Early diagnosis of lymphoedema helps to reduce its psychological and social impact

Many nurses have a limited knowledge of lymphoedema but its impact on patients is considerable. Accurate diagnosis is crucial to prevent or minimise complications.

AUTHOR Garry Cooper BSc, SCPHN, DipHE Nursing, is Macmillan lymphoedema nurse specialist at Walsall Lymphoedema Service, Walsall Community Health.


Lymphoedema is often unrecognised by both health professionals and patients. In addition, its impact is often underestimated. This article discusses how to recognise the condition, the consequences of misdiagnosis, reducing or preventing complications and various treatment options.

Primary lymphoedema affects between one in 6,000 and one in 10,000 people (Lymphoedema Framework, 2006; Rockson, 2001). Secondary lymphoedema is estimated to affect 100,000 people in the UK (Moffatt et al, 2003). The differences between these two types are outlined in Box 1.

The condition is one about which patients and, in some cases, health professionals have limited knowledge. The International Society of Lymphology (2003) defines it as the accumulation of fluid and other elements – for example protein – in the tissue spaces, due to an imbalance between interstitial fluid production and transport. As a result of this imbalance, lymphoedema can occur in any part of the body due to lymphatic failure, or through damage or trauma (Lymphoedema Support Network, 2010).

REASONS FOR UNDER REPORTING

Many leading health professionals support the notion that lymphoedema is more prevalent within the UK than is estimated (Rockson and Rivera, 2008; Moffatt, 2007). One of the reasons the condition is underestimated is that there are insufficient lymphoedema services available within the UK (Morgan and Moffatt, 2007). In addition, many health professionals have a limited knowledge and awareness of the condition. Such lack of knowledge, according to Rockson (2007) and Ward et al (2009), results in patients receiving neither an appropriate diagnosis nor treatment.

There is no standardised education in England on lymphoedema for health professionals, but there is an internationally agreed document on recognising and treating it (Lymphoedema Framework, 2006). Wales and Northern Ireland have guidelines (Welsh Assembly Government et al, 2010; Clinical Resource Efficiency Support Team, 2008) but England and Scotland have yet to address the condition in a structured way. Existing guidelines recognise the impact of lymphoedema and strengthen the argument that health professionals need access to educational material and programmes on lymphoedema. This may help to identify a greater proportion of people with the condition.

Limited awareness and knowledge about lymphoedema can contribute to the idea that it is solely a cancer related condition, leading to services being set up that focus purely on this area (Morgan and Moffatt, 2007). This perception has led to inequity in service provision to those with lymphoedema that is not related to cancer (Moffatt, 2007; Williams et al, 2005). It is this disparity that makes it likely the impact of the condition is under reported (Sitzia et al, 1998).

Under-reporting affects not only the accurate recording of the number of people who have lymphoedema but also patients whose condition is not related to cancer. Inappropriate services or a lack of any service can also contribute to an underestimation of its prevalence.

Services are commissioned based on analyses of population needs; however, because of limited awareness or knowledge of lymphoedema, commissioners may not be able to gather robust and detailed data (Morgan and Moffatt, 2007). Moffatt (2007) also noted that some areas of the UK have no lymphoedema service provision, or have only services that focus solely on cancer related lymphoedema.

If the latest estimates of primary and secondary lymphoedema are used as a basis for prediction (CREST, 2008), it can be assumed that in any town or city there are people who have yet to be diagnosed with lymphoedema. Without the provision of a lymphoedema service, these people may continue to be misdiagnosed, which will contribute to the overall underestimation of the condition.

COMPLICATIONS

The importance of recognising lymphoedema extends beyond the need to have accurate estimates – the condition can cause complications in patients who do not receive treatment. If treatment is not instigated promptly, these complications can have lasting effects and a major impact on patients' quality of life.
psychological, social and financial impact on patients (Passik and McDonald, 1998).

The psychological and social impact of lymphoedema varies according to the patient and diagnosis. Patients with cancer perceive lymphoedema as a constant reminder of this, while non-cancer patients may view it in terms of altered body image (Woods, 2000). This has led to patients developing a range of psychological conditions, for example depression, stress and anxiety (Passik and McDonald, 1998). The psychological impact of lymphoedema can lead to patients isolating themselves from other people and can also cause relationship difficulties (Woods, 2000).

Controlling the physical impact of lymphoedema can help reduce its psychological and social impact. Physically, complications may involve minor to severe increases in limb size leading to skin changes, for example the development of papillomas, skin folds and increased epidermises of infections (CREST, 2008; Lymphoedema Framework, 2006). This can lead to mobility difficulties because of the excessive volume of the limb as well as increased pain (Twycross, 2000; Woods, 2000).

If lymphoedema is diagnosed early, its physical complications can often be minimised, but this depends on its causes and patients' ability to accept their condition.

From a financial perspective, the impact of lymphoedema on patients can lead to long term disability and increased difficulties obtaining or continuing with employment (Moffatt, 2007). For example, infection associated with lymphoedema will take longer to resolve than those not related to lymphoedema (British Lymphology Society, 2010). This will lead to increased sickness and absences from work, or may prevent patients from obtaining and completing work.

This issue is particularly pertinent given the current climate of increasing unemployment and the government agenda to reduce the financial burden of people on incapacity benefit (Wintour et al, 2010).

**SIGNS AND SYMPTOMS**

Box 2 shows the signs and symptoms of lymphoedema. These indicate whether the patient has lymphoedema but should not be the sole basis for diagnosis as other comorbidities – such as renal failure and heart failure – may present with similar symptoms (CREST, 2008).

Lymphoedema also has a number of stages, which will help health professionals identify the severity of the condition (International Society of Lymphology, 2003).

**TREATMENT PATHWAYS**

Patients diagnosed with lymphoedema can expect to receive a single treatment or a combination of treatments depending on the cause and severity of the condition, as well as any comorbidities.

Conventional lymphatic therapy (DLT) – also known as complex decongestive therapy (CDT) – is split into either an intensive or maintenance phase (CREST, 2008). Patients whose condition is mild will require only the maintenance phase.

There is no standard costing for delivering treatment as it depends on the service model used and patient need. Box 3 illustrates the two treatment phases.

Patients with lymphoedema can expect to receive skin care, exercise, manual or simple lymphatic drainage, compression bandaging and hosiery (Lymphoedema Framework, 2006) (see Box 4).

Robust trial evidence on each component is still insufficient (CREST, 2008; Szuba et al, 2002) but an international consensus supports DLT to treat lymphoedema (Lymphoedema Framework, 2006).

The aim of treatment is to reduce and manage the condition, then transfer care back to the patient (CREST, 2008; Lymphoedema Framework, 2006). This involves educating patients about lymphoedema and may require regular reviews to ensure their condition is stable before discharge. However, if their condition deteriorates, they may never be discharged and may need further support.

While lymphoedema is a long term condition, patients can be empowered by being supported to manage it and to function fully within society.
Patients identified as having signs of lymphoedema should be referred to a local lymphoedema service. This will ensure their diagnosis is confirmed and treatment can be started, helping them to avoid further complications. This will also reduce the costs incurred if they are not treated effectively.

However, in areas where there is no lymphoedema service, health professionals need access to education about the condition so patient care can be managed effectively.

If the demand for a lymphoedema service is evident in an area, health professionals or even patient groups could make a business case for a service to be commissioned.

CONCLUSION
Lymphoedema is an underestimated condition and can affect patients in many ways. Underestimating its impact and prevalence has led to inequity in service provision.

It is only by increasing awareness, knowledge and patient access to lymphoedemaseserviceswillitstrueimpactbe understood.

Achieving this goal will require all the mainstakeholders, including patients, health professionals and commissioners, to work together.

Developingalymphoedemasevice.London:MedicalEducationPartnership.


RECOMMENDATIONS
Patients identified as having signs of lymphoedema should be referred to a local lymphoedema service. This will ensure their diagnosis is confirmed and treatment can be started, helping them to avoid further complications. This will also reduce the costs incurred if they are not treated effectively.

However, in areas where there is no lymphoedema service, health professionals need access to education about the condition so patient care can be managed effectively.

If the demand for a lymphoedema service is evident in an area, health professionals or even patient groups could make a business case for a service to be commissioned.

CONCLUSION
Lymphoedema is an underestimated condition and can affect patients in many ways. Underestimating its impact and prevalence has led to inequity in service provision.

It is only by increasing awareness, knowledge and patient access to lymphoedema services will its true impact be understood.

Achieving this goal will require all the main stakeholders, including patients, health professionals and commissioners, to work together.

Developing a lymphoedema service. London: Medical Education Partnership.