

A SHIFT TO CHRONIC DISEASE CARE MANAGEMENT

Byron Shier

Lymphoedema is a chronic medical condition which may reduce a person's quality of life by negatively impacting on his or her medical, physical, psychosocial and functional status. This article argues that lymphoedema progression can be more effectively controlled by focusing clinical care delivery on client self-management, to better address the possible complications of this condition, such as recurrent cellulitis infections. The author compares the way lymphoedema is treated in Canada, with US and UK models.

Key words

Chronic care
Acute care
Self-management
Cellulitis

Effective lymphoedema treatment and management requires an interdisciplinary focus, consistent self-management and access to appropriate healthcare services throughout the client's life, as well as timely intervention from various healthcare providers (Morgan et al, 2005).

Lymphoedema is caused by lymphatic fluid accumulation, which results in persistent and progressive swelling in one or more areas of the body (Ramos et al, 1999). Appropriate assessment and treatment may involve various professional disciplines, including medicine, nursing, psychology and social work, and rehabilitation across acute and community-based care.

Appropriate care for clients with lymphoedema requires a shift of focus from traditional acute care

with its emphasis on episodic clinical interventions, including intensive lymphoedema rehabilitation and immediate clinical issues, to a chronic disease management model.

This requires a shift in focus to better engage clients as partners in the care and treatment process, as it is they who will ultimately have to live with and manage this condition. Clinicians also need to make use of emerging e-health technologies to better meet modern client needs.

A chronic disease model

Chronic lymphoedema disease management requires a reallocation of healthcare resources away from acute service delivery. Fulton et al (2001) suggest that the acute care model is inadequate for addressing chronic conditions, resulting in increased allocation of clinical resources for diagnostics and treatment. Acute medical episodes also contribute to the progression of underlying chronic lymphoedema, further increasing the risk of acute clinical episodes, increased direct treatment interventions, and resulting in a concurrent negative impact on client's daily living function and overall quality of life. Acute care services are also more expensive to deliver and have a poorer outcome in this population.

One complication caused by lymphoedema is the risk of recurrent

cellulitis infections (Pavlotsky et al, 2004; Vaillant, 2007). Cellulitis is a commonplace diagnosis seen in emergency departments. Brunton and Boychuk's study, as cited in Dong et al (2001), report on a review of one urban emergency department in Edmonton, Alberta, Canada, where 5–14% of all visits were for the provision of outpatient parenteral therapy, of which the majority involved administering antibiotics to treat cellulitis infections.

Individuals presenting acutely in an emergency department with lymphoedema and a concurrent cellulitis infection in the affected limb will be treated for the cellulitis infection. However, treating this will not address the underlying lymphoedema, which is a risk factor for recurrent infections.

The role of the emergency department may also make it the least appropriate setting to provide comprehensive lymphoedema treatment and follow-up services, due to its focus on treating the acute presentation. Instead, evidence demonstrates that offering lymphoedema rehabilitation services in alternative healthcare settings promotes effective treatment, client education and self-management, as well as helping to prevent secondary medical complications, for instance, by reducing infection rates.

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Chronic disease and self-care

Dicken et al (1998) report on lymphoedema clients who, after self-managing their own complete decongestive therapy as part of their treatment plan, showed a reduction in infection incidence from 1.10 to 0.65 infections per client annually. This reduction translates to fewer emergency department visits due to lymphoedema-related cellulitis infection. Therefore, there is evidence to support the implementation of assessment and treatment programmes that have an emphasis on self-care.

A focus on self-management may improve long-term clinical presentation through controlling lymphoedema progression and reducing the frequency and duration of direct clinical care. Wagner (1998) suggests that chronic disease management will support clients by:

- » Establishing system-wide assessment and treatment guidelines
- » Ensuring regular interactions with clinicians
- » Focusing treatment on the client's ability to perform activities of daily living and self-management
- » Preventing disease exacerbation and secondary complications.

Similarly, clients who have a practical knowledge of lymphoedema are empowered to practise self-management. Alongside an understanding of potential healthcare complications and ready access to community health providers, these clients may be more proactive about their care and reduce any potential acuity. This approach also encourages healthcare providers to engage their lymphoedema clients as active partners in care.

With the support of the clinical team, clients can learn appropriate strategies to manage lymphoedema alongside their daily living activities. For instance, clients who recognise the early signs and symptoms of an infection, and initiate a prompt assessment by their physician, may be more effectively treated in the community, avoiding emergency department visits or

hospital admission. This service model promotes healthier outcomes, while reducing the burden on acute care services and lowering medication costs.

Investment in health resources to promote chronic lymphoedema management also offers a cost-effective service model, which promotes superior clinical outcomes. Fulton et al (2001) recommend initiatives that shift the focus of service delivery by aligning community resources, policies and service organisation toward proactive solutions that emphasise client self-management. A programme model focusing on providing community-based, accessible interdisciplinary care will improve clients' disease management and promote improved functional performance of daily activities.

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Funding and self-management

Unfortunately, a recent example of healthcare management decision-making simply served to reinforce a fragmented acute treatment model in Canada. A Calgary-based outpatient interdisciplinary rehabilitation lymphoedema clinic, previously operated by the author, received contract funding between November 2006 and March 2009 from the Alberta Cancer Board, a provincial oncology healthcare management organisation. The funding covered direct client care services, clinical supplies and a monthly client education session.

However, the funding did not include coordination of client follow-up, leaving the clinicians to complete this in their personal time. This model discouraged interdisciplinary collaboration between clinicians as well as inhibiting client access to clinicians outside of the provision of direct treatment. It also

Key points

- » An acute care service model is both inefficient and inadequate when providing effective lymphoedema care for a client's lifetime.
- » Lymphoedema clients may present with a complex array of physical, psychosocial, and functional complaints throughout and will benefit from the input of various medical and allied healthcare providers to meet those needs.
- » A focus on healthcare that emphasises client self-care is a proactive approach to improving long-term clinical presentation through effectively controlling lymphoedema progression.
- » Using e-health records and e-health initiatives offer opportunities to improve client's timely access to interdisciplinary care.

excluded non-oncology-related lymphoedema clients, leaving them to pay privately for any treatment.

Taken over all, the programme resulted in uneven client access based on diagnostic history. Unfortunately, clients who elect not to access treatment are at a greater risk of other clinical issues, such as cellulitis infections, resulting in an increasing level of acuity when they inevitably access care from other funded healthcare services.

Extending equal funding across all populations and diagnostic groups who develop lymphoedema would immediately breakdown any barriers to clients accessing treatment. Lymphoedema clients present with an array of physical, psycho-emotional, functional and medical issues while managing their lymphoedema alongside

other morbidities. Service leaders should take into account the return on investment with regards to improved quality, outcomes, and service efficiency, gained through funding interdisciplinary collaboration.

International perspective

There is a growing interest in chronic lymphoedema disease management outside of Canada.

The UK model

The UK has taken the lead in developing a framework for comprehensive care. The UK standards of practice for lymphoedema services (Moffatt et al, 2006), incorporate a chronic disease management service model.

One recommended standard is the early identification of those at risk of developing lymphoedema or those that have the condition. This standard identifies the need for systems to be designed, implemented, and monitored, to identify those at risk of, or those with lymphoedema, regardless of cause. The standard also recognises the need to support clients in receiving quality, evidence-based education and lifelong care.

Another standard identifies the need for clinical care that integrates community, hospital, and hospice-based services. This standard acknowledges the need for clients to have ready access to trained interdisciplinary clinicians to better manage their complex needs. The practice standard recommends that following comprehensive assessment, any client at risk of, or with lymphoedema, who requires multi-agency support, will have access to and receive appropriate care from health and social services. This recognises the need for a client-centred programme, derived from assessment findings, tailored to meet the client's specific needs.

Morgan et al (2006) report that the National Lymphoedema Framework Project supports the development and continuous evaluation of integrated

lymphoedema services across the UK. This standard recognises the importance of integrating quality control mechanisms to emphasise service improvement over time.

The US model

The US is considering the *Lymphoedema Diagnosis and Treatment Cost Saving Act of 2010*, introduced to Congress by Larry Kissell (Lymphoedema Treatment Act, 2010). If this Act were passed it would mean that people with lymphoedema who have access to Medicare would receive treatment coverage, regardless

Web technology, such as Skype, can now potentially enable the clinician to have a real-time remote discussion with clients.

of clinical cause. This would extend funded treatment to all US seniors on Medicare and could be a major step towards offering comprehensive lymphoedema treatment to US citizens receiving private employer-based health insurance. This outcome would result in funded coverage for the large majority of the US population.

E-health for chronic disease management

Electronic health records and e-health initiatives offer the opportunity to improve the quality of care for clients with chronic lymphoedema. Throughout their life, they will access care in various settings and electronic records provide valuable information about past interventions, making it easier to address lymphoedema-related issues and co-morbidities. For instance, a family physician may find a documented history of graduated compression helpful when completing follow-up prescriptions.

A comprehensive e-health record will also ensure notes about lymphoedema history and treatment are available when the client is being seen for other

clinical issues. This will help to prevent, for instance, an assessing physician ordering unnecessary and costly diagnostic procedures to rule out other clinical pathologies.

Similarly, an e-health record documenting the client's history will assist service providers in coordinating follow-up care. E-health records can be easily transferred if the client relocates and they can even complement direct follow-up visits, allowing the clinician to provide treatment in a more efficient manner. In turn, clients are able to access their clinicians directly, which can help encourage autonomy.

Other benefits include helping clients who have limited access to outpatient services due to transport and distance. These issues can be particularly relevant to Canadians living in rural communities.

Web 2.0 technologies have evolved and offer an increasingly interactive and user-friendly platform, providing an opportunity to enhance clients' care experience and support chronic disease management. For instance, technology, such as Skype, enables clinicians to have a real-time remote discussions with clients, as well as providing direct visual assessment.

Client education, a key component to preparing lymphoedema clients for treatment and self-management, may be enhanced by using web 2.0 technologies. Matthews et al (2007) found that public education sessions improved the knowledge and attitude of breast cancer clients at risk of developing lymphoedema. Clinicians can offer community-based information sessions to inform the public and help manage treatment expectations. Video or online streaming of professional presentations also offers an opportunity for clients to access relevant lymphoedema information in a flexible timeframe and a location suitable to their needs. Since lymphoedema is a chronic, manageable medical condition, providing accessible client education is crucial in developing

their understanding of the importance of self-management strategies.

Integrating web technologies into clinical practice poses numerous challenges, however. Any policy changes need to support and encourage increased integration of e-health technology into clinical practice. Juzwishin (2009) argues that information system interoperability in current fragmented healthcare systems will not be accomplished until governance, structural, and process barriers are addressed. The potential benefits of enhanced clinical care in Canada warrant the continued efforts of healthcare leaders and stakeholders to resolve these issues.

A prospective model for service delivery

An outpatient interdisciplinary clinic with mobile clinicians able to provide homecare services may be one approach to providing an accessible, community-based service that focuses on chronic disease management.

Physician and specialist referrals would be accepted into this lymphoedema outpatient-based clinic. An interdisciplinary assessment could provide the framework for developing a comprehensive, client-centered programme. The assessment process would involve an outpatient client meeting with several members of the healthcare team for screening purposes. Potential team members would likely be physicians, occupational therapists, physiotherapists, psychologists, kinesiologists and nutritionists.

A client-centered treatment programme would then be designed to meet specific client goals. For instance, some might benefit from extensive nutritional counselling to support weight-management goals, while others might require further medical follow-up and investigations.

These services can also be adapted based on a client's changing needs over time. Treatment goals may be met by one primary treating clinician, but

will more likely require varying degrees of involvement from various team members. Services could be extended to other settings, such as homecare as appropriate.

A primary clinician could be assigned specific files to assist with care coordination. Clinicians could also be dispatched to provide acute care, homecare, hospice visits and outpatient assessment/treatment services, or provide online clinical support, based on the client's needs and location.

Canadians living with lymphoedema should, therefore, have access to interdisciplinary chronic disease management programmes, to help them manage this condition and allow them to maintain daily living activities.

Conclusion

Standards of practice in the UK may offer a model to guide programme development in Canada. This model could be replicated in different areas, offering Canadians a relatively consistent, equitable, accessible service wherever they happen to live.

A chronic disease management approach emphasising interdisciplinary collaboration and client-centred care is a proactive and cost-effective approach to meeting clients' lifelong needs. Lymphoedema clients will benefit from regular, scheduled follow-up appointments with clinicians, and a flexible clinical service.

Canadians living with lymphoedema should, therefore, have access to interdisciplinary chronic disease management programmes, to help them manage this condition and allow them to maintain daily living activities. **JL**

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