

Provision of Lymphoedema Risk-Reduction Information by Health Care Professionals to Women Undergoing Gynaecological Cancer Treatment

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Background

Women undergoing surgical and/or radiological treatment for gynaecological cancer are at risk of developing lower-limb oedema. Best Practice guidelines highlight that every person at risk of developing Lymphoedema requires risk-reduction information (LRRi) (SIGN, 1998; Lymphoedema Framework Project, 2006; SMASAC Report, 2014).

This should include

- What lymphoedema is
- How to minimize the risk
- Who to contact if swelling develops
- Why the person is at risk
- Early signs and symptoms

Incidence

- Ovarian 10%
- Cervical 20%
- Endometrial 20%
- Vulvar 50%

Literature Review and Rationale for Study

A review of the literature highlights a low level of LRRi provision to at-risk women following treatment for both breast and gynaecological cancers. However, patient recall of such information received is not always accurate. Therefore, it was decided to investigate self-report of LRRi provision by the health care professionals (HCPs) involved in the care of women undergoing gynaecological cancer treatment.

Study

Looked at what, when and by whom LRRi is given to women at risk of developing lymphoedema following gynaecological cancer treatment in one Health Board in Scotland, along with the factors that influenced such information provision.

Questionnaire sent to a total population of the 125 HCPs identified within the local Health Board (see below) followed by two focus groups conducted with volunteering HCPs.

Medical Staff	Nursing Staff	Physiotherapist	Radiographer
Oncologists	Clinical Nurse Specialist	Surgical	External beam
Radiation oncologists	Oncology	Oncology	Brachytherapy
Surgeons	Surgical		
Oncology SpRs	Surgical pre-assessment		
Surgical SpRs	Chemotherapy		
Oncology FY/STs	Radiotherapy		
Surgical FY/STs	New patient clinics		
	Out-patient clinics		

Questionnaire Results

- 93/125 returned (74%)
- 17 (18%) of responding HCPs provided LRRi
- Only medical and nursing staff reported providing LRRi
- Predominantly clinical nurse specialists, oncology, surgical nurses, and surgeons.

Conclusions from Questionnaire

- LRRi infrequently provided in accordance with treatment-related risk factors
- Large gaps in provision, both in terms of patients receiving it and its frequency, content and timing
- LRRi provision is not standardised, even among HCPs from the same discipline and clinical area.

Focus group

Each focus group was composed of 5 volunteering HCPs. Below are the themes identified

Theme	Sub-Themes
Patient need for LRRi	Informed consent Protection from information overload Timing of information Information to empower
Whose role is it to provide LRRi?	My role Everybody's role Somebody else's role
Barriers to LRRi provision	Not seen as a problem Lack of knowledge Lack of communication between HCPs Limited time and access to patients
Improving LRRi provision	Education for staff Standardised information for patients Raising the profile of LRRi Identifying key HCPs

HCP Education Level regarding Lymphoedema

- Formal Training = 5
- No Education = 60
- Experiential Learning = 27 (mostly nurses)

- Knowledge of risk-factors and risk-reducing strategies commonly cited as barriers to providing LRRi to patients
- Both focus groups highlighted education for HCPs on lymphoedema and its prevention as a key strategy to improve LRRi provision to gynaecological cancer patients.

Two-Phased Approach

Debate over effectiveness of Pre-treatment LRRi

- Informed consent verses emotional distress
 - Also issues of retention
- Therefore a two-phased approach is recommended.

Pre-treatment

- Outline at-risk status and pathogenesis of lymphoedema

Post-treatment

- Re-inforce the above information
- Add in information about risk-reduction strategies, signs and symptoms and who to contact.

Recommendations

- Standardised LRRi must be provided routinely to all gynaecological cancer patients with treatment-related risk factors
- Provided by key HCPs at identified points along the patients' cancer journeys (see below)
- Deliver education to these HCPs to enable them to provide this information
- Develop a patient information leaflet to give to all at-risk patients
- Local lymphoedema service to conduct 6 monthly audit of referral of these women to service.

