

Knowledge of lymphoedema among primary health care teams: a questionnaire survey

VINNY LOGAN

STEPHEN BARCLAY

WOODY CAAN

JANET MCCABE

MARYLOU REID

SUMMARY

Lymphoedema usually develops following surgery or radiotherapy for cancer, but can also occur in advanced malignant disease or be primary in origin. Lower limb lymphoedema may present particular difficulties in diagnosis, treatment and management. All types of lymphoedema can seriously impair quality of life for those affected. This study aimed to determine the level of knowledge among primary health care team members concerning the identification and management of patients at risk of developing lymphoedema, the current treatment options available for patients with established lymphoedema, and the awareness of local services available within the Cambridge Health District. A postal questionnaire survey obtained an 84.3% response rate. Many primary health care professionals were not aware of some important issues in the prevention and management of lymphoedema. This information proved useful in enabling the specialist service to develop appropriate educational initiatives.

Keywords: lymphoedema; management; postal questionnaires.

Introduction

LYMPHOEDEMA is a chronic progressive condition caused by fluid accumulation in subcutaneous tissues, and is due to an inability of the lymphatic system to maintain normal tissue homeostasis.¹ It can cause severe psychological and functional morbidity for those affected.

It is estimated that 25% of women treated for breast cancer may develop lymphoedema and this can happen years after the original cancer treatment.^{2,3} Despite the increasing trend towards conservative management of the patient with breast cancer, the problem of upper limb lymphoedema does not appear to be decreasing.⁴

The prevalence of lower limb lymphoedema is unknown, but many lymphoedema clinics are experiencing increased referrals for patients with leg problems. Anecdotal evidence from patients

attending the lymphoedema clinic at Arthur Rank House in Cambridge seemed to suggest a lack of awareness about lymphoedema among health professionals. It seemed worthwhile, therefore, to determine health professionals' knowledge of this condition.

Methods

In May 1994, a postal questionnaire was sent to all the 187 general practice principals and 139 practice nurses working within the Cambridge Health district, together with the 48 district nursing sisters and 28 physiotherapists employed by Lifespan NHS Trust. The questionnaire addressed the following issues: number of patients with established lymphoedema seen within the last 18 months; awareness of the specialist service in Cambridge; number of patients referred to that service; referral when swelling was minimal; aims of treatment; availability of treatment for lower limb lymphoedema; use of diuretics; and desire for further education. One question focused on patients at risk of developing lymphoedema by presenting three clinical vignettes.

Respondents were also asked to indicate, in free text, what possible psychological difficulties a lymphoedema patient might experience, and what preventive advice, if any, they would give to women considered to be at risk of developing lymphoedema.

Results

A response rate of 84.3% was achieved; 39.5% of respondents reported that they had seen one or more patients with lymphoedema within the previous 18 months. Respondents who had seen patients with lymphoedema were significantly more likely to know of the local specialist service ($P < 0.00001$; chi-square test); 51.6%, the majority of whom were practice nurses, did not previously know of this service.

Although the benefits of early referral for patients with mild swelling is acknowledged in the literature, 65.5% of respondents either would not refer a patient for treatment if swelling was minimal, or were unsure if they would do so. Those professionals who knew of the value of referring patients with minimal swelling had seen more patients with lymphoedema than those who did not appreciate the benefits of early referral ($P < 0.0001$; Rank sum test).

The majority of respondents knew that diuretics have limited value in the management of lymphoedema, but 29.1% were unsure of their value. There were significant differences between professions, with general practitioners being the least likely to consider them useful ($P < 0.00001$; chi-square test).

Only 39.5% of respondents knew that effective treatment exists for lower limb lymphoedema. Professional groups differed substantially in their answers on leg treatment. Psychological difficulties likely to be experienced by lymphoedema patients were well recognized by respondents; issues about body image were mentioned most frequently.

More than 80% of respondents were aware that patients who had received axillary interference during cancer treatment were at risk of developing lymphoedema; most of those who were unsure were practice nurses. Only 27.5% of respondents were able to suggest appropriate preventive advice for such patients. Few suggestions were made either for avoiding activities which

Vinny Logan, BN, Macmillan clinical services manager; Woody Caan, MA, DPhil, head of research and development; and Janet McCabe, MB, BS, senior clinical medical officer in palliative medicine, Lifespan Healthcare, Cambridge. Stephen Barclay, MA, MRCP, general practitioner, Macmillan general practice facilitator, East Barnwell Health Centre, Cambridge. Marylou Reid, MA, MSc, formerly research associate, Institute of Public Health, University of Cambridge.

Submitted: 23 May 1995; accepted: 8 March 1996.

© British Journal of General Practice, 1996, 46, 607-608.

could exacerbate the development of lymphoedema, or for 'protective' behaviour ($P < 0.0001$; analysis of variance).

Nearly two-thirds (65.7%) of respondents expressed an interest in further study concerning lymphoedema management. The clinicians with the least experience and knowledge of lymphoedema were those least likely to want further education or training.

Discussion

Lymphoedema has been regarded as a rare condition, yet our data suggest that a significant number of primary care professionals will encounter it. Diagnosing lymphoedema can be problematic and it may often go unrecognized. Many professionals, especially nurses and physiotherapists, need to appreciate that diuretics are of little value in the management of lymphoedema. General practitioners, in particular, could help their patients by realizing that referral to a specialist lymphoedema clinic for early intervention and treatment will maximise therapeutic benefit and minimise the prospect of any swelling progressing.⁵

Many respondents were able to identify patients at risk of developing lymphoedema, but were unsure how they should be advised and managed. These patients should be encouraged to look for early signs of infection, to be aware of the importance of good skin care and, where possible, to avoid minor trauma to the limb, such as that caused by insect bites and sunburn. Professionals should try to avoid carrying out minor invasive procedures (e.g. venepuncture, and injections and blood pressure monitoring on limbs at risk, and on limbs which are already lymphoedematous).

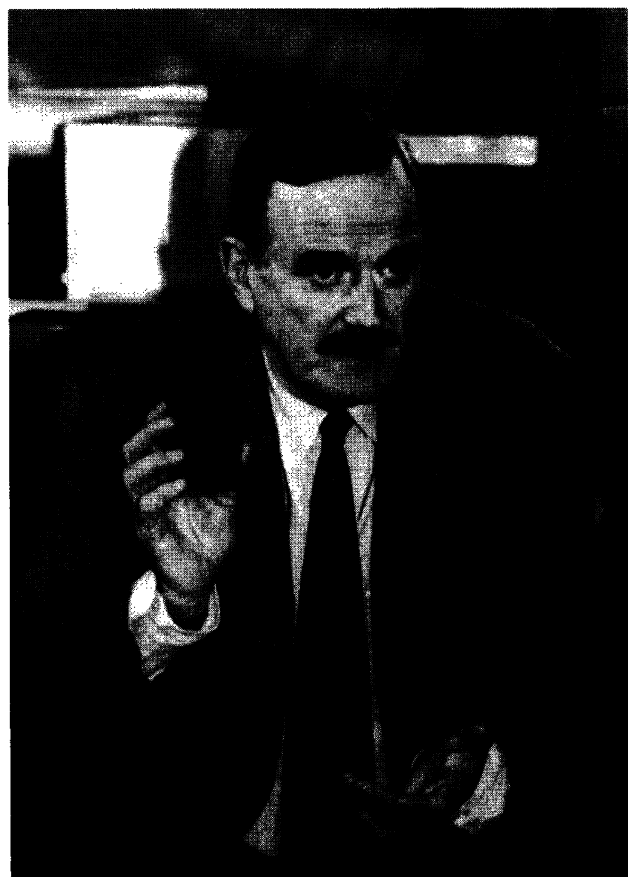
The interface between primary care services and the specialist service needs to be improved. Detailed knowledge of lymphoedema management may not be necessary for primary health care professionals, but there is currently much avoidable suffering among lymphoedema patients owing to a lack of awareness of effective treatment options.

References

1. Badger C. Lymphoedema. *Professional Nurse* 1987; **2**: 100-102.
2. Kissen MW, Querci Della Roveret G, Easton D, Westbury G. Risk of lymphoedema following the treatment of breast cancer. *Br J Surg* 1986; **73**: 580-584.
3. Logan V. Incidence and prevalence of lymphoedema: a literature review. *Journal of Clinical Nursing* 1995; **4**: 213-219.
4. Tobin MB, Lacey H, Meyer L, Mortimer PS. The psychological morbidity of breast cancer-related arm swelling. *Cancer* 1993; **72**: 3248-3252.
5. Badger C. The management of oedema. *Nursing Standard* 1990; **4**: 28-30.
6. Brennan MJ. Lymphoedema following the surgical treatment of breast cancer; a review of pathophysiology and treatment. *J Pain Symptom Manage* 1992; **7**: 110-116.

Address for correspondence

Ms Vinny Logan, Lifespan Healthcare, Arthur Rank House, Brookfields Hospital, 351 Mill Road, Cambridge CB1 3DF.



Videos for Patients

Your Choice of Programmes

"What You Really Need To Know About..."

- | | |
|--|--|
| <input type="checkbox"/> Acne | <input type="checkbox"/> Hepatitis |
| <input type="checkbox"/> Angina | <input type="checkbox"/> High Blood Pressure |
| <input type="checkbox"/> Asthma | <input type="checkbox"/> Hormone Replacement Therapy |
| <input type="checkbox"/> Anxiety, Phobias and Panic Attacks | <input type="checkbox"/> Infant Nutrition |
| <input type="checkbox"/> Breast Cancer | <input type="checkbox"/> Insulin Dependent Diabetes |
| <input type="checkbox"/> Cancer Pain | <input type="checkbox"/> Non-Insulin Dependent Diabetes |
| <input type="checkbox"/> Cholesterol | <input type="checkbox"/> Irritable Bowel Syndrome |
| <input type="checkbox"/> Chronic Bronchitis and Emphysema | <input type="checkbox"/> Leg Ulcers |
| <input type="checkbox"/> Chronic Lymphatic Leukaemia | <input type="checkbox"/> Migraine |
| <input type="checkbox"/> Colostomies, Ileostomies and Urostomies | <input type="checkbox"/> Obsessive Compulsive Disorder |
| <input type="checkbox"/> Constipation | <input type="checkbox"/> Oesophagitis and Hiatus Hernia |
| <input type="checkbox"/> Contraception | <input type="checkbox"/> Osteoarthritis |
| <input type="checkbox"/> Crohn's Disease | <input type="checkbox"/> Peptic Ulcers |
| <input type="checkbox"/> Cystic Fibrosis | <input type="checkbox"/> Prostate Cancer |
| <input type="checkbox"/> Cystitis | <input type="checkbox"/> Rheumatoid Arthritis |
| <input type="checkbox"/> Depression | <input type="checkbox"/> Schizophrenia |
| <input type="checkbox"/> Ear Infections and Glue Ear | <input type="checkbox"/> Shingles |
| <input type="checkbox"/> Eczema | <input type="checkbox"/> Stress |
| <input type="checkbox"/> Enlarged Prostate | <input type="checkbox"/> Strokes |
| <input type="checkbox"/> Epilepsy | <input type="checkbox"/> The Pap Test and Cancer of the Cervix |
| <input type="checkbox"/> Problems with Fertility | <input type="checkbox"/> Thrush |
| <input type="checkbox"/> Heart Attacks | <input type="checkbox"/> Ulcerative Colitis |
| | <input type="checkbox"/> Weight Control |



Please send purchase order or cheque to:

Videos for Patients

122 Holland Park Avenue, London, W11 4UA

Tel: 0171 229 5161 Fax: 0171 221 3832

Price per video £15 (incl. VAT. P&P).