Mapping an integrated lymphoedema patient pathway

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For many specialist practitioners who work alone with lymphoedema patients, engaging generalist healthcare professionals to help provide care remains a daunting task. This article presents an algorithm to be used when integrating services across multiple care sectors that can establish a pathway for patients with lymphoedema. It focuses on the types of symptoms the patient may experience and suggests the education and skills needed to help alleviate them. It is crucial that there are clear recommendations about the responsibilities of each practitioner and the level of training that should be undertaken.

The recent pressure to provide quality care while reducing expenditure means that any development of new primary or secondary services is virtually impossible. With this in mind, it is crucial that there are clear recommendations about the responsibilities of each practitioner, the level of training that should be undertaken and the recommended Knowledge and Skills Framework level to be achieved (Department of Health [DH], 2004).

Background

The service development discussed in this article was driven by a bid that was put into Macmillan Cancer Support for investment in the local lymphoedema service. The funding was to be used to create the right skill-mix within the specialist team and integrate care services across primary, secondary and voluntary sector providers.

An algorithm (Figure 1) was used for ease of presentation and with two possible applications — to present a pathway to the commissioner and operational manager of the local PCT and to the local Macmillan service development manager. However, it soon became clear that it represented the best way to demonstrate the principles outlined in previous literature (Lymphoedema Framework, 2006) relating to:

- Severity of the condition
- Help with diagnostic processes
- Education strategies
- Career framework levels (part of the Agenda for Change strategy) linked to the Knowledge and Skills Framework responsibilities (DH, 2004).

In short, this algorithm demonstrates an emerging care pathway using published guidelines to explain the practicalities of cross-service care provision, with particular emphasis on non-specialist intervention. It is an attempt to amalgamate various published material into a format useful to those setting up or commissioning a lymphoedema service.

The algorithm uses the patient, or, more precisely, the patient’s symptoms as the main focus on which to build the infrastructure of the pathway. However, from the outset it was decided to focus on clinical symptoms rather than the...
Clinical PRACTICE DEVELOPMENT

Figure 1. Mapping of a lymphoedema service: towards a patient pathway.

Key

**International Society of Lymphology (ISL) Lymphoedema Staging**

- **ISL Stage 0**: A subclinical state where swelling is not evident despite impaired lymph transport. This stage may exist for months or years before oedema becomes evident.
- **ISL Stage I**: This represents early onset of the condition where there is accumulation of tissue fluid that subsides with limb elevation. The oedema may be pitting at this stage.
- **ISL Stage II**: Limb elevation alone rarely reduces swelling and pitting is manifest.
- **ISL Late Stage II**: There may or may not be pitting as tissue fibrosis is more evident.
- **ISL Stage III**: The tissue is hard (fibrotic) and pitting is absent. Skin changes such as thickening, hyperpigmentation, increased skin folds, fat deposits and warty overgrowths develop.

**NOTE:**

- Individual patient treatment plans will be formulated using agreed, countywide assessment, monitoring and treatment protocols in accordance with Best Practice Guidelines (LFP, 2006).

**Lymphoedema Staging**

- **ISL Stage 0**: Lymphoedema practitioner (Career Framework Level 1), KSF level 1/2
- **ISL Stage I**: Lymphoedema assistant practitioner (Career Framework Level 2), KSF level 3
- **ISL Stage II**: Lymphoedema advanced practitioner (Career Framework Level 3), KSF level 4
- **ISL Stage III**: Lymphoedema specialist practitioner (Career Framework Level 4), KSF level 5
- **ISL Late Stage II**: Lymphoedema specialist practitioner (Career Framework Level 5), KSF level 6
- **ISL Stage IV**: Lymphoedema specialist practitioner (Career Framework Level 6), KSF level 7

**Intensive treatment**

- **Intensive Care Unit (ICU)**
- **Acute Care Unit (ACU)**
- **Specialist Lymphoedema Service**

**Supporting role**

- **LAP (CFL4)**: To work as directed by LSP (CFL6)
- **LAP (CFL7)**: To work as directed by LSP (CFL6)

**Education level (EL)/training**

- **EL 1 (All HCP):** Awareness training
  - One Day Only
  - No individual assessment
- **EL 2 (LAsP):** Awareness training and competency-based learning contract with minimum of five days placement with specialist service
- **EL 3 (LP):** Awareness training and competency-based learning contract. Case study based assignment
- **EL 4 (LSP):** Accredited lymphoedema course (10 days) with clinical placement assessing competence
- **EL 5 (LAP):** Accredited lymphoedema course to advanced level. Prior clinical competency assessment. Clinical placement dependent on institution of study

**BLS – Chronic Oedema Population and Needs, 2001**

- **Group 1:** Patients at risk
- **Group 2:** People with mild and uncomplicated oedema
- **Group 3:** People with moderate to severe or complicated oedema
- **Group 4:** People with oedema and advanced malignancy

**Clinical Framework Levels**

- **EL1: Framework Level 1
- EL2: Framework Level 2
- EL3: Framework Level 3
- EL4/5: Framework Level 4
- EL6/7: Framework Level 5

**PCT:** Primary care trust

**HCP:** Healthcare professional

**LAP:** Lymphoedema assistant practitioner (Career Framework Level 4), KSF level 1/2

**LSP:** Lymphoedema specialist practitioner (Career Framework Level 6), KSF level 4

**LAP:** Lymphoedema advanced practitioner (Career Framework Level 7)
psychological, social or spiritual impact of lymphoedema. Therefore, there is an assumption that all patients will need some form of care for non-clinical symptoms, such as psychosocial and spiritual issues, and this should be included in any education programmes.

The diagnostic indicators for lymphoedema have historically undergone much scrutiny and debate. In the UK there have been two main classifications used — the British Lymphology Society’s, Chronic Oedema Population and Needs (BLS, 2001) and the International Society of Lymphology’s lymphoedema staging recommendations (ISL, 2003) (Table 1). However, both of these classifications have themselves been the subject of scrutiny and the BLS is currently reviewing and updating its published literature.

For the purpose of this article the algorithm has been kept fairly simple so that it can be easily updated, and, more importantly, understood by those with little or no knowledge of lymphoedema. The above-mentioned classifications have been used jointly to demonstrate the types of clinical presentations commonly seen with this patient group and to divide them into appropriate care sub-groups. It is acknowledged that patients do not always fit into specific categories and that the implications of lymphoedema are often more complicated than these classifications suggest. However, for ease of understanding the avoidance of over-complicated professional jargon is paramount.

Skill-mix

The next consideration was who would provide the actual care. The majority of lymphoedema care has historically been provided by specialists. However, with an aging population and a growing awareness of lymphoedema, greater numbers of patients are requiring treatment, thereby making specialist services a less cost-effective and efficient means of providing care. If patient care is to become equitable regardless of severity, cause or locality, it needs to be sourced from a variety of healthcare professionals.

Using different care sectors will reflect the current NHS ethos of providing integrated services for health conditions, such as heart disease and diabetes. The emphasis is on providing the majority of care in the primary sector; accessing specialist care from the acute sector, and contracting the social and voluntary sectors for specific provision, e.g. palliative care. However, given the recent drive in the UK toward GPs commissioning, this may all change. With this in mind, the algorithm is flexible and can be adapted to incorporate care provided in primary, secondary or voluntary sectors, or a combination as presented in this example.

Awareness and identification

The algorithm starts in the generalist sector. Healthcare professionals should have an awareness of lymphoedema in case they come across any patients with the condition. This is especially true of GPs who would be expected to diagnose. Best practice guidelines (Lymphoedema Framework, 2006) suggest that a medical assessment is vital to arriving at a diagnosis. However, in reality, the referring party may suspect lymphoedema but this is not confirmed until a specialist assesses the patient, which in the UK is likely to be a nurse or allied healthcare professional. Recent campaigns have done a lot to raise awareness, but there remains much to do. Generalists need to attend lymphoedema awareness training at education level one. Usually offered as a study day, the training includes anatomy, physiology, causes, types, indicators, prevention strategies, symptoms and a broad outline of treatment modalities.

At this stage a patient may meet a range of healthcare professionals, and so Knowledge and Skills Framework
dimension levels are not specified. Likewise, there would be no individual competence assessment, therefore, it is assumed that attending a study day would impart an appropriate level of knowledge. It is suggested that patients who are known to have lymphatic malformation or damage will be monitored by practitioners educated to level one. Prevention and early identification rather than differential diagnosis are key responsibilities.

Lymphoedema practitioners
The next phase comes after a patient’s swelling has been identified. Again, there is debate over who should undertake the initial assessment to diagnose lymphoedema. In view of the multiple causes of oedema, it would be more cost-effective and possibly less distressing for patients if the practitioner at this level remained a primary care generalist. One of the difficulties in the author’s locality was the number of referrals received for specialist intervention that did not require this level of care, or for patients who did not even have lymphoedema.

The lymphoedema practitioner would be educated to level two and would undertake training in awareness, completing a competency-based assessment with specialist services.

The term lymphoedema practitioner could be used here to describe a healthcare professional who incorporates lymphoedema provision as part of another role.

One of the difficulties in the author’s locality was the number of referrals received for specialist intervention that did not require this level of care.

The Knowledge and Skills Framework dimensions required are level three for core dimensions and level two/three for specific dimensions, an ethos of prevention and the development of self-care (Tables 2 and 3).

Lymphoedema specialists
The next level of the algorithm describes patients with essentially moderate bordering on severe lymphoedema. This category concerns patients who may be experiencing more severe symptoms, but neither need nor want intensive lymphoedema treatment. Their symptoms are such that they are happy to continue with a maintenance phase of treatment, but may need more frequent monitoring or a complex compression garment (for example, some patients may require made-to-measure flat-knit garments or a bespoke garment because of the location and extent of their swelling).

This group of patients needs to be monitored by practitioners with specialist skills. This does not necessarily mean a lymphoedema specialist, as a healthcare professional may have acquired these skills as part of their role.

Depending on the commissioned pathway, this practitioner could work in any of the care sectors. In the author’s locality, these practitioners come from acute services, for example, breast care nurses have undertaken this role after appropriate training. However, in the case of patients requiring palliative care, provision comes from both the acute and primary sector, depending on the needs of the patient at any given time.

Education to level 3 or 4 is recommended for this role. At level 3 this involves a succession from awareness to a competency-based learning contract (used to help the learner identify their needs and for the teacher to ensure that they are met), with a minimum of five days’ specialist

Table 2
Knowledge and Skills Framework (KSF): dimension levels

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<th>CORE DIMENSIONS</th>
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<tr>
<td></td>
<td>Communication</td>
<td>Personal and people development</td>
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<td>Lymphoedema practitioner</td>
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<td>Lymphoedema advanced practitioner</td>
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placement and a case study-focused assignment. Level 4 study is achieved by attending a ten-day programme involving competency-based assessment, an academic assignment and OSCE (objective structured clinical examination). The Knowledge and Skills Framework dimension levels required are three to four (Tables 2 and 3).

**Lymphoedema advanced practitioners**
The final phase concerns patients with severe and complicated lymphoedema, who require intensive lymphoedema treatment and the ongoing services of a lymphoedema specialist.

Patients in this group display symptoms that are hard to manage, fluctuate frequently or simply fail to improve unless intensive treatment is repeated on a regular basis. This group includes those with lymphoedema in more than two sites, or those with comorbidities that may influence the efficacy of treatment.

A practitioner caring for this group of patients has to be in a specialist post, be educated to level 4 and have progressed through the second Knowledge and Skills Framework gateway. The required Knowledge and Skills Framework dimensions are all at level 4.

Such practitioners should have many years of experience and a proven track record of complex clinical problem-solving. Usually educated to Masters level and known as a lead specialist or consultant, they will also be responsible for strategic activities and involved in training at an academic institution, possibly teaching to an advanced level (Table 2).

It is suggested that this role is likely to be located within the acute sector with access to specialist integrated facilities, including imaging, genetics, surgery and microbiology. Consequently, this involves ensuring that patients are cared for by a multidisciplinary team.

Strategic activities are an integral part of this role. Historically, many lymphoedema specialists have started out as lone practitioners before taking

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**Table 3**

| Knowledge and Skills Framework (KSF): specific lymphoedema dimensions |
|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
| Dimension                  | Level 1                      | Level 2                      | Level 3                      | Level 4                      |
| HWB6 – assessment and treatment planning | Provides information for basic skin care, exercise | Supports with patient assessment including limb volume, skin condition, exercise ability | Undertakes assessment for mild/uncomplicated lymphoedema | Undertakes assessment for complicated lymphoedema |
|                            | Taking demographic assessment details | Undertakes report writing for monitoring, Fits compression garments | Prescribes appropriate compression and fits | Prescribes complex compression garments |
|                            | Supporting individuals at risk of development, or mild symptoms | Assesses and monitors patient progress during intervention/treatment | Implements skin care, exercise programme | Instigates and plans multilayer lymphoedema bandaging (MLLB) |

| HWB7 – interventions and treatments | Undertakes skin care and monitors exercise | Undertakes care as in Level 1 | Assesses and monitors patient progress during complex intervention/treatment | Assesses and monitors patient progress during complex intervention/treatment |
|                                   | Undertakes modified manual lymphatic drainage (MLD) | Undertakes MLLB under supervision | Undertakes MLD | Undertakes complex MLLB |
|                                   | Reports treatment outcomes | Reports treatment outcomes | Undertakes complex MLLB | Demonstrates high standards of clinical skill |

| G1 – learning and development | Able to undertake post in informal teaching, especially for patients/carers in relation to undertaking lymphoedema, skin care, care of compression garments, instruction of simple lymphatic drainage (SLD) | Teaches patients/carers/ HCPs to undertake skin care, SLD, exercise activities, donning/doffing of compression garments | Can plan, deliver and evaluate formal and informal education programmes for patients/carers and healthcare professionals | Can plan, deliver and evaluate formal and informal education programmes, including MLD |
|                               |                                    | Can undertake the above formally and informally | Works with colleagues from national organisations to increase awareness and promote standards for training | Delivers education programme with higher education accreditation at Level 6 and 7 |
|                               |                                    | Undertakes basic lymphoedema education including causes, symptoms and treatment modalities |                                | Works with colleagues from national organisations to influence policy and standards of practice |
on a lesser clinical role as the team develops. This inadvertently leads to the most experienced practitioners having little to do with patients. In view of this, it may be prudent to consider employing managers to fulfil this role, especially in primary care. Furthermore, in the current economic climate, it may be more realistic for this type of practitioner to work in more than one lymphoedema service, or only in lymphoedema services which have become centres for expert intervention, such as children’s services.

**Supporting role**
No skill-mix would be complete without the inclusion of assistant practitioners

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**Figure 2. Clinic call-back protocol (Gloucestershire Lymphoedema Service).**

NB: Patients switch from pathway A or B if their condition changes, for instance, if a patient on pathway B becomes stable they will change over to pathway A, and vice versa.
be they in nursing, physiotherapy or occupational therapy. The role of these practitioners is ever-evolving. In nursing, healthcare assistants (HCAs) form an essential part of many services.

Some suggest that they are simply a cost-cutting initiative, but others insist that they are fundamental to providing basic care, especially considering the ever-growing technical burden on registered nurses (for the purpose of this article the abbreviation HCA will be used to refer to any assistant practitioner, regardless of healthcare discipline).

The role of an HCA in lymphoedema largely depends on the service’s host organisation. In this instance, the role is one of support in specialist areas and caring for those with moderate to severely complicated symptoms.

However, there is no valid reason why an HCA could not take part in the care of those with milder symptoms, except that it may be more cost-effective for them to be part of a complex care strategy and have access to more supervision.

Education at level 2 should be considered appropriate for HCAs, and the competency assessment should focus on tasks and basic understanding rather than the more in-depth knowledge and skills analysis required for the lymphoedema practitioner. Specific Knowledge and Skills Framework dimensions should reflect a level 2 (Tables 2 and 3).

HCAs are ordinarily educated using the National Vocational Qualification (NVQ) system. It would be sensible to establish correlation between the NVQ system, the Knowledge and Skills Framework and the training needed in specialist areas of health care such as lymphoedema. Any such work has yet to be published.

The HCA role is continually developing and may offer considerable scope for improving the patient experience, while leaving those with specialist skills to address the needs of patients who would gain most benefit.

Policies and protocols
To encourage the standardisation of service policies, it is planned that all practitioners use standard assessment tools, documentation and intervention strategies, for example, the clinic callback protocol is shown in (Figure 2).

No skill-mix would be complete without the inclusion of assistant practitioners, be they in nursing, physiotherapy or occupational therapy.

The use of common job descriptions, incorporating the aforementioned Knowledge and Skills Framework dimensions, will help to focus curricula and assist in the regularity of grading. Furthermore, a career succession pathway will emerge, encouraging those with an interest in this healthcare arena to develop skills in reward for promotion.

Conclusion
This article offers a framework for skills analysis and competence, with the algorithm being a representation of one particular service model. Along with the supporting documentation (Figures 1–2; Tables 1–3), it demonstrates a practical guide to assisting practitioners in developing new ways of working or expanding existing services. 18

Acknowledgement
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References

Key points
- The literature relating to lymphoedema management has increased three-fold recently, with many publications suggesting models, frameworks or standards of care.
- For many specialists working alone, encouraging generalist healthcare professionals to participate in providing care for this patient group remains a daunting task.
- Much of the literature relies on consensus of opinion and the lack of robust evidence still makes it difficult to demonstrate treatment efficacy.
- It is crucial that there are clear recommendations about the responsibilities of each practitioner and the level of training when providing lymphoedema services.
- This article offers a framework, algorithm for skills analysis and competence.
- To encourage the standardisation of service policies, it is planned that all practitioners use standard assessment tools and documentation.