

AUSTRALIAN PHYSIOTHERAPY ASSOCIATION SUBMISSION TO THE SENATE INQUIRY INTO GYNAECOLOGICAL CANCER IN AUSTRALIA

Presented to

Committee Secretary
Community Affairs Committee
Department of the Senate

Prepared by the

Australian Physiotherapy Association

June 2006

Authorised by

APA President, Cathy Nall

Australian Physiotherapy Association 3/201 Fitzroy Street
St Kilda Vic 3182

Tel: (03) 9534 9400 Fax: (03) 9534 9199

Email: national.office@physiotherapy.asn.au

www.physiotherapy.asn.au

INTRODUCTION

The Australian Physiotherapy Association (APA) is pleased have the opportunity to make a submission to the Senate Community Affairs Committee regarding the inquiry into Gynaecological Cancer in Australia. Physiotherapists with expertise in oncology and women's health are key members of the multidisciplinary care team that support women with gynaecological cancer. Physiotherapists have particular expertise in treating conditions which may result from gynaecological cancer treatment such as lymphoedema and incontinence, and can also assist with physical fitness and mobility.

The APA contends that health support programs for women with gynaecological cancer could be greatly improved by increasing access to specialised physiotherapy services.

RECOMMENDATIONS

- All public sector patients with lymphoedema should have free access to specialised lymphoedema garments if these are required to manage their condition. For private patients, these garments should be fully subsidised by their health insurance fund.
- 2. Access to publicly funded lymphoedema management services should be increased to reduce waiting times.
- All patients with gynaecological cancer should be screened for continence problems and appropriately referred to specialist continence management services.
- 4. Access to publicly funded continence services, including physiotherapy management, should be increased to reduce waiting times.
- 5. Continence physiotherapy services should be covered by Medicare.
- 6. Physiotherapists should be included as key members of specialist palliative care teams for patients with gynaecological cancer.
- Where patients in palliative care demonstrate specific indicators for physiotherapy, the specialist palliative care team must be able to refer correctly and in a timely manner to publicly funded physiotherapy services.
- 8. The number of physiotherapy services in rural and remote areas should be increased to ensure high quality, equitable access to health care services.

- State/Territory and Federal governments should increase investment in satellite centres and outreach services to enable treatment closer to home for Indigenous and non-Indigenous people living in rural and remote areas.
- 10. Funding for physiotherapy education, including clinical education, should be increased to ensure that there are sufficient physiotherapists with expertise in oncology and women's health, to meet the needs of the community.
- 11. Indigenous health workers should be trained to provide cervical screening for Indigenous women and should have access to appropriate resources to implement such screening programs.
- 12. Aboriginal Community Controlled Health Services (ACCHS) should be funded to expand primary and preventive health care including provision of appropriate physiotherapy services.

PHYSIOTHERAPY AND GYNAECOLOGICAL CANCER

Physiotherapists are a vital part of the team of professionals dedicated to the effective treatment and management of gynaecological cancer. Physiotherapists ensure that patients are physically prepared for surgery, and assist them during recovery from surgery. Physiotherapists also educate patients about some of the possible physical side effects of gynaecological surgery (such as lymphoedema), and how these side effects may be prevented and managed.

One in 70 women gets some kind of gynaecological cancer. The most common types of gynaecological cancers are cervical, endometrial, ovarian and vulval cancers. Treatment for all of these cancers involves surgery and/or radiotherapy, which can damage the lymphatic drainage systems and put the patient at risk of developing lymphoedema.

Lymphoedema is swelling in one or more parts of the body which occurs when the lymphatic system does not work properly. People who have lymphoedema, as a result of gynaecological cancer treatment, may notice swelling that they cannot explain in the leg, lower abdomen, genital and buttock areas. The area may feel heavy, painful or uncomfortable. Unlike breast cancer, most gynaecological cancer surgeries have a bilateral risk for lymphoedema – i.e. no "control" limb. Physiotherapy management has been shown in both breast and gynaecological cancers to minimise the risk of lymphoedema, and that monitoring and providing early intervention when lymphoedema does occur reduces the severity of the impact of lymphoedema.

A retrospective Australian study showed an 18 per cent incidence of lymphoedema following gynaecological cancer treatment. Of these, 53 per cent were diagnosed within three months of treatment, a further 18 per cent within six months, 13 per cent within 12 months, and the remaining 16 per cent up to 5 years following treatment. Women most at risk for developing lower limb lymphoedema were those who had treatment for vulvar cancer with removal of lymph nodes and follow up radiotherapy. For this sub-sample, the prevalence was 47 per cent (Ryan et al 2003a).

The finding that lower limb lymphoedema occurs within the first year is earlier than generally believed (Ryan et al 2003a) and another study of women's experiences with lymphoedema found that women received inappropriate advice and as many as three assessments prior to referral to appropriate specialists (Ryan et al 2003b). It is therefore imperative for all health professionals to include care and assessment of the legs particularly during the immediate preand postoperative period (Ryan et al 2003a). On discharge, women need to be aware of early signs and symptoms of lymphoedema and how to access qualified, specialised therapists so that early and effective management can be initiated (Ryan et al 2003b). If a patient should develop lymphoedema, a physiotherapist qualified and experienced in managing lymphoedema should be consulted.

Physiotherapists are able to design appropriate exercise programs and assess the need for aids and equipment which assist women with gynaecological cancer to improve mobility. This includes moving around the bed, moving in and out of bed, bed to chair transfers, walking, and toileting. If surgery results in the development of a respiratory infection, then an appropriate physiotherapy regime targeting the chest can also be developed.

PRIMARY DUTIES OF THE PHYSIOTHERAPIST

Physiotherapists are usually consulted in both the acute (surgical, usually at preop clinics) and non-acute (when patients are admitted for other reasons, such as chemotherapy and radiation therapy) stage of gynaecological cancer treatment.

Primary duties include:

- Pre-operative assessment and education baseline evaluations are established to assess the impact of lymphoedema.
- Immediate postoperative care in hospital many patients take several days to mobilise, for example, use stairs.
- Follow up via clinics or appointments diagnosis and management of lymphoedema if it occurs.

• Diagnosis and management of musculoskeletal problems associated with the surgery, for example, hip pain; and/or respiratory infection.

IMPROVING HEALTH SUPPORT PROGRAMS

Health support programs need to be more comprehensive than just medical and psychosocial care. There are a number of areas where physiotherapy can greatly improve recovery and quality of life following gynaecological cancer treatment.

Lymphoedema

Swollen lower limbs, and the altered body image which results, is a serious issue for many gynaecological cancer patients. Lymphoedema management, education and support are important in helping to overcome this problem. Minimising the effects of lymphoedema, through access to timely physiotherapy services, minimises the risk of resultant cardiovascular complications, including ulcers and infections, as well the more severe psychosocial impacts. Unfortunately, due to a lack of funding and staff shortages there are long waiting times for access to specialised physiotherapy services.

Costs to the patient with lymphoedema are high. Lower limb lymphoedema has an impact on appearance, mobility, finances, and self-image (Ryan et al 2003b) which in turn affects a woman's ability to continue employment, family and lifestyle activities. Effective treatment for lymphoedema may require the purchase of specialised lymphoedema pressure garments, and women with lymphoedema often find it difficult to buy clothes that fit.

While we have not done an exhaustive survey of the various state systems, the information that we do have indicates that patients receive very little reimbursement from health funds for garment provision. The APA contends that funding programs for garments such as those in Victoria and Tasmania would address some of the cost burden to the patient and could be emulated by other state governments, or a federal program could be introduced.

In 2002 the Australasian Lymphology Association conducted a nationwide survey of garment provision. The survey found no consistency between hospitals, between private and public sectors, or between states. Even health funds vary from office to office on rebate policy. Variability ranged from full cost borne by the patient to full subsidy by the government. Some equity is needed to provide fairer health care to those with lymphoedema.

Recommendations

1. All public sector patients with lymphoedema should have free access to specialised lymphoedema garments if these are required to manage their

- condition. For private patients, these garments should be fully subsidised by their health insurance fund.
- 2. Access to publicly funded lymphoedema management services should be increased to reduce waiting times.

Continence

Women undergoing treatment for gynaecological cancer are also at risk of developing incontinence (Naik et al 2001). There is a substantial body of evidence of the efficacy of physiotherapy in continence management. One of the most recent studies, published in the Australia and New Zealand Journal of Obstetrics and Gynaecology, found that 82 per cent of women were cured of stress urinary incontinence after one episode of physiotherapy care (Neumann et al 2005). Patients receiving treatment for gynaecological cancer should have access to information about continence issues and receive appropriate referral to physiotherapy and/or medical care if they are experiencing continence problems. Again, there are long waiting times to access public sector continence services due to a lack of funds and staff shortages.

Recommendations

- All patients with gynaecological cancer should be screened for continence problems and appropriately referred to specialist continence management services.
- 4. Access to publicly funded continence services, including physiotherapy management, should be increased to reduce waiting times.
- 5. Continence physiotherapy services should be covered by Medicare.

Referral to palliative care services

Unfortunately, not all gynaecological cancer will respond to treatment and some women will require referral to specialist palliative care (SPC) services. In previous submissions the APA has identified the need for better referral to physiotherapy within SPC services. Where palliative patients demonstrate specific indicators for physiotherapy, and where it is likely that timely physiotherapy intervention will have a significant impact on quality of life, the SPC team must be able to refer correctly and in a timely manner to the appropriate health professional. It is often the case, that appropriate referral is overlooked when either the specific health discipline is not in the team or if other more emergent factors have brought the patient to the attention of the team.

In a Commonwealth-funded physiotherapy survey of 78 consecutive patients attending for hospital outpatient radiation therapy (McAuliffe et al 1997):

- 22% of the survey population was receiving palliative radiation therapy;
- 65% of all cancer patients surveyed demonstrated indications for physiotherapy intervention; and
- Of these, <u>only 12.8% were receiving physiotherapy</u> and mostly those in a younger age group.

Of those receiving **palliative** radiation, 82.4% of patients demonstrated indications for physiotherapy intervention (compared to 91% of palliative inpatients in the same study). Table 1 demonstrates the number and percentage of indication rate per diagnosis.

Table 1: Proportion of cancer patients indicated for physiotherapy care.

Diagnosis	No. of subjects	Indications for physiotherapy (%)		
Breast	25	22 (88)		
Cervix	5	4 (80)		
Lung	8	6 (75)		
Oral	8	2 (25)		
Prostate	11	6 (55)		
Skin	6	3 (50)		
Other	15	8 (53)		

Source: McAuliffe et al 1997.

Table 2 demonstrates the intervention-related indication rates for each major diagnosis specifically where physiotherapy may have a major impact on quality of life.

Table 2: Indication rate for physiotherapy intervention by diagnosis.

Physiotherapy	Musculoskeletal	Lymphoedema	Pain	Respiratory	Incontinence
specialty	%	%	%	%	%
Diagnosis					
Breast	55	95	23	14	0
Cervix	0	0	0	25	100
Lung	17	0	17	83	0
Prostate	33	0	50	17	50

Source: McAuliffe et al 1997.

When one is defining palliative care in the context of quality of life, it would appear from the data above that even when patients are attending an oncology service, they are not necessarily being identified as having a problem amenable to physiotherapy; they are not being referred appropriately for that problem; much less being managed appropriately for problems which, if addressed adequately, may improve quality of life.

While this study does not focus specifically on gynaecological cancer it can be reasonably assumed that similar results would be found within this population.

Recommendations

- 6. Physiotherapists should be included as key members of specialist palliative care teams for patients with gynaecological cancer.
- 7. Where palliative patients demonstrate specific indicators for physiotherapy, the specialist palliative care team must be able to refer correctly and in a timely manner to publicly funded physiotherapy services.

MEETING THE NEEDS OF RURAL, REMOTE AND INDIGENOUS CLIENTS

The capacity of existing health and medical services to meet the needs of rural, remote and Indigenous clients is inadequate. Increasing the number of physiotherapy services in regional and remote areas, and in some metropolitan areas, would improve client access and reduce the strain on the major metropolitan hospitals which currently take most of the burden of lymphoedema related to gynaecological cancer. For example, in Queensland 70 per cent of the patients come from outside Brisbane, so physiotherapy follow up for monitoring is done in conjunction with the gynaecological clinic medical follow up, to reduce the travelling for the patient. Some clients travel several hundred kilometres. Greater investment in satellite centres and outreach to enable treatment closer to home would improve access and level of services to Indigenous and non-Indigenous people living in rural and remote areas.

The demand for physiotherapists with training in the management of lymphoedema is not being met and there is too few health staff in regional areas. More funding for physiotherapy education, including clinical education, would go some way to increasing the number of physiotherapists with expertise in oncology and women's health; and would therefore assist in a more equitable distribution of the health workforce.

The cultural needs of Indigenous clients are difficult to meet when women are transferred far from family and supports, for example from Mornington Island and Mt Isa to Brisbane. While it is commendable that some Indigenous support staff are available at major tertiary hospitals, there is a need for more of these staff and for improved training for all health professionals to meet the cultural needs of Indigenous women. The rate of Indigenous women having regular Pap smears is well below that of the rest of the population. A recent study identified that cervical screening participation rates in Queensland was 30 per lower than the rest of Queensland (Michael et al 2002). Indigenous health workers could be trained to

provide cervical screening for Indigenous women, thereby reducing the morbidity and mortality of Indigenous women by detecting gynaecological cancers earlier.

In 2005 the APA completed a small research study which demonstrated that Indigenous people rarely access private physiotherapy, that overwhelmingly Indigenous people are accessing health care through ACCHS (Aboriginal Community Controlled Health Services), and that most ACCHS do not provide physiotherapy services. Access to primary care physiotherapy for Indigenous people was mainly at the public hospitals and rather than accessing primary care during the earlier stages of their condition(s) or illness(es), Indigenous people tended to wait until the condition worsened and hospital admission was required. While this study was not specific to gynaecological cancer patients it indicates that there is a high risk that Indigenous women with gynaecological cancer, with complications amenable to physiotherapy treatment, may not get the care that they need.

Recommendations

- 8. The number of physiotherapy services in rural and remote areas should be increased to ensure high quality, equitable access to health care services.
- State/Territory and federal governments should increase investment in satellite centres and outreach services to enable treatment closer to home for Indigenous and non-Indigenous people living in rural and remote areas.
- 10. Funding for physiotherapy education, including clinical education, should be increased to ensure that there are sufficient physiotherapists with expertise in oncology and women's health, to meet the needs of the community.
- 11. Indigenous health workers should be trained to provide cervical screening for Indigenous women and should have access to appropriate resources to implement such screening programs.
- 12. Aboriginal Community Controlled Health Services should be funded to expand primary and preventive health care including provision of appropriate physiotherapy services.

AUSTRALIAN PHYSIOTHERAPY ASSOCIATION

The Australian Physiotherapy Association (APA) is the voice of the physiotherapy profession in Australia and leads the profession internationally. Physiotherapists must be fully qualified and eligible for registration with the Physiotherapists' Registration Board in their respective state or territory to be eligible for full APA membership. Australia has approximately 11 300 registered practising physiotherapists. The APA has more than 10 000 members. The APA national office is located in Melbourne, with branch offices in every state and territory. Further information on the APA is available at www.physiotherapy.asn.au

REFERENCES

McAuliffe AJ, Cantlay A and Laakso EL (1997): A Review of Physiotherapy Services to Palliative Care Patients in Australia: Volumes 1 and 2. The Commonwealth Department of Health and Human Services. (A copy of this report might be obtained from the Physiotherapy Department, Royal Brisbane and Women's Hospitals, Herston Queensland 4029)

Coory MD, Fagan PS, Muller JM and Dunn NAM (2002): Participation in cervical cancer screening by women in rural and remote Aboriginal and Torres Strait Islander communities in Queensland, *Medical Journal of Australia* 177: 544-547

Naik R, Nwabinelli J, Mayne C, Nordin A, de Barros Lopes A, Monaghan JM, Hilton P (2001): Prevalence and management of (non-fistulous) urinary incontinence in women following radical hysterectomy for early stage cervical cancer. *European Journal of Gynaecological Oncology* 22: 26-30.

Neumann PB, Grimmer KA, Grant RE and Gill VA (2005): Physiotherapy for female stress urinary incontinence: a multicentre observational study. *Australian and New Zealand Journal of Obstetrics and Gynaecology* 45: 226–232.

Ryan M, Stainton MC, Slaytor EK, Jaconelli C, Watts S and Mackenzie P (2003a): Aetiology and prevalence of lower limb lymphoedema following treatment for gynaecological cancer. *Australian and New Zealand Journal of Obstetrics and Gynaecology* 43: 148–151.

Ryan M, Stainton MC, Jaconelli C, Watts S, MacKenzie P and Mansberg T (2003b): The experience of lower limb lymphedema for women after treatment for gynaecologic cancer. *Oncology Nursing Forum* 30: 417–423.