Senate Inquiry into Gynaecologic Cancer Services

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Services for Women with Gynaecologic Cancers in Tasmania

Introduction

Tasmania has a population of 470,000. In the region of 120 women are diagnosed each year with a gynaecologic malignancy. In 2003 there were 45 women diagnosed with uterine cancer, 14 diagnosed with cervical cancer, 24 diagnosed with invasive ovarian cancer and 9 with vulval cancer. Because of the small numbers involved these fluctuate considerably from year to year.

Centers of excellence dedicated to the management of women with gynaecological malignancies have been established in the majority of population centers around Australia. These centers, via a variety of models, initially practiced a holistic approach to the care on women with gynaecologic malignancies. Now most centers embrace multidisciplinary care. For the last six years I have been responsible for the provision of the Statewide Gynaecologic cancer services in Tasmania. It is from this perspective that I can provide some insight to the challenges of providing services in a small state which has a considerable proportion of its population outside of the capital city.

Central assessment of women with gynaecologic malignancies by Gynaecologic Oncology units is preferable, at the outset, allowing prompt consideration of the site and extent of disease. Centralization of surgical services for women with gynaecologic cancers is also a key component of the service since this requires a highly specialized expertise across a large number of medical, nursing and allied health specialties. Surgery is necessary for a high proportion of women and since gynaecological cancers are relatively rare, such expertise can only be developed when care is centralized. In Tasmania outpatient clinics are regularly run in the north and south of the state. All surgery for gynaecologic cancers referred to the service is carried out in Hobart where a full multidisciplinary team is available.

Key components necessary for the care of women with gynaecologic malignancies:

1) For optimal disease related outcomes there is clear data suggesting improved care for most women with gynaecologic malignancies when their management is coordinated by a multidisciplinary team. Practically this will usually be coordinated by a Gynaecologic Oncology unit.

2) Appropriate referral by gynaecologists and family doctors is required.

3) Integral parts of a Gynaecologic Oncology Units include:-

    a. A single sex female surgical ward with access to:-

i. adequate operating theatre allocation,
ii. a high dependency unit and intensive care unit

b. Outpatient facilities sensitive to the needs of women undergoing gynaecologic examinations for malignancies

c. Medical teams skilled in the management of women with gynaecological malignancies including

i. Gynaecologic Oncologist
ii. Radiation Oncologist
iii. Medical Oncologist
iv. Radiologist
v. Anesthetist
vi. Pathologist
vii. Palliative care physician
viii. General physician

d. Nursing staff skilled in the surgical and medical management of women with gynaecologic malignancies and dedicated cancer care coordinator

e. Allied Health Workers

i. Social worker
ii. Pharmacist
iii. Physiotherapist
iv. Psychologist
v. Genetic counseling service

f. Data Manager

g. Research Staff

For women with the diagnosis of a gynaecologic malignancy there is not only the major challenge of a cancer diagnosis and the treatment that may be necessary, but it is well recognized that woman will frequently face a huge challenge to their feminity and sexuality.

Barriers to the delivery of appropriate support and care to women with gynaecologic malignancies in Tasmania

Local Infrastructure

1) Inpatient care of women with Gynaecologic Malignancies. Resource and space allocation within Hospitals often lead to arguments against the requirement for single sex female surgical wards focusing on the care of women undergoing major surgery for gynaecological malignancies. These wards frequently care for all gynaecology patients and some models include care for breast cancer patients. There are no gynaecology wards in the North of Tasmania and it has been a considerable struggle to

convince Hospital administrators of the importance of this at the Royal Hobart Hospital where gynaecologic oncology services are centered. Loss of such a ward would also mean the loss of nurses skilled in the care of women undergoing treatment for gynaecologic cancers.

2) Outpatient Facilities. Equipment necessary to examine women with gynaecologic cancer is similar to that necessary for the examination of obstetric and gynaecology patients. Outpatient areas are frequently used for many purposes (i.e. antenatal care and general gynaecology) and because of limited resources there is a lack of attention given to the sensitivities of women attending for advice regarding their gynaecologic cancer.

3) Cancer care coordinator. Although a Gynaecologic Oncologist is a necessary figure in providing services to women with gynecologic cancers it is imperative that the disease focused service provided by the medical specialist is backed up by adequate psychological and social support. There is plentiful data suggesting the role of a cancer care coordinator considerably assists patients on their cancer journey and this was fully recognized and supported by a recent senate enquiry. In addition this service should ideally cover women in both the private and public systems. Such positions are fundamental to the delivery of gynaecologic cancer services and bridge gaps for patients between medical and other service providers. This role is a key to supporting women in rural and remote areas.

4) Tumour Board Case Review. A key component of most Gynaecologic Oncology Services is the Tumour Board Meeting. At Tumour Board Meetings expert pathological review is undertaken and individual patient cases are reviewed and discussed and subsequent management is decided upon. Usually members of the multidisciplinary team will be invited and involved. In regional areas this broad model is much harder to promote because of time constraints on specialist medical providers such as radiation and medical oncologists. Such meetings also require secretarial support and infrastructure.

5) Manpower Issues. Simplistic formulae based on population statistics should not be applied to services to rural areas such as Tasmania in order to justify the appointment of medical and other specialized personal in Oncology services. In order to carry out clinics in rural areas travel time for the staff involved needs to be factored in. In addition there are the requirements of necessary equipment and clerical and nursing staff in local clinics and the logistics of dealing with multiple sets of hospital notes. All of this takes considerable time and effort over above normal service provision. This is seldom recognized by administrators who when assessing service needs frequently try to bring comparisons between other successful models from around Australia.

6) Access to allied health expertise This is frequently lacking in rural areas and is also a challenge in the population centers in Tasmania. Funding does need to be set aside by governments to support the rehabilitation of gynaecologic cancer sufferers and address their psychological, social and psycho-sexual needs.

Travel Assistance and Support.

Patients from rural and remote areas frequently have to travel long distances for their care. This is appropriate when their care is complex and needs the full support of a specialized team. Those who find this the most challenging are frequently those with limited personal financial resources. Family members also will often have to take time off work to assist in the travel arrangement and support. In Tasmania such assistance runs to 10cents per km travel assistance and $30 per night assistance for support of a single family member away from home.

Research.

Involvement in Research is challenging when the service is seeing smaller numbers of patients compared to other major Australian centers. However rural populations are frequently stable (as in Tasmania) and recruitment can be facilitated because of the limited personnel involved. Participating in research is challenging because of the lack of supportive infrastructure and time constraints when running a clinical service. Such infrastructure needs to be available in rural areas since there are many benefits to patients from taking part in clinical trials. The development of ANZCOG (Australian and New Zealand Gynaecological Oncology Group) trials consortium has meant the broader access to international and national trials. Central co-ordination of trials enables smaller centers to participate. Certainly it is disappointing that the present systems and criteria for the assessment for grant applications mean surgical trials and trials involving rare cancers are not supported. The submission of ASGO addresses this issue further.

Audit and Outcome Data Collection.

Outcome data based on site, histology and stage of cancer is not available through State Cancer Registries or through hospital audit systems. Such data is a crucial quality control measure of the service provided and it facilitates research. I fully support the concept proposed by ASGO of the development of a central data set to which all Australian Gynaecologic Oncology Centers can contribute. In addition to the necessary central infrastructure and funding for this to be developed, there is also a requirement for adequate funding to support data collection and input at a local level. This is even more of a challenge in rural areas with multiple sites and staffs involved.

Most Gynaecologic Cancer Centers in Australia have hospital based cancer registers. These vary in their level of development and sophistication. Funding such data collection is a considerable challenge particularly in smaller states with limited manpower resources.

Screening for gynaecologic malignancies and educative and preventative strategies

Cervical Cancer

Although the Australian National Cervical Screening Programme has resulted in a decline in the incidence and mortality from cervical cancer, this success is by no means uniform across all states. Considerably higher rates of cervical cancer are seen in rural and remote areas such as the Northern Territory, far north Queensland, and Tasmania. Barriers to women in remote areas seeking attention for gynaecologic symptoms, and

also attending for cervical screening, include the lack of female personnel and unwillingness to visit a local doctor for these services.

There is still no doubt that strategy that increase recruitment of unscreened women to the National Cervical Screening Program should remain a funding priority.

Furthermore, one of the most significant recent developments is the "cervical cancer" HPV vaccine which is likely to reduce the incidence of cervical cancer by at least 70% in years to come. As well as exploring strategies to improve uptake of cervical screening by indigenous women and women living in remote areas, it is imperative to ensure the availability of the HPV vaccine to these populations.

Endometrial Cancer

The majority of women with endometrial cancer will be cured by surgery. Major risk factors include anovulatory cycles in younger women, and obesity. Public education should include that obesity is a risk factor for this cancer and weight reduction can prevent disease. In addition education for women and family practitioners regarding the requirement for prompt investigation and management of abnormal bleeding, especially in post menopausal women, is important. This allows prompt diagnosis and treatment. Too frequently women in rural areas delay seeking advice regarding abnormal bleeding for similar reasons to those that dissuade them from attending for pap smears. Perhaps mobile clinics similar to those used for Breast Screen should be used in rural areas.

Ovarian Cancer

The majority of women with epithelial ovarian cancer will eventually succumb to their disease. Those women who present with early stage disease have a much improved chance of cure (85-90%). The symptoms are vague, common and there is no evidence that they differ dramatically between early and late stage disease. The evolution of the disease is poorly understood.

Increasing awareness of the disease for women and the medical profession is unlikely to see any major shift in the statistics, but may assist individual women. In addition, although several very large international studies are underway no effecting screening test is available. At present improving outcomes for women with ovarian cancer is best achieved by optimizing treatment within a multidisciplinary setting.

Conclusion

Opinion relevant to the delivery of services for women with gynaecologic malignancies in Tasmania has been proffered in this short submission. There is no doubt that providing a service to women in rural Australia is challenging and that there are major hurdles for women in rural Australia to receiving optimized care. Certainly a major factor is the limited local resources available compared to major population centers.