



Living with lymphoedema in Ireland: patient and service provider perspectives

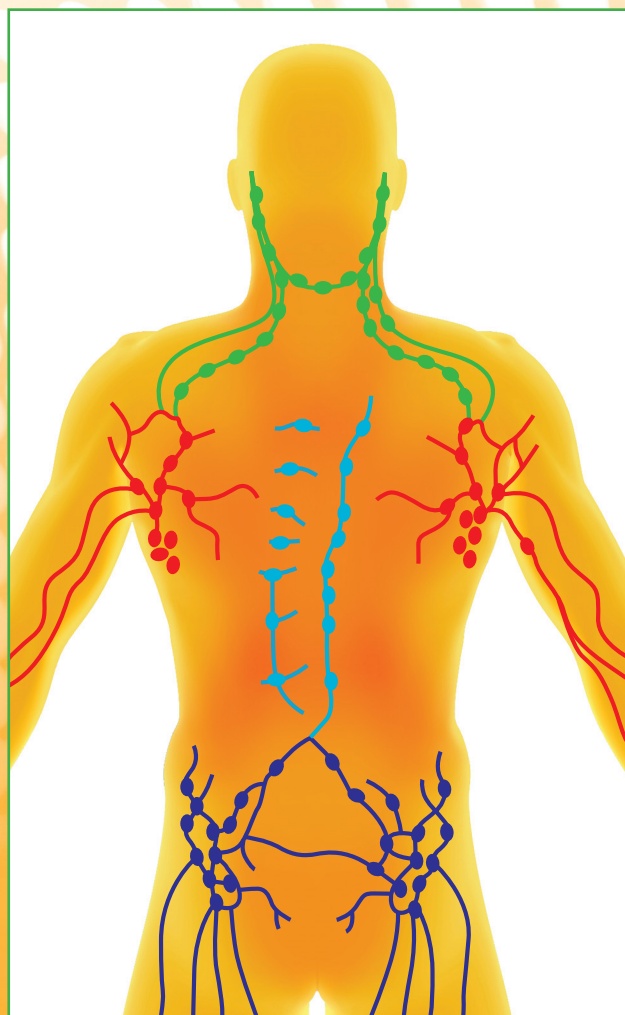
BACKGROUND

A research team from Dublin City University in association with the Irish Cancer Society led a study to investigate services for people with lymphoedema from the perspective of service providers and the experiences of people living with lymphoedema in Ireland. The study was published in February 2010.

Lymphoedema refers to swelling, comprised of lymph fluid. It is caused by damage to or malformation of the lymphatic system and frequently develops after cancer treatment, most often breast cancer but also cervical, prostate, bladder and bowel cancer. Furthermore it can occur as a complication of non-cancer related conditions or can develop independently. Lymphoedema is a chronic condition and in addition to the physical aspects, it can also have significant psychological and social consequences.

RESEARCH METHODOLOGY

The research was conducted in three phases. Phase one comprised a postal survey of 320 lymphoedema service providers (42% response rate). Lymphoedema service providers include physiotherapists, occupational therapists, manual lymphatic drainage therapists and nurses. Phase two comprised five focus groups to explore patients' experiences of accessing treatment and living with lymphoedema. Phase three comprised a postal survey of 1529 lymphoedema patients (56% response rate) to investigate the experiences of a wider group of lymphoedema patients.



KEY FINDINGS

From service provider survey:

- Lymphoedema services are insufficient and patchy.
- Key challenges exist with regard to the sustainability of services.

From patient focus groups and survey:

- Barriers to effective treatment identified.
- Tension with some healthcare professionals evident.
- Experiences and the availability of services differ depending on type of lymphoedema.
- Living with lymphoedema has financial, physical, social, emotional and psychological implications.

KEY RECOMMENDATIONS

Service development

- Increase availability of services for people with all types of lymphoedema, primary and secondary, and cancer and non-cancer related lymphoedema. Where possible, these services should be independent and not solely located in cancer clinics.
- Lymphoedema practitioners and services should work together, share protocols and standards and develop practice guidelines.
- Promote individual and/or group psychological support.
- Lobby for funding that would be specifically available for the strategic planning and provision of coordinated, equitably-located, and comprehensive lymphoedema services.

Raising awareness of lymphoedema and lymphoedema training amongst healthcare professionals

- Include information on lymphoedema in the undergraduate curricula of relevant healthcare professional disciplines.
- Provide continuous professional development programmes to existing healthcare professionals.
- Target healthcare professionals in primary care, especially General Practitioners, as they play an important role in identifying primary and non cancer related lymphoedema.
- Make available ongoing training for lymphoedema practitioners.

Raising awareness of lymphoedema amongst people at risk and patients with lymphoedema

- Develop standardised information and provide prevention programmes to all patients who may be at risk of developing lymphoedema.
- Develop and make available in various formats, information on all aspects of lymphoedema to lymphoedema patients and their families across all lymphoedema services.
- Promote self-management interventions.
- Expand and set up local fora and support groups such as those set up by Lymphoedema Ireland.

CONCLUSIONS

- Lymphoedema rates are likely to increase both nationally and internationally given the predicted increase in cancer incidence.
- The Irish Cancer Society will play an active role in advocating for the implementation of the above recommendations.

The full executive summary and research report are available on www.cancer.ie / www.lymphireland.com

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