Ovarian cancer – the need for change in service delivery in Northern Ireland

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SUMMARY
This paper provides local data on the provision of services for patients diagnosed with ovarian cancer in 1996 prior to the reorganisation of cancer services. It documents a service for 140 patients provided by 80 consultant teams and illustrates the need for reorganisation to meet the evidence base already in existence for improvement in survival and will serve as a baseline for future audits in this area.

INTRODUCTION
Driven by some of the worst survival rates in Western Europe¹ there has been widespread reorganisation in recent years of the way cancer services in the UK are delivered.² Given the need to improve service quality and to justify the massive resource commitment required, monitoring and evaluation of the changes in terms of care processes and outcomes are clearly required. These may be measured using the patient care pathway. We report here an example relating to ovarian cancer.

In 1996 the Campbell report ³ made wide-ranging recommendations for change in the way cancer services were organised in Northern Ireland. Broadly in line with those made by the Calman Hine report for the NHS in England and Wales,² they included centralising care for the 1.7 million population within 5 cancer units and 1 cancer centre, providing care by designated specialists working in multidisciplinary teams and enhancing communication between primary and secondary care.

Recommendations specific to ovarian cancer were the use of ultrasound scanning and measurement of blood tumour marker levels as part of the assessment process, and the development of regionally agreed management guidelines to be used within a network of care. The latest regional guidance determines that treatment should only take place in the cancer centre or in a cancer unit and only under the care of a lead clinician in gynaecological oncology. If treatment is proposed to take place in a cancer unit the patient’s management plan should be agreed with the multidisciplinary team at the cancer centre.⁴

Observational studies of patients with ovarian cancer lend broad support to these recommendations. The involvement of a gynaecologist at both presentation and treatment, and further management by a multidisciplinary team have been shown to improve survival.⁵ ⁶ ⁷ Operation by specialist gynaecologists has also been found to improve survival among women with stage III disease.⁸ However, the case for ensuring operators treat an optimum volume of patients is unproven to date.⁷

Part of a larger study of the overall cancer service changes in Northern Ireland, this paper aims to provide a baseline description of the care received

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by women diagnosed in 1996 with ovarian cancer, prior to anticipated service change.

METHODS
All ovarian cancer notifications for 1996 were extracted from the Northern Ireland Cancer Registry. This included both fully malignant and borderline malignant tumours, in accordance with the ICD-O-2 classification. A retrospective review of records was undertaken by one trained researcher (RM). For inclusion in the study each case was required to have at least one of the following: hospital case notes; General Practitioner records or histopathology reports.

In addition to the basic demographic information, details of presenting symptoms, the referral and assessment processes, diagnostic procedures, tumour information, treatment details, and outcomes were collected.

Information was recorded on a Microsoft Access database and analysed using SPSS software. Follow-up of patients was carried out up to 31 December 1999. Cox's proportional hazards regression model was fitted to the data, in order to investigate if age at diagnosis (under and over 65 years), stage of disease and treatment were significant predictors of survival.

RESULTS
144 incident cases of ovarian cancer and borderline malignancy were reported to the Northern Ireland Cancer Registry. Three cases of serous cystadenomas wrongly registered as "serous cystadenocarcinomas" and one case of pseudomyxoma peritonei were found on examination of notes; these cases were excluded from the study. 137 (97.9%) cases met our criteria for inclusion in the study. For four of these, only histopathology records were available.

Patient/disease characteristics
The mean age of the patients was 62 years (range 15 to 91, median 63). Surgical FIGO staging was recorded in the notes of only 69 (55.2%) cases. However, using the various data sources available it was possible for the researcher to stage 119 patients. Using the FIGO system 15 (12.6%) had borderline malignancy, 29 (24.4%) were stage I, 12 (10.1%) were stage II, and 63 (52.9%) were stage III or IV.

Referral
The source of referral was available for 110 cases. 90 (81.8%) cases were referred by their GP. 56 (50%) cases were seen as an outpatient referral, with 49 (43.7%) as emergency admissions. Based on 108 cases, 58% of patients were seen the same day as referral, with 75% within 10 days of referral (range 0-164).

Assessment
Details of presenting symptoms were available for 117 patients. Abdominal pain 75 (64.1%) and abdominal distension 44 (37.6%) were the most common presenting symptoms. Others included weight loss 22 (18.8%), dyspepsia 18 (15.4%), urinary frequency 11 (9.4%), anorexia 5 (4.3%), altered bowel habit 5 (4.3%), and weight gain 4 (3.4%). Nine (7.7%) cases were asymptomatic at presentation. The median duration of abdominal pain at presentation to hospital was two months (range one week to two years).

Patients presented to 80 different consultant teams, 56 of whom assessed only one case each. The largest caseload at presentation was five patients. 16 cases were unattributable to a particular team. Initial assessment was by obstetricians or gynaecologists in 67 (55.4%) cases, general surgeons in 27 (22.3%), physicians in 21 (17.4%), and urologists in two (1.5%) cases. However, in 109 (79.6%) patients a gynaecological opinion was received, while in eight (5.8%) cases this was not sought. For 20 (14.6%) patients these details are unknown.

Details of pre-surgical assessment were available for 115 patients. Investigations included CA 125 in 59 (43%) cases, ultrasound scan 96 (70%), and CT scan in 35 (25.5%). 46 (40%) patients had both CA125 and ultrasound scan including transvaginal ultrasound performed.

Based on an analysis of 115 cases the median time from first hospital visit to diagnosis was 13 days, 70% were diagnosed within 33 days and 90% of within 108 days (range 0-399).

Surgical treatment
114 (83.2%) patients underwent some form of surgical procedure (see Table 1). In four cases this was limited to pleural tap or paracentesis. The type of surgical procedure varied across the stages of disease. Table 2 gives details for cases where stage was derived by examination of notes.

Operator details
65 different clinicians operated on these patients with 43 operating on only one case each. Four
TABLE I

| Stage       | Pleural tap/paracentesis | Biopsy/laparotomy | SO/BSO | SO/BSO/OM | TAH/BSO | TAH/BSO/OM | Other |
|-------------|--------------------------|-------------------|-------|-----------|--------|-----------|-------|
| Borderline  | 0                        | 0                 | 9     | 1         | 4      | 1         |       |
| Other       | 0                        | 0                 | 8     | 3         | 15     | 3         |       |
| Stage I     | 0                        | 0                 | 1     | 1         | 15     | 3         |       |
| Stage III   | 1                        | 4                 | 6     | 11        | 13     | 6         |       |
| Stage IV    | 2                        | 1                 | 1     | 3         | 0      | 0         | 3     |
| Unknown     | 0                        | 1                 | 0     | 0         | 5      | 0         | 2     |
| Total       | 4                        | 6                 | 27    | 20        | 39     | 13        | 5     |

so = Salpingo Oophorectomy
BSO = Bilateral SO
OM = Omentectomy
TAH = Total Abdominal Hysterectomy
Procedure Unknown = 11 patients

clinchens operated on five or more, with the highest caseload being nine. Operations took place at 21 different hospital sites across Northern Ireland.

Based on data for 99 cases, obstetricians or gynaecologists operated on 79 (79.8%). This includes three clinicians with specialist gynaecological oncology training who operated on 20 (20.2%) patients. General surgeons operated on 17 (17.2%), including four patients with stage I disease.

Adjuvant treatment
75 (54.7%) cases were discussed with an oncologist, while 22 (16%) were recorded as not discussed. In 40 (29.2%) cases this was not recorded or notes were unavailable. Although eight oncologists were involved, 58 of the cases were discussed with one oncologist who specialises in the treatment of gynaecological cancer. The median time from referral to being seen by an oncologist was one day (range 0-32).

75 (54.7%) patients had chemotherapy, eight (10.6%) did not, and in 54 (39.4%) cases this was not recorded or notes were unavailable. 23 (30.7%) patients were offered entry into a clinical trial: 18 (24%) accepted. Based on 69 case notes the median time from diagnosis to receipt of chemotherapy was 28 days (range 0-138).

Communication
In 63 (46%) cases, the diagnosis was discussed with the patient and in four (2.9%) the diagnosis was recorded as not discussed. For 70 (51.1%) this was not recorded or notes were unavailable.

There was evidence of a letter to the patient’s GP in 114 (83%) cases. The prognosis was recorded in 53 (46.5%) of these. In 45 (39.5%) the letter recorded that the diagnosis was discussed with the patient.

Status at 30 days post operatively
After 30 days, 100 (88.0%) cases were alive, eight (7.0%) were deceased and the status of six (5.0%) was unknown for this period.

Survival
Whether a patient received radiotherapy and/or chemotherapy did not have a significant effect (P>0.05) on the hazard of ovarian cancer death; however the numbers of patients involved are small. Only the stage of disease was found to be a significant predictor of the risk of death from ovarian cancer (P<0.05). For each stage of disease, the hazard for ovarian cancer death was higher.
than the hazard of borderline ovarian cancer death. The relative survival rates for each stage of disease are given in Table II and Figure.

DISCUSSION

Against a background of the introduction of evidence-based recommendations for changes in cancer service provision in Northern Ireland, this study aimed to provide a baseline picture of the process of care and patient outcome for ovarian cancer prior to service reorganisation.

Service organisation

A large number of clinicians from different specialisms working in many different hospital sites were involved in diagnosing and treating women with ovarian cancer in Northern Ireland in 1996. Consequently the majority of individuals or their teams looked after only one such case per year. Similar patterns have been reported by audits conducted in England in 1991 and 1996. While 80% of women received a gynaecological opinion during the process at least 5.8% (and possibly up to 20%) of cases did not, this despite published evidence of the benefit of such a consultation.

Care processes

Variations in surgical practice exist although we must be careful in further interpretation, as the total information which could influence treatment including patient views were not available to us. While only 11.4% of women received the currently advocated surgical treatment of TAH/BSO/Omentectomy, this might be confounded by technical difficulties in advanced disease, by previous gynaecological surgery, or by younger women wishing to preserve their fertility. Omentectomy when considered in Borderline/Stage I disease is not subject to these confounders and may be a better marker of appropriateness.

This however was a component of treatment in only eight (18.2%) such cases, raising the potential for understaging and under treatment of disease.

Again, audits elsewhere have emphasised the variation in surgical practice and shown similar results for cases with disease staging recorded and the percentage receiving chemotherapy. Poor availability of routine stage information at the time of diagnosis will result in problems interpreting reasons for change in survival overtime.

Communication

These results focus attention on communication at the hospital/primary care interface. While a letter to the patient’s GP was found in the majority of cases, only a minority included whether the diagnosis or prognosis had been discussed with the patient. The Campbell report is explicit in its recognition of the central role of primary care and its need for “timely and appropriate communication with the hospital sector”.

Four patients had a written record indicating that non-discussion of their diagnosis was an active
part of their management. This has implications for the acquisition of informed consent, an issue currently under discussion in relation to research in general.

Study methodology
This work was carried out in a population-based cancer registry. Cancer registries are ideally placed to assist in the key public health function of service evaluation. Working in established partnerships with numerous reporting agencies they have considerable expertise in the collection, collation, analysis and dissemination of population-based data within a data protection framework.

The main limitation of the study lies in the fact that it was carried out some three to four years after the majority of patient treatment had occurred. Underreporting of the true picture can be a problem in any retrospective study, but is compounded in this case by our inability to differentiate between data genuinely “not recorded” and that missing because of unavailable casenotes, as we did not record which data sources were accessed for each case. In addition, there is the impression that notes tended to be unavailable for deceased patients as opposed to survivors. This missing data may therefore be more representative of women with advanced disease at presentation.

CONCLUSION
This population-based study documents both the process and outcomes of care for women diagnosed with ovarian cancer in Northern Ireland in 1996. The findings suggest a picture of service provision very different from that later recommended by the Campbell Report, yet similar to that seen elsewhere in the UK at that time. A study of cases incident in 2001 is now underway to close the audit loop.

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