using Therabite versus wooden spatulas (standard care) to prevent or relieve trismus in patients with stage 3 and 4 oral/oropharyngeal cancer.

Secondary Aims :

(i) assess whether Therabite or

Wooden Spatula intervention

improves patients' quality of life (QoL) using validated QoL questionnaires

(ii) whether intervention can reduce the level of post-treatment clinical management/health care utilisation required by mouth cancer patients.

Results

37 patients were randomised to receive the Therabite (T) device and 34 the wooden spatulas (WS) for jaw exercises. Mean post intervention mouth opening increased in both groups. After adjustment for baseline MO, centre, surgery and chemoradiation, the difference (T – WS) in average mouth opening at the '6 month' assessment was -2.43 with 95% CI (-8.15, 3.29). This is not a statistically significant difference ($p=0.39$). Acceptability of exercises' in both groups were comparable. Lessons learnt from the semi structured telephone interviews: Allow patients to have more of a say in the exercise regimen ie reduce to 3 times a day (from 5) and take a variable break of up to 6 weeks when side effects from RT are at their worst; this will aid compliance right through to end of study (which should be prolonged to 9 months post intervention).

Conclusions

Prophylactic exercises during and after radiotherapy treatment can ameliorate trismus for stage 3 and 4 oral, oropharyngeal cancers. Both interventions are acceptable. Allow patients to take a variable break (up to 6 weeks) from the exercises when side effects of radiotherapy are at their worst.

More regular contact with the patients for encouragement and support. Lessons learnt demonstrate the value of having a feasibility study.

Abstracts: Friday 11th November, Morning Session

Meaning of work and the process of returning after head and neck cancer

Authors : *Joakim Isaksson 1 & Torben Wilms 2, 3 & Göran Laurell 4 & Per Fransson 5 & Ylva Tiblom Ehrsson 4*

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Background

Approximately 90% of patients with head and neck cancer in Sweden are treated with a curative intention. The overall 5-year survival is 69%, and many of the long-term survivors are under 67 years of age.

Aim

To investigate employment status at diagnosis, sick-leave and returning to work patterns in correlation to quality of life, anxiety and depression in patients treated for head and neck cancer, and to explore patients' experiences of the process of returning to work.

Patients

Sixty-six.

Methods

Consecutive patients were repeatedly interviewed over a period of 24 months. Sixty-six of 135 eligible patients were at diagnosis working, unemployed or on temporary sick leave. The interviews were thematically structured and statement that concerned the patients' experiences and ideas about work were categorised using the similarities– differences technique. Questionnaires on quality of life, anxiety, and depression were used to describe the patient characteristics and the differences between groups.

Results

In total, 35 of the 66 patients (53%) had returned to work at 24 months after treatment, and 17% were deceased. Several quality of life parameters were significantly worse for patients not working at 24 months. Nine categories were found to describe the return-to-work process starting with symptoms causing sick leave, thoughts about the sick leave, and ending with the return to work and/or retirement.

Clinical implications

Returning to work is an important part of rehabilitation as it structures everyday life and strengthens the individual's identity. The patients need to be both physically and mentally prepared for the process of returning to work. It is important to take an individual rehabilitation approach to guide and support the patients in returning to work. In such an approach, it is vital to understand the patients' overall life context and the patients' own perspective on the process and meaning associated with work.

Abstracts: Friday 11th November, Morning Session

Does disease stage and treatment complexity affect expressing fear of recurrence in head and neck cancer patients?

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Aim:

Fear of cancer recurrence (FoR) is one of the most common problems faced by cancer survivors and their carers. This study aimed to explore the effect of cancer stage and treatment complexity on head and neck cancer patients' expression of FoR.

Methods:

25 consultations was audio-recorded from 25 early or late stage head and neck cancer survivors (16 men) and one clinician during routine follow-up consultations at Liverpool Aintree University Hospital. Audio data was coded for patients' expressions of emotional distress including FoR using the Verona Coding Definitions of Emotional Sequences (VR-CoDES). Independent samples t-tests were performed to assess the difference between the expressions of FoR in patients diagnosed with early or late stage cancer, as well as patients receiving various treatment regimens (i.e. one versus two or more treatment types).

Results:

Expressing FoR was not affected by disease severity, but by the complexity of treatment, as patients who received two or more types of treatment had less instances of FoR compared to patients who received only one treatment.

Discussion:

The findings highlighted the importance of clinicians demonstrating an awareness and understanding of the impact of treatment regimens on patient's anxiety towards cancer recurrence.

Key Words: *head and neck cancer, fear of recurrence, emotional distress, VR-CoDES*

Abstracts: Friday 11th November, Morning Session

Relationships between Self-management and Quality of Life in Post-Primary Treatment Head and Neck Cancer Survivors.

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Background/Aim:

Self-management is a key component of effective chronic illness care and improved patient outcomes. Research focusing on self-management among head and neck cancer (HNC) survivors, however, has been lacking. This study addresses that knowledge gap by investigating the role of specific self-management behaviours in predicting post-primary-treatment HNC survivors' health related quality of life (HRQL).

Patient/Methods:

Participants (N=395) recruited to participate in a national survey were HNC survivors, aged 18yrs+ at diagnosis and 1-5yrs post-primary treatment. Canonical-Correlation-Analysis (CCA) explored the relationships between self-management (using heiQ subscales - emotional distress, constructive-attitudes/approaches, skill/technique acquisition, positive/active engagement, social-integration/support, health directed activity, health service navigation and self-monitoring/insight) and health-related quality of life (using FACT-H&N subscales - social, emotional, physical, and functional-wellbeing and HNC specific symptoms).

Results: The CCA uncovered a large and significant relationship between self-management and HRQL. The full model was significant ($\Lambda = .76, p < .01$) and further yielded two significant dimensions. The first dimension represented 60.6% of overlapping variance between self-management and HRQL variables and the second dimension represented 28.9%. The first dimension indicated that lower emotional distress (.87) and higher constructive-attitudes/approaches (-.72), social-integration/support (-.59) and skill/technique acquisition (-.59) respectively, were associated with higher functional wellbeing (-.92), emotional wellbeing (-.85), and physical-wellbeing (-.81), and HNC specific symptoms (-.72). The second dimension indicated that higher social-integration/support (-.77) was associated with higher social wellbeing (-.83).

Clinical Implications: This is the first study to provide evidence of a relationship between self-management and HRQL among HNC survivors. It also demonstrates how specific dimensions of self-management and HRQL relate to each other following primary treatment for HNC. These findings point to the value of developing a targeted self-management intervention to improve the HRQL of this patient group.

Abstracts: Friday 11th November, Morning Session

The psychosocial impact of a diagnosis of HPV-related head and neck cancer on patients and their partners

Rachael Dodd, Laura Marlow, Alice Forster, Jo Waller

Background

It has long been recognised that a diagnosis of head and neck cancer (HNC) is associated with psychological distress. Human papillomavirus (HPV) has been well established as a causal factor for an increasing number of HNCs and may present additional psychological challenges due to the sexually transmitted nature of the virus.

Aim

Our aim was to explore the psychosocial impact of HPV-related HNC on patients and their partners.

Patients and methods

In-depth interviews were conducted with 20 patients with HPV-related HNC recruited from UK hospitals and a participatory advisory group, and 12 of their partners. Patient and partner interviews were conducted separately. Interviews were audio recorded and transcribed verbatim. Framework Analysis was used to generate themes that related to the psychological impact of the HPV-related diagnosis and make comparisons both within and between participants.

Results

Many psychological implications were associated with a diagnosis of HNC, many not directly related to HPV. Of the 20 patients, only 12 had been told their cancer was caused by HPV. Participants described being embarrassed and reluctant to disclose HPV as the cause of their cancer to others. Some messages conveyed by health professionals, such as how common HPV is, helped patients to become more comfortable disclosing HPV as the cause. The better prognosis related to HPV-related HNCs was reassuring information. Participants believed HPV as the cause of their cancer should be disclosed close to the time of diagnosis. Most participants sought further information about HPV and were concerned about whether they still had HPV, how long they had been carrying it and also whether their children are more at risk of HPV.

Clinical implications

Additional psychological implications are associated with HNC caused by HPV, for both patients and their partners. Communicating messages to normalise HPV and provide answers questions may help reduce the impact of this diagnosis.

Abstracts: Friday 11th November, Morning Session

How men with HNC experience appearance and functional change in first 12 months following diagnosis

Author: Caroline Rennie Macmillan Nurse Consultant, NHS Ayrshire & Arran

HNC incidence and mortality is greater in men and is associated with high risk behaviours and social deprivation. HNC is frequently diagnosed at advanced stages requiring multi-modality treatment which can have a significant impact on appearance and function. Gender can influence health behaviours yet research into male experiences of cancer has primarily focussed on prostate cancer and HNC is an area which is under investigated.

The aim of this study was to explore how men with HNC experience appearance and functional change in the first 12 months following diagnosis. Grounded theory methodology (GT) was chosen as the overall purpose of GT is the generation of theory from the data which has explanatory power and advances the understanding of social and psychological phenomena. Twelve retrospective semi-structured interviews were performed with men who were 12 to 24 months post-diagnosis. Key components of GT practice used were simultaneous data collection and analysis, constructing analytic categories from the data, constant comparison, memo-writing and theoretical sampling.

Four core categories emerged from the data which were inter-related: functioning; normalising change; 'under siege'; getting through treatment and reclaiming function. The core category was reconciling change; a new normal which reflects the social and psychological processes involved in accommodating and assimilating change in appearance and function for men with HNC. The substantive theory provides insight into how men with HNC prioritise function and actively distance themselves from concerns regarding appearance. Furthermore, it identifies men who are at risk of social anxiety and isolation due to multiple changes or body incompetence. This study builds on theories of masculinity, body image and disfigurement. The substantive theory developed provides health and social care professionals with new knowledge to support clinical practice and improve care provision.

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Abstracts: Friday 11th November, Afternoon Session

Activity that creates experiences of flow for persons suffering of head and neck cancer

Author/affiliations: Margereth Björklund, Department of Nursing, School of Health and Welfare, Jönköping University, Sweden

Background

The identification of positive outcomes when living with head and neck cancer could help the persons to maintain and regain health and wellbeing in everyday life. The flow theory of Csikszentmihalyi describes as an optimal experience associated with a deep involvement in an activity that gives experiences of pleasure, aliveness or vitality.

Aim:

To describe activities creating experiences of flow for persons suffering of head and neck cancer.

Patient and methods:

A deductive and descriptive design guided by the flow theory was used. Interviews of 40 persons suffering head and neck cancer were conducted and analyzed using qualitative content analysis.

Results:

The main theme that emerged was: Skills aimed on individual goals that contribute rapidly feedback from the activity. This main theme was divided in two categories: Intrinsic inspiration was on acting from inner self and something that occurred without any noticeable external input and Extrinsic inspiration referred to accomplish activities for having external rewards.

Clinical implications:

Positive reappraisal and individual tailored care for persons with head and neck cancer should be encouraged by focusing on activities creating experiences of flow and ways of pleasure and happiness. This could relieve the stress of having cancer and drawing attention away from symptoms and worry about illness and further facilitating confidence, control and psychological growth.

Abstracts: Friday 11th November, Afternoon Session

The role of occupational therapy in Head and Neck Cancer rehabilitation

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Background

A majority of head and neck cancer (HNC)-survivors experience impairments and disabilities after treatment affecting their health-related quality of life (HRQoL). At the Netherlands Cancer Institute, multidisciplinary HNC-specific rehabilitation (HNR) is offered to patients with rehabilitation needs.¹ Occupational therapy (OT) aims to improve activities of daily life (ADL). Studies on OT for cancer survivors are scarce, and ADL-problems that HNC-patients experience have not been systematically reported.

Aim

To explore the reasons for OT-consultation by HNC-patients and outcome of OT interventions, within the HNR-program.

Methods

In this observational study, we analyzed prospectively collected data of HNC-patients receiving OT between 2010 and 2015 as part of HNR. All subjects had routinely completed the Canadian Occupational Performance Measurement (COPM, score range 1-10, higher scores indicating better performance)² and the EORTC-QLQ-C30 HRQoL questionnaire³ during their HNR.

Results

Fifty HNC-patients were included (mean age 54, median time since diagnosis 29 weeks). The main reasons for OT consultation, in the Disability domain of the International Classification of Functioning, Disability and Health, were problems with recreation and leisure (n= 42), carrying out daily routine (n= 16), acquiring, keeping and terminating a job (n= 19), walking (n= 13), and driving (n= 13). In the Body functions domain, the most reported problems were related to sleep (n= 9).

After OT, patients reported significantly improved performance (mean change 3.3 points; 95%CI 2.8 - 3.8; p<.0001) and satisfaction (mean change 3.5 points; 95%CI 3.0 - 4.0; p<.0001). A clinically important change (>2.5 points) on the COPM was observed in 33 cases (66%). A clinically relevant, and statistically significant, improvement in global HRQoL was observed between start and end of HNR (mean change 22.27; 95%CI 15.34 – 29.19; p<.0001).

Clinical implications

For HNC-patients experiencing ADL problems, OT could provide a relevant contribution to rehabilitation.

Abstracts: Friday 11th November, Morning Session

Title: Does socioeconomic status influence doctor-patient communication in head and neck oncology clinics?

Authors: Allen, S., Rogers, S.N., Harris, R.V., Brown, S., Humphris, G. & Zhou, Y.

Background:

Previous studies suggest that doctor-patient communication differs depending upon the patient's socioeconomic status (SES), with low SES patients participating less actively and being less involved by healthcare professionals in consultations. This has been reported with a number of different patient groups, however it has not yet been studied with head and neck cancer patients.

Aim:

This study aimed to investigate how doctor-patient communication differed with head and neck cancer patients across the socioeconomic gradient.

Patients and methods:

110 head and neck review consultations were audiotaped as part of another study and analysed using the Verona Coding Definitions of Emotional Sequences (VRCoDES) as a way of measuring doctor-patient communication. Patient SES was measured using English Indices of Multiple Deprivation (IMD) 2015 scores and grouped into deciles so that the VRCoDES could be compared by patient SES.

Results:

Most of the patients were from the most deprived decile (30.9%) and the mean age was 62.85 years, with most of the patients being male (63.6%). There were no significant correlations between IMD decile and the number and type of cues and concerns or the type of healthcare provider responses.

Clinical implications:

The number and type of emotional expressions and the way the healthcare provider responds to these expressions does not seem to differ based on patient SES in this sample. There could be a number of possible reasons for this and needs to be investigated further with larger sample sizes and several healthcare professionals.

Abstracts: Friday 11th November, Afternoon Session

Evaluation of a MDT facilitated Psychosocial Group for Head and Neck Cancer.

Authors:

Sonia Wilson & Lorna Raby

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Background:

Psychosocial groups are one mechanism used to provide survivorship support post treatment. For the past 15 years our local strategy, at Sunderland Royal Hospital, is to offer a professional led psychosocial group.

Aim:

To reflect on our experience of running a professional led psychosocial group for Head and Neck Cancer patients and investigating outcome measures for this intervention.

Patients & Methods:

Over the past 3 years, the group has run annually for six, fortnightly 90-minute sessions. Participants were identified from referrals to Speech and Language Therapy. The Patient Concern Inventory (PCI) was used to plan topics for the group. Pre and post intervention, participants completed the PCI to capture change in concerns. The Hospital Anxiety and Depression Scale and Post Traumatic Growth Inventory have also been used as candidate outcome measures. Participants completed a Likert rating scale of 'usefulness' after each session and a post-intervention feedback questionnaire.

Results:

Since 2014, a total of 126 patients were identified as potential participants, of which 31 attended. The group was rated as being 'useful' (4.45/5). From comments received on the feedback questionnaire four broad themes were identified: 'organisation of the group', 'not alone', 'learning from others' and 'moving forward'. Comparisons of the pre and post outcome measures have shown a positive change.

Clinical Implications:

Only a small number of patients attended the group, from those invited. The PCI was a good foundation to plan topics based on the participant feedback. Objectively measuring change was difficult as any differences could be affected by factors unconnected to the psychosocial group. Data analysis was limited due to the small sample size. Future groups will continue to trial outcome measures and focus on reaching more patients.

Abstracts: Friday 11th November, Afternoon Session

Pre-operative counselling of patients undergoing total laryngectomy surgery in Ireland; analysing three differing perspectives

Authors

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Submission Type

Oral Presentation

Purpose:

To collect, describe and compare the pre-operative counselling experiences of a sample of total laryngectomy patients in Ireland, together with their carers and specialist Speech and Language Therapists (SLTs), with a view to identifying current practices and improving future intervention.

Methodology:

This qualitative study used grounded theory to analyse data from three focus groups (FGs) of purposefully recruited patients, carers and SLT clinicians. Sessions were audio-recorded and data were then transcribed and analysed post hoc. Convergent and divergent themes were identified, compared and contrasted, across and within the three FGs.

Results:

Although SLTs identified themselves as the main information providers for patients and carers, this was not identified by the patients or carers.

There were clear differences in the themes elicited from SLTs, compared with patients and/or carers. Although they varied, patient and carer views about pre-operative counselling were largely in agreement. They could identify the key information that they thought should be provided for future patients and carers, and they described important shortfalls in current practices.

Conclusion:

There is a need to improve the experiences of patients and carers in Ireland, based on these reported needs and experiences. SLTs working with HNC patients need to clearly identify their role in the pre-operative counselling process.

Abstracts: Friday 11th November, Afternoon Session

Head and neck cancer survivors' experiences of self-managing their condition following primary treatment.

Authors: *Simon Dunne¹, Laura Coffey², Linda Sharp³, Aileen Timmons⁴, Deirdre Desmond², Rachael Gooberman-Hill⁵, Eleanor O'Sullivan⁶, Ivan Keogh⁷, Conrad Timon⁸, Pamela Gallagher¹.*

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Background/Aim:

Head & Neck Cancer (HNC) survivors face unique challenges following treatment which can strongly impact their physical, functional, social, and psychological wellbeing. Research from other domains suggests that self-management practices may help to assist HNC survivors to overcome these challenges. In this context, the main aim of the current study was to explore HNC survivors' experiences of self-managing their condition following primary treatment.

Patients/Methods:

Twenty-seven individuals who had completed primary treatment for HNC were recruited from four designated cancer centres in Ireland and interviewed about their experiences of self-managing their condition following primary treatment. Interviews were audio-recorded, transcribed and analysed using thematic analysis.

Results:

HNC survivors identified a range of experiences related to their post-treatment self-management, including embarrassment over self-management in public, difficulties managing negative emotions before hospital appointments, the need to feel control over symptoms through self-management practices, the need for attention to detail with self-management practices and how self-management can put a strain on interpersonal relationships. Issues relating to eating such as loss of taste and dietary changes were experienced as particularly difficult for HNC survivors to manage following primary treatment but these, like many other symptoms and side effects, became more manageable over time. Finally, HNC survivors indicated that their self-management was aided by adopting an attitude of will and determination in relation to self-management practices and being open and responsive to newfound limitations arising from treatment consequences.

Clinical-Implications:

The current study is the first of its kind to explore HNC survivors' experiences of post-treatment self-management. This information is important for the design and implementation of self-management interventions tailored specifically for HNC survivors in the post-treatment period.

Abstracts: Friday 11th November, Afternoon Session

Assessing the validity of EQ-5D-5L in for people with Head & Neck Cancer

Amy Davies, Andrea Waylen, Steve Thomas, Sam Leary and Andy Ness (University of Bristol)

Background:

Head and neck cancers (HNC) are an important cause of ill health. People with this diagnosis are increasingly likely to survive with compromised function and appearance and it is important to understand how quality of life (QoL) is affected over time. The EuroQoL EQ-5D-5L is a short generic QoL measure comprising five domains (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) and a Visual Analogue Scale that enables participants to summarise their current health as a single value. To date validity has been assessed within general and other patient populations but little work has been done with people with HNC.

Aim:

Our primary aim is to validate the EQ-5D-5L by assessing repeatability, internal consistency and construct validity in people with HNC. Secondary analysis will assess the level of agreement between EQ-5D-5L and the European Organisation for Research and Treatment of Cancer HNC-specific questionnaire (EORTC QLQ-HN35).

Patient and Methods:

We used data from the head and neck 5000 longitudinal study. Before treatment, and four and 12 months later, 5511 participants from around the United Kingdom completed health and lifestyle and QoL questionnaires. Exploratory data analysis will explore whether differences in self-reported QoL are associated with cancer site and demographic and treatment factors. Statistical techniques will be used to validate the EQ5D measure. Secondary analysis will compare the EQ-5D-5L and EORTC-C35 questionnaires for further validation.

Results:

Full results will be presented at the conference.

Clinical Implications:

This generic QoL questionnaire will enable accurate reporting of self-perceived QoL as well as accurate assessment of quality-adjusted life years for health-care decision-making.

Abstracts: Friday 11th November, Afternoon Session

Discharge from hospital on the laryngectomy enhanced recovery pathway: A patient experience study

Anna White, Highly Specialist Speech and Language Therapist

Background:

This study explored the experience of patients on a new enhanced recovery pathway (ERP) after total laryngectomy (TL) surgery. Literature on ERP focuses on surgical outcomes and the potential for reduced length of hospital stay; Patient experience is essential to fully understand the impact of ERP but is poorly considered in the literature.

Methods:

Six semi-structured domiciliary interviews were carried out with patients on the laryngectomy ERP. Participants (3-12months post-discharge) were encouraged to discuss their experiences of discharge and adjustment once home. Interviews were audio and video recorded, transcribed and analysed using the Framework Method; a thematic analysis approach.

Results:

Four key themes in patient experience 1) *ward based training*, 2) *loss of control* 3) *heightened levels of emotion* and 4) *importance of high quality support* were influenced by an overarching theme; *Barriers to communication*. The loss of the patient's larynx, unique to this population, and the subsequent impact on their ability to communicate, affected relationships and heightened feelings of anxiety and frustration. Participants reported minimal training to manage their tracheostoma before leaving hospital, contributing to distress and anxiety after discharge. Participants who had close family support described the psychological and practical benefits of this. All subjects expressed the importance of access to high quality professional support. Whilst this need was sometimes met, complex or socially isolated participants required more help and support.

Conclusions and Clinical implications:

Participants' narratives confirmed assertions in the literature that shorter hospital stays are desirable from a patient's perspective. However, a fundamental principle of the ERP is "optimum recovery" and this was not the experience of many. This study suggests that for ERP to be successful in this population, patients require structured ward-based training and high quality tailored community support to enable them to come to terms with the impact of multi-level physical, emotional and communication changes after laryngectomy.

Jungerman, I (7)

Validation into Portuguese–Brazil of the Head and Neck Cancer

Patients Concerns Inventory, Assessment of their Concerns and Expectations and Relationship with Quality of Life.

[Thesis].

São Paulo. School of Medicine, University of São Paulo; 2016.

Spaulding (31)

Improving knowledge and confidence of health care professionals to support patients with the psycho-social impact of disfiguring.

Dawson, Jane (3)

A Ghana Experience

Brown, T (4)

Prophylactic gastrostomy placement is a common method of nutrition support in patients with HNSCC, however there are concerns this approach leads to long term tube dependency.

Mortensen, A (5)

Early and late physical and psychosocial effects of primary surgery in patients with oral and oropharyngeal cancers: a systematic review

Blick, K (AWAITING)16

MARS: Helping post-treatment head and neck cancer patients back to work, rest and play.

Dholam Kanchan (15)

Impact of oral rehabilitation on patients with head and neck cancer: A study of 100 patients with the Liverpool Oral Rehabilitation Questionnaire(LORQv3) and the Oral Health Impact Profile (OHIP-14).

Abstracts: Poster Presentations

Validation in Portuguese- Brazil of the Head and Neck Cancer Patients Concerns Inventory, Assessment of their concerns and Expectations and Relationship with Quality of Life ,

I Jungerman

Introduction

Given the centrality of the head and face for a number of different aspects of life, changes in their anatomy and/or function can have devastating consequences. The impact of cancer diagnosis and consequence of its treatment have a major effect on quality of life on these patients.

Objectives

To perform a psychometric validation of the Patients Concerns Inventory – PCI-H&N in Portuguese-Brazil and characterize, at pre-treatment, and at 6 and 12 months after diagnosis, the degree of anxiety and depression of head and neck cancer patients, their quality of life, severity of symptoms presented, their needs, preferences and attitudes regarding information on cancer, their concerns, expectations (pre-treatment), extent to which expectations were met (6 and 12 months post-treatment), and to determine associations between the extent to which expectations were met and quality of life.

Methods

Part I: Cross-sectional study. After the translation and transcultural adaptation stages, construct validity was determined by comparing the PCI against the University of Washington Quality of Life Questionnaire (UW-QOL). Part II: Prospective, longitudinal study. Participants completed the Anxiety and Depression Scale (HADS), the University of Washington Quality of Life Questionnaire (UW-QOL), the MD Anderson Symptom Inventory (MDASI-H&N), the Information Styles Questionnaire (ISQ), the validated Portuguese version of the Patient Concerns Inventory (PCI), the Expectations Assessment Protocol (EAP) at pre-treatment, and the Meeting Expectations Protocol (MEP) at 6 and 12 months post-treatment. In stage one, non-parametric Mann-Whitney (two categories) or Kruskal-Wallis (three categories) tests were employed to assess the association of number of items/professionals selected with patient characteristics. The Mann-Whitney test was also used to associate scores of the UW-QOL, domains with specific items/professionals selected by patients. The associations of the UW-QOL domains with age and time since diagnosis, and also with number of items/professionals selected, were determined by Spearman's correlation coefficient. Associations of specific items/professionals selected with patient characteristics were assessed using the Chi-square or Fisher Exact tests. In the second stage, associations between MEP items and UW-QOL global score were assessed using the Mann-Whitney non-parametric test. A significance level of 0.01 was adopted.

Conclusion

The Patient Concerns Inventory-PCI was shown to be appropriate and psychometrically valid for use in Brazilian head and neck cancer patients at all stages of treatment. During the course of one year after diagnosis, the head and neck cancer patients tended to exhibit a decrease in comorbidities (anxiety and depression), good quality of life (with initial decline at 6 months), predominance of physical/functional symptoms associated with concerns, desire for all possible information, predominantly physical/functional concerns, associated with fear of disease recurrence and prioritized contact with the physicians responsible for treatment and rehabilitation of treatment sequela, had general expectations met (except food-related aspects), and the extent to which expectations were met impacted global quality of life.

Abstracts: Poster Presentations

Improving the Knowledge and Confidence of Healthcare professionals to support patients with psycho-social impact of disfiguring conditions

Henrietta Spalding, Ivon Van Heugten, James Partridge, Elizabeth Noble

Background

Changing Faces is the UK charity that supports patients and their families living with the psychological and social challenges of disfigurement. We are caring campaigners – helping to build people’s confidence to live their life on their terms and challenging prejudice, respecting differences and speaking to a world that needs to change. Our work includes providing training for health care professionals to support their patients’ psycho-social needs.

Aim

We seek to raise the awareness, skills and confidence of health care professionals working with patients with disfigurements: to identify the signs and symptoms of distress and anxiety that they may display and their role in providing psycho-social care for these patients.

Patient and methods

Changing Faces offers evidence-based training for health care professionals, developed to support a range of needs and learning styles in a range of different formats including study days, online modules, factsheets and lectures. The training provides opportunities to explore patients’ psycho-social needs, discover the myths and misconceptions around disfigurement and their impact on patients and their families, recognise factors that might predict ‘adjustment’ and develop the strategies, processes and resources to address them. We provide specific techniques on supporting patients and their families and offer suggestions for integrating the new techniques into work with patients.

Results

Results from training delivered in 2014 – 2015 have demonstrated significant impact with 96% of professionals reporting that the training was useful to their practice, improving awareness of how and why psycho-social care is vital to patients. Health care professionals also stated that the course content was new to them and provided them with practical tools to embed into their practice to better support patients.

Clinical implications

Feedback suggests increased awareness of psycho-social needs of patients with disfigurement and their families leading to improvement in care and patient outcomes.

Abstracts: Poster Presentations

A Ghana Experience

Jane Dawson ,Principal Speech and Language Therapist, (Head and Neck Oncology), Queen Victoria Hospital,

This presentation narrates the experience of visiting the ENT and SLT departments in the main teaching hospital in Accra, Ghana, in March 2016. There are only three teaching hospitals for the whole of Ghana, which has a population of approximately 25 million.

The focus of the visit was to work alongside the ENT doctors, in outpatients and on the ward and to demonstrate the value of being able to have an SLT on their team. In addition, patients were seen with the SLTs in their outpatient department, offering suggestions and practical advice on different head and neck cancer patients (and other patients). Some teaching was given on what can be achieved from an SLT perspective in terms of rehabilitation, including quality of life considerations.

SLT services in Ghana are in the early stages of development; there are a wide range of head and neck cancer cases, including some non-malignant tumours, for which the treatment nonetheless impacts on both swallowing and communication.

The experience gave me insight into quality of life concerns against a very different backdrop of a country which is still in the process of developing.

Abstracts: Poster Presentations

Prophylactic gastrostomy use in patients with head and neck cancer (HNSCC) post treatment – is there really a problem?

Teresa Brown^{1,2}, Merrilyn Banks², Brett G. M. Hughes^{3,4}, Charles Lin^{3,4}, Lizbeth Moira Kenny^{3,4}, Judith D. Bauer¹

¹Centre for Dietetics Research (C-DIET-R), School of Human Movement Studies, University of Queensland, Queensland, Australia, ²Department of Nutrition and Dietetics, Royal Brisbane and Women's Hospital, Brisbane, Queensland, Australia, ³Cancer Care Services, Royal Brisbane and Women's Hospital, Brisbane, Queensland, Australia, ⁴School of Medicine, University of Queensland, Queensland, Australia.

Background

Prophylactic gastrostomy placement is a common method of nutrition support in patients with HNSCC, however there are concerns this approach leads to long term tube dependency.

Aim

The aim of this study was to determine patterns of gastrostomy use post treatment and associations with tube removal/retention.

Patients and Methods

Patients with HNSCC with prophylactic gastrostomy were observed monthly post treatment to six and twelve months to determine tube use and removal time. Patients were part of a randomised controlled trial comparing an early feeding intervention via the gastrostomy (n=61) versus usual care which commenced feeding when clinically indicated (n=70). Nutrition outcomes were collected at three months post treatment. Factors associated with time to tube removal were explored using linear regression.

Abstracts: Poster Presentations

Early and late physical and psychosocial effects of primary surgery in patients with oral and oropharyngeal cancers: a systematic review

Authors:

Annelise Mortensen, RN, MHA; Mary Jarden, MScN, PhD

Background:

The purpose of the systematic narrative literature review is to explore the early and late physical and psychosocial effects of patients treated with primary surgery for oral and oropharyngeal cancers and to investigate the factors that influence these effects.

Materials and methods:

PubMed, Cinahl and PsycInfo were searched for studies concerning patients diagnosed and treated with primary surgery for oral and oropharyngeal cancers and followed the treatment trajectory from time of diagnosis and nine years onwards; studies measured quantitative assessments and qualitative experiences of patient's physical and psychosocial wellbeing.

Results:

438 articles were accessed. 20 articles qualified for inclusion, of which 16 and four are quantitative and qualitative articles and mainly Quality of Life assessments. Time of measurement ranged from time of diagnosis to nine years after the surgical procedure. The total number of patients included in this review is n=3386; treated by surgery alone (n=1996), and combined surgery and adjuvant RT and/or CT (n=1390).

Conclusion:

Studies showed that patients are negatively affected by treatment for oral and oropharyngeal cancers, with both early and late effects, due to the nature of the illness; the different types of surgical treatment and side-effects of adjuvant therapy.

The review is published in Oral Surgery, Oral Medicine, Oral Pathology, Oral Radiology, June 2016.

Abstracts: Poster Presentations

MARS: Helping post treatment head and neck cancer patient's back to work, rest and play.

Kate Blick

Head & Neck Cancer (HNC) patients are a complex group with multiple physical and social needs. Treatment for HNC impacts on fundamental activities of eating, drinking, speaking and breathing. HNC patients report high unmet supportive care needs and feel most vulnerable in the post-treatment phase, particularly at treatment end when they have less input from specialist services.

The need for rehabilitation is increasingly recognised as more people survive and live with cancer. Allied Health Professionals play a major role in minimising the acute and chronic side-effects of treatment, promoting recovery, and supporting patients to self-manage where appropriate. Failure to provide adequate supportive measures can compromise delivery of curative therapy, result in significant morbidity and mortality, and cause diminished quality of life (QoL) for both patients and carers.

MARS aims to provide specialist, high-quality, multidisciplinary rehabilitation services at locations accessible to HNC patients. They have been successful in decreasing avoidable readmissions to hospital, reducing post treatment complications rates by improving nutritional status. Significantly reducing patient reliance on oral and enteral nutrition support by timely goal directed support and providing timely proactive advice to support laryngectomy patients. They also run a moving on from Head and Neck Cancer Programme which consists of advice sessions for patients and their support network. The first three year's results will be discussed.

The MARS team consist of two Dietitians Claire Hanika and Nicola Porter, two Speech and Language Therapists: Kate Blick and Amanda Skilton; a Nutrition Nurse Specialist: Karen Matthews and Elizabeth Seymour who is the Macmillan Care Co-ordinator for the team.

Abstracts: Poster Presentations

Impact of oral rehabilitation on patients with head and neck cancer: A study of 100 patients with the Liverpool Oral Rehabilitation Questionnaire(LORQv₃) and the Oral Health Impact Profile (OHIP-14).

Dr K. P. Dholam, G Choksey, J Dugad

Statement of problem:

Evaluation of effects of the disease, treatment and rehabilitation should be done to measure the benefits and cure rendered to the patient. Liverpool oral rehabilitation questionnaire (LORQv₃) and Oral health impact profile questionnaire (OHIP-14) are specific to assessment of oral rehabilitation

Aim:

To assess the impact of oral rehabilitation on hundred patients with head and neck cancer with the LORQv₃ and the OHIP-14.

Material and Methods:

LORQv₃ and OHIP-14 questionnaire were administered to 100 oral cancer patients, who were in need of oral rehabilitation. . Participants were asked to rate their experience of dental problems before fabrication of prosthesis, and at follow-up visit after 1 year.

Result:

LORQV3 :

After prosthetic rehabilitation there was a 10 to 38 % improvement noticed in the domain of oral functions: mastication (33%), swallowing (26%), salivation (10%), mouth opening (13%), and speech (38%), orofacial appearance (28%) and social interaction (37%). Statistically significant difference were seen in all the domains of LORQv₃ except for social interaction ($P=0.451$).

OHIP :

Prior to rehabilitation patients had more problems in the domain of psychological discomfort (29%), functional limitation (26%), physical disability (24%) . After one year of prosthetic rehabilitation, no problems were seen in the domains of psychological, social disability and handicap. Change was noticed in all the domains [psychological discomfort (26%), functional limitation (24%), physical disability (20%), psychological disability (18 %), physical pain

Conclusions:

For all the items of LORQv₃ there was 10% to 38% improvement in function.

OHIP-14 showed a 11% to 26% improvements in all the domains.

Prosthetic rehabilitation contributed to an improvement of patients, in view of the decreased scores on the Likert scale after prosthetic treatment.

Clinical implications:

To assess the various interventions and benefits of oral rehabilitations in head and neck cancer patients. To seek new research directions for enhancing quality of oral health outcome.

'What will I be like'

Searchable web design

What will I be like?

Interactive Quality of Life Searchable Database

HOW WILL HEAD & NECK CANCER AFFECT MY LIFE?

What will I be like is a unique feature of this website. It contains questionnaires completed by patients that gives their perspective of outcome following their cancer treatment at around 18 months following treatment. We have found that the 18 month responses are very similar to the long-term outcomes thus they give a very reasonable indication of what to expect when cured of the cancer.

The questionnaire database is searchable by key factors such as age, gender, site, stage and treatment so the search can be closely matched to individuals. The issues are those on the University of Washington Head and Neck Cancer Scale and include:

- Activity
- Anxiety
- Appearance
- Chewing
- Mood
- Pain
- Overall Quality of Life
- Recreation
- Saliva
- Shoulder
- Speech
- Swallowing
- Taste.

The database of patients replies will grow year on year so in the future more detailed searches will be possible.

Search Now

Results for 'Saliva'

These are the results of your search of our quality of life information. Your search matched questionnaires completed by 137 people. This is 9.1% of the number of questionnaires in our system (1511). The answers people gave concerning the issue of 'Saliva' are shown below. Roll your cursor over the graph for more information.

| | |
|--|-------|
| My saliva is of normal consistency | 21.9% |
| I have less saliva than normal, but it is enough | 46.1% |
| I have too little saliva | 27.7% |
| I have no saliva | 10.2% |

You searched for:

- Age: Any age
- Gender: Male or female
- Site: Oral
- Stage: Advanced (3 and 4)
- Treatment: Surgery followed by radiotherapy
- Issue: Saliva

Key facts...

Out of all the people that matched your search:

- 59 (43.1%) stated that the issue of 'Saliva' was one of the three most important to them.
- 81 (59.1%) stated that their overall quality of life was good, very good or outstanding.

The people that matched your search stated that these were the three most important factors affecting them:

- 'Saliva' - 50 (43.1%) stated this was important
- 'Swallowing' - 56 (40.9%) stated this was important
- 'Chewing' - 50 (36.5%) stated this was important

Select another issue...

Health-Related Quality of Life at 2 years

Use the form below to search our database of health-related quality of life following head & neck cancer surgery. Use the drop-down menu options to select a clinical scenario and click 'Search' to find questionnaire data from people that matched your search.

Age:
 Any age Less than 55 55-64 65 and over

Gender:

Site:
 Any site Oral Laryngeal Oropharyngeal Other

Stage:

Treatment:

Click a button to see data relating to that issue:

| | | | |
|------------|------------|----------|------------|
| Pain | Appearance | Activity | Recreation |
| Swallowing | Chewing | Speech | Shoulder |
| Taste | Saliva | Mood | Anxiety |

Advice sheets

Laryngeal Cancer

[Laryngectomy](#)

[Early Stage Laryngeal Cancer Surgery](#)

[Early Stage Laryngeal Cancer Combined Treatment](#)

[Early Stage Laryngeal Cancer Radiotherapy](#)

[Late Stage Laryngeal Cancer Surgery](#)

[Late Stage Laryngeal Cancer Combined Treatment](#)

[Late Stage Laryngeal Cancer Radiotherapy](#)

Other Head and Neck Cancer

[Early Stage Other Sites Cancer Surgery](#)

[Early Stage Other Sites Cancer Combined Treatment](#)

[Early Stage Other Sites Cancer Radiotherapy](#)

[Late Stage Other Sites Cancer Surgery](#)

[Late Stage Other Sites Cancer Combined Treatment](#)

[Late Stage Other Sites Cancer Radiotherapy](#)

To compare the results with more 'normative' responses their dentist were asked the same questions.

[Click here for the 'Normative' responses sheet.](#)

"What will I be like following head and neck cancer?"

Normative reference population

Number of individual giving feedback is 349 attending a their dentist
 Published Oral Oncology 2006; 42 (3): 281-287

Percentage of patients scoring on the best two responses for each domain

| | | |
|--|----|-----|
| Activity - I am as active as I have ever been/there are times when I can't keep up my old pace, but not often | Ac | 87% |
| Appearance - There is no change in my appearance/there is a change in my appearance is minor | Ap | 87% |
| Anxiety - I am not anxious about my cancer/I am a little anxious about my cancer | An | 87% |
| Chewing - I can chew as well as ever/I can eat soft solids but cannot chew some food | C | 87% |
| Mood - My mood is excellent and unaffected by my cancer/My mood is generally good and only occasionally affected | M | 87% |
| Pain - I have no pain/there is mild pain not needing medication | P | 87% |
| Recreation - There are no limitations to recreation/there are a few things I can't do but I still get out and enjoy life | R | 87% |
| Saliva - My saliva is of normal consistency/I have less saliva than normal, but it is enough | Sa | 87% |
| Speech - My speech is the same as always/I have difficulty saying some words but I can understand over the phone | Sp | 87% |
| Shoulder - I have no problems with my shoulder/My shoulder is stiff but it has not affected my activity or strength | Sh | 87% |
| Swallowing - I can swallow as well as ever/I cannot swallow certain solid foods | Sw | 87% |
| Taste - I can taste food normally/I can taste most foods normally | T | 87% |

Quality of Life

87% Good or better

Yellow show percentage with Top 2 responses
 Red show percentage with 'significant' problem

| | |
|-------------|----|
| Outstanding | 8 |
| Very Good | 45 |
| Good | 34 |
| Fair | 11 |
| Poor | 2 |
| Very poor | 0 |

Most important issue

Prominence of word approximates how often it was considered one of the top three most important issues

Shoulder, Swallowing, Speech, Saliva, Anxiety, Activity, Pain, Mood, Appearance, Chewing, Taste, Recreation

More information and an interactive search at www.headandneckcancer.co.uk website

Mouth Cancer

[Early Stage Mouth Cancer Surgery](#)

[Early Stage Mouth Cancer Combined Treatment](#)

[Early Stage Mouth Cancer Radiotherapy](#)

[Late Stage Mouth Cancer Surgery](#)

[Late Stage Mouth Cancer Combined Treatment](#)

[Late Stage Mouth Cancer Radiotherapy](#)

Throat Cancer

[Transoral Laser Resection](#)

[Early Stage Throat Cancer Surgery](#)

[Early Stage Throat Cancer Combined Treatment](#)

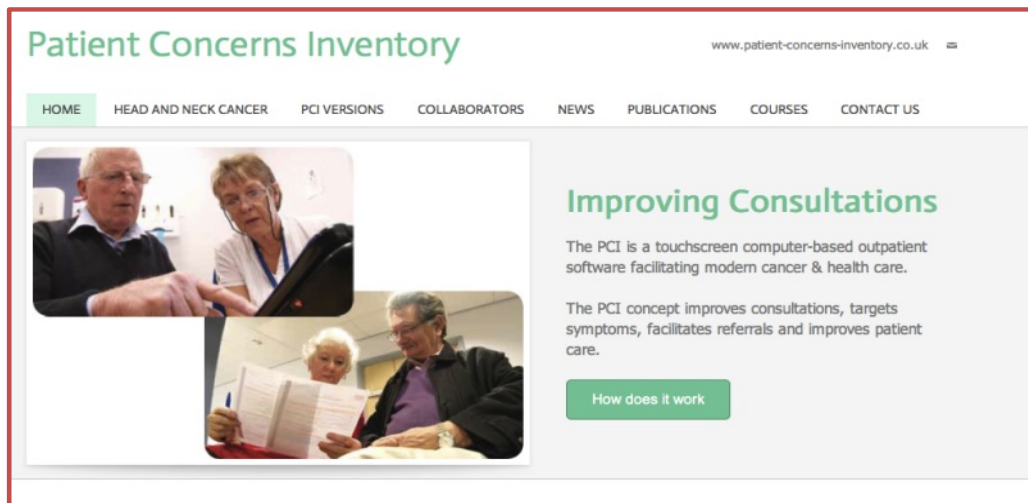
[Early Stage Throat Cancer Radiotherapy](#)

[Late Stage Throat Cancer Surgery](#)

[Late Stage Throat Cancer Combined Treatment](#)

[Late Stage Throat Cancer Radiotherapy](#)

Patient Concerns Inventory



Improving quality of life through the routine use of the Patient Concerns Inventory for head and neck cancer patients

Aims

To determine if the routine use of the PCI in review clinics during the first year following treatment can improve overall quality of life, reduce the social-emotional impact of cancer and reduce significant levels of distress.

Furthermore, we aim to describe the economic costs and benefits of using the PCI.

The design is a pragmatic cluster randomised control trial with at least 10 consultants randomised to either 'using or 'not using' the PCI at clinic. Two sites are involved: Leeds and Liverpool. It is expected that just over **416** patients are required to show a clinically meaningful difference in the primary outcome.

Trial Manager: Cher Lowies <CHERMAINE.LOWIES@aintree.nhs.uk>

Start date January 2017

RfPB reference number: PB-PG-0215-36047

The current PCI on iPad has been recently upgraded:


The PCI system is written using MVC4 and SQL 2012, to get it working in your Trust you will need to have the correct IT infrastructure setup:

1. You will need a webserver to host the PCI on.
- 2 You will need a SQL server to store the patient information on (SQL 2008 or above).
3. You will need somebody from you Software Development team to install, configure and support it on your servers (you may also need them to make changes as it is currently branded for Aintree Hospital, the system is written in C#\MVC 4)

QOL in H&N Cancer: 10th International Conference

HaNDLE-on-QoL

Head and Neck Database Listing Evidence on QoL



[Home](#) | [Search the database](#) | [About](#) | [Contact](#)

About...

What is HaNDLE-on-QoL?

HaNDLE-on-QoL is a unique online searchable database of all papers published from 1982 to present on quality of life in head and neck cancer that have used questionnaires.

Questionnaires are the main source of quality of life data. Currently HaNDLE-on-QoL has 800 papers and a list of 200 different questionnaires.

[Search the database>>](#)

It is hard to entity relevant papers published on the different facets of QOL in H&N Cancer. Pubmed Search on Head and Neck Cancer, Quality of life currently gives over 5,000 hits. It is difficult and time consuming to search the web for specific issues such as pain, nausea, speech without the risk of missing key articles.

- QOL in H&N is a growing field in terms of numbers of publications each year and it is difficult for the clinicians, nurses, and researches to keep up to date. An up to date knowledge base will help improve patient care.
- Although there are review articles in the literature, these are a selection of papers with no ability to keep up to date and search.
- When searching the literature considerable amount of time is need to check abstracts, hand search articles, exclude papers that are duplicates or not relevant.
- There is a huge array of questionnaires use in studies and this reflects the complexity of what is 'quality of life'. It is useful to have a repository that clearly identifies the questionnaires used so similarities, key messages and comparisons in future studies are possible.
- HaNDLE-on-QoL will be a tremendous educational resource for the healthcare professionals working in head and neck cancer.
- HaNDLE-on-QoL saves precious time for busy staff in searching for the HRQOL studies so that they can stay up to date more efficiently. It allows a functional dataset that can be interrogated by member of the clinical and research fraternity.
- HaNDLE-on-QoL helps staff build skills and knowledge of HRQOL outcomes, so that they can be better informed though the evidence based when providing healthcare, undertaking audits/service evaluations and designing trials.

| | |
|----------------------------------|--|
| Title: | <input type="text"/> |
| First author: | <input type="text"/> |
| Year of publication: | <input type="text"/> |
| Keywords: (comma separated) help | <input type="text"/> |
| Cohort: | <input type="text" value="Head and Neck"/> |
| Design: help | <input type="text" value="Longitudinal"/> |
| Theme: help | <input type="text" value="Functional"/> |
| Type: help | <input type="text" value="Questionnaire"/> |
| Questionnaire type: | <input type="text" value="[all]"/> |

Errors / omissions

HaNDLE-on-QoL will be regularly updated and will include new papers as they become available.

We ask you please to contact us if you are aware that any relevant papers are missing or if you experience any problems in navigating around this website in terms of its functionality. It would be helpful if authors active in this field could let us know if any of their papers are missing. This will help maintain the usefulness of this resource in the longer term.

<http://www.handle-on-qol.com>

NOTES