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Oral Papers

Age and Ethnicity Session

Serious comorbidity among unselected cancer patients in South-eastern Netherlands

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1. Objective

With the rising proportion of elderly cancer patients in industrialised countries, more patients will present with comorbidity. Besides affecting the life expectancy *per se*, comorbid conditions may complicate the clinical management of cancer patients. Patients with serious comorbid conditions are generally ineligible for clinical trials, which implies that few data are available on outcome of treatment of these patients. The purpose of this study was to determine the prevalence of serious comorbidity among cancer patients and the influence on treatment choice and both short-term and long-term survival.

2. Method

About 34 000 newly diagnosed cancer patients were recorded in the Eindhoven Cancer Registry between 1993 and 1996: subsequently, data on serious comorbidity, classified according to the Charlson scheme, were collected from the clinical records by registry personnel.

3. Results

The prevalence of comorbidity increased from 12% below 45 years of age to 63% of patients over 75 years of age. The prevalence was highest for patients with lung. kidney. stomach, bladder and prostate cancer. Males exhibited a 10% higher prevalence than females with similar tumours. Among patients over 60 years, the most frequent conditions were heart and vascular diseases (ranging across the various tumours from 10 to 30%). hypertension (11–25%). another cancer (10–20%). Chronic obstructive pulmonary disease (COPD) (3–25%) and diabetes mellitus (5–25%). Most patients with comorbidity were treated less aggressively and comorbidity had a negative influence on survival.

4. Conclusions

Inclusion of frequent comorbid conditions in prognostic research as well as the development of specific guidelines for patient care seems warranted.

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Major colorectal cancer resection should not be denied to the elderly patient

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1. Objective

Surgery for colorectal cancer in patients aged over 80 years is often deferred due to the perceived high mortality and morbidity associated with these procedures (NCEPOD). The population is getting older and living longer. Should surgery be denied to this age group based on the above assumption?

2. Methods

Data were collected on all patients undergoing colorectal cancer resections between January 1994 and July 2000. 276 patients were included, 59 (21.3%) were aged 80 years or over (Group I). The mean follow-up period was 46 months in Group I and 53 months in Group II.

3. Results

There were 80 deaths, 19 (32%) in Group I and 61 (28%) in Group II ($P=0.51$). The 'in hospital' mortality was 11.9% in Group I, and 4.1% in Group II ($P=0.025$). The 5-year survival (all-cause-mortality) in Group I was 64.8% and 68.9% in Group II ($P=0.02$). 47% of deaths in Group I and 63% of deaths in Group II were directly attributable to cancer. Group II had predominantly later stage (Dukes') tumours than Group I ($P=n/s$). Cox regression analysis of all patients identified the following factors to be independently related to overall survival: Age >80 years, post-operative anastomotic leak, increasing Dukes' stage, postoperative radiotherapy, and distant recurrence of disease.

4. Conclusion

There was no significant difference in the number of deaths between the two groups. 'In-hospital mortality' and crude 5-year survival is better (only just) for patients under 80 years. Whilst age >80 years is an independent risk factor for postoperative mortality, patients should not be denied surgery for colorectal malignancy based on their age as the outcomes are comparable.

Age-specific differences in treatment and survival of patients with cervical cancer in the East and South of The Netherlands, 1975–1996

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1. Objective

The purpose of this study was to determine the influence of age on treatment and survival of patients with cervical cancer in the South and Eastern part of The Netherlands.

2. Method

In this population-based retrospective study, 1559 patients diagnosed with invasive cervical cancer between 1975 and 1996 were included. Information about treatment and survival (on 1 January 1998) was provided by three regional cancer registries. Population and mortality data were obtained from statistics for The Netherlands. Relative survival rates were calculated and, with a regression model for relative survival rates, relative risks of excess mortality due to cancer were estimated.

3. Results

Among older patients, stage 1A tumours occurred less often, whereas stage 2B-4A tumours occurred more often than in younger patients. Older patients (70+ years) with stage 1B-2A were largely treated with radiotherapy (RT) only (59%), whereas patients younger than 50 years mostly received surgical treatment only (73%). Older patients with stages 2B-4A mostly received RT only (70%), whereas the younger patients were treated with RT only (43%) or RI in combination with surgery (42%). Overall 5-year relative survival rate (RSR) was 67%. Stage at diagnosis was strongly associated with patient survival, the 5-year RSRs for stage 1A, 1B-2A. 2B-4A and 4B being 96, 84, 43 and 15%, respectively. When stage was taken into account, relative risks of excess mortality due to cancer increased with increasing age, being 1.2 (CI 1.0–1.5) for the age-group 50–69 years and 1.7 (CI 1.3–2.1) for the 70+ years age group with age $<=49$ years as a reference category.

4. Conclusions

Choice of treatment for women diagnosed with cervical cancer depends not only on stage but also on age. Older women have a worse prognosis than the younger ones, irrespective of stage. Survival improved in time for the younger age groups but not for the older patients.

Breast conserving therapy in older patients: the need for randomised trials to underpin cost-effective best practice for postoperative radiotherapy

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Around half of all breast cancers occur in women over the age of 65 years. In Scotland, there were 6636 incident cases in this age group from 1992 to 1995 (42% of all breast cancers). The number is set to rise due to the age-specific incidence of the disease and demographic changes in the population. With the extension of the upper age limit of the breast screening programme from 64 to 69 years, the proportion of women with small tumours suitable for breast conserving therapy (BCT) has increased. Recruitment of patients into randomised controlled trials (RCTs) is a priority of the Calman proposals for cancer services in the UK. Measurement of quality of life (QL) is an important endpoint in MRC cancer trials. Little is known about the impact of breast radiotherapy on QL in older women treated by BCT. The evidence base for the use of breast radiotherapy in older patients is weak since most RCTs for breast

cancer have excluded women over the age of 70 years. Radical radiotherapy (RT) reduces the risk of local recurrence 4-fold overall in women.

Our initial experience in a randomised trial assessing the impact on quality of life and health resource usage of breast RT in 'low-risk' older patients (post-operative radiotherapy in minimum-risk elderly (PRIME)) shows good acceptance rates for older patients (56%). A larger national/international trial of 870 patients is proposed to assess the impact of breast radiotherapy on local control in this good prognosis group.

1. Conclusion

Large RCTs in older patients with early breast cancer are needed on an international basis to assess the clinical and economic impact of breast irradiation to underpin best practices.

Inequality even in terminal illness?

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1. Object

To compare the use of palliative care services by Asian and non-Asian cancer patients.

2. Method

A case–control study of deaths among patients registered with cancer in the period 1990–1997 who were residents of Leicestershire. Cases were deaths known to occur in a hospice and the exposure variable was Asian ethnicity, based on the patient's name.

3. Results

Our study sample of 5082 subjects consisted of 847 cases with five controls per case. After adjusting for cause, period and age at death by multiple logistic regression, the odds ratio for 'Asian' ethnicity was 0.54 (95% confidence limits 0.32–0.92, $P = 0.023$). The results for ethnicity were similar whether or not additional adjustment was made for deprivation (expressed as quintile of Townsend scores for Leicestershire) and was not materially affected by adjustment for misclassification.

4. Conclusion

There is a *prima facie* case that Asian patients are less likely to use palliative care services than other patients. Possible reasons for this underrepresentation are: people from minority communities are less likely to be given the necessary advice and information by GPs — access is difficult because hospices are perceived as an inappropriate environment to cater to religious and cultural needs. Our results establish the need for further research to explore this issue.

Guidelines, Standards and Audits Session 1

Improving patient care for colorectal cancer patients in a hospital trust

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1. Objective

To develop a system to monitor and improve the standard of care given to colorectal cancer patients in Tayside University Hospitals Trust.

2. Method

Prospective audit based on the Scottish Intercollegiate Guidelines Network guidelines and standards from Clinical Standards Board for Scotland (CSBS).

3. Results

Audit of 303 patients (aged 18–98 years; mean 71 years) diagnosed 0l/07/1999–30/06/2000, of whom 217 had completed primary treatment and 189 underwent surgical resection, revealed that eight out of 13 key standards were met (Table 1).

Table 1
Performance against key standards (CSBS Draft Standards 2000)

Criteria	Standard (%)	Performance (%)
Operated on within 4 weeks of decision to treat	100	48
Starting radiotherapy within 4 weeks of seeing oncologist	100	33
Started chemotherapy within 6 weeks of surgery	90	49
Rectum and whole colon visualised pre-operatively	> = 70	72
Pre-operative liver imaging and chest X-ray	> = 80 and 100	80 and 90
Antibiotic and DVT prophylaxis	> 80 and 70	> 96
Anastomitic leak after rectal and colonic anastomsii	< 10 and < 5	13 and 2
Postoperative death following elective surgery	< 5	3
Receiving chemotherapy following curative resection	> 15	21
Receiving post-op radiotherapy when involved circumferential margins	100[a]	83[b]

[a] Unless there is a documented contra-indication.
[b] True in remaining 17%.

4. Conclusions

The audit has highlighted many areas of good practice; however, long intervals between decision to operate and surgery, chemotherapy and radiotherapy need attention. During the second half of the audit, there were problems with failing radiotherapy equipment. The effect of such difficulties on delivery of care is highlighted. Continuation of prospective audit is essential to facilitate an improvement in the quality of care provided.

Developing measures of clinical process and outcome for colorectal cancer

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1. Objective

To develop and test indicators of quality and outcomes of clinical care for colorectal cancers; and to compare current care with the recommendations of national and local clinical guidelines.

2. Methods

Information on the care of colorectal cancer patients has been collected prospectively in nine hospitals referring to a single cancer centre (Mount Vernon) in north west London since 1998. The clinicians used specially developed structured case-notes. then the information was input onto a central database at Thames Cancer Registry, and analysed in conjunction with the lead surgeon and oncologist in the local colorectal network. Analysis focused on the national guidelines from the Association of Coloproctology (ACP) and the Clinical Outcomes Group (COG).

3. Results

Preliminary results are available for 583 patients (52% colon, 48% rectum), diagnosed in 1998–1999. Only 18 (3%) were emergency admissions. Those referred routinely had a mean wait of 18 days from GP referral to first visit. The first treatment was surgery for the majority (76%), radiotherapy for 39 (7%) and chemotherapy for 19 (3%). Guideline targets were not met in several aspects. The median wait for first treatment was 31 days for surgery, 40 days for radiotherapy and 48 days for chemotherapy. No specialist surgeon was present at the operation for 30% of patients. Closure of temporary stomas within 6 months was very low (14%).

4. Conclusions

The guideline standards proved to be complex and difficult to define for analysis. The value of the information is in highlighting areas of underprovision, as potential target areas for additional resources in order to improve care and outcomes.

A prospective survey of waiting times to breast cancer teams in Wales

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1. Objective

Monitoring Government cancer waiting time guarantees involves ongoing data collection on all patients. This is time-consuming and expensive without appropriate information systems in place. An alternative interim strategy was developed in Wales based on a prospective survey of new clinic attendees run over a 4-week period.

2. Method

A proforma, produced with advice from the All Wales Breast Cancer Steering Group, was used to collect waiting times from first attendance for assessment to treatment. 'Urgency' was determined by the specialist based on the information provided by the referring GP. Data were provided and verified by the breast multidisciplinary teams (MDTs) with central analysis.

3. Results

All MDTs across Wales participated, with 1417 proformas returned. The findings were: (1) 70.2% of urgent referrals were sent via letter only; (2) categorisation of 'urgency' varied between MDTs (11.6–83.0%); (3) 88.1% of urgent referrals were offered appointments within 10 working days of receipt of the referral; (4) 99.2% had all their diagnostic tests within two visits; (5) 94.3% were given their results within 5 working days from the date of last diagnostic test; (6) 79.1% were offered an appointment for surgical treatment within 14 working days from the time they were informed of the diagnosis.

4. Conclusions

This approach was acceptable and 'owned' by clinicians. Results were available to the service quickly with findings similar to those of an earlier pilot study. The findings have resulted in funding to support GP referral processes and guideline development which will include guidance on criteria for urgent referrals.

A single centre experience of adjuvant CMF in over 700 cases of early breast cancer

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We are currently auditing the outcomes for women in early breast cancer given adjuvant intravenous (i.v.) CMF chemotherapy. 788 women have been identified as eligible, being treated between 1981 and 1998 within the Edinburgh Breast Clinic. To date, data are available on 340 women and all 786 case notes will have been reviewed by February 2001. EBCCTG suggest that there may be a reduced benefit from adjuvant chemotherapy in older women.

Age range	% node positive	% node negative	% ER positive	% ER negative	% dose delay	% dose reduction	% not completing six cycles
< 50	63.9	35.2	36.6	41.6	48	7.4	9.9
50–59	73.2	25.8	57.7	28.9	54.6	6.2	4.1
60 +	81.6	18.4	55.3	39.5	65.8	13.2	2.6

1. Results

The data collected to date show that 50% of patients have a treatment delay due to toxicity and that this percentage increases with age. Also, around 10% of women have a toxicity-related dose reduction, with twice as many dose reductions being noted in older patients. 5-year cause-specific survival figures have been calculated for all of the 786 women and show decreasing survival rates with age: 73.1% of age under 50 years; 67.2% of 50–59 year olds; 61.2% of age 60 years and over. A more detailed analysis of the relationship between -received dose intensity and survival will be presented.

2. Conclusion

Delivering full-dose, on-time adjuvant chemotherapy is difficult outside trials and this could be a Significant contributory factor in the apparently reduced effect of adjuvant chemotherapy in older women.

Management and survival of lung cancer patients diagnosed in 1995 in Scotland: results of a national, population-based study

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1. Objective

To document factors influencing referral, diagnostic evaluation, treatment and survival in patients with lung cancer.

2. Method

Patients diagnosed with lung cancer during 1995 were identified from the Scottish Cancer Registry and their medical records were reviewed. Adequate records were available in 91.2% of all potentially eligible cases.

3. Results

In 1995, patients with lung cancer in Scotland had a high rate of microscopic verification (74.1%) and 75.3% were assessed by a respiratory physician. However, only 56.8% received active treatment (resection 10.7%, any radiotherapy 35.8% and chemotherapy 16.1%) and only 2.9% participated in a clinical trial. Survival was poor with a median of 3.6 months, 21.1% (95% CI 19.8%, 22.4%) were alive at 1 year and 7.0% (95% CI 6.2%, 7.8%) at 3 years. After adjustment for available prognostic variables, management by a respiratory physician, oncologist or thoracic surgeon was an independent predictor of access to 'potentially curative treatment' and better survival.

4. Conclusions

This national, population-based study demonstrates low use of active treatment and poor survival and suggests an influence of process of care on survival. Implementation of evidence-based guidelines will require substantial changes in practice. Increasing the number of patients receiving active treatment may improve survival.

A Scottish audit of malignant spinal cord compression (MSCC): sources of delay in diagnosis. Social deprivation and policy implications

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1. Objective

For malignant spinal cord compression (MSCC) in three Scottish cancer centres, (a) to examine the process of diagnosis, clinical management and outcome and (b) to identify remediable causes of delay in the diagnosis and treatment of MSCC.

2. Methods

A prospective audit was undertaken in Edinburgh, Aberdeen and Glasgow of 3l9 patients over 12 months from 1/99 of all consenting patients with MSCC.

3. Results

89% were >50 years. 60% were known to have cancer at presentation with MSCC. Lung, prostate and breast accounted for 58% of cases. The median duration of pain prior to presentation to a GP was 25 days. Median time from the patient reporting back pain to their GP (a) to hospital referral was 20 days and (b) to diagnosis of MSCC was 65 days. The latter did not vary between centres but was longer in patients from socially deprived areas. Back pain was radicular in the majority of patients (84%) and was present for a median duration of 90 days from onset to time of imaging. Weakness was present in 84%, sensory loss and bladder symptoms in 52%. Delays in radiological diagnosis were incurred by preceding plain radiographs or bone scans. The thoracic cord was the commonest site of compression (68%). MRI was the most reliable imaging modality identifying 290 cases of MSCC. At 1 month post-treatment, 14 (44%) of ambulant patients remained so. Only 3 (7%) of non-ambulant patients regained ambulation.

4. Conclusions

Earlier diagnosis and treatment for MSCC could be facilitated by (i) raising patient awareness, (ii) identifying patients aged >50 years of lower socio-economic groups with thoracic or lumbar radicular pain and (iii) resourcing rapid access to neuro-oncological assessment, MRI imaging and surgical/radiotherapeutic treatment.

Guidelines, Standards and Audits Session 2

Clinical guidelines for the management of patients with breast cancer have an impact on patient care in Australia

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1. Objectives

In 1995, the Australian NHMRC and National Breast Cancer Centre disseminated clinical practice guidelines for early breast cancer. Ensuring such guidelines are adopted and followed is difficult. The management of breast cancer in Victoria, Australia, has been surveyed in 1986, 1990 and, most recently, 1995 — this latter period for the 6 months prior to the introduction of those national guidelines. One aspect of care of considerable concern has been the low use of postoperative radiotherapy after breast conserving surgery (BCS). The data on patient management for those diagnosed in Victoria by the breast screening programme since 1994 has been analysed to determine if that data, presented annually, can be used as a surrogate to monitor the effect of the guidelines on that aspect of care.

2. Method

The data on the use of adjuvant radiotherapy after BCS for all women diagnosed with breast cancer through BreastScreen Victoria — the state-wide mammographic screening programme — has been analysed for the years 1994–1998.

3. Results

The state-wide surveys of 1986, 1990 and 1995 reveal an increasing BCS rate in early breast cancer of 22, 42 and 54%, respectively. The use of post operative radiotherapy was, however, 44, 43 and 58%, respectively, in BCS patients.

BreastScreen data reveal a BCS rate with radiotherapy of 55.6, 63.2, 72.9 and 77.4% for the five successive calendar years 1994–1998. These latter years compare well with the national rate in 1995 of 70%.

4. Conclusion

The annual data from the state breast screening programme may be used as a surrogate measure of compliance with guidelines. These data suggest the well publicised 1995 guidelines are being followed increasingly with respect to radiotherapy following BCS.

Adherence to regional guidelines for adenocarcinomas of the corpus uteri staged FIGO I in The Netherlands

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1. Objective

Since 1989, regional guidelines on diagnostic procedures and treatment for all gynaecological malignancies were developed in the Middle West region of The Netherlands. One university hospital and nine general hospitals are

located in this region with 1.6 million inhabitants. A population-based study was conducted to evaluate these regional guidelines for all patients diagnosed in the period 1995–1999.

2. Method

Detailed data on diagnostic procedures, stage of the tumour, treatment, pathology reports and survival were abstracted from medical records by three medical coding clerks. This study will focus on the evaluation of patients with a (papillary) adenocarcinoma of the corpus uteri staged FIGO I (grade I–III).

3. Results

More than 650 patients were diagnosed with a tumour of the corpus uteri; over 90% of them were diagnosed and treated in general hospitals. 85% of them had a (papillary) adenocarcinoma. The majority of these patients (80%) were treated according to the regional guidelines. In the subgroup of patients staged FIGO I grade III, one third did not receive adjuvant radiotherapy. Plausible reasons for not receiving adjuvant radiotherapy were advanced age (above 75), comorbidity or patient refusal. The outcome of this evaluation led to a discussion in the Gynaecologicgal Oncology workgroup of the CCCW whether or not regional guidelines need to be better enforced or need to be adapted.

4. Conclusions

The majority of patients staged FIGO I were treated according to the regional guidelines. High age, comorbidity and patient refusal are explanations for non-adherence to the guidelines for patients staged FIGO I grade III.

Factors affecting the quality of staging and its importance to patients' subsequent management in endometrial cancer

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1. Aim

To investigate the factors associated with observed variations in surgical staging in endometrial cancer and to investigate whether staging influences subsequent management.

2. Methods

It was a retrospective cohort study based upon the total Scottish population. In-patient and day-case hospital discharge data (SMR-1) and cancer registration (SMR-6) were used to identify cases. 95% of medical case records were retrieved. 781 patients with histologically verified endometrial cancer were diagnosed in Scotland during 1996 and 1997.

3. Results

The overall quality of surgical staging was poor. The FIGO stage was defined in the medical notes in only 36.4% of cases. Multiple logistic regression analysis suggested that the use of FIGO staging was more likely if the surgeon was classified as a 'specialist' (odds ratio 2.7 (95% CI 1.5–4.6, $P = 0.0005$)), passed the MRCOG examination after 1989 (odds ratio 1.6 (95% CI 1.1–2.4, $P = 0.0098$)) but was not related to surgical caseload. The subsequent use of adjuvant

radiotherapy was related to whether the FIGO stage was defined in the medical record (odds ratio 2.6 (95% CI 1.5–4.4, $P = 0.0004$)).

4. Conclusions

FIGO staging changed in 1988 and it is likely that the surgeon's knowledge of staging is related to its use. Secondly, the use of FIGO staging influences patient management. This study emphasises the importance of quality information in the management of the patient with endometrial cancer. This may be particularly important where multidisciplinary treatment is integral to the patient's overall management.

START, a European, evidence-based, state-of-the-art instrument for the clinical oncologist

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START ('State-of-the-Art Oncology in Europe'), a project from the European School of Oncology, is aimed at rendering state-of-the-art clinical treatment of human tumours from a European perspective. START is under construction, but 19 chapters are already available on single tumours or areas of clinical oncology. START is accessed for free at the Web address www.cancerworld.org/start

Each START chapter is put online after a consensus development process and then undergoes continuous refinement and updating. It is drafted by a Clinical Editor, in collaboration with a Statistical Editor, on the basis of contributions from a few specialists. It is peer-reviewed by an internal Reviewer, along with Reviewers from the main European scientific cancer societies. An external formalised feedback, by the same societies and by the whole medical community, adds to the internal reviewing mechanism.

START is an evidence-based instrument. Each critical statement is codified. A diagnostic/therapeutic option can be 'standard', 'investigation' or 'individualised'. An 'individualised' option is suitable for individual clinical use, outside a clinical trial, though it is not 'standardard'. This is peculiar choice made by START, in comparison with other instruments and guidelines. Then, the option can be based on a level of evidence, 'randomised/strong', 'randomised/weak', 'uncontrolled' or on wide 'consensus' or a 'rational' justification. The 'rational' basis is another peculiarity of START, implying that an option is selected due to logical inference, rather than direct evidence.

The first feedback project, supported by the European Union, disclosed a high degree of consensus. A second feedback project is ongoing.

Promoting public confidence in cancer services in the NHS in Scotland

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1. Objectives

The task of the Clinical Standards Board for Scotland is to develop and run a national system of quality assurance and accreditation of clinical services to promote public confidence in the National Health Service Scotland.

2. Method

- Develop standards.
- Measure performance against agreed standards.
- Public report.

1. Developing standards — standards subject to consultation
   - Distribution within NHS and public, open and focus group meetings with written comments.
   - Standards refined as result of consultation and pilots.
   - Self-assessment tool developed.
2. Measuring performance against agreed standards
   - Pilot peer review visits, to test standards on the ground and to fine-tune the review methodology.
3. Report to public
   - Publish national reports following accreditation visit

3. Results

3.1. Negative

- Piloting showed gaps in availability of data and some relevant data were not being collected. SCTN and SIGN databases showed a degree of incompatibility.
- Difficulties in assessing performance and grading standards.

3.2. Positive

- Palliative care standards have been incorporated in site specific cancer standards.
- Improved communication.
- Multi-professional working.
- Self-assessment tool enables Trusts to identify gaps in service and identify good practice.
- Unification of relevant databases.

4. Conclusion

This is an inclusive process generating enthusiasm and sense of ownership of both professionals and the public in healthcare in Scotland. The standards support the profession in improving the quality and equality of patient care and address issues related to clinical governance. The process is pivotal for the evolution of integrated managed clinical networks.

Defining standards for cancer care: the Welsh approach

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Throughout the UK, there is a drive to routinely monitor the processes and outcomes of cancer care. This requires the definition of criteria and standards against which performance can be measured. Who defines them and how? Should there be 'minimum', 'average' or 'ideal' standards?

To avoid tile perception of arbitrary standards being imposed on the clinicians, the approach in Wales has been to involve specialist clinicians in setting the standards for themselves and their colleagues. There are nine 'Tumour Site Advisory Groups' consisting of key clinicians (of all professions) with an interest in that tumour. Among their responsibilities is the setting of minimum standards for clinical care. These standards are then approved by the Mini-

mum Standards Sub-Group of the Cancer Services Co-ordinating Group for Wales, and include both generic standards common to all cancers and site-specific standards. These minimum standards are seen as fostering a developmental approach. They are revised and, if necessary, 'tightened' every year. The responsibility for monitoring these standards and effecting change rests with the Health Authorities.

Compliance with these standards was monitored for 1999 for three tumours (breast, colorectal and lung) and varied between teams and tumour types. Compliance was generally best for breast cancer teams and worst for lung cancer, reflecting the existing investment in tile services and multidisciplinary team development. The strength of this approach is that it is 'bottom-up' and credible, involving clinicians who are answerable to their peers. It seems to be sensitive to the needs for service development.

Influences on Survival Session

Improvement in survival from breast cancer between 1987 and 1993 — earlier diagnosis or better treatment?

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1. Objective

To quantify the increase in 5-year survival for women with breast cancer between 1987 and 1993, and to identify whether early diagnosis or improved treatment was the main contributing factor.

2. Method

National, population-based, retrospective audit data were analysed for all women with invasive breast cancer identified by the Scottish Cancer Registry in 1987 and 1993.

3. Results

In 1987 and 1993, respectively, 1617 and 2077 women with non-metastatic disease underwent surgery. In 1993, compared with 1987, more women in the 50–64 years age group had node negative disease and small tumours, reflecting the introduction of the national breast screening programme. The use of breast conservation, radiotherapy and adjuvant systemic therapy increased between 1987 and 1993. Women were more likely to be seen by high caseload surgeons and oncologists in 1993.

Observed 5-year survival figures were significantly better in 1993 (77.8%; 95% CI 76.0, 79.6) than 1987 (70.9%; 95% CI 68.7, 73.1). There were improvements in survival for women receiving all treatment modalities, and in both screen-detected and non-screen-detected women. The variation in survival between Health Boards appeared to decrease between 1987 and 1993. Multivariate analysis will be used to examine the contribution of earlier diagnosis to the improvement in survival, and also to investigate the contribution of changes in treatment.

4. Conclusions

Survival has improved over this period. Preliminary analysis suggests that the survival gain may not be due solely to screening and lead time bias, but may also be due to changes in the delivery of treatment.

Influence of surgeon caseload on survival from breast cancer

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1. Objective

To determine the variation in surgeon caseload over time and to assess the impact of variation on survival.

2. Method

Retrospective population-based study, using Northern and Yorkshire Cancer Registry and Information Service data. Univariate and multivariate survival analyses.

3. Results

16 092 breast cancer patients diagnosed between 1986 and 1994 were analysed. Surgeons with a low mean annual caseload of less than 10 managed 6% of patients, surgeons with a caseload of 10–29 treated 26%, 30–49 33%, while 35% were managed by surgeons with the highest caseload of more than 50. Over the study period, there was a trend to increasing numbers of patients being treated by surgeons with higher caseloads. During 1986–1988, surgeons managing 50 or more patients per year treated 26% of cases. By 1992–1994, this had increased to 42%.

Overall 5-year survival was 62%. Patients treated by the higher workload surgeons had significantly better survival. Survival 5 years from diagnosis was 58% in the lowest consultant caseload category compared to 67% in the highest workload category. This difference could not be explained by differences in case mix (age, disease extent, socio-economic profile and time period) or treatment.

4. Conclusion

The findings confirm earlier evidence that management by high caseload surgeons improves overall survival from breast cancer.

The effect of workload on outcome for upper gastrointestinal cancers

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1. Objective

Variations in the outcomes of upper gastrointestinal (UGI) cancers have been suggested to be related to both the specialisation and workload of the treating clinicians. This study aimed to determine if clinician or hospital workload affects either postoperative mortality or overall survival in patients with oesophageal, gastric or pancreatic cancer.

2. Methods

A retrospective study of population-based data collected by the Northern and Yorkshire Cancer Registry and Information Service between 1986 and 1994 was undertaken. Outcome measures included 30-day postoperative mortality and overall survival with a median follow-up period of 5 years.

3. Results

A total of 13 020 UGI cancer patients were included in the analysis. Survival was shown to be better in UGI cancer patients treated by high workload consultants than by low workload consultants (a 48, 40 and 49% improved survival rate in pancreatic, oesophageal and gastric cancer patients, respectively). There was also a trend towards better survival in high volume hospitals (an 18, 15 and 24% improved survival rate in pancreatic, oesophageal and gastric cancer patients, respectively). Although diminished, the majority of the trends remained following adjustment for casemix. Similarly, postoperative mortality was generally lowest in patients treated by high workload consultants and in high volume hospitals.

4. Conclusions

The evidence suggests that concentrating surgical management in centres with high workload surgeons and specialist supportive teams will reduce postoperative mortality and improve overall survival.

Specialisation and survival outcome in melanoma

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1. Aim

To compare the survival outcome of melanoma patients in the West of Scotland in relation to the specialty of the operating surgeon.

2. Methods

All cases diagnosed in the geographical area of the West of Scotland (population 2.6 million) between 1979 and 1998 and registered with the Scottish National Melanoma Group database have been followed to the end of 1998. Death information is available from the Registrar General (Scotland) for the 4499 cases. Casemix information is available for age, gender, Breslow thickness (the main, staging variable), histogenic type, year of surgery and anatomical site of the lesion. Cox's proportional hazards model has been used to compare the relative risk if dying for those treated by dermatologists and general surgeons in relation to plastic surgeons (baseline).

3. Results

1129 patients were treated by dermatologists, 1776 patients by plastic surgeons and 1594 patients by general surgeons. Dermatologists are now treating 40% of patients compared with about 5% in the early l980s. Substantial variation existed in the tumour thickness distribution with dermatologists managing a greater proportion of thinner lesions and younger patients. The odds ratio for dying was most favourable if the patient was treated by a dermatologist (RHR = 0.53, age and gender adjusted) but much of this difference was attributable to their treating a

favourable group of patients (RHR = 0.83, 95% CI 0.65–l.05; adjusted for all prognostic variables). There was sonic evidence to suggest that the benefit was more apparent when treating smaller tumours.

4. Conclusions

Treatment by a dermatologist appears to deliver a better survival outcome.

Comparing outcomes in lung cancer: the denominator problem

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1. Objective

To measure the survival of patients diagnosed with lung cancer in a defined locality in England and to assess what variation in observed survival rates is due to the use of different denominators.

2. Method

Several case finding methods were used to identify every patient with lung cancer diagnosed in 1995 in the catchment area of the James Paget Hospital. Cases were identified from the East Anglian Cancer Registry, Hospital Episode Statistics, bronchoscopy records and the local pathology laboratory records. The case records of a sample of 100 cases were checked for accuracy.

3. Results

183 cases were identified (estimated incidence 83/100 000). For the 170 patients in the cancer registry, the median survival was 78 days and 1-year survival 15%. For the 100 reviewed cases, the median survival was 156 days and 1-year survival 24%. For patients ever seen by a respiratory physician, the median survival was 183 days and 1-year survival 29%. For patients referred to a respiratory physician for diagnosis, the median survival was 190 days and 1-year survival 31%.

4. Conclusions

Careful study of outcomes is important for improving the delivery of care. Individual centres reporting their own experience often report outcomes of cases referred, without reference to the total number of cases with lung cancer. This study shows that the use of different denominators has a large effect on outcome measures, with a variation in the 1-year survival rate of 100%.

Casemix and survival — EUROCARE II criteria applied to patients with primary malignant brain tumours in South East Wales

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1. Objective

Velindre Hospital provides the main non-surgical oncology service for South East Wales (catchment area ~1.6 million). Outcome data for patients with primary CNS malignancies were audited and compared to the results obtained for patients with primary malignant brain tumours as presented in the EUROCARE II study.

2. Method

All case records of hospital patients with primary CNS malignancies registered between 1/07/1997 and 30/09/2000 were reviewed and checked for internal consistency. Overall survival was calculated from the date of diagnosis and assessed by the product-limit method of Kaplan–Meier for patients defined by code 191 (ICD 9) forming the basis of the EUROCARE II outcome data for malignant brain tumours. Prognostic variables assessed were age, gender, histopathology (high–grade glioma, low–grade glioma, brainstem glioma, ependymoma, primitive neuroectodermal tumour. other), type of diagnosis (new, recurrent, long-standing) and treatment intent (radical, palliative, none). Subgroup analysis was performed for selected variables.

3. Results

292/308 (95%) registered patients at Velindre corresponded to code 191. Median annual number of patients registered was 92 (EUROCARE countries 61, range 10–1336). The age, histopathology and treatment intent were prognostic variables ($P < 0.001$). Only age distribution, which was not evenly balanced between the countries, was reviewed in the EUROCARE study.

4. Conclusion

Survival probability for patients with primary malignant brain tumours varies depending on prognostic factors in addition to age. Casemix significantly influences overall survival and could account for apparent survival variation between European countries. The use of epidemiological data of small patient samples outside the clinical context is misleading.

International Comparisons Session

Childhood cancer survival in European and US populations

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1. Objective

Highly comparable population based data on survival of European children with cancer have recently become available to researchers and healthcare planners in a special issue of the *European Journal of Cancer*. Survival data on US cancer patients can be accessed from the publicly available SEER database. The aim of this presentation is to describe survival for European and American children diagnosed with malignant tumours, elucidating differences in relation to country.

2. Methods

We analysed 16 175 European and 3476 US children, whose disease was diagnosed in 1985–1989, obtained from 40 EUROCARE population-based cancer registries representing 17 countries and nine US SEER registries. Observed survival was estimated by the actuarial method for the major International Classification of Childhood Cancer (ICCC) diagnostic groups, adjusted for age and gender through a direct standardisation. To increase the power of geographical comparisons, we have computed an overall survival score for all childhood cancers together, adjusted for age, gender and ICCC group for geographical areas/countries.

3. Results

Five-year survival in Nordic countries (Finland, Iceland and Sweden) was the highest in Europe (75%). Difference was particularly remarkable with respect to Eastern countries (55%). In the other Western European populations, survival ranged between 72% in Germany, 69% in the other Central and Southern European countries and 66% in Denmark and UK, American children had comparable survival with the Western European children.

4. Conclusions

Survival for all the childhood malignancies may help comparing the overall performance of the paediatric oncology of different countries. Survival in Finland, Iceland and Sweden seems to represent a gold standard to which all countries who devote similar resources and have comparable health systems can reasonably aspire. Further studies are needed to understand how much the differences could be overcome through healthcare planning, and to disentangle which aspects of cancer care require priority investment.

Differences in stage and therapy for breast cancer across Europe

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1. Objective

To analyse variations in therapies given and stage at diagnosis for breast cancer in Europe.

1.1. Method

Seventeen population-based cancer registries in six European countries contributed all, or representative samples of, breast cancers diagnosed in 1990. The clinical records of 4480 cases were examined and the distribution of stage and therapy analysed by registry and country.

2. Results

Stage at diagnosis was earliest in the French registries followed by those of Italy and Eindhoven (The Netherlands). The proportion of stage I cancers was highest in French areas with screening in place. Estonia, the English registries and Granada had the most advanced stage at diagnosis. The French and English registries had the highest proportions of cases treated by conservative surgery (54 and 55%, respectively); Estonia and Grenada (Spain) had the lowest (6 and 11%, respectively). Italy and Grenada had the highest percentages of Halsted mastectomies (10 and 7%, respec-

tively). In all countries except England, 90% or more of operations included axillary lymphadenectomy, 76% of patients received adjuvant chemotherapy, radiotherapy or hormonotherapy. Medical treatment only was given to 8% of cases (mostly advanced). Estonia and the English registries had the highest proportions given medical treatment only (21 and 14%, respectively).

3. Conclusions

These wide differences in breast cancer care across Europe in the early 1990s indicate a need for continual monitoring of past treatments to help ensure application of the most effective protocols. Similar surveys on breast cancers diagnosed in 1997 are ongoing.

Measuring and interpreting differences in European stomach cancer survival

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1. Objective

Variability in European cancer survival assessed in previous studies will be detected and interpreted through a parametric model whose parameters represent the proportion of cured patients and the timing to death of fatal cases.

2. Method

Mixed cure models for relative survival are estimated as a constant curve representing the proportion of cured cases and a fatal cases curve, whose main outcome is the mean time to death. Cured cases mortality is assumed to be similar to the general population one. The model is applied to European relative survival data (EUROCARE-II), analysed by age, gender, country, and period of diagnosis.

3. Results

Stomach cancer survival was quite constant in Europe in the 1980s: the proportion of cured cases increased from 9.6% in 1978–1980 to 12.1% in 1987–1989 and the mean survival time was about 7 months. The proportion of cured in European stomach cancer patients was greater for younger than for older (18% at 15–54 years; 6.5% at 75+ years), both for males and females. The corresponding mean survival time was about 14 and 5 months, respectively. Geographical range varies from 6% (Poland) to nearly 20% (France and Germany) for the proportion of cured cases (European mean is about 15%) and from half a year (England) to 1 year (France) for the mean survival time.

4. Conclusion

Increasing survival rates of stomach cancer patients are reflected mainly in a higher proportion of cured. As regards geographical variability, higher survival is associated with both a higher proportion of cured and the longer survival of people bound to die of cancer. These results cannot be fully interpreted in terms of lead-time bias, and support the hypothesis that the observed survival differences are mainly due to a real improvement in management and therapy of cancer patients.

Comparison of stomach cancer incidence and survival in four continents

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1. Objective

To study comparability of stomach cancer incidence and survival data between four cancer registry (CR) areas in four continents and to present net differences in patients' survival, having adjusted for subsite and histology in addition to other common confounding factors.

2. Methods

In order to maximise variability of both incidence and patients survival, we chose CR areas as: Campinas, Brasil (Latin America), Iowa state. US (North America), Varese province, Italy (Europe) and Osaka, Japan (Asia). A proportional hazard regression method is applied to relative survival to obtain geographic differences adjusted for all the factors and for the general mortality. We selected the most important factors explaining survival differences by means of a proportional hazards model. Once important factors are identified, the proportional hazard method on the relative survival is applied. The PHREG and GENMOD procedures from the SAS package are used.

3. Results

Iowa has both the poorer relative survival and the lower incidence rates, while Osaka has the better relative survival and highest incidence rates with respect to the other areas. When stage is included in the model, most of the survival differences between the four registries disappeared. Risk of death, with respect to Osaka, changes from 1.14 to 1.04 in Varese. 1.38 to 1.13 in Iowa and 1.19 to 0.91 in Campinas. In a restricted analysis including Iowa and Varese with high quality and complete data, the risk ratio of Iowa (with respect to Varese) changed from 1.33 to 1.06 (95% CI 1.00–1.12), after controlling by gender, period, stage and subsite.

4. Conclusions

Although comparability of stage among different areas and different time periods can be questioned, stage proved to be the most important determinant of stomach cancer incidence and survival differences.

Measuring and interpreting trends on incidence and survival for prostate cancer using survival mixture models

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1. Objective

Incidence and survival of prostate cancer increased considerably in most European countries during the 1980s and particularly among the oldest patients. The observed changes also reflect the introduction of new diagnostic techniques such as prostate-specific antigen test (PSA) and transrectal ultrasound. Decomposing survival by mixture models is here used to help in the interpretation of prostatic cancer trends.

2. Methods

Parametric mixture models have been applied to estimate the proportion of cured patients (F) and the mean survival time (T) for fatal cases. These estimates have been obtained by non-linear regression on EUROCARE study data, for patients diagnosed in 1978–1989 and followed up to 1994.

3. Results

For the European pool, an increase in the proportion of cured patients from 20 to 24% is observed over the period considered, while the mean survival time presents an opposite trend from about 5 to 4.5 years. Larger variations resulted from country-specific analysis, from 10 to 30% for P and from 6 to 3 years for T in England. The number of 'curable' and 'fatal' incident cases is derived using the P parameter and their increase over time results are steeper for curable cases, particularly for patients aged between 55 and 74 years, and smoother for the fatal patients.

4. Conclusions

We estimated an increasing trend in proportion of cured patients and a simultaneous decrease of mean survival time of fatal cases. This suggests that sonic patients that would have been bound to die in the early l980s have been successfully treated in the late l980s, causing an adverse selection effect among fatal cases.

Explaining the variability of cancer prevalence in Europe

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1. Objective

Information on cancer prevalence is scarce: the Europreval project will provide systematic figures for Europe. Preliminary results reveal impressive large intercountry differences in prevalence. This contribution shows prevalence for all cancers combined: it also estimates the role of determinants (incidence, survival and age structure of population) in explaining differences between countries.

2. Methods

Thirty-eight population-based cancer registries (CRs) in 16 European countries contributed with 2 983 619 cases diagnosed up 1992. Period of registration differed between registries. By using the Preval software, observed prevalence was estimated. When cancer registration was limited and did not cover a long period (say 40 years), total prevalence was estimated by applying a correction factor to observed prevalence data. Finally, using a scenario approach, we estimated for different countries the prevalence that one would expect with different levels of incidence, survival or population structure.

3. Example

The wide range of survival rates is dependent on a different casemix in different populations. Health planning interventions may affect incidence and survival in different ways for cancer sites. However, the scenario which hypothesises the same incidence in all countries indicates the major role of incidence in determining prevalence. Prevalence for all cancers combined ranged from 1758.8 in Slovakia to 3302.5 per 100 000 in South Swedish CR with a ratio of 1.88. Assuming the same incidence in all countries, the ratio of the expected prevalence between Swedish CR and Slovakia CR became 1.58.

4. Conclusion

This kind of analysis can be generalised to help in predicting need and resources allocation when different cancer strategies are considered.

Listening to the Patient Session

Concordance of symptom assessment in advanced cancer patients

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1. Objective

To examine the concordance of symptom assessment in advanced cancer patients by multiple raters.

2. Method

Patient, nurse and junior resident completed the Edmonton Symptom Assessment System on 2 consecutive days in 50 patients. Cognitive functions were evaluated with the Mini Mental State Examination (MMSE). Concordance of the assessment was analysed by linear regression.

3. Results

Preliminary results of 22 patients (12 men, 10 women) are shown. Mean age is 72.8 ± 8.6 years (range 52–88 years). Cancers were of digestive tract (6), breast (3), genitourinary (5), lung (6), thyroid (1) and myeloproliferative disorders (1). Mean MMSE was 27.2 ± 1.5 (range 24–30). First assessment was completed 22 days after the admission (range 3–198 years). Tiredness, worse well-being and loss of appetite were the predominant symptoms. On both days (day 1/day 2), reliability coefficients were significant for appetite (r 0.84/0.71) and well-being (r 0.85/0.71) but not significant for shortness of breath (r 0.68/0.79) and drowsiness (r 0.72/0.66). Reliability coefficients are not significant the second day for pain (r 092/0.63) and nausea (r 0.81/0.10) assessment.

4. Conclusions

These preliminary data already show a good concordance between care givers for appetite and well-being of the patients. Other assessments varied between days 1 and 2 but the results must be confirmed upon study completion.

Investigating the health education needs of women with breast cancer invited to enter a clinical trial

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1. Objectives

To study the experience of breast cancer patients invited to participate in clinical trials, to identify their educational needs and to establish optimal timing of trial recruitment.

2. Method

A qualitative study using short questionnaires, semi-structured interviews and focus group discussions was performed on 33 women treated for early breast cancer (age range 42–78 years) in the Humberside region 1 year post-treatment and clinically disease-free. 23 women had been invited to participate in one of several trials being conducted in the region (ATAC, RADAR, DCIS trial and sentinel node biopsy). Of these, 10 accepted, 10 declined and 3 initially accepted but then chose to withdraw at a later date. 10 breast cancer patients not asked to enter a trial acted as controls.

3. Results

All respondents were concerned at being invited so soon after diagnosis (range 2 weeks–11 months for trial acceptors; 3 weeks–3 months for decliners). The most important educational need for trial entry was perceived to be a greater understanding of cancer biology. Interest was shown in the rationale for clinical trials and the need for research was considered to be very important.

4. Conclusions

This study confirms the altruistic rationale underpinning patient acceptance of clinical trial entry. It raises concerns about effective communication and informed consent by demonstrating a strong correlation between trial entry and degree of trust established with 'first contact' clinician. The comments on the need for partial ownership of the research echo current issues of consumer involvement in research direction and design.

The implementation of interprofessional collaboration and education in a cancer service

A. David, A. Bahl, J. Counsell, M. Greham, F. Simpson, H. Langton, A. Hodgetts

1. Objectives

To develop interprofessional work and education to improve the provision of care for cancer patients; to encourage user involvement in the design of healthcare; to ensure the accurate and timely provision of information for patients embarking on radical courses of radiotherapy.

2. Method

A team consisting of two therapy radiographers, two breastcare nurses, one oncology clinic nurse, one specialist oncology registrar and one pharmacist assisted by a facilitator from the University carried out:

- an evaluation of the literature available to breast cancer patients attending the Bristol Oncology Centre and 29 other centres;
- study of the advice given and the medication available to patients receiving radiotherapy in Bristol;
- a survey of the experiences of former Bristol Oncology Centre patients, thus developing a partnership between users and professionals.

3. Results

- Although advice and medication used were evidence-based, the quality of the written information was sometimes inferior to that available in other centres.
- The users reported that advice and information given was consistent but that the information about radiotherapy was given too late to patients who had received chemotherapy first.

4. Conclusion

- Information sheets about radiotherapy and its side-effects will be improved.
- Verbal information about radiotherapy will be given sooner, as suggested by users.
- Users are being involved in the development of healthcare with the assistance of the Patient Survey Unit.
- The team will continue to work together to provide and improve the service.
- Care pathways will be developed with the help of users.

Contrasting views of staff and patients on oncology services at the Western General Hospital, Edinburgh

E. Preston, S. Bruster

The Lothian University Hospitals NHS Trust, in collaboration with Picker Institute Europe (a charitable research institute based in Oxford), has undertaken a major study to understand the views and experiences of cancer patients treated at the Trust.

This presentation discusses the developmental qualitative work with patients and staff used to help design the survey questionnaire.

Focus groups of staff were run first, followed by focus groups of patients. Separate groups were run for patients with breast, lung, colorectal and gynaecological cancers — one group for each cancer with newly diagnosed patients and another with patients diagnosed more than 6 months previously.

The issues raised by patients and staff will be discussed with vivid positive and negative comments shown. In particular, the interesting differences between what staff and patients view as being important to patients in their cancer care will be highlighted. Although there is agreement between staff and patients, the differences show that only patients can be expert witnesses to the healthcare process and that staff should try to see the care they provide through the patients' eyes.

Cancervoices: involving cancer service users☆

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1. Objectives

- To develop a national network of cancer service users to work in partnership with oncology service providers.
- To develop appropriate training, information resources and support for cancer service users to be effective in influencing service developments.

2. Description of the project

Cancerlink has developed this action research project together with service users and health professionals who form an Advisory Group. It is developing a national network of cancer service users who link with existing cancer self-help and support groups on a regional basis. This provides service users with information, support and training to be more effective in helping the NHS to shape services. It includes:

- Network development meetings, which are held in each NHS region to bring together service users to share experiences and ideas.
- Training courses for user and multidisciplinary groups in effective partnership working.
- Telephone and web-site access to information and support.
- Outreach work with minority ethnic groups to enable the views of a wider range of service users to be heard.

3. Findings

Current involvement of cancer service users is patchy and *ad hoc* in spite of supportive Government policy. Networking enables users to learn from each other and avoid duplication of effort. Evidence from service users shows that training and support are essential if they are to reflect wider users' views effectively.

☆Service user includes patient, carer, family member or advocate.

Measuring outcomes from adjuvant hormone therapy: the patients' view of the minimum acceptable benefit from treatment

J. Houghton, D. Fellowes, L. Fallowfield, C. Saunders

1. Aim

This study developed an interview-based methodology for assessing minimum acceptable survival benefits from endocrine treatment. Women interviewed for this study had participated in the Cancer Research Campaign (CRC) Adjuvant Breast Trial for Patients Under the Age of Fifty.

2. Method

A semi-structured interview schedule was developed to establish quantitative trade-offs between potential survival gains from the treatments in the trial (tamoxifen and Zladex), and side-effects which may be experienced from the therapies. A visual aid was used to explain possible survival gains in terms of increased survival time and improved 5-year survival rates. Trial therapy was scheduled to last for 2 years, and interviews were conducted at least 6 months after the end of the trial therapy. The intended sample of 75 interviewees has been exceeded.

3. Results

Preliminary results suggest that the method is feasible, in that interviewees are able to make quantitative assessments of acceptable benefits and answers vary between interviewees. Test–retest reliability of the scenarios with healthy volunteers is reasonable. As many of the scenarios build from each other, checks for consistency and understanding were also possible. Interviewers assessed the acceptability of the questions after each interview. All patients interviewed ($n = 81$) were considered to have understood the purpose of the interview, with less than 3% having difficulties understanding the scenarios 'very much so', 5 of the 81 patients interviewed were considered to have been upset at least a little by one or more of the scenario questions. In 10% of cases, issues were raised by the interview which required further discussion.

4. Conclusion

This study helped develop a useful new method for patient evaluation of therapy and it is hoped that the methodology will be transferable to other treatments and diseases.

Networking Session

Contribution of SCAN (managed clinical network for cancer services) to evidence-based healthcare in South-east Scotland

A. Gregor, A. Allen, O. Shipp, J. Wilson, J. Rodgers, A. Stark on behalf of SCAN

Deaconess House, Edinburgh, UK

1. Objective

To deliver evidence-based care to patients with breast, colon, lung and gynaecological cancer in Lothian, Fife, Borders, and Dumfries and Galloway.

2. Method

Development of SCAN as managed clinical network in South-east Scotland: population 1 376 200; annual incidence of 950 breast, 1153 lung, 926 colorectal and 192 ovarian cancers. Seven large acute hospitals provide cancer diagnosis and treatment of which one (the nominal cancer centre) provides radiotherapy. As a multidisciplinary network virtual organisation, SCAN is committed to improving access, quality and efficiency of cancer services and to moving from an institution-based, disease-oriented approach to a 'seamless' patient-focused care process. The framework is evidence-based (SIGN/other national guidelines). The structure consists of tumour-specific multidisciplinary groups (MDGs) supported by a manager with a core group of Lead Cancer Clinicians linking SCAN to the nine NHS trusts and four health boards responsible for healthcare planning and provision.

3. Results

The MDGs have reviewed and adopted care pathways and protocols covering key aspects of cancer journeys. Quality is monitored by prospective audit of agreed core datasets strengthened by recently promulgated national standards.

4. Conclusions

Managed clinical networks offer a successful model for achieving equity of access to evidence-based care in large geographical areas. Further improvements and sustainability of ongoing QA will require Information Management and Technology support.

A Web-based support system for managed clinical networks in cancer care

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Managed clinical networks (MCNs) are evolving as an organisational framework by which to provide health services effectively. Much of the information they need to function is accessible via the Web and it can provide a platform for facilities necessary to set up and maintain such clinical networks.

Preliminary work has been done on identifying ways in which to take forward the provision of easy. systematic access to relevant information and facilities and also means of efficiently organising overall management of networks focused on clinical cancer care.

This paper describes a Web-based system which functions as a multidimensional management matrix with recursive use of display and descriptive templates which can be applied to cancer services of all types at all levels of detail. The approach being taken allows the progressive increase in content and facilities on an evolutionary basis as and when need and available resources dictate.

Linkage into ISD cancer datasets and analyses are a feature of the system and provide a Scottish context for audit comparisons by which to direct service improvements.

The paper will provide a description of the system and outline of its use to support cancer MCNs.

Telepathology for remote consultation and training in Scotland

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1. Objectives

To evaluate the uses that can be made of telepathology between sites for second-opinion consultation, remote diagnosis and remote teaching sessions of pathology trainees.

2. Method

We have linked dynamic telepathology systems at the Pathology department at Teviot Place and the Western General Hospital in Edinburgh, and the Pathology department at the Glasgow Royal Infirmary. Pathologists use the systems to consult on cases that would otherwise have been physically sent for examination, and meetings between sites are held remotely. Data was collected through a combination of questionnaires and interviews.

3. Results

Pre-preparation of images followed by an online discussion of the case is more time-effective for the critical online period than an unprepared live session. In a small number of cases, when there is still uncertainty, the slide can be placed on the microscope and re-examined remotely. These sessions have been deemed useful and have resulted in a saved journey and an enhanced mutual learning experience. There has been limited call for remote consultation within a large teaching hospital, due in part to available expertise onsite, and in part to a regular established system for specimen exchange between sites. For training purposes, there is reduction in time lost in travelling to meetings, and more trainees can view cases simultaneously than via a multiheaded microscope, with very high image quality.

4. Conclusions

While there are significant demands on pathologists' time in preparing sessions and engaging in live remote sessions, telepathology is proving to be a useful additional resource in linking expertise from different sites. This utility will increase with the distance between sites and where there is greater need to refer cases to outside expertise.

The use of telepathology and digital imaging in clinical meetings

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1. Objective

To assess the use of this telepathology in clinical meetings and teaching.

2. Method

Images are acquired in advance on the telepathology equipment and saved within a session file with annotations. Sessions can then be presented via a freely distributable viewer program on a laptop connected to a digital projector. Data for this study was collected through a combination of questionnaires and interviews.

3. Results

The multidisciplinary meetings where this technology has been used have included combined gynaecology and oncology, liver and liver transplant pathology and lymphoma meetings.

3.1. Subjective assessment

The equipment has proved to be very easy to use, gives excellent image quality and the ability to scan in an overview of the whole specimen for presentation is a valuable feature.

3.2. Objective assessment

Pre-preparation of cases takes between 5 and 15 min per case, depending on the number of images selected and the amount of annotation. This investment of time is repaid in the meetings themselves, where many more cases can be presented in a faster and more organised manner with a much better image quality than previously. The ability to annotate the images improves the clarity of the presentation. The clinicians attending have been very appreciative of these improvements and gain more from the meetings as a consequence.

4. Conclusions

The use of telepathology equipment, coupled with digital projection facilities, for presentation of cases at multidisciplinary clinical meetings has proved to be a very useful advance on the traditional method of live videomicroscopy in the meeting room. We are now extending this application to presenting clinical meetings remotely using the built-in videoconferencing facility in the telepathology software.

The Italian network on rare tumours as an attempt to exploit telemedicine to share patients with uncommon tumours

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Rare tumours entail special difficulties in terms of quality of care, equal access to resources and research. This is due to dispersion of expertise and facilities and paucity of case series. Telemedicine has been widely demonstrated, but its best employment is still to be assessed. In Italy, a 'network on rare tumours' has been established, aimed at: (1) sharing patients at distance; (2) harmonising diagnosis and treatment; (3) rationalising patient access to available facilities. The network has completed a 3-year construction phase and has now entered a 1-year feasibility evaluation phase. It deals with cases of sarcoma, mesothelioma, thymoma, very rare histotypes and other uncommon neoplasms.

Some 50-plus oncology units scattered over the whole nation are participating. Internet access is the only telematics requirement. Cases are shared through a secure Web resource hosting patient data and messages among centres. A database stores all data, images and transactions. Patients may be: (1) 'logically' shared, whenever their case is approached according to agreed criteria; (2) 'virtually' shared, whenever their case is discussed over the network by two or more centres; (3) 'physically' shared, whenever they move from one centre to another for appropriate care. Pathological diagnosis and local treatment are among the main concerns. Differentiated Web-based modalities to share pathological and radiological images are used, depending on clinical needs in each case. Data will automatically feed an ongoing national register of rare diseases, and can be used to fill clinical trial flowsheets. Partnership with population-based cancer registries has been agreed.

Population-based data collection in haematological malignancy provides reality-based data for uniform care delivery

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1. Objective

To create a continuous population-based programme of clinically relevant data collection for leukaemia and lvmphoma including treatment and outcome, to provide uniform treatment strategies and clinical trials and provide a vehicle for research into practice.

2. Method

Total leukaemia data collection in adults was instituted in the NRHG in 1982 for a population of 3 million. The continuous process has used clinical pathways and subsequent adoption by all physicians concerned of uniform treatment, options and trials since 1990. Broad-based audit and uniformity of care are in place. In lymphoma, the SNLG data collection programme began in 1979 and since 1994 greater than 95% of information, treatment and outcome has been collected for HD and NHL for an 8.5 million population (Northern UK and Scotland). Trials and studies have been superimposed and model uniform treatment when no trial is possible.

3. Results and discussion

Data on >1200 consecutive acute leukaemia patients in the adult age group confirm the age-related survival patterns. A 5-year difference in median age is consistent with a 5% difference in survival. The data explain substantial differences in outcome of leukaemia on various treatments in both trials and studies. An age-related trial structure linked to cytogenetics must emerge. 13 000 population-representative patients with lymphoma patterns of survival relate substantially to age. Only stage I patients have a significant difference in survival. Patients >stage II have similar survival in all age groups. Extra-nodal lymphoma accounts for 35% of all lymphoma in the population and current trial methodology is inappropriate for their study. The population programme has enabled input into randomised trials to accrue (>70% of the target population in Hodgkin's disease and low grade non-Hodgkin's lymphoma). Reality-based data emerge from the programme and the doctor ownership of the process leads to uniformity of approach and care, and marked increase in trial input. The PACE (population-adjusted clinical epidemiology) programme can be recommended in other areas of cancer.

Practical Issues Session

Assessing the forces of nihilism in lung cancer care

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1. Introduction

Lung cancer is the most common cancer in Europe and the major cause of cancer death. The EUROCARE study has identified international differences in survival, with the UK comparing unfavourably with the rest of Europe and published figures suggest that the US survival is higher still. This paper examines the possible reasons for the worse survival in the UK, focusing on both physician and patient nihilism as contributing factors to the differences in treatment policy.

2. Discussion

The poor UK survival for lung cancer has been attributed to a number of potential factors: (1) resource constraints such as lower numbers of oncologists and thoracic surgeons, less radiotherapy facilities and lower availability of expensive cytotoxic drugs; (2) more accurate cancer registration data such that the frail and elderly who never receive

treatment are included in the UK statistics; (3) UK physician nihilism in treatment of lung cancer; (4) lower expectations/lack of assertiveness in UK lung cancer patients.

This paper assesses the differences in treatment schedules used most commonly in the UK contrasted with Europe and the US, and questions why these differences exist. We focus specifically on the West of Scotland, where the incidence of lung cancer is among the highest in the world and the survival is among the lowest and, within this context, we will discuss the possible influences of patient expectation and physician nihilism in the determination of management plans.

Palliative chemotherapy in the real world

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1. Objective

To analyse the use and effectiveness of palliative chemotherapy in a routine clinical setting.

2. Method

An electronic patient record system was developed at the Derbyshire Royal Infirmary in 1995. This system also generates the chemotherapy treatment prescription and thus permits precise documentation of clinical practice and outcome. All patients starting first-line palliative chemotherapy between April 1996 and September 1997 were identified and patterns of care analysed.

3. Results

In all, 213 patients attended on 1372 occasions and received 776 cycles of chemotherapy. All patients were followed-up until death or for a minimum of 3 years. Patterns of care and survival outcome for the entire cohort will be presented and also analyses by age and tumour site will be shown. These shed light on the realities of transferring results from clinical trials into routine everyday practice. The implications for patient selection, clinical care and resource utilisation will be discussed.

Clinical trials recruitment: the impact of adequate funding

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1. Introduction

Only between 2 and 5% of eligible cancer patients currently enter clinical trials in the UK. Lack of funding and dedicated research staff are among the reasons for this. Whilst the need for extra costs is recognised, national bodies like the MRC do not cover the full costs.

2. Method

In 1998, we applied to the Directorate of Research and Development for excess support costs for clinical trials. We developed a realistic model to include the costs of the consenting procedure, data collection and follow-up. The model indicated the time spent for each activity which was appropriately costed. This process was individualised for each trial.

3. Outcome

The outcomes of this were:
The costs as calculated were approved and:

1. Trial recruitment increased over 400% from 39 patients in 1997 to 185 in 1999.
2. Three full-time dedicated staff are employed to support clinical trials.
3. Our trials portfolio continues to increase.

4. Conclusion

The extra costs of clinical trial participation must be recognised and funded if the recruitment into trials is to be encouraged. This is especially true for the smaller centres and is even more important now that the Government is planning to establish the National Cancer Research Institute. Details of the model and method of costing the excess support costs will be presented.

TACT and TANGO — a UK partnership for women with breast cancer

H. Earl, J. Dunn, C. Poole, P. Barrett-Lee, P. Ellis for the TACT and TANGO Steering Committees

The use of adjuvant taxanes has already been widely adopted in the US for women with moderate and high-risk primary breast cancer. The existing data, however, suggest that the majority of benefit may be in women with a worse prognosis. UK breast cancer specialists have therefore established two adjuvant chemotherapy trials in partnership with the CRC, UKCCCR and the pharmaceutical industry. The first trial, TACT, will look at the addition of a taxane in women where the taxane indication is uncertain. The second, TANGO, will provide all women with a taxane and look at the addition of gemcitabine. The taxanes will all be provided free in the first instance.

If UK specialists were to adopt a US approach, the potential costs would be enormous and can be easily calculated. However, the approach of the UK is research-orientated, but also represents a rational and responsible way forward. Trial recruitment will increase, the delivery of expensive new treatments to women with breast cancer which we could otherwise ill-afford will happen and the UK population will receive better standards of care. Novel molecular analyses will be carried out in these trials and will allow for the increasing individualisation of therapy in the future. The long-term benefits of our strategy are very clear.

Adjuvant breast cancer chemotherapy — an audit of neutropenia, dose intensity and G-CSF use in the UK

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1. Objectives

Evidence suggests that maintaining dose intensity (DI) is important in the adjuvant chemotherapy of primary breast cancer. The principal reason for dose modification is neutropenia, although data indicating the number of patients affected by neutropenia in clinical practice and the impact of neutropenia on overall DI received are limited. The aims of this study were to: (1) record the incidence of neutropenic events (hospitalisation due to febrile neutropenia, dose delay of $\geqslant$1 week due to neutropenia, or dose reduction of $\geqslant$15% due to neutropenia); (2) evaluate the impact of neutropenic events on overall DI received; (3) review the use of G-CSF and its impact on DI in patients with primary breast cancer.

2. Methods

Prospective or retrospective data were collected from 15 centres.

3. Results

Data relating to 422 patients with stage I–III primary breast cancer were collected. A variety of regimens were administered, primarily CMF- or anthracycline-based (61 and 37% of patients, respectively). Only 6% of patients received G-CSF. Overall, 29% of patients experienced a neutropenic event, with dose delay being the most common strategy to minimise subsequent risk if no sepsis was seen. Neutropenic events bad a significant impact on the ability to deliver planned DI: in those who experienced a neutropenic event, around one-third of patients received $<$85% DI, and 3 and 9% of patients receiving CMF- or anthracycline-based regimens, respectively, achieved $<$70% DI. Overall, a trend towards improved DI was seen in those neutropenic patients treated with G-CSF. Patients who experienced one neutropenic event were at high risk of experiencing a second event; this risk was 56 and 72% in patients receiving CMF- and anthracycline-based regimens, respectively.

4. Conclusion

In the adjuvant chemotherapy of primary breast cancer, neutropenic events are common, very likely to be repeated in an individual patient and have a significant impact on received dose intensity.

Developing and evaluating a regional patient information strategy

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1. Objectives

To develop a regional cancer patient information strategy and evaluate the impact of intensifying patient education on patient satisfaction.

2. Methods

A 3-year longitudinal study from February 1997 to February 2000. Over this time, four strategies were implemented in stages. Firstly, nurse-led information clinics, where the nurse who attended the doctor–patient consultation then had a separate consultation to ensure the patient understood what was said, provided further advice and information materials. Secondly, an information video 'Chemotherapy & Radiotherapy' now offered to all patients free to take home before treatment (available from Cancer BACUP or Health Education Publication +44-2920-403-022, health.education@btinternet.com). Thirdly, an individual hand held A4 file (folding to A5) which is updated by individual advice sheets are inserted at appropriate times in the management from our fourth strategy — a designated Web site which links all our hospitals under one information umbrella (cancrnet.co.uk).

3. Results

A satisfaction questionnaire was developed by the IPRG helped by panel of patients and health professionals. Within two oncology departments, the same questionnaire was given to 100 patients attending the same clinics over the same 2-week period every February from 1997 to 2000. On a five-point scale, patients indicated they were satisfied (S) or very satisfied (VS) as follows. 1997 (S — 21%, VS — 10%) 1998 (S — 30%,VS — 18%), 1999 (S — 52%, VS — 37%), 2000 (S — 37%, VS — 58%). Other measurable criteria of satisfaction were letters from patients, which have been recorded and stored since 1996. Official 'thank you letters' have increased from 7 in 6 months in 1996, to 76 in the 6 months prior to February 2000, despite new patient numbers doubling over the same time. 'Letters of complaint' decreased from 12 in the first year to two in the last.

4. Conclusion

These information strategies have created a culture of information provision and a massive change in patient satisfaction and resulted in a significant reduction in potential expensive litigation.

Quality of Care Session

Evaluation of patient satisfaction with care in a regional oncology institute

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1. Objective

The Aquitaine regional cancer center (Institute Bergonié) organised in March 2000 a survey among hospitalised patients to assess cancer patients' opinion of care quality and to help clinicians and decision makers improve their care, identifying subgroups of patients according to satisfaction.

2. Method

We used a multidimensional questionnaire developed and validated in 17 hospitals in our region. We asked consecutive patients discharged during 1 week from our Institute to complete, on the last day, a 57-item self-administered

questionnaire. Most items referred to an aspect of care (admission, care, technical aspects, operating room, accommodation and discharge) rated on a five-point scale (1: poor; 5: excellent).

3. Results

This questionnaire was presented to 142 out of 168 patients discharged (exhaustive rate 85%) and the acceptance rate was 93% (132 patients). The responders were satisfied (95% were satisfied or fully satisfied). The principal points of dissatisfaction (score <3.5) concerned: (1) ease of access outside and inside the Institute; (2) food; (3) provision of information concerning side-effects of the treatment at home. In a preliminary factor analysis among 76 patients, we separated, according to 12 items, two groups of patients (score >3 versus others). Using a factor analysis and a multiple logistic regression analysis, four variables (hospital discharge planning, care given, comfort of accommodation and welcoming in wards) were found to be good predictors of general satisfaction.

4. Conclusion

This generic questionnaire showed an excellent acceptability and feasibility in an oncology institute; our results to predict satisfaction will be confirmed by repetition of this survey.

Meeting the JCCO 'quality control in cancer chemotherapy' agenda with ISO9000

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Most radiotherapy departments in the UK either have certificated ISO9000 quality systems or are actively working towards this endpoint. Comparatively few have included chemotherapy. Yet the processes of radiotherapy and chemotherapy treatment delivery have similarities. The need for adequate quality control in chemotherapy treatments has long been established (highlighted in a report in the UK in 1994).

Edinburgh decided some time ago to include chemotherapy and radiotherapy within its quality system. We were due for certification by an external body for the chemotherapy 'arm' during winter 2000.

This paper describes how this quality assurance system ensures we deliver on the requirements in the 1994 JCCO report and its sister publication 'Clinical Outcome Measures in Oncology' (January 2000). It outlines how the system has been implemented within our clinical environment (medical doctors, nurses, pharmacists and administration staff). It further describes the additional benefits accrued during the establishment of the system in a large medical oncology department employing in excess of 100 staff and treating typically 700 patients each month.

Patient and carer satisfaction with follow-up in the management of malignant brain tumours

S. McNamara, M. Walker

The Edinburgh Centre for Neuro-Oncology Objective, UK

1. Objective

The Edinburgh Centre for Neuro-Oncology aims to provide optimal care for patients with malignant brain tumours. To avoid the continuing practice of basing the provision of care on little or no empirical evidence, it is recommended that healthcare professionals make rigorous evaluations of the service they offer and listen and act upon the views of patients and their families [1].

2. Method

As part of a larger randomised study, looking at the evaluation telephone follow-up compared to routine hospital follow-up, information was collected on levels of patient satisfaction. A questionnaire developed from Hill [2] was adapted to suit this patient group and included the following aspects of care:

Group A — General satisfaction
Group B — Giving of information
Group C — Empathy with the patient
Group D — Technical quality and competence
Group E — Attitude towards the patient
Group F — Access to the service and continuity of care.

3. Results

Overall, the responses indicated that patients and family carers were satisfied with care provided by the Edinburgh Centre for Neuro-Oncology. Indeed, no worrying areas were identified. Interestingly, patient and carer satisfaction was not affected by quality of life or the length of time spent with them during a consultation.

4. Conclusion

Overall, the results were positive; nevertheless, the study did highlight areas for improvement and should be repeated when current practice has been reviewed.

References

1. Avis, 1997.
2. Hill, 1997.

Clinical trials subsidise cancer patient care

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1. Objective

To determine the financial impact of undertaking clinical trials on cancer patients on the drug budget of a regional cancer centre.

2. Method

The study subjects were all patients entered into cancer chemotherapy trials where an established standard treatment existed during the fiscal year 1999–2000. The total cost of chemotherapy administered to these patients was

calculated using British National Formulary prices (excluding VAT, any NHS discounting and any supportive drug costs such as antiemetics). Income received from trial sponsors to fund chemotherapy drugs was identified and the difference between this sum and the total cost identified the drug cost incurred by the NHS. By subtracting the NHS contribution to treating patients in a trial from the cost of offering the same patients standard chemotherapy outside of a trial, the net financial impact on the cancer centre's budget was determined.

3. Results

202 patients were treated in 28 different trials, receiving a total of 965 cycles of chemotherapy. The total cost of chemotherapy drugs was $511.5K. Income received from trial sponsors provided $326.4K towards drug costs, industry being the main contributor. The NHS therefore spent $185.1K on the chemotherapy of this group of patients Administration of standard chemotherapy outside of a clinical trial would have cost the NHS $436.8K. Thus, the NHS gained $251.7K, equivalent to 10% of the departmental drug budget that year.

4. Conclusions

Contrary to concerns that clinical trials cost the NHS, we have clearly shown that they significantly subsidise the patient care budget.

Breast cancer: stage distribution, treatment and survival comparisons between two neighbouring countries

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1. Objective

To find explanations for the inferior survival rates of Danish breast cancer patients compared with the other Nordic countries. The study compares in detail the extent of disease at diagnosis, treatment given and outcome in population-based cohorts of patients diagnosed with primary invasive breast cancer during 1983–1989 in selected counties of Denmark and Sweden. The Danish county was characterised by a decentralised organisation with no screening, whereas the city of Malmö had a completely centralised organisation and a partly screened population.

2. Method

In the National Cancer Registers, 1757 Danish and 1012 Swedish patients were identified and hospital records were found. Survival data were given from the National Population Registries.

3. Results

A 10-year overall survival difference of 8.4% was found in benefit to the Swedish region. This could be explained by significant differences in tumour size and nodal status. Tumour size were 18 versus 20 mm median, and 40% versus 43% were node-positive. Also, significant differences in the quality of surgical procedures were revealed. In the Danish cohort median, five nodes were removed, whereas in the Swedish cohort the median was 11 nodes.

4. Conclusions

Extent of disease was the most important predictor of survival. Differences in the axillary quality of surgical procedures can be important.

Development of training workshops in improving skills in breaking bad news for senior healthcare professionals at Derriford Hospital, Plymouth

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1. Aims

In 1997, Plymouth Hospital NHS Trust designated breaking bad news a trust quality initiative. A team of doctors and nurses from the psycho-social and palliative care teams were asked to develop a training programme. A multiprofessional training programme entitled 'Improving your skills in breaking bad news' was set up and run over a 2-year period at Derriford Hospital.

2. Methods

The model formulated by Maguire and his coworkers at the Christie CRC Research Centre in Manchester was chosen as the basis for half-day workshops. Teachers from the Psychological Medicine Group in Manchester gave a 2-day workshop to a core group of professionals to train trainers. Following this. 14 half-day workshops were run. The programme of the workshops included presentation of guidelines on breaking bad news using a 10-step approach, an interactive demonstration and role play using participants' real-life experiences.

3. Results and analysis

140 healthcare professionals attended a total of 14 workshops over 2 years. This included 56 doctors. 24 of whom were consultants. The remainder were senior nurses, midwives, physiotherapists, radiographers and sonographers. The course was evaluated by giving a precourse confidence questionnaire which was repeated at *3* months. A post-course evaluation focused on the content of the course. Over 95% of the participants found the course very worthwhile. The role play was considered the most valuable part of the day by 75%. The confidence questionnaires were analysed using SPSS statistics package. A paired sample *t*-test showed an overall 20% increase in confidence over breaking bad news issues, using a six-point Likert scale, reaching very high levels of statistical significance.

4. Conclusions

A total of 140 people were trained in a multiprofessional setting. The workshops were successful in their aims, confirming existing skills of breaking bad news, developing new skills and increasing the confidence of participants.

Socioeconomic Status and Outcomes Session

Relationship between socioeconomic status and tumour stage in patients with breast, ovarian, colorectal and lung cancer

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1. Objective

To investigate the relationship between socioeconomic status and tumour stage at presentation in patients with breast, colorectal, ovarian and lung cancer.

2. Method

Study populations were identified from the National Scottish Cancer Registry and data were abstracted from medical records. The years of diagnosis for patients with breast, colorectal, ovarian and lung cancer were 1993, 1993, 1992–1994 and 1995, respectively. Medical records were available for 2518, 2778, 1387 and 3855 patients, respectively, representing more than 90% of potentially eligible cases for each cancer site. Patients were assigned to a 1991 census-derived deprivation category based on their postcode of residence at diagnosis.

3. Results

There was no evidence that patients from deprived communities were likely to present with more advanced disease at diagnosis for either breast cancer $\chi^2 = 9.89$. $P = 0.13$ for pathological tumour size: $\chi^2 = 7.79$, $P = 0.25$ for pathological node status: $\chi^2 = 3.89$, $P = 0.14$ for metastatic status) or colorectal cancer $\chi^2 = 4.74$, $P = 0.79$). This was true across all age groups. For ovarian cancer, there was a suggestion that deprived patients may have more advanced disease $\chi^2 = 14.96$, $P = 0.06$), but this was balanced by the observation that deprived patients with lung cancer were more likely to present with localised disease $\chi^2 = 13.52$, $P = 0.04$).

4. Conclusions

Our results suggest that there is no consistent evidence of patients from deprived communities presenting with more advanced disease for the four cancers studied.

Explaining the deprivation gradient: the impact of treatment, presentation and host factors on survival from colorectal cancer

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1. Introduction

Reasons for the relationship between deprivation and survival from many cancers are not well understood. Delay in presentation, comorbidity and inequity of treatment are all possible factors. We investigated the effect of deprivation on survival from colorectal cancer while controlling for prognostic factors of age, gender, site, Dukes' stage, comorbidity, emergency versus elective initial surgery and specialist versus non-specialist surgeon.

2. Methods

All incident cases of colorectal cancer in residents of Wessex between l991 and 1994 were included ($n = 5176$). All patients with complete data were included in the survival analysis ($n = 4327$). Deprivation was measured using three groups of the Townsend score, based on the national distribution of deprivation scores. χ^2 tests were used to identify differences between included and excluded cases. Log-hazard plots and Cox regression on single variables were used to confirm the effect of the above variables on survival in this population. We estimated survival in the deprivation groups using Cox regression on all significant predictors of survival.

3. Results

The unadjusted hazard ratio for dying from colorectal cancer (most deprived versus most affluent) was 1.20 (95% CI 1.09–1.32). After adjustment for independently significant prognostic factors, the effect of deprivation is reduced but it remains a significant predictor of survival, with a hazard ratio of 1.13 (95% CI 1.02–1.25) for the most deprived versus the most affluent group. All previously identified predictive variables remain significant in the model with deprivation.

4. Conclusions

In this population-based cohort, survival from colorectal cancer is associated with material deprivation. The deprivation gradient cannot be fully explained in terms of known prognostic factors such as the stage of disease at diagnosis, initial health status or surgical treatment. Further investigation at the level of individual patients is necessary to identify the underlying causes of such survival differences.

Survival differences by socioeconomic status: distribution of prognostic factors for breast cancer by deprivation category

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1. Objective

To quantify the magnitude of the difference in 10-year survival from breast cancer between women resident in affluent and deprived areas and to examine the contribution of variation in the distributions of prognostic factors by deprivation category.

2. Methods

Scottish cancer registration data (21 751 women; diagnosed between 1978 and 1987) were used to obtain a precise estimate of the magnitude of the survival difference between affluent and deprived women aged under 85 years with invasive breast cancer. Separately, national population-based retrospective audit data for 1987 (2035 women) were analysed to examine the influence of prognostic factors on this observed survival difference.

3. Results

Both datasets showed survival differences of 10% between affluent and deprived women, across all age groups. In the audit data, tumour size, node status and clinical stage did not differ significantly in relation to deprivation. However, amongst women aged under 65 years, the incidence of oestrogen receptor (ER)-positive tumours was 65 and 48% in affluent and deprived women, respectively; 65 and 50% of affluent and deprived women received adjuvant endocrine therapy, respectively. Nevertheless, we estimate the difference in ER status only accounted for about 20% of the observed survival difference.

4. Conclusions

Women from affluent areas with breast cancer have better survival than women from deprived areas. Differences in ER status by deprivation category can only partly explain this survival difference and further research is needed to identify other explanations.

The relevance of co-existing physical and psychological morbidity to outcomes from breast cancer

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1. Objective

Deprived women have poorer survival rates from breast cancer than affluent women. This paper describes evidence relating to the presence of co-existing physical and psychological morbidity, which may help to explain survival differences.

2. Method

Case note review of hospital and general practice records of women diagnosed with breast cancer in Greater Glasgow Health Board in 1992 and 1993, and who lived in Deprivation categories (Carstairs' area-based measure) 1,2 (least deprived, $n = 157$) and 6,7 (most deprived, $n = 264$) at time of diagnosis, followed by a postal questionnaire sent to survivors.

3. Results

Admissions to hospital for problems not related to breast cancer were more common in those living in deprived areas ($\chi^2 = 11.82$, $P = 0.003$). After diagnosis, women in deprived areas consulted their GPs more frequently than

women in affluent areas (consulting >12 times per year: 27.0% versus 15.9% $\chi^2 = 12.67$, $P = 0.027$). Assessment of psychological status using SF-36 resulted in significant differences for each of the SF-36 scales, with the exception of bodily pain in favour of those living in affluent areas. Women living in deprived areas expressed greater anxiety regarding money (2.8% versus 12.2%, $P = 0.02$), other health problems (8.2% versus 22.1%, $P = 0.02$) and family problems (6.9% versus 17.5%, $P = 0.049$).

4. Conclusions

Data presented demonstrate evidence of more physical comorbidity and psychological difficulties in deprived women. A greater understanding is needed of the interaction of different diseases and psychological problems within individuals in considering outcomes.

Is the increased incidence and mortality in less affluent patients due to a more malignant phenotype?

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The incidence of cervical cancer in the most socio-economically deprived is 3 times more common than in the most affluent in the West of Scotland. Moreover, the more deprived are more likely to die as the cancer tends to be more advanced at diagnosis. To try and identify the most important parameter contributing to advanced stage, the duration of symptoms as recorded from patients scheduled for radiotherapy ($n = 141$) or radical hysterectomy ($n = 36$). In 146 cases, tumour-proliferation rates were evaluated following *in vivo* labelling with tile DNA precursor Budr. For symptomatic patients, there was no association between duration of symptoms and stage at presentation. There was a significant trend for patients with increasing tumour stage to have more rapidly proliferating tumours with higher mean labelling index (LI) measurements ($P = 0.001$) and a shorter potential doubling time (T_{pot}) ($P = 0.023$). Values from socio-economically deprived patients were significantly shorter than those from affluent patients.

The conclusion from this data is that stage at diagnosis is more dependent on the biological behaviour of the tumour as expressed by proliferation rates than delay in presentation.

Recent trends in the place of death of cancer patients: a cancer registry-based study (1989–1996)

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1. Objective

To examine trends in the place of death of Yorkshire cancer patients between 1989 and 1996 and the relationships of selected socio-demographic and clinical variables to the place of death.

2. Method

We used registry data from the former Yorkshire Region. Associations between place of death and other variables were examined using the Chi-square Test and Pearson correlation (r).

3. Results

The proportion of Yorkshire cancer patients who died in an NHS hospital fell gradually from 46 to 43%. Over the same period, the percentage who died at home also declined from 33 to 28%. This decline was most marked during the period of greatest proportional increase in hospice deaths, which rose by 6% over the period. In all age groups, men were more likely than women to die in hospitals or at home, and women were more likely than men to die in hospices or nursing homes. Whilst the proportion of deaths at home was higher amongst patients from the upper super profile groups, death in hospital was proportionally more frequent amongst patients from lower super profile groups. Hospital was the most common place of death for all cancer types, with the exception of breast cancer and colorectal cancer patients.

4. Conclusions

Monitoring the trends in place of death is an important indicator of the equity of provision of palliative and terminal care services. A range of service models is required to cope with different combinations of clinical need, personal circumstance and patient and carer choice.

Strategic Approaches Session

Assuring the quality of cancer services in Scotland

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The Clinical Standards Board for Scotland was established by the Scottish Executive in 1999 to develop and run a national system of quality assurance and accreditation of clinical services, designed to promote public confidence that the services provided by the NHS in Scotland meet nationally agreed standards. In partnership with healthcare professionals and members of the public, its role is to define standards, undertake external peer review of performance across the NHS against the standards and to publish its conclusions and recommendations.

Initially, the Board has focused on the national clinical priorities of cancer, coronary heart disease and mental health. It is currently undertaking reviews into four common cancers: breast, colorectal, lung and ovarian. The standards follow the patient's journey of care and palliative care standards have been incorporated into the tumour site-specific reviews.

After outlining the context in which the Board is operating, notably the introduction of clinical governance, the presentation will focus on the progress of the cancer reviews in developing and consulting widely over the standards and in piloting both them and the external review process in a number of locations. The presentation will also explore a number of challenges facing the Board in delivering its remit, including gaps in the availability and quality of data to monitor the standards, difficulties in assessing and grading performance, involving patients and the public in each part of the process, and reporting the findings in the public domain.

Making Calman–Hine work for Wales

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The approach in Wales has been different from the rest of the UK. The Cameron Report of 1996 was commissioned to identify the existing services and make recommendations for the future of cancer services in Wales. The Cancer Services Co-ordinating Group (CSCG) was established to take up the baton of implementation. The positioning and composition of the CSCG has been vital to its success. The CSCG is seen as independent and draws together patients, clinicians, commissioners and providers at a national level. Our approach is based around the building block of multidisciplinary teams and on the concept of continuous improvement not on single accreditation.

Taking advice from clinicians, we have developed minimum standards and a monitoring process for cancer services. We have also improved information collection and exchange with the aim to improve the patient experience. Key areas for discussion are the balance of burden to bonus for clinicians, patients and managers. As a result of the last 3 years, CSCG are now able to identify the successes and obstacles to implementation of policy as it impacts on funding and information and accountability.

Our approach to the political arena of the National Assembly for Wales has been to ensure that cancer services remain a high priority. Devolution is certain to have an influence on the ability of the UK countries to provide a consistent service. There are lessons to be shared from our experience in cancer services with the new National Service Frameworks.

Standards, options and recommendations for the management of patients with adenocarcinoma of the rectum

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1. Background

Since 1993, the French Federation of Comprehensive Cancer Centers (FNLCC) has been developing clinical practice guidelines (CPGs) for oncology known as the Standards, Options and Recommendations (SOR). This project was initiated by the health professionals themselves. The primary objective of the CPGs was to improve the quality of healthcare and patients' outcome in oncology. These guidelines cover all aspects of patient management from diagnosis to supportive care. The development process involves a multidisciplinary experts group. A systematic literature review is performed to issue evidence-based recommendations in a process involving feedback from specialists in cancer-care delivery.

2. Objectives

To develop clinical practice guidelines for the management of patients with adenocarcinoma of the rectum and to optimise their dissemination using adequate support.

3. Methods

The main steps of the development process, according to the general methodology developed for the SOR, were: (1) multidisciplinary working parties, (2) literature searches carried out by a librarian to find supporting evidence, (3) critical appraisal of the evidence, (4) drawing-up of the recommendations and decision trees and (5) validation of the guidelines.

4. Results

The key recommendations for the treatment of non-metastatic cancer of the rectum are, according to stage:

1. For T1N0M0 tumours, complete surgical resection with sphincter preservation by a specialist surgeon is the standard treatment. For T1 sub-peritoneal tumours, the total removal of the mesorectum can be considered (level of evidence D). Postoperative external radiotherapy at appropriate dose, with or without extensive surgery, is indicated if the histology of the resected section shows incomplete clearance and/or the presence of metastatic nodes and/or invasion of the perirectal fat (option).
2. For T2N0M0 tumours, primary, complete surgical resection with preservation of the sphincter by a specialist surgeon should be undertaken if possible (standard). Preoperative external radiotherapy is an option. If the local resection is histologically incomplete, additional treatment with radiotherapy with or without extensive surgery can be undertaken (level of evidence C). For T2 sub-peritoneal tumours, total removal of the mesorectum can be considered (level of evidence D).
3. For T3 or T4 or node-positive irrespective of T, M0 tumours, external radiotherapy followed by surgery is standard treatment. Surgery preserving sphincter function should be undertaken whenever possible, depending on the location of the tumour in relation to the sphincter, the volume of tumour and the anatomy of the patient (narrow pelvis, obesity, etc.) (standard). Removal of the mesorectum has to be considered for sub-peritoneal tumours (level of evidence C). After resection of a N+ UICC pTNM cancer, six courses of bolus 5-FU/folinic acid days 1–5 can be considered (option). Patients should be included in prospective randomised clinical trials to determine the precise role and the optimal use of radiotherapy and chemotherapy in this context (expert agreement).

5. Conclusion

Easily used in current practice, the corresponding decision trees for these recommendations will be presented.

Future linear accelerator capacity requirements for the United Kingdom

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1. Objective

A previous Royal College of Radiologists report recommended four Linear Accelerators (Linacs) per million of population for the UK. The Department of Health (DOH) Survey on Radiotherapy Services 2000 noted wide variations in levels of provision and practice in England. Long waiting lists to commence radiotherapy, evidence of compromised outcomes, a failure to adopt modern fractionation schedules and techniques and an inability to implement systems to reduce the impact of gaps in radiotherapy and CHART are evidence of a large shortfall in Linac capacity.

This report aims to produce guidance for future planning and calculate targets for levels of service provision taking estimates for demographic shift into account.

2. Method

Three methods of calculating the required Linac capacity for 2001, 2006 and 2011 were used. This helps validate the different models. The models were:

A. General standards and international comparisons.
B. Empirical calculation model using population, access rate, incidence, fractionation patterns and workload per Linac.
C. The DOH algorithm.

3. Results

The models produce a consistent answer predicting a need for a rapid catch up phase to reach five Linacs per million in 2006 and 5.5–6.0 Linacs per million in 2011.

4. Conclusion

In order to reach this target, a major expansion in revenue funding and recruitment of radiographers, medical physicists and clinical oncologists is required and a re-examination of working practices. A robust funding mechanism is necessary to allow the expansion of equipment as well as to replace Linacs, simulators and treatment planning systems at the end of their defined working life.

A national strategic approach for providing radiotherapy equipment in Scotland: physics staffing implications as a potential limitation

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The Scottish Executive Department of Health (SEDoH) began a national strategic review of the provision of major items of radiotherapy equipment in Scotland in 1998. It was based on an initial 5-year programme intended to replace outdated equipment in the short term (some units being over 20 years old), implement a longer-term planned replacement programme, and to consider priorities for an expansion of the number of treatment units. The Strategic Review Group includes professional representatives (radiation oncologists or physicists) of the five NHS radiotherapy centres in Scotland and planning and economic representatives of the SEDoH. The first phase is well under way, with provision enabling building works and purchase of the first waves of linear accelerators and simulators. Currently, funds are available which go part way towards replacement of all equipment over the agreed clinical lifetime of 10 years. Some older units cannot be immediately replaced but only after another installation which can take over their function and clinical load as the clinical service must be maintained throughout. The time for removal of an existing linear accelerator, installation of a replacement and the acceptance testing, calibration and commissioning necessary before clinical use is typically 6–12 months depending on the complexity of the unit, and longer if building work is required. This period requires very significant effort by radiotherapy physics staff, in addition to maintaining their routine clinical service, and the cumulative demands are made worse when a number of new units are acquired close

together. More complex modern equipment brings additional facilities and modalities and hence more complex or new treatment techniques, requiring further large physics effort to develop and implement clinically. Current recommendations are four linear accelerators per million population, requiring an extra six units for Scotland, an approximately 35% increase (5 per million, i.e. a further five to six units by 2006). These in turn require additional physics staff to ensure that the potential benefits of providing this equipment are to be realised and not restricted. However, the pool of trained radiotherapy physics and physics technicians is limited, requiring investment in training and recruitment as part of the planned programme.