

WELCOME

*'Yesterday,
All my troubles seemed so far away,
Now it looks as though they're here to stay,
Oh, I believe in yesterday.*

*Suddenly,
I'm not half the man I used to be,
There's a shadow hanging over me,
Oh, yesterday came suddenly.*

Yet another warm welcome to Liverpool, the city where the Beatles gave us 'Yesterday'. We meet today recognising that for most patients the diagnosis and consequence of head and neck cancer is sudden and unexpected. Also there are many consequences that are here to stay and some feel that there is a shadow hanging over them. Yet we hope as health professionals caring for both patients and carers we might help them not necessarily to believe in yesterday but come to terms with today in the expectation that they might have a better 'tomorrow'.

This is the 6th International 'Quality of life' in head and neck cancer workshop. The Maritime Museum is a wonderful venue and the museum gives a fascinating insight in to Liverpool's nautical heritage.

We are on a 'Quality of life' journey. The first workshop was held in November 1999 at which we explored the issue of 'what is quality of life'. In our second meeting in February 2001, we considered the types of questionnaires available. At the third meeting in October 2002, we looked in more detail at predictors of health-related quality of life. At our 4th meeting in November 2004 we explored organ preservation and function, and information and psychological distress. At our 5th meeting we focused on how to use 'quality of life' outcomes to enhance clinical practice, the information needs of patient and carers, and also we explored the issue of coping and patient and carer support.

A new aspect to the 6th workshop is the patient and carer focal point on Friday afternoon. There has been a free invite for patients and carers and the topics and speakers reflect the programme. I wonder if it is the first time that such a group specific to head and neck cancer have come together in such a way. Perhaps with this opportunity to meet and share experiences a common purpose might emerge and may be it could be the start of UK specific H&N cancer patient and carer interest group?

Throughout the workshop I have brought together an international faculty with wide experience in the field. I am most grateful for their contribution and am excited about the exchange of ideas and views that will aired over the next two days. There will be diverse opinion and no right or wrong answers. Your clinical experience will add to the workshop, so please may I encourage you to participate and make your views known. I have tried to build in time for discussion so let's use it. Contributions from a variety of backgrounds and disciplines will help to consolidate a wide spectrum of viewpoints and provide a unique opportunity for coherent dialogue.

I am very grateful for your participation as I appreciate that the purse strings on study leave budgets are tight and that we all have demanding clinical and family commitments. I was excited at the prospect of having the next meeting in 2008 when Liverpool would be European city of culture. However what I did not anticipate were the problems it would cause with accommodation. I am sorry if it has caused you inconvenience. Make the most of Liverpool during your stay, if you get time!!! The new Liverpool 1 shopping centre is amazing. Also the meeting is not all hard work and I hope you can make the course dinner.

Please do not hesitate to let me know if there are any problems during the workshop and I will do my best to deal with them for you. Also please take the opportunity to complete the course evaluation forms.

Finally I wish to express my thanks to Gillian Allman for her tremendous administrative skills and dedication in support of the course.

NB: We will try to put as many presentations as possible on the website www.headandneckcancer.co.uk after the workshop, we will ask speakers if it is alright to make the presentations text only to reduce the size for compatibility for the website.

Finally a date for your diary

7th Quality of Life Conference November 2010

FACULTY

Professor Hans Aarstad

Department of Surgical Sciences, Faculty of Medicine, University of Bergen, N-5021 Bergen, Norway & Department of Otolaryngology/Head and Neck Surgery, Haukeland University Hospital, 5021 Bergen, Norway.

Professor Irma Verdonck

Dr. Irma Verdonck-de Leeuw graduated as a psychologist, speech pathologist, and phonetic scientist. She is senior researcher in the VUmc Department of Otorhinolaryngology / Head & Neck Surgery, supervising health related quality of life projects focussing on speech and swallowing functioning and psychosocial aspects of head and neck cancer patients and their relatives. She is member of the Committee "Screening" of the Dutch Association of Psycho-Oncology, Member of the International Psychosocial Oncology Society, Dutch Committee Member of the European COST 2103 project on voice and speech assessment, member of the EORTC group on the development of an Oral Function Module, and board member of the International Association of Logopedics and Phoniatrics.

Dr Sonia Duffy

Sonia A. Duffy, Ph.D, R.N., is an Associate Professor at the University of Michigan, School of Nursing, Department of Otolaryngology and Psychiatry, and the VA Ann Arbor Healthcare System. During her National Cancer Institute-sponsored predoctoral fellowship, Dr. Duffy was educated in health behavior and epidemiology. Since then, Dr. Duffy's research interests have focused on the association of health behaviors (smoking, alcohol use, sleep and depression) and quality of life, recurrence and survival, particularly among head and neck cancer patients. As a means of more efficient delivery of health care services for both patients and providers, Dr. Duffy is interested in multifaceted, cancer-related interventions that can be administered in combination (e.g., combined smoking, alcohol, and depression interventions) as opposed to one dimensional programmatic approaches. Due to her past work in hospice care, Dr. Duffy also remains interested in end-of-life issues.

Mrs Sheila Fisher

MSc, FRCS, received her medical degree from the University of Birmingham in 1985 and her dental degree from the University of Manchester in 1974. She completed her Fellowship in Dental Surgery (RCS England) in 1977 and her Fellowship in Surgery (Clinical Surgery in General, RCS England) in 1989. She trained in maxillofacial surgery with a primary interest in oncology and trauma in Middlesbrough and

Liverpool. Her surgical practice has centered on the care of patients with head and neck cancer and facial trauma and she was appointed Consultant Maxillofacial Surgeon to the University Hospital, Nottingham in 1992. In 2000 she moved to the University of Leeds as Senior Lecturer / Hon Consultant in Maxillofacial Surgery, where her research interests include new diagnostic and therapeutic interventions in the care of patients with head & neck cancer and assessment of quality of life as part of routine care.

Mr Hisham Mehanna - Coventry

Dr Cherith Semple

Cherith Semple completed her BSc (Hons) in Nursing at the University of Ulster in 1995 and was appointed as Macmillan Clinical Nurse Specialist (CNS) in Head and Neck Oncology during 1999. In 2002, Cherith was awarded a three year Research and Development Fellowship from the R&D Office in Northern Ireland and undertook full-time doctoral studies from 2002-2005.

She is currently working as the Macmillan CNS in Head and Neck Oncology at the SET, N. Ireland. Her research interests include quality of life issues for patients with head and neck cancer, and more specifically, information needs, post-treatment psychosocial intervention and support needs of parents with young children who have been diagnosed with head and neck cancer.

Dr Rob deLeeuw - Utrecht

Dr Chris Nutting

Dr Chris Nutting is a Consultant and Senior Lecturer in Clinical Oncology at the Royal Marsden Hospital. He specializes in head and neck cancer radiotherapy, and has a special interest in the development and evaluation of new radiotherapy techniques aimed at maximizing tumour control, minimizing complications and thereby maximizing quality of life after treatment.

Professor Gerry Humphris

I studied Psychology at Reading University (1973-76) before going to Guy's Hospital to complete a PhD (1983). I gained my clinical psychology qualification at Liverpool (1986) and after 10 years being involved in undergraduate teaching of 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 Bute Medical School, University of St Andrews (Nov 2003). I have an interest in understanding the communication processes between clinician and patient in particular conditions, including the assessment and description of the processes involved. I attend joint head and neck cancer clinics at the Edinburgh Cancer Centre and interested in the design of psychological interventions.

Dr Kaye Radford

Kaye is Chief Speech and Language Therapist for Sandwell & West Birmingham Hospital Trust at City Hospital in Birmingham. She has specialised in the field of head & neck cancer for over 20 years with a particular interest in surgical voice restoration, dysphagia, quality of life and multi-disciplinary team working.

She is presently Chair of the national RCSLT Specific Interest Group in head and neck oncology and a RCSLT adviser. She has represented the SLT profession over many years in several national groups working to maintain the profile of SLTs working with head and neck patients. In October 2007 she was awarded the fellowship of the RCSLT for her contribution to the profession.

As well as a clinician she is actively engaged in research. She completed her PhD at Birmingham University in 2004 on the subject of voice rehabilitation after laryngectomy. She is a member of the NCRI survivorship head & neck research group and is currently researching the effects of chemo radiation on swallowing.

She has many projects she wants to see through before she hands over the baton at the race to retirement!

SESSION 1

Thursday 6th November 2008

SESSION 1

- 8.30 – 9.00** Registration, Tea & Coffee
- 9.00** Welcome - Mr Simon Rogers
- 9.15 – 10.00** Computerised screening for psychological distress & quality of life
Professor Irma Verdonck
- 10.00 – 10.45** Title
Professor Hans Aarstad
- 10.45 – 11.15** MID MORNING BREAK
- 11.15 – 11.45** Application of new radiotherapy technologies
Including IMRT to maximize HRQOL
Dr Chris Nutting
- 11.45 – 12.15** Hard to swallow? A study of the effects of chemoradiation
Dr Kaye Radford
- 12.15 - 13.00** **Free papers and discussion**
- 12.15 – 12.30** Kate Macfarlane Clinical Lead Speech & Language therapist:
Understanding Why Patients with Head & Neck Cancer
Continue to smoke: A Qualitative Approach
- 12.30- 12.45** Mr Anthony Morley Specialist Registrar ENT
'Taste as a functional loss in Head & Neck cancer'
- 12.45 -13.00** Annette Zuydam – A longitudinal study of swallowing function
following surgery for Head & Neck Cancer
- 13.00 – 14.00** LUNCH (Meeting of the North of England Psychology Group)

Computerised screening for psychological distress & quality of life

Professor Irma Verdonck

Touch screen computer-assisted health-related quality of life and distress data collection in head and neck cancer patients

Worldwide approximately 500,000 patients are diagnosed with primary head and neck cancer every year. Next to traditional outcome measures of overall survival, tumor control, and complications, health related quality of life and functional health status measures, have grown to become standard outcome parameters in clinical studies. With the incorporation of such tools, research has demonstrated that head and neck cancer and its treatment has a distinct impact on daily life. In addition to general complaints of cancer patients such as pain and fatigue, head and neck cancer patients are often confronted with changes in facial appearance, voice, speech and swallowing problems and related social withdrawal and emotional distress.

It has thus become essential to systematically measure and record these data at various points in time during and after treatment. HRQOL questionnaires were used originally as a research tool but their use has now expanded into the clinical arena.

Completion of HRQOL questionnaires can improve better patient-doctor interaction and understanding. It allows expression of concern that the patient is otherwise reluctant to mention and will discover additional information to that found in conventional medical notes. Self-reported screening questionnaires for psychological distress result in better detection rates for anxiety, depression, and other psychological distress than those found in standard clinical practice. The presentation will give insight in the development and implementation and first results of OncoQuest: a touch screen computer-assisted health-related quality of life and distress data collection system in clinical practice.

Quality of life (QoL) and the association with psychological characteristics of the patient

Aarstad, Hans J.

Department of Surgical Sciences, Faculty of Medicine, University of Bergen, N-5021 Bergen, Norway & Department of Otolaryngology/Head and Neck Surgery, Haukeland University Hospital, 5021 Bergen, Norway.

In 2002, there were approximately 650 000 new cases of cancers of the oral cavity, pharynx and larynx reported worldwide, making head and neck (HN) cancer the fifth most common cancer in the world. About 90% of these cancers are squamous cell carcinomas (SCC). HNSCC is common in many developing countries like India. In Norway, the incidence of HNSCC accounts for about 2.15% of the total cancer incidence. Treatment of HNSCC is curative for about half of diagnosed patients and affects relatively young persons, creating a high number of patients who have

survived HNSCC, compared to other cancer diseases. Health-related quality of life (HRQoL) studies in former HNSCC patients are therefore highly relevant.

Interestingly, most investigators have shown that reported general HRQoL of surviving HNSCC patients is remarkably similar to that of the general population. Furthermore, reported HRQoL differences between patients who have received extended treatment with many sequels, compared to those who have had limited treatment without specific sequels, are also relatively small. Thus, the question arises as to which parameters, in addition to levels of treatment and demographic variables, determine HRQoL. It is therefore of interest to study relations between HRQoL and psychosocial characteristics of patients such as social support, anxiety, depressed mood, personality and choice of coping.

Two hundred members of the Norwegian Society of Laryngectomees (NSL), a subsidiary of Norwegian Cancer Society, were invited to answer questions assessing Quality of life (HRQoL) and some of their psychosocial conditions. 104 patients returned the questionnaires anonymously. This sample was analysed together with responses from all HNSCC treatment survivors in Western Norway between 1992 and 1997. This sample included 96 out of 106 eligible patients.

HRQoL was assessed by the EORTC QLQ-C30 (ver.3.0) and QLQ-H&N35 HRQoL questionnaire. Personality was determined by the Eysenck personality Inventory/ Questionnaire (EPI/EPQ), mood by the Beck Depression Inventory (BDI) scores, level of social support by the Murberg social support test, general choice of coping including drinking to cope (DTC) and coping by humor by the COPE questionnaire. Marital and educational statuses were also determined as well as level of education and number of persons in the household. Activity levels of each patient within NSL were also assessed among the laryngectomized group and reported alcohol and tobacco use among the Western Norway group.

Clinical variables (TNM stage and treatment level) were obtained from medical records. Information about other diseases and medication were obtained from interviews/questionnaires.

Fifty-five out of 58 eligible Western Norway patients were interviewed a second time, 47±1 months after the first interview. This time neuroticism and HRQoL questionnaires were answered. The Western Norway group was subjected to standardized interviews and laryngectomized patients answered anonymous questionnaires.

QLQ-C30 symptom scores, e.g., dyspnoe, smell and taste, but not QLQ-C30 functional scores or disease specific scores, of laryngectomees differed from the general HNSCC-treated population. The level of social support by family, friends and neighbours was not associated with HRQoL, whereas high BDI scores were associated with reduced HRQoL by most measured indexes. Furthermore, a positive association was demonstrated between level of activity within the NSL and HRQoL. This relation was to some extent secondary to differential BDI scores.

Neuroticism scores were test/re-test reliable as judged by neuroticism scores measured at the time of primary HNSCC diagnosis for a sub-sample (N=22) of included patients. High neuroticism was associated with low HRQoL in both patient samples. The neuroticism score was associated with the QLQ-C30 scales (common

variance (CV): 17-25%) in both groups and the QLQ-H&N35 scores in the laryngectomized group (CV: 11-25%). Associations could still be shown when adjusted for gender, age, marital status, educational level, number of children and level of treatment. Extraversion was associated with general HRQoL, physical, and emotional scores in the Western Norway group. Radiation therapy in the Western Norway sample was associated with H&N35 symptom scores, but different ones than those associated with neuroticism.

In the Western Norway sample, level of problem-focused coping style was associated with T stage and whether or not radiotherapy was administered to the neck. Lowered HRQoL was generally associated with an avoidance-focused coping style. Employment of emotional focused coping was associated with low HRQoL among patients treated with surgery only, and associated with increased HRQoL among patients treated with radiation therapy only. Associations between HRQoL and coping style levels were stronger for HRQoL indexes, reflecting cognitive/emotional function, than for HRQoL indexes, reflecting physical function.

Reported level of alcohol consumption was associated with global HRQoL ($r=-0.22$) and DTC ($r=0.31$). Reported smoking level was associated with DTC ($r=0.26$) and inversely with C30 functional/symptom sum HRQoL ($r=-0.31/0.27$) scores. Level of DTC was associated with C30 global ($r=-0.30$) and C30 functional/symptom sum HRQoL scores ($r=-0.31/0.27$) and this association was still present after adjusting for gender, age, levels of neuroticism and avoidance coping.

When measured longitudinally, numerical T stage was inversely associated with secondary HRQoL scores (CV: 10-24%). High neuroticism generally predicted low secondary HRQoL scores both directly (CV: 17-25%) and adjusted by HRQoL values measured simultaneously as neuroticism (CV: 11-25%). Avoidance-focused coping style, problem-focused coping style, drinking to cope and coping by humour, all predicted HRQoL scores (CV: 8.5-15%). The present association pattern could still be shown when adjusted for gender, age, and educational level when studied by multiple regression analyses.

In conclusion, as measured by survey analysis, the HRQoL of laryngectomees is relatively similar to that of a general population of patients treated due to HNSCC, is related to the activity level within a patient interest organization, and is associated with decreased mood. High neuroticism, but not extraversion, is broadly associated with lowered HRQoL. The level of problem-focused coping style was associated with T stage and whether radiotherapy was administered to the neck. Level of avoidance coping was inversely associated with HRQoL, and level of emotional coping was associated with HRQoL in a complex manner. Level of coping by alcohol consumption was broadly associated with level of general HRQoL. As measured by longitudinal analysis, a high T stage, high neuroticism, coping by humour and coping by problem solving directly predicted low HRQoL, whereas neuroticism was also associated with HRQoL through avoidance coping.

The survival of the included Western Norway patients were also determined 5 years following initial inclusion. It was shown that the EORTC H&N QoL scores predicted HRQoL. When employing Cox regression analysis, this was also determined with the EORTC C30 general QoL scores when these were adjusted by the neuroticism scores of the patients. This survival prediction was mostly not related to HNSCC disease factors.

In conclusion, we suggest that the EORTC QoL score depend on psychological factors, on HNSCC disease and treatment related factors as well as a factor related to mortality separated from the before mentioned factors.

Application of new radiotherapy technologies including IMRT to maximize HRQOL

Dr Chris Nutting Consultant Clinical Oncologist

The application of computer designed focus radiation techniques such as IMRT has now become one of the standards of care for irradiating patients with locally advanced head and neck cancer. The application of these techniques has been aimed to reduce some of the long-term complications of radiotherapy particularly dysphagia and xerostomia. The emergence of quality long-term follow-up data for patients treated with these techniques has been slow, but during this talk I will present our own experience with Head and Neck IMRT and discuss the potential benefits of these technologies in improving patients' long-term quality of live.

Hard to swallow ? A study of the effects of chemoradiation

Authors: Kaye Radford, Pauly Wong, Andrew Batch, John Glaholm
City and University Hospitals, Birmingham

Background

It is well documented in the literature that improvement in survival after head and neck cancer treated with chemoradiation (CRT) is at the expense of significant morbidity particularly with swallowing. Evidence is mainly from the US and reports on the effects of CRT on swallowing function, quality of life and nutritional intake. Few studies are prospective, data from the UK is scarce and most report on only one or two specific assessments of swallowing, nutrition and quality of life.

Aims

This study is an attempt to provide some prospective data on outcomes from UK practice using a range of assessments to measure fully the effects of CRT.

Methods

A prospective study was carried out with 17 patients with advanced head and neck cancer sites from two centres in Birmingham having chemoradiation as primary treatment.

Assessments took place at three times: pre-treatment (1), one – three months post treatment (2) and nine to twelve months post treatment (3). These were videofluoroscopy, University of Washington Quality of Life, M.D. Anderson Inventory (MDADI) and a range of dietary and nutritional measures. Semi-structured

interviews took place at the final interview. Seventeen patients completed assessments 1 & 2 and 15 completed 3.

Results

All assessments showed problems pre-CRT treatment.

PEGs

All patients had PEGs fitted prior to treatment and all but two used it during the treatment. PEG days ranged from 80-430 days with three patients still having a PEG at final assessment. Many reported complications and effects on day-to-day activities.

Nutritional Intake

Most patients managed oral intake pre-treatment and at the final assessments but the majority needed supplementary nutritional support at the second assessment.

University of Washington – Quality of Life

Swallowing was rated an important issue at all three assessments. Mean domain scores showed swallowing impaired pre-treatment, worse at (1) but not recovered to pre-treatment levels by (3). Speech and mood were worse at the final assessment.

There were statistically significant differences in results for swallowing, chewing and saliva over the three assessments.

MDADI

Global scores showed deterioration post treatment and all three domains (physical, function and emotion) showed significant difference over time with results at the final assessment below those at pre-treatment.

Videofluoroscopy

Only seven patients had normal swallows pre-treatment.

A range of problems with the pharyngeal stages of the swallow were evident at all three assessments.

Interview Data

All patients reported problems and complications from the treatment including PEGs, dental extractions, hearing and infections. All seventeen had dental extractions prior to treatment.

Most patients smoked before treatment (only four did not), some continued during treatment and most resumed after treatment.

Twelve drank alcohol prior to treatment, eight of these stopped during treatment and most who continued post-treatment reduced the number of units.

Conclusions

Recruitment of patients to a study in the time before starting CRT treatment is problematic for a variety of reasons.

All assessments showed many patients had problems pre-treatment with significant changes post treatment. Patients self reported a range of problems and complications.

Three patients still required PEG feeding at final assessment but most were on oral diet.

A comprehensive range of assessments carried out from the time of pre-CRT treatment to one year by the speech and language therapist and dietitian allows for the early identification of problems that otherwise may be undetected and facilitates the provision of timely intervention.

Understanding Why Patients Treated for Head and Neck Cancer Continue to Smoke: A Qualitative Approach

Kate Macfarlane BSc (Hons) MSc Cert. MRCSLT

*Clinical Lead Speech and Language Therapy
Head and Neck Unit
Royal Marsden Hospital NHS Foundation Trust*

Head and neck cancer is a rare and life threatening disease that it is on the increase. The cancer can result in impaired speech and swallowing functions and thus reduces an individual's quality of life. In the majority of cases it is a preventable disease with smoking a major contributing factor. Up to a quarter of patients continue to smoke following treatment for head and neck cancer and by doing so increase the risk of recurrence, which may be fatal. The aim of this study was to examine why this particular cohort chooses to risk the chance of further cancer by continuing to smoke. As most literature to date has been quantitative in nature a qualitative approach was chosen to allow in depth exploration of the topic. Qualitative analysis of semi structured interviews was carried out using a Framework Analysis approach which is informed by Grounded Theory and has its background in social policy research. This study looked at the perceptions of six male patients, successfully treated for head and neck cancer. The results identified five themes; addiction, coping, conflict, justification and information and the complex interaction between the themes, with sub themes and main themes crossing over in many areas. In conclusion the data from this qualitative study adds to the literature and further confirms that the rationale for ongoing smoking is multifactorial. Recommendations are made for smoking cessation in this population.

Taste as a functional loss in head and neck cancer patients

AUTHORS Morley AD, Simcock R, Weighill JS

INTRODUCTION

Taste plays a significant role in the function of patients with head and neck cancer. Historically however, taste loss has not received much attention from healthcare providers universally. Severe taste loss carries important risks for the individual, especially when psychologically challenged during cancer treatments.

AIMS

To establish to what quantitative degree taste function is impaired following treatment for various head and neck cancers.

METHOD

Pilot study of 19 head and neck cancer patients approached in a Regional Cancer Clinic. Individuals were questioned regarding taste impairment. The cancer diagnosis and treatment (including nerve section) were noted. Electrogustometry was performed with the TR-06 Rion, using accepted psychophysical techniques. Demographics included age, presence of a taste problem, duration post-RT, type of cancer (larynx, oropharynx, oral cavity, salivary) and smoking status. Comparisons were made of the anterior tongue, posterior tongue and soft palate on the affected and opposite sides. Results were compared to normal data for this age group (*Nakazato*). Further analyses utilised a score representing global taste to compare the influence of gender, awareness of a taste problem, duration post-RT and smoking. MiniTab (Release 13.1) was used.

RESULTS

Results and their significance will be presented from the group studied (mean age 66 years; 15 males, 4 females; 7 oropharyngeal cancers, 6 laryngeal, 5 salivary, 1 oral cancer; mean duration post-radiotherapy completion 21 months, excluding two outliers).

CONCLUSION

Taste awareness is largely neglected in patients undergoing treatment for the head and neck. Poor taste impacts the nutrition, quality of life and functional outcomes of these patients significantly.

ACKNOWLEDGEMENT

This work was funded generously by the Bardhan Research and Education Trust, the Sir Halley Stewart Trust, the Get-Ahead Charity and the Brighton ENT Department.

A longitudinal study of swallowing function following surgery for Head and Neck Cancer

*A.C. Zuydam, D.Lowe, SN Rogers
Aintree University Hospitals NHS Trust Liverpool etc*

The treatments currently available for Head and Neck Cancer can result in a range of physical, functional and psychosocial problems including impairment in swallowing. Despite the advent of advanced treatments, the procedure will often involve removal of, or damage to, tissue in areas where mobility of structures and intact sensation are essential. A number of factors have been found to be relevant in determining patterns of recovery. These relate to a number of surgical factors as well as the nature of treatment, and it is important that they are considered when looking at data to account for any differences observed within or across groups.

The aims of the study were to describe in detail the nature of the swallowing impairment and how this related to various surgical and other treatment factors.

Subjects were patients referred following surgery in a Regional Head and Neck Cancer Unit .MDADI and UWQOL swallowing domain questionnaires were completed at 6 months and 12 months post surgery.

Highly significant correlations were found between the UWQOL and the MDADI with the strongest correlation being with the physical subscale of the MDADI. There was little change seen over time.

The MDADI seems to provide more detailed information on the impact of swallowing function on everyday life. Ongoing data collection will contribute to informed treatment decisions, and allow for the planning of appropriately timed rehabilitation programmes.

Annette Zuydam
Head Speech and Language Therapist

SESSION 2

Thursday 6th November

- 14.00 – 14.30** How to look at Quality of Life in clinics: lessons from Listening to our patients
Mrs Sheila Fisher
- 14.30 – 15.00** Does QoL predict survival in HNC
Mr Hisham Mehanna
- 15.00 – 15.30** Speech & swallowing impairment in head & neck Cancer
Professor Irma Verdonck
- 15.30 – 16.00** MID AFTERNOON BREAK
- 16.00 – 18.00** **Free papers & discussion**
- 16.00 – 16.15** **Zoe Knight** -The development & validation of a self rating questionnaire to measure the outcome of speech & language therapy intervention in the head & neck cancer population
- 16.15 – 16.30** **Suzy Forgie** -The evaluation of the Brief ICF Core Set for Head and Neck Cancer as a patient self-completed questionnaire.
- 16.30 – 16.45** **Margereth Bjorklund** - Health promotion from the perspective of living with head and neck cancer
- 16.45 – 17.00** **Kirsten Becker**- Quality of life of tumour patients following surgery & reconstruction of the oro-mandibular region
- 17.00 – 17.15** **Martijn Stuiver** – Impact of shoulder complaints after Neck dissection on shoulder disability & Quality of life
- 17.15 – 17.30** **Sam Harding** – A Qualitative Investigation into the impact of pegs
- 17.30 – 17.45** **Devendra Chauker** – Quality of life in Head & Neck Cancer: A longitudinal study
- 17.45 – 18.00** **Aram Badalyan** – Recent approaches to treatment of Larynx Cancer of Stage III (T3NOMO)
- 18.00 – 18.15** **Lesley Freeman** – Dietetic-led gastrostomy service – Experience in a UK tertiary head & neck cancer centre
- 19.00** **COURSE DINNER**
Tai Pan Restaurant Blackstone Street, Liverpool L5 9TZ

How to look at Quality of Life in clinics: lessons from listening to our patients

In this talk I will outline our findings to date from our study of the opinions and preferences of patients for consultations and questionnaire assessment. The main areas are summarised below:

Background:

HRQoL assessment of Head and neck (H&N) cancer patients is complex. Our hypothesis is: 'carefully designed questionnaires can contribute to patient care'.

Purpose of Study:

To assess patient opinions on:

- HRQoL questionnaires.
- medical consultations

Method:

Patients with oral, laryngeal and thyroid cancer, at least 1 year after therapy were invited to complete a touch-screen assessment of general questionnaires: SF-36, EORTC QLQ C30, FACT-G and H&N questionnaires: EORTC H&N, FACT H&N and UWQoL v4. For consultations we adapted the method published by Detmar (*JCO*, 2000, 18, 3295).

Results:

Of 152 patients recruited. 101 had no preference. 31 favoured FACT-G, 20 SF-36 and 16 EORTCQLQ-C30. FACT-G was considered by 106 (63.5% of returns) to reflect 'important' issues, compared with 95 (57.2% of returns) for EORTC and SF-36. The EORTC scored highest for being 'well written' (100, 59.9%) compared to FACT-G (98, 58.7%) and SF-36 (85, 51.2%).

On 'attitude to consultation' patients wanted to discuss 'disease specific limitations' (136 returns, 80.4%). This scored more highly than 'symptoms and side effects' (123, 72.8%). On 'perceived content of consultations' 'symptoms and side effects' was most likely to be discussed (60.7% often or always) compared to 'limitations' in 33.2% at the same level. The greatest discrepancy was 'emotional' aspects. 62.7% wished for inclusion but it was 'often or almost always' raised in 26% of consultations.

Conclusions:

Patients have clear views on HRQoL questionnaires and can define priorities for discussion in medical consultations.

Acknowledgements:

To BAOMS and Charitable Trustees of LTHT for their support.

To the Psychosocial Oncology and Clinical Practice Research Group, University of Leeds for hosting the study and sharing their expertise.

Does QoL predict survival in HNC

Mr Hisham Mehanna

Purpose

Quality of life (QoL) is an important outcome measure in head and neck cancer (HNC). There are now several well-validated and commonly used questionnaires to measure QoL in HNC. Results are usually reported in terms of differences between mean scores between groups eg mean of +3 or -15 points (with confidence intervals) using one of these questionnaires. It is hard however to understand how research reported using different questionnaires relate to each other, as to date there has been no way to relate the scores obtained by different questionnaires.

We aim to relate the scores of different HNC QoL questionnaires to each other to devise a normogram that can translate scores of one questionnaire to another.

Material/Methods

80 newly diagnosed HNC patients were asked to complete three widely used, validated HNC questionnaires – EORTC C35, FACT HN35, University of Washington QLQ v4- in random order. Distribution-based (Effect Size) methods were used to determine the magnitude of small, (ES 0.2) intermediate, (ES 0.5) and large (ES 0.8) clinically significant differences in the scores of the respective domains of different questionnaires, which were then compared and their correlation assessed using Spearman rank correlation coefficient. Finally a normogram was devised to relate the scores of the different questionnaires together.

Results

The results of global QoL domain are presented below in table 1. The results for each of the pain, speech, swallowing, energy and emotional domains will also be presented. We also present the correlation between each of the questionnaires for that domain. For example for the global QoL domain, EORTC overall scale showed a poor correlation (coeff 0.28) with UW questionnaire and moderate correlation (coeff 0.58) with FACT. Finally a normogram to allow the relation (or translation) of a score obtained using one instrument to the respective one of the other instruments will be demonstrated.

Conclusion

By comparing the different questionnaire scores, it is now possible to relate the findings reported by different studies and in different clinical settings using different QoL instruments, and thus better understand them. It also enables us to present findings in ways that are more easily understandable to clinicians.

Table 1

Means and standardised differences for the global QoL domain in the four questionnaires (some questionnaires have more than one domain)

Scale/item	Mean	SD	Benchmark score differences			# of patients
			Small (0.2 SD)	Medium (0.5 SD)	Large (0.8 SD)	
EORTC QLQ C30 scale	32.4	19.5	3.9	9.75	15.6	68
EORTC overall health	33.4	20.3	4.1	10.2	16.2	68
EORTC overall QL	31.3	21.3	4.3	10.7	17.0	68
FACT QL right now	33.5	30.7	6.1	15.4	24.6	71
UW health related QL 1mth	42.3	26.4	5.3	13.2	21.1	68
UW health related QL 1wk	41.7	19.6	3.9	9.8	15.7	71
UW overall QL 7 days	37.7	19.4	3.9	9.7	15.5	70
UW combined	40.4	17.1	3.4	8.6	13.7	71
AQLQ life satisfaction	27.9	15.2	3.0	7.6	12.2	67

Speech & swallowing impairment in head & neck cancer

Professor Irma Verdonck

The past decade has shown an improvement in the technical, surgical, and medical possibilities available to optimize speech and swallowing function of head and neck cancer patients. However, despite the medical/technical improvements, many patients still have voice, speech, or swallowing problems after treatment and require ongoing management by speech language pathologists. For this reason, measures of the functional status of voice, speech, swallowing pre and post treatment are necessary to fully document patient outcome. In order to compile this necessary data, a working knowledge of the generic and specific outcome measures available for use with for the head and neck population, is essential. The purpose of the presentation is to provide an overview of the main types of outcomes measures and assessment tools used in the evaluation of patient reported outcome, and functional voice, speech, and swallowing outcomes.

The development and validation of a self rating questionnaire to measure the outcome of speech and language therapy intervention in the head and neck cancer population

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Background

Measuring the outcome of treatment has become increasingly important in clinical practice to determine efficacy of treatment. A group of specialist clinicians identified the need for a questionnaire to measure the outcome of Speech and Language Therapy (SLT) in those with Head and Neck Cancer (HNC).

Aims

To develop and validate a questionnaire which is practical for use in the clinical setting but sensitive to the difficulties of this client group.

Method and Procedures

Two groups of participants were recruited into this cross sectional study; a group of individuals with a diagnosis of HNC (n = 64) and a Control group (n= 64) of those referred to SLT by Ear, Nose and Throat (ENT). Each group was asked to complete the proposed questionnaire targeting communication and swallowing and additional assessments of patients functioning; quality of life (QOL) and symptomatology were taken. Correlations between questionnaires were investigated along with group differences.

Results and Outcomes

An 11-item SaltOM Questionnaire was developed. Analysis revealed that the proposed questionnaire demonstrated a correlation with the total scores of other questionnaires. Correlation between the Performance Status Scale and the proposed questionnaire was 0.762 $p=0.001$. This was similar to the correlation between University of Washington QOL questionnaire and the proposed questionnaire (0.766 $p=0.001$). An ANOVA revealed, HNC patients to score worse in functioning (mean = 93.51, SD = 20.80) than the ENT group (mean = 99.05, SD = 12.67); however this result did not reach significance, Brown-Forsythe $F_{(1,104.103)} = 3.313$, $p = 0.072$). The results indicated that the proposed questionnaire compares with other validated questionnaires whilst targeting the difficulties of those individuals with HNC.

Conclusion and Implications

The proposed questionnaire has demonstrated validity on the analysis completed thus far; however for it to be useable in the clinical environment further research needs to be completed.

The evaluation of the Brief ICF Core Set for Head and Neck Cancer as a patient self-completed questionnaire.

AUTHORS Suzy Forgie, Derek Lowe and Professor Simon Rogers

INTRODUCTION

In 2001 the World Health Assembly adopted the International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organisation. This is a comprehensive classification system containing over 1400 items for health and health related states. To make it more clinically applicable Core Sets and Brief Sets have been developed for specific illnesses, the Core set for head and neck cancer is currently being validated in clinical practice. The validation phase involves a clinician led and rated interview with the patient using the ICF Core Set. This pilot study involves the development of the ICF Brief Set into a patient self completed questionnaire to see if it is a valid and feasible clinical tool for evaluating a patient's functional outcome and quality of life after head and neck cancer.

AIMS

- (1) To reformat the Brief Core Set into a patient self completed questionnaire.
- (2) To compare the results between the Brief ICF questionnaire as completed by a patient with one scored by a clinician at interview.
- (3) To evaluate patients views on its content and design.

METHOD

The Brief ICF Core Set was formatted into a questionnaire which the patient can self-complete. All eligible patients were invited to participate in the study and those who agreed were given the option to complete both the questionnaire and be interviewed or just complete the questionnaire only. All the participants were asked to complete the same questionnaire twice, about one week apart

RESULTS

There was a trend for the clinician to over-score the problems which the patient reported compared to how the patient rated their problems. However test-retest analysis on the self-completed questionnaire data showed good agreement. We found that patients generally felt that it was easy to understand and complete and suggested improvements such as adding further domains and more free text space.

CONCLUSION

The Clinician rated interview is a very subjective way of recording and measuring patients functional outcomes. As a patient self completed measure it is an objective assessment of their problems and issues and thus is a more accurate gauge in which to direct any rehabilitation or intervention.

The ICF Brief Core Set has potential to be a valuable tool for international comparisons of data because it is derived from a WHO Classification.

(24)

Health promotion from the perspective of living with head and neck cancer

AUTHORS

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INTRODUCTION

Little is known about what promotes health from the perspective of individuals living with head and neck cancer. To a great extent, research in this area is confined to the disease itself, its treatment and side effects such as difficulty breathing, speaking, drinking and eating. It seems fair to assume that increased knowledge of what promotes health from an insider perspective could result in a new understanding of what could ease everyday life for the individual with this cancer.

AIMS

The aim was to illuminate health promotion from the perspective of individuals living with head and neck cancer.

METHOD

Eight participants aged 52-83 years, four of each, were interviewed and latent content analysis was used to interpret the data.

RESULTS

The participants' ability to promote health varied and was dependent of their enabling of performance for to regain control and empower themselves. Empowerment, the goal of health promotion, was shown as an ongoing process of

internal and external enabling. Internal enabling was shown when trying to contact one's inner self and was important and had a deep existential value. It creates individual progress such as transformed and enhanced self-esteem as well as improved self-determination. External enabling was provided in connection and relations with nature, hobbies or activities, family and friends.

CONCLUSION

The empowerment process was different for each individual and was shown as interplay between internal and external enabling for to promote health. These findings may inspire health professionals to facilitate the individual's empowerment process and pose non-pathology oriented questions such as "what improves your health?" or "what makes you feel good?"

(25)

Quality of life of tumour patients following surgery and reconstruction of the oro-mandibular region.

Authors:

Kirsten Becker-Bikowski, Prof. Dr. Silke Birgitta Gahleitner, Christin Dubrow, Robin Schiel, Dr. Dr. Kolja Freier, PD Dr. Dr. Christof Hofele

The contribution of the hospital clinical social work service to psycho-social care.

Introduction:

Cancer of the oral and maxillofacial region in most cases results in a severe impairment of the patients' quality of life. Progress in medical care has contributed to a prolongation of life and to an improvement in quality of life, which is also determined by psychosocial factors (Larbrig & Tschuschke, 2000), whereby coping strategies (Spiegel & Kato, 2000) and „sense of coherence“ (Antonovsky, 1997) play an important role. There are numerous hints that psychosocial variables have an influence on the course of the disease. Now it has to be determined which type of patient with which oncological pattern, gender or state of the disease profits most (Tschuschke, 2003; Stump & Koch, 1998).

The object of our investigation is the multi-dimensional term "quality of life", which plays an increasingly important role in the therapy of tumour patients (Gandek et al., 1998; Kohlbrunner et al., 2001).

Aims:

How do patients with tumours in the region of head and neck cope with their situation and how can the hospital clinical social work service influence the patients' quality of life positively?

Method:

21 Problem-centred, explorative, preliminary interviews with an open introductory question (Witzel, 1985) were carried out in order to reach an access to the reality of life of the patients concerned. The interviews were evaluated according to Mayring (1993, 2000).

Results:

- (a) The illness is a pivotal turning point in the cancer patients' lives which becomes the starting point for numerous changes.
- (b) Patients cope with their illness by falling back on strategies that have proved successful for them in the past and in which their own self-concepts and subjective concepts of sickness play an important role, but are also profoundly shaken.
- (c) The ambivalence between being realistic (accepting) on the one hand and avoidance on the other determines the characteristic poles between which the strategies for coping with the illness stretch.
- (d) In professional care-giving the medical and social fields become polarised. The powerful medical machinery is contrasted with a need for "humane" counselling and support.
- (e) The social work service plays an important role in the provision of support for changes in and coping with the tasks of daily living, developing constructive subjective concepts of the altered life circumstances, the threat of death, and work with relatives and other social contacts.

Conclusion:

The results indicate that the success of professional support in the field of palliative cancer care and during the terminal phase depends on the quality of the helping relationships and on whether the support provided by the patient's social environment is taken into consideration. In contrast, previous theories in clinical psychology and medicine have focused on variables relating to the individual rather than on context factors and a comprehensive mode of handling the professional relationship.

Impact of shoulder complaints after neck dissection on shoulder disability and quality of life.**AUTHORS**

Martijn M Stuiver, Cornelis P van Wilgen, Eriijn M de Boer, Cees JT de Goede, Muriel Koolstra, Anita van Opzeeland, Piet Venema, Margriet W Sterken, Andrew Vincent and Pieter U Dijkstra.

INTRODUCTION

Incidence of shoulder complaints after neck dissection (ND) ranges from 18-100%, depending on the type of ND. The impact of shoulder complaints on disability and quality of life (QOL) has been investigated scarcely. Intensive exercise seems to be effective to prevent or attenuate shoulder complaints after ND. However, not all

patients may need early intensive exercise. Identifying predictors for shoulder disability could help identify patients at high risk.

AIMS

To explore the relationships between ND related shoulder complaints, shoulder disability and QOL and to identify predictors for shoulder disability.

METHOD

Shoulder pain, mobility and droop, scores on Shoulder Disability Questionnaire (SDQ) and RAND-36 (QOL), were measured at baseline, discharge (T1) and 4 months postoperatively (T2) on 139 patients admitted for ND to major head and neck centres in the Netherlands.

RESULTS

Shoulder abduction reduced significantly after ND (median decrease: 34° at T1, 50° at T2). Significant relations existed between SDQ score and shoulder droop ($r=0.65$), shoulder abduction ($r=-0.61$) and shoulder pain ($r=0.70$). SDQ score was significantly related to physical functioning ($r=-0.37$) and bodily pain ($r=-0.53$). Interrelated clinical symptoms predicting shoulder disability were: declined active mobility of the shoulder, non-selective ND and shoulder droop (joint influence $p=0.007$); and pain on external rotation of the shoulder and shoulder pain (joint influence $p=0.03$) (model $r^2=0.50$).

CONCLUSION

Deterioration of shoulder function after ND predicts shoulder disability and is related to physical functioning and bodily pain. Patients at increased risk for mid-long term shoulder disability can be identified through clinical characteristics.

A Qualitative Investigation into the impact of PEGs

AUTHORS

Harding, S., Anand, P. & Courtney, DJ.

INTRODUCTION

Research by this team showed an initial reduction in Quality of Life (QoL) due to the effects and demands of treatment as measured by the questionnaires, but participants want to add detail about specific areas of concern to themselves. One of these issues is the use of PEGs.

AIMS

The aim of this work was to explore the views of patients regarding the impact of having a PEG in-situ.

METHOD

Ten patients were recruited prior to treatment for Head and Neck Cancer. They participated in a semi-structured interview and then completed the University of Washington and EORTC-C30 and HN35 QoL questionnaires to ensure comparability

with previous studies. Follow-up data was collected at 1, 3, and 6 months post treatment.

RESULTS

Data revealed that those participants with a PEG in-situ had issues with clothing, activities, and sex, which were not apparent in those non-PEG participants. All rationalised the placement of the PEG, but expressed a desire for the PEG to be removed in order to more freely socialise, not be restricted in activity and start 'feeling normal'. Communication with clinicians about the expected duration of use was described as poor. Patients needing new dentures prior to removal of the PEG reported feeling 'abandoned' by the hospital and 'not confident in their dentists'.

Quality of life in Head and Neck cancer: A longitudinal study.

AUTHORS :

Chaukar D, Deshpande M, Pai P, Pantavaidya G, Chaturvedi P, Dcruz A.

INTRODUCTION:

Quality of life (QOL) is an important endpoint in Head and Neck cancer due to the functional and cosmetic impact of treatment. Studying the changes in QOL during various stages of treatment helps us make treatment decisions and plan rehabilitation.

AIMS:

To examine the changes in QOL that occurs over time.

METHOD:

215 surgically (with or without adjuvant therapy) treated patients filled the EORTC QOL questionnaire preoperatively, following adjuvant therapy i.e at 3 mths, 6mths and at 1 year.

RESULTS:

The scores were at their worst at 3 and 6 months and improved at end of 1 year. Most returned to baseline with the exception of coughing, dry mouth and problems with social contact and senses which persisted to be a problem. A clinically significant change (>10 point change, decline) was seen at 3 and 6 months in appetite, fatigue, insomnia, QOL, cough, dry mouth, social contact and senses. Overall QOL and insomnia scores were significantly better than baseline at the end of 1 year.

CONCLUSION:

Treatment for head and neck cancer results in short term morbidity, most of which resolves within one year. In contrary to the assumption, the impact of disease and its treatment in long term seems to be less severe.

Recent Approaches to Treatment of Larynx Cancer of Stage III (T3N0M0)

AUTHORS: R.Azizyan, A.Badalyan

*Department of Upper Aerodigestive Tract Tumors,
Russian Oncological Research Centre, Moscow*

Larynx Cancer makes 2, 2 % in the general structure of cancer abundance among the population and its frequency annually rises. Widespread forms of the disease (T3, T4) are diagnosed at 60-70 % of the patients and only in 30-40 % the limited tumoral affections (T1, T2) are observed. At Larynx Cancer of local extension the efficiency of radiotherapy makes 25-30 %, and the performance of functionally sparing operations is practically impossible. In connection with this the combined treatment is traditional, with various sequences of radio and surgical methods. The results of the treatment are high enough – five-year survival rate reaches 75 %. However the main method of radical surgical intervention is laryngectomy, but it leads to physical and social disability of the patient. Therefore the possibilities of conservative treatment of Larynx Cancer of local extension have been intensively studied throughout long period of time. At present chemo-radiation method is considered to be the most worth-while.

Materials and Methods.

In the Department of Upper Aerodigestive Tract Tumors in RORC the chemo-radiation treatment of squamous cell Larynx Cancer T3N0M0 was carried out at 228 patients. The treatment was started with carrying out one or two courses of chemotherapy and in the pattern of treatment there were preparations of platinum and 5-Fluorouracil (5-FU) which made a good showing at the treatment of squamous cell Larynx Cancer. Further the radiation of the primary tumor and zones of regional metastases was carried out by the split course in a multifractional way to total focal doses 66-70 Gr.

25 patients received one course of chemotherapy by preparations Cisplatin, 5-FU, Bleomycin and also multifractional radiation. The disease free survival current was noted at 18 (72 %) patients, residual tumors and relapses were diagnosed at 7 (28 %) patients. Five -year survival rate made 76 %.

Two courses of chemotherapy by preparations Cisplatin, 5-FU, Bleomycin and radiation therapy in a multifractional way were carried out at 123 patients. The disease-free survival was observed at 106 (86, 2 %) patients. The treatment failures made 13 %, five years' survival rate made 83 %.

80 patients received the treatment by preparations Cisplatin, 5-FU, Leucovorin (2 courses) and also multifractional radiation. Absence of effect was noted at 11 (13, 7 %) patients, five-year survival made 87 %.

Conclusions.

Thus the 5-year survival rate at carrying out chemotherapy by preparations Cisplatin, 5-FU and Bleomycin turned out to be higher in comparison with other applied patterns. The combination of the split courses of radiation in a multifractional way with two courses of chemotherapy (prior to the beginning of radiation and after the 1st stage) by preparations Cisplatin, 5-FU, Bleomycin is optimum at chemo-radiation treatment of Larynx Cancer T3N0M0.

Dietetic-led gastrostomy service – experience in a UK tertiary head and neck cancer centre

Authors: Rachael Donnelly¹, Lesley Freeman¹, Pippa Lowe¹, Lucy Mowatt¹, Ricard Simo², Jean-Pierre Jeannon², Mary O’Connell³, Frances Calman³, Richard Salter⁴, Terry Wong⁵, Azhar Ansari⁵, Michelle McCarthy⁵.

Departments of Nutrition & Dietetics¹, ENT Surgery², Clinical Oncology³, Radiology⁴ and Gastroenterology⁵ Guy’s and St Thomas’ NHS Foundation Trust, London, UK.

Purpose

Feeding gastrostomies are well-established as a method of providing adequate nutritional support in patients undergoing treatment for head and neck cancer (HNC). A 12 month review of the gastrostomy service was undertaken in 2004 and highlighted deficiencies in the insertion process. These included: poor patient selection, inconsistent referrals, inadequate patient preparation and ultimately a high proportion of nutrition related complications during treatment. The aim of this paper is to report our experience of establishing a dietetic-led gastrostomy service for HNC patients from 2005 to date (August 2008) and to highlight its benefits.

Material

The dietetic department identified key stakeholders including dietetics, gastroenterology, radiology, surgical teams and clinical oncologists to develop a coordinated gastrostomy pathway. Patients were interviewed and their experiences recorded. A dietetic time-in-motion study was undertaken to determine what additional roles were appropriate for the dietitians to undertake and whether this would improve the pathway. Problems were identified and a pathway was developed and implemented. The current dietetic-led pathway includes defined patient referral criteria, protocol for airway assessment, dietetic assessment and pre and post insertion guidelines.

Results

Between January 2003 and August 2008, 342 gastrostomies have been inserted in patients with a diagnosis of HNC. Of these, 283 were PEGs, 56 were RIGs and 3 were surgically placed (Figure 1).

	Jan 03- Dec 03	Jan 04 - Dec 04	Jan 05 - Dec 05	Jan 06 - Dec 06	Jan 07 - Dec 07	Jan 08 - Aug 08
PEGs	12	38	64	56	56	57
RIGs	0	0	2	10	23	21
Surgical	0	0	2	1	0	0
TOTAL	12	38	68	67	79	78

Figure 1

Prior to the introduction of the dietetic led service there was 1 death (2%) and 1 major complication (2%) out of 50 tube insertions. Since introduction of the dietetic led service there have been no deaths (0%) and only 3 major complications (1%) out of 292 tube insertions. In addition the number of insertions has increased following the implementation of the pathway (Figure 1).

Conclusion

In our experience the lack of a co-ordinated gastrostomy service has led to a higher incidence of mortality and morbidity. A dietetic led service has reduced both mortality and morbidity related to gastrostomy insertion. In addition it has enhanced multi-disciplinary working and improved the patient experience. More research is needed especially on QoL related issues and gastrostomy feeding.

Session 3

Friday 7th November

8.00 – 8.30	Tea, Coffee & biscuits
8.30 – 9.15	Factors influencing the quality of life , recurrence, and survival of head & cancer patients Dr Sonia Duffy
9.15 – 10.00	Depression as an outcome measure in Head and Neck cancer Dr Rob deLeeuw
10.00 – 10.30	The latest in the design of complex psycho-social interventions: from research to practice Professor Gerry Humphris
10.30 – 11.00	Support needs of parents with head & neck cancer caring for children Dr Cherith Semple
11.00 – 11.30	MID MORNING BREAK
11.30 – 13.00	Free papers
11.30 - 11.45	Charles Kelly: Return to work after treatment plan as a further measure of Quality of Life for head and neck cancer patients.
11.45 – 12.00	Elizabeth Precious: Patient perception of carer burden: SSM Medical Student Project
12.00 – 12.15	Jo Patterson: Carer quality of life in head & neck cancer A longitudinal study
12.15 12.30	Heidi Lang: Experiencing head and neck cancer: A meta- synthesis of qualitative studies
12.30-12.45	Dr Joseph El-Sheikha: A Patients Concerns Inventory (PCI) to help raise patients concerns in a routine head and neck clinic: a pilot study
12.45 – 13.00	Ann Taylor: Information and its role: experiences of people affected with laryngeal cancer
13.00 – 14.00	LUNCH

Factors influencing the quality of life recurrence , and survival of head & neck cancer patients

AUTHOR

Dr Sonia Duffy, PHD, RN

Outline

- I. Why study quality of life?
- II. Description of longitudinal study of over 800 head and neck cancer patients
- III. Health behaviors in the first year after diagnosis
- IV. Interrelationship among health behaviors
- V. Health behaviors and quality of life
- VI. Health behaviors and survival
- VII. Disparities and Survival
- VIII. Mind-body characteristics and recurrence/survival
- IX. Biomarkers and survival
- X. Model for psychosocial intervention
- XI. Comments

Depression as an outcome measure in Head and Neck cancer

AUTHOR

Dr Rob deLeeuw

Depression is a common but not universal reaction to cancer, is frequently under-diagnosed and hence frequently under-treated in patients with cancer. Head and neck cancer and its treatment can have important psychosocial implications and many patients become depressed. Patients with head and neck cancer are prone to psychosocial problems because social interaction and emotional expression depend to a great extent upon the structural and functional integrity of the head and neck region.

In many studies about head and neck cancer and its treatment, depression is used as a primary or secondary outcome measure.

In this presentation advantages and drawbacks will be given of using depression as an outcome measure in studies with head and neck cancer patients. Furthermore, a review will be given of studies about head and neck cancer patients at the Utrecht University Hospital using depression as a major outcome measure. Several longitudinal studies showed large percentages of patients with many depressive symptoms. Relationships of depression with other variables like quality of life, sex, age and coping are explored and studies showed that it is possible to predict which patients are at risk to become depressed after treatment.

Several studies have resulted in a large RCT on the effect of comprehensive counselling by a nurse specialist on depressive symptoms.

The latest in the design of complex psycho-social interventions: from research to practice

AUTHOR: Professor Gerry Humphris

In previous presentations to this meeting I have extolled the virtues of designing and testing psychological interventions with a focus on discreet psychological concerns such as fears of recurrence. This work is made challenging within the context of service delivery in head and neck cancer units. Notable issues focus on the targeting of suitable participants, recruitment, level of burden placed upon the patient (i.e. number of sessions), suitable assessments, timing of intervention and selection of outcome variables. With the issue of new advice from the Medical Research Council on the development of complex interventions on 29th September 2008 <http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC004871>

I hope to present a summary of the latest advice which is a considerable improvement on a previous statement in 2000. I hope to illustrate the development of interventions targeted at depression and at fears of recurrence to show that careful and considered steps are required. In addition, the research practitioner needs to keep a focus on making any effective programme deliverable within the current clinical environment or at least have an eye to encourage implementation.

Experience of parents diagnosed with head and neck cancer who are caring for young children

Authors: ***Dr Cherith Semple***
*Macmillan Clinical Nurse Specialist–Head and Neck Cancer
Cancer Services, Ulster Hospital*

Prof Tanya McCance
*Co-Director of Nursing R&D, Belfast H&SC Trust/Mona Grey Prof for
Nursing R&D, University of Ulster*

Background:

The incidence of head and neck cancer is steadily rising in the United Kingdom, with over 4,000 new cases reported annually (Cancer Research UK, 2005). Furthermore, evidence would suggest that there are changes in the epidemiology of this disease, with a notable increase in the incidence of head and neck cancer in men and woman in their 40s and 50s. For example, over the past three decades, the rate of oral cancer has doubled from 3.6 to 8.4 per 100,000 for men aged 40-49 and from 11.5 to 22.9 per 100,000 for men aged 50-59 (Cancer Research UK, 2005). As a direct consequence, more parents of young children are being diagnosed with head and neck cancer, which has important implications for patients and their families. Within this context it is surprising that limited research has been conducted on the experience of cancer patients who are caring for young children. This area of work has, however, evolved over the past 10 years. Of the literature that is currently

available, the majority of studies have focused on the experience of mothers, and mainly those with a diagnosis of breast cancer (Stiffler et al. 2008, Ohlen & Holm 2006, Elmberger et al. 2005, Walsh et al. 2005, Billhult & Segesten 2003, Barnes et al. 2000, Elmberger et al. 2000, Shands et al. 2000). One study was identified that focused solely on the experience of men as parents, who had been diagnosed with various haematological cancers (Elmberger et al. 2002).

Aims and objectives:

The overall aim of this study was to explore the experience of parents diagnosed with head and neck cancer who are caring for young children. The specific research objectives were to:-

1. explore what support was provided to assist patients to function as a parent
2. identify who provided this support
3. explore perceived changes in support needs for parents overtime in their cancer journey.

Methodology:

A qualitative descriptive design was used to address the research objectives. The study was carried out retrospectively, which involved identifying patients who had completed their cancer treatment. In-depth one-to-one interviews were used as the main method of data collection. The interviews were unstructured with a topic guide developed in an attempt to frame the interview. Interviews were conducted in the patient's own home, or a venue of their choice. Cognitive mapping was used to analysis the data. This is a process that involves coding, categorising and interpreting data through identifying connections, which are captured visually.

Findings: A total of 12 patients were interviewed, 10 mothers and 2 fathers, with one or more children under the age of 16. Parents experienced different emotions and support needs throughout their cancer journey. At diagnosis the overriding emotion was fear; fear of missing milestones in the life of their children, and fear of telling the children about their diagnosis. During treatment all parents had to spend considerable time in hospital, often with repeated admissions. The focus for the parents at this time was separation from their children and the need to prepare their children for hospital visits, particularly the first visit, which for some was after major head and neck surgery. Treatment received by parents had a profound effect on their parental role and on family life. The physical side-effects of treatment often enforced role change for family members, with the most marked change experienced by the spouse/partner. Treatment also had a significant impact on fundamental activities of daily living, particularly around eating and speaking. This led to major changes in family activities, which centred on mealtimes and socialising. The experience of parents living with cancer gave them an increased appreciation of life, but at the same time they were living with uncertainties as a result of their cancer diagnosis. After treatment parents had an overriding desire to re-establish a routine for family life. Throughout their illness, parents gained support from different sources such spouse/partner, other family members, friends and support network within their community. Support was also provided by healthcare professionals but despite this, some parents in this study identified unmet needs at different times in their cancer journey.

Conclusion:

The findings of this study reflect a challenging and complex transition process in the lives of parents with head and neck cancer who have young children. This transition process was complex, multi-dimensional and dynamic. Parents faced coping with

fears and uncertainties resulting from having cancer, along with balancing the physical effects of treatment and meeting the needs of their children. This led to an internal struggle that centred around their parental responsibilities and the impact of their illness and treatment on family life. This study emphasised the need for increased support from health care professionals for parents: at diagnosis (sharing the news of their cancer with their children); during treatment (preparing children for their first hospital visit, preparation for role change); and after treatment (financial support and adjustment to living with cancer).

Return to work after treatment plan as a further measure of Quality of Life for head and neck cancer patients.

AUTHORS C.G.Kelly, R.Singleton, J.P.Kelly V.Paleri
Northern Centre for Cancer Treatment, Newcastle General Hospital & Dept of Otolaryngology, Freeman Hospital, Newcastle upon Tyne.

INTRODUCTION

This study was conducted in the head & neck cancer clinics at the Northern Centre for Cancer Treatment and Freeman Hospital Newcastle upon Tyne. Twenty eight patients of working age (less than 65 years) at diagnosis were interviewed, at least nine months after completing treatment, in relation to their employment before, during and after treatment.

AIMS

The aims of this pilot study were to obtain an approximation of the number of head and neck cancer patients who were in work before treatment started, how many could return to work and in what capacity and to investigate if return to work could be used as a surrogate measure in overall quality of life assessment.

METHOD

The interviews were based on previous work by CancerBACUP has published in "*Work and Cancer : how cancer affects working lives.*" 2005

RESULTS

Twenty of the 28 patients were in full-time employment prior to the treatment and following treatment, 13 (65%) were able to return to full time work. Acute treatment morbidity was not a cause of failing to return to work, and 16 out of 18 patients who worked with colleagues informed co-workers of their condition and treatment. Patients felt that they had not been adequately warned how treatment would affect their ability to work, and only five patients were aware that they may be protected under the Disability Discrimination Act.

CONCLUSION

The study identified further information needs for head and neck cancer patients undergoing treatment which are now being addressed within our HNC clinic. It confirmed that information regarding employment can be collected relatively easily in

the follow-up clinic environment and can be useful information for assessing overall post treatment quality of life.

Patient perception of carer burden: SSM Medical Student Project

AUTHORS: Elizabeth Precious, Shaun Haran, Derek Lowe, Simon Rogers

Introduction

One very important aspect in head and neck cancer that is under reported is carer burden. The aim of this study was to briefly ask the patients for their perception and to relate this to patient characteristics and health-related quality of life.

Method

6 questions on carer burden were include in the annual cross-sectional survey of head and neck cancer survivors in April 2008

- Question 1: To identify those who lived alone.
- Question 2: the amount of care and support the patient felt they needed
- Question 3: Used to Identify if the patient had a 'carer' and who this individual was.
- Question 4: Roles fulfilled by the carer (adapted from Amy P. et al [1])
- Questions 5 and 6: to guage the patient's perceived burden of their health status on their family and caregiver Khafif et al [2]

Results

The response rate was 51% (386/751). There were no notable difference in characteristics between responders and non responders. The sample was weighted towards oral cancer (58%) and early disease (72% T1 or T2).

- **X% lived alone**
- 70% reported needing none or a little care and support
- 54% reported not having a caregiver (in over 60% this was the spouse/partner). Having a caregiver was influenced by age, time since treatment, disease severity and HRQOL scores (UW-OL physical and social-emotional composite scores)
- The main roles of the caregiver were emotional, taking to appointments, cleaning home, supermarket shopping. The role was related HRQOL scores.
- Severity of burden cause by physical status (no burden 1 to significant burden 5): 14% responded either 4 or 5. The response related mainly to HRQOL and to a lesser degree age.
- How hard is it for the caregiver to take care of you (not hard at all 1 to very hard 5); 8% reported either 4 or 5. The response related to HRQOL rather than the other patient characteristics

Discussion

It was surprising how many patients do not have a caregiver. There is a definite carer burden, which seems to be mainly emotional and practical. Patients HRQOL influences their perception of the severity of burden and how hard it is for the carer.

REFS

Carer quality of life in head & neck cancer; a longitudinal study

AUTHORS

Patterson J¹, Carding P², Wilson J³, Kelly C⁴, McColl E⁵

¹NIHR Research Fellow, Newcastle University / Macmillan SALT, Sunderland

²Professor in Voice Pathology, Freeman Hospital, Newcastle University

³Professor in Otolaryngology, Newcastle University

⁴Clinical Oncologist, Northern Centre for Cancer Treatment, Newcastle General Hospital

⁵ Professor, Institute Health & Society, Newcastle University

Background

Family members play a crucial role in cancer care. However, there are few studies relating to how head and neck cancer impacts on the carers' quality of life (QOL). These patients experience changes to basic functions which increase dependency on others. Caring for them is challenging, both emotionally and medically. This is a preliminary study, looking at the QOL of informal carers of head and neck cancer patients.

Aim

To explore carer QOL pre- and post-treatment and whether there is an association with patient QOL

Methods

Patients with head and neck cancer referred for radiotherapy were asked to complete a QOL questionnaire (UWQOL scales) pre-treatment, 3, 6 and 12 months post-treatment. They were asked to identify a carer. With the patients' consent, carers were given a QOL questionnaire (Caregiver QOL-Cancer) at the same time points.

Results

68% of patients were able to identify a carer. 72% carers returned a questionnaire at least one time point. There was no significant change in CQOL-C scores, but there was a trend for improvement over time. There was a good correlation between the two QOL questionnaires post-treatment ($r=.62$ to $.78$).

Conclusions

This study found a high proportion of head and neck cancer patients did not have someone they could identify as their carer. There were difficulties in accessing information on carers' QOL and maintaining participation in a longitudinal study. However, initial findings suggest that there is a relationship between the QOL of patients and carers. This has implications for interventions and clinical practice. More work is needed looking at carer QOL over time.

Experiencing head and neck cancer: A meta-synthesis of qualitative studies

AUTHORS

Heidi Lang, Brian Williams, Mary Wells & Gerry Humphris

INTRODUCTION

Quality of life studies dominate in the head and neck cancer (HNC) literature, but it is debatable whether these measures adequately represent patients' experiences. Qualitative methods best capture the depth and richness of subjective experiences of serious illness, but studies of HNC are widely dispersed in the literature and therefore difficult to assimilate. Qualitative meta-synthesis integrates the findings of a body of work, hence more sophisticated conclusions can be drawn and their potential impact is heightened. This presentation provides an overview of the methodology and findings of a meta-synthesis which addressed the question – what is it like to have head and neck cancer?

AIMS

To synthesize existing qualitative research into patients' experiences of living with HNC

METHOD

7 databases including Medline and Cinahl were searched using thesaurus, free text, and broad based terms to identify appropriate studies. Relevant papers were critically appraised, and Noblit & Hare's (1988) approach was used to synthesise the included papers.

RESULTS

114, 311 records were retrieved, 1,401 of which were identified as potentially relevant. Abstract review resulted in 109 being retained for full text review. 21 of 47 papers survived appraisal and were included in the synthesis. Findings centred on four main areas: experience of cancer, treatment(s), HNC services, and information. Approx 60% cited the impact of cancer on patients' lives as their primary concern. The collective scope of the studies allowed us to examine the entire trajectory from pre-diagnosis to post-treatment. While there was considerable unity in issues raised by patients, some important concerns were identified only in isolated papers, e.g. the need for staff to validate patients' suffering.

CONCLUSION

Synthesising these studies enabled us to plot patients' experiences of HNC throughout the disease course. The scale and depth of our inquiry provides clinicians with significant insights into the reality of HNC.

A Patients Concerns Inventory (PCI) to help raise patients concerns in a routine head & neck clinic: A pilot study

AUTHORS:

Dr Joseph El-Sheikha

Rogers SN¹, El-Sheikha J², Lowe D¹

Introduction

The purpose of the Patients Concerns Inventory (PCI) is to identify the concerns that patients would like to discuss during their consultation. The PCI covers a range of issues including hearing, intimacy, fatigue, financial/benefits, PEG tube, relationships, regret, support for family, and wound healing. It also lists MDT members that patients would like to see or be referred on to.

Method

The PCI is completed using a touchscreen computer (TST) immediately before consultation. Responses are networked into the consultation room. A 28 week pilot for one consultant ran from August 2007 with 123 (of maximum 150) patients. The median time to complete the TST was 8 minutes.

Results

Patients most frequently selected fear of recurrence (37%), dental health/teeth (27%), chewing (24%), pain in head/neck (20%), fatigue/tiredness (19%), saliva (18%) and swallowing (18%). The two MDT members they wished to see were dentist (19%) and speech/language therapist (10%). The vast majority felt the PCI made a difference (quite a bit /very much) to their consultation as it made it 'a bit more personal', 'reminds them of the points they want discussed', 'allows the consultation to get straight to the point'. Although the PCI can raise many issues it did not noticeably prolong the consultation (median 8 minutes with PCI , 7 minutes without PCI).

Conclusion

The Patients Concerns Inventory (PCI) helps focus the consultation onto patient needs and promotes multidisciplinary care. Following this very successful pilot the PCI is being rolled out to other consultants in the H&N clinic.

Information and its role: experiences of people affected with laryngeal cancer

AUTHORS

Mrs Anne Taylor BSc Hons; RGN

INTRODUCTION

It is well documented in the literature that patients require timely and appropriate information specific to their needs to assist them manage their cancer diagnosis. A diagnosis of laryngeal cancer can have a profound effect on the individual and their family's life and little is known about how they use information to help them manage

the physical, psychological and social impact of their diagnosis across the cancer trajectory

AIM

The purpose of this study was to describe the information that patients and carers received over the cancer trajectory and how they used it to make sense of the diagnosis and subsequent treatment.

METHOD

Exploratory, in-depth longitudinal interviews were used with a purposive sample of 20 patients and their carer from across five clinical sites in the West of Scotland.

Interviews were carried out towards the end of treatment (Int1) and six months into follow up (Int2). All interviews were transcribed verbatim and analysed using thematic framework analysis.

RESULTS

The findings are based on interviews one (Int1):

- Physical symptoms and symptom management dominates the information provided
- Carers play a significant role in the provision of information
- There is a gap of information initially after treatment has completed.

CONCLUSION

The findings suggest that the information provided is directed towards symptom management related to treatment. Emotional and psychological issues are less well addressed especially at the end of treatment. The role of the carer needs to be valued more as they can play a major role in the provision of information at this time point.

Session 4

Friday 7th November

Session 4	Patient and Carers
14.00 – 14.20	Northern psychology group / emotional support therapy Ellie.Hurrell / Veronica Oliver-Jenkins
14.20 – 14.45	Living with facial disfigurement: the patients and carer perspective Christine Piff
14.45 – 15.10	Living with laryngectomy: the patient and carer perspective Bertram J. Culling MBE
15.10 – 15.35	Not just a tick in the box: Experiences of a user in academic research Christine Allmark
15.35 – 15.55	Involving people affected by cancer in the design and conduct of research: the Macmillan Award Scheme Dr Katie Booth
15.50	Closing remarks Simon
16.00	Closing and departing tea & biscuits

Northern psychology group / emotional support therapy

AUTHORS:

Veronica Oliver-Jenkins / Ellie.Hurrell

Dr Veronica Oliver-Jenkins, BSc (Hons), C. Psychol, Psychology in Healthcare, Newcastle Primary Care Trust

Veronica Oliver-Jenkins qualified as a Clinical Psychologist in 2002. In 2005 after working in adult mental health services Veronica gained a position in the Department of Health Psychology at Bishop Auckland General Hospital, Durham. In 2006 she moved to the Department on Health Psychology at the Royal Victoria Infirmary, Newcastle-upon-Tyne.

With a keen interest in clinical oncology, since 2007 Veronica has provided a clinical psychology service to patients under the care of the Head and Neck Cancer Team at Freeman Hospital, Newcastle upon Tyne. She is a member of the Northern Cancer Network Psychological Health Subgroup and British Psychological Society Special Interest Group in Oncology and Palliative Care.

Living with facial disfigurement: the patients and carer perspective

CHRISTINE PIFF - FOUNDER/CHIEF EXECUTIVE

LET'S FACE IT The Support Network for the Facially Disfigured

In 1977 Christine suffered a rare facial cancer and had to sacrifice half her face including her eye to save her life.

In January 1984 she took part in a television programme and launched the Support Network for the facially disfigured called **Let's Face It**. This was to enable people to share experiences and support and help one another, by passing on information and advice on ways of dealing with individual problems. 1985 Christine's book, also called **Let's Face It**, telling her story was published by Gollancz.

The television programme and the publicity for the book created media interest and Christine has made numerous television programmes including a number of documentaries about facial cancer and disfigurement.

In 1989 Christine won a Winston Churchill Travel Fellowship and visited Sweden and America to study facial reconstruction and rehabilitation. This gained her the Pol Roger Award. In 1990 Christine was awarded a Paul Harris Fellowship from the Rotarians for her work in helping the community. She has been awarded an Honorary Member of the Institute Maxillo Facial Technologists, for the work she has done promoting Facial Prosthetics. In November 1998 Christine won the Regional Whitbread Volunteer Action Award for the South and was the overall individual winner in recognition for her outstanding service to the community. In June 1999 she

was awarded Outstanding Cancer Patient Award from Cancer - BACUP. In August 2000 Christine won the fourth Glyn Harris Award from Cancer Care.

Christine continues to run the Network with the support of her P/A in Kent and regional Co-ordinators throughout the UK. LFI is now an International Network. It involves setting up meetings for facially disfigured people and their families. There is also "Junior Let's Face It" for the children and their parents. Her time is spent lecturing to professionals, linking patients, professionals and other disciplines together. In 1999 a series of Workshops took place throughout the country and will continue to reach new patients. Her contacts within the head/neck field make it possible for resources of information to be available for all facially disfigured people, supplying them with whatever information or support they need.

In 1999 Christine gained a Diploma in Professional Counselling and has a private practice. She attends LFI meeting, television, press, lecturing and writing numerous articles for professional journals, as well as Chief Executive to the Network. She sits on the clinical development of DAHNO (Data Analysis Head and Neck Oncology) and other allied associations. Much of her time is spent running the Network, fund-raising and telephone counselling.

Living with laryngectomy: The patient and carer perspective

Bertram J. Culling MBE

Bert Culling by his wife

In his previous life he was a workaholic who owned and ran a small heavy engineering company. He was diagnosed with Laryngeal cancer at the age of 47 in 1982 and underwent Laryngectomy in 1985 after failed Radiotherapy. He met up with the National Association of Laryngectomee Clubs when he began swim training in London and took up the Presidency of that organisation after his retirement in 1996 (retirement due to wife pressure of the blackmail type) and has worked since then, as a volunteer, for the welfare of Laryngectomees in whatever area of need NALC finds itself involved in. At present he is one of NALCs vice presidents.

I have already given you the gist of Berts presentation in another e-mail and will forward a disk of his presentation when we have your address. If you feel this is not appropriate please let me know, won't be huffed, honest. I tried to send the presentation electronically but have failed dismally I'm afraid.

Regards Ethel Culling.

Not just a tick in the box: Experiences of a user in academic research

AUTHOR: *Christine Allmark*

*User Research Lead
Macmillan 'Home but not Alone' Study
Psycho-Social Oncology and Clinical Research Group,
University of Leeds.*

Biography:

Mrs Christine Allmark B.A (Hons).
User Research Lead, Macmillan 'Home but not Alone' Study,
Honorary research assistant, Psycho-Social Oncology and Clinical Research Group,
University of Leeds.

Diagnosed with Head and Neck Cancer in 2002, Christine made a successful recovery and built on personal experience of chronic health problems ,related voluntary sector activity and professional work in adult and higher education to become a tutor in communication skills to medical students and formally employed in academic research.

She is possibly the first research appointee wherein personal health experience counted co-equally with academic qualifications as requirements for the post .Consumer involvement includes membership of local ,regional and national network user and site- specific clinical groups, peer reviewing and advising on other studies.

Abstract:

What is a User Research Lead?

The background to Christine's academic appointment is involvement in a successful bid in the first Macmillan Research Grant Competition for User-led Research in 2006.She was included in all stages of the application and ultimately was appointed as User Research Lead and research assistant within the Macmillan 'Home but not Alone' Study.

The study is looking at whether user mentor support can be effective for head and neck cancer patients in the period after home discharge following first in-hospital treatment. Methods are: analysis of perceived needs, focus groups and contemporaneous diaries, development of training packages and pilot testing.

Challenges encountered by Christine included the culture shock of entry into the closed world of academic research despite 'mere' graduate status, leading to

feelings of being back on the first day at a new school , having to learn a different language, loss of confidence and feelings of inadequacy.

Concerns centred around issues of responsibility and expectations, chronic personal health problems, reliability and the discipline of returning to work in a formal environment.

Coping strategies were getting on with the job, learning and asking along the way, accessing formal training and taking part in teamwork activities on an equal basis in order to challenge any suspicion of tokenism .Expanding contacts and roles was a natural consequence.

Help given from a supportive team with different skills and expertise ,sharing and training led to a positive impact of new skills and confidence and a healthy respect for those involved in the complex world of academic clinical research, as well as ideas around partnership and collaboration.

The outcomes so far are: a new sense of direction, identity, mindset, ambitions, plans and eager anticipation of what happens next!

Issues for consideration are: barriers to users in research and what makes the ideal researcher?

Conclusion

Christine now has the confidence, inspiration and ideas about how to implement, complement and supplement partnerships between users and researchers to mutual benefit.

We have made the transition from research being done to users, to research being done with users and by users.

Involving people affected by cancer in the design and conduct of research: the Macmillan Award Scheme

Macmillan Cancer Support

Dr Katie Booth PhD MSc BSc RGN RHV PGDE

Previously Director Macmillan Research Unit University of Manchester
Now Macmillan Research Capacity Development Advisor

I have a wide background in hospital and community nursing and also in health care research in multidisciplinary settings. Over the years I have maintained a strong research interest in the evaluation of nurse led interventions, the needs of cancer patients and the needs of those who care for them.

Since I took early retirement I have continued to work with Macmillan Cancer Support on a consultancy basis. The main thrust of the work for Macmillan has been the development and management of the Macmillan Research Fellowship Schemes and User-Led research.

EPRC



Edge Hill University
FACULTY OF HEALTH

Aims of the Evidence-based Practice Research Centre (EPRC)

- Develop programmes of research concerning evidence-based clinical and education practice and evaluation;
- Maximise opportunities to generate research income from external sources;
- Undertake consultancy on evidence-based practice and deliver bespoke courses on evidence based practice;
- Develop, maintain and enhance a research culture within the Faculty of Health and to sustain a supportive environment for Faculty staff engaging in research and scholarly activity;
- Build upon established networks and partnerships to identify and further develop collaborative opportunities for research and scholarly activity;
- Promote and enhance the national and international reputation of the University, Faculty and Centre by disseminating research findings through a variety of media including publication and conference presentations;
- Develop further support systems available to post-graduate and research students undertaking MPhil and PhD studies and their supervisors

Evidence-based Practice Research Centre: Research Themes

The Centre has a dedicated research team with expertise in:

- Clinical-based research including investigations into chronic diseases, quality of life, and supportive and palliative care;
- Health, social and post graduate medical education with a particular interest in practice-based investigations;
- Health services research incorporating the use of evaluative research methodologies;
- The social and health needs of children and young people; a recently emerging area of interest.

In the near future, we intend to develop mental health as the final strand of the Centre themes.

Team Members

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Research Practitioner

Dr Jeremy Brown BA(Joint Hons), PGCE, PhD
Senior Lecturer

Professor Barbara Jack PhD, MSc, BSc (econ), PGDE, RGN, RNT
Head of Research and Scholarship/ Director EPRC

Professor Annette Jinks RN, NDN, BA, MA, PhD
Professor of Nursing

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1. Innocenti H et al. Journal of Pain and Symptom Management 2002; 24(5): 464-467
2. De Groot D et al. CTO 2001 Abstract 3



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QUALITY OF LIFE IN HEAD AND NECK CANCER COURSE EVALUATION WORKSHOP AUTUMN 2008

Please rate your level of satisfaction on a scale

1= Very poor 2= Poor 3= Satisfactory 4= Average 5 = Good

6 = Very Good 7 = Excellent

	1	2	3	4	5	6	7
Thursday morning Session 1							
Computerised screening for psychological distress & quality of life							
Quality of life and the association with psychological characteristics of the patient							
Application of new radiotherapy technologies including IMRT to maximize HRQOL							
Hard to swallow? A study of the effects of chemoradiation							
Understanding Why Patients Treated for Head and Neck Cancer Continue to Smoke: A Qualitative Approach							
Taste as a functional loss in Head & Neck cancer							
A longitudinal study of swallowing function following surgery for Head & Neck Cancer							
Thursday afternoon Session 2							
How to look at Quality of life in clinics: Lessons from listening to our patients							
Does QoL predict survival in HNC							
Speech & swallowing impairment in head & neck cancer							
The development & validation of a self rating questionnaire to measure the outcome of speech & language therapy intervention in the head & neck cancer population							

The evaluation of the Brief ICF Core Set for Head and Neck Cancer as a patient self-completed questionnaire							
Health promotion from the perspective of living with head and neck cancer							
Quality of life of tumour patients following surgery and reconstruction of the oro-mandibular region							
Impact of shoulder complaints after neck dissection on shoulder disability and quality of life							
A Qualitative Investigation into the impact of PEGs							
Quality of life in Head and Neck cancer: A longitudinal study							
Recent Approaches to treatment of Larynx Cancer of Stage III							
Dietetic-led gastrostomy service – experience in a UK tertiary head and neck cancer centre							
Friday morning Session 3							
Factors influencing the quality of life, recurrence and survival of head and neck cancer patients							
Depression as an outcome measure in Head and Neck cancer							
The latest in the design of complex psych-social interventions: from research to practice							
Experience of parents diagnosed with head and neck cancer who are caring for young children							
Return to work after treatment plan as a further measure of Quality of life for head and neck cancer patients							
Patient perception of carer burden							

Carer quality of life in head and neck cancer: a longitudinal study							
Experiencing head and neck cancer: A meta-synthesis of qualitative studies							
A patient Concerns Inventory (PCI) to help raise patients concerns in a routine head and neck clinic: A pilot study							
Information and its role: experiences of people affected with laryngeal cancer							
Sam Harding							
Friday afternoon Session 4							
Northern Psychology group							
Living with facial disfigurement: the patients and carer perspective							
Living with laryngectomy: the patients and carer perspective							
Not just a tick in the box: Experiences of a user in academic research							
Involving people affected by cancer in the design and conduct of research: the Macmillan Award Scheme							
Overall	1	2	3	4	5	6	7
Venue							
Refreshments							
Coverage of topics							
Clarity of discussions							
Usefulness of course							

Where there any additional topics you would have liked to have been covered?

- 1.....
- 2.....
- 3.....

Would you like to suggest a theme for the QoL H&N Workshop planned for 2010?

.....

Thank you for taking time to complete the course evaluation. Please detach on the day or forward them via post to

Miss G Allman Maxillofacial Department University Hospital Aintree

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