Population Health: The need for chronic disease Lymphedema care management in Canada.

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Executive Summary

Lymphedema is a chronic medical condition which may negatively impact client's medical, physical, psychosocial, and functional status, thereby impacting quality of life. Effective Lymphedema treatment and management requires an interdisciplinary focus, consistent client self-management, and timely client access to appropriate healthcare services throughout their lifespan. Lymphedema clients are ideally suited to a chronic disease management care model.

Lymphedema is a chronic medical condition caused by lymphatic fluid accumulation resulting in persistent and progressive swelling in one or more areas of the body (Ramos, O'Donnell, & Knight. 1999). Lymphedema clients may present with multiple physical, psychosocial, and functional complaints over their lifespan, requiring timely intervention from various healthcare providers. Appropriate treatment may involve: Medicine, Nursing, Psychology, Social Work, and Rehabilitation disciplines across settings ranging from acute to community based care.

Lymphedema chronic disease management will require changes from the current acute care service paradigm. Fulton, Penney, and Taft (2001) suggest that the current acute care service model is both inefficient and inadequate to most effectively address chronic medical conditions. Focusing service delivery on acute care results in higher client acuity on presentation, thereby requiring increased overall healthcare resource consumption. For instance, one common complication of individuals developing Lymphedema is a risk factor for recurrent cellulitis infections (Pavlotsky, Amrani, & Trau, 2004; Vaillant. 2007). Cellulitis infections are a commonplace diagnosis seen in emergency departments. Brunton and Boychuk's study (as cited in Dong, Kelly, Oland, Holroyd, & Rowe, 2001), report in a review of one urban emergency department, 5% to 14% of all visits were for outpatient parenteral therapy, of which the majority were for antibiotic administration to treat cellulitis infections. Fortunately for Lymphedema clients, evidence supports the efficacy of Lymphedema rehabilitation and client education to reduce infection incidence rates. Dicken, Ko, Lerner, Klose, & Cosimi (1998) report Lymphedema clients who had appropriate treatment and integrated self-management into their care, reduced infection incidence rates from 1.10 infections to 0.65 infections per

client annually. This reduction in infection frequency will translate to fewer emergency department visits for individuals with a Lymphedema related cellulitis infection. Therefore, evidence supports implementing assessment and treatment programs with emphasis on client's consistent self-care to reduce infection risk and to improve Lymphedema client's long-term health and wellness.

A healthcare service focus on supporting client self-management may improve long-term clinical presentation through effectively controlling Lymphedema progression and reducing the frequency and duration of direct clinical care required. Wagner (1998) suggests chronic disease management will support clients: to have system-wide assessment and treatment guidelines; to have regular interactions with their care providers; to focus treatment on client function and self-management; and to prevent disease exacerbation and secondary complications. Clinical treatment guidelines and evidence supports emphasizing client integration of daily self-management strategies for long-term care. Client's empowered to practice self-management with a practical knowledge of Lymphedema, an understanding of potential healthcare complications, and ready access to community health providers, may tend to be more proactive in their care and thereby reduce potential acuity. For instance, Lymphedema clients who recognize the early signs and symptoms of an infection, with early assessment from their family physician, may be effectively treated in the community and avoid an emergency department visit or possible hospital admission. This service model will promote healthier client outcomes while concurrently reducing acute care service needs including: human resource utilization, diagnostic utilization, and medication costs, thereby allowing

for a more efficient allocation of finite acute care resources to focus on other more urgent medical needs.

Investment of health resources to promote proactive Lymphedema chronic disease management will offer a cost effective service model which concurrently promotes superior clinical outcomes. Fulton et al. (2001) recommends initiatives to shift focus of healthcare service delivery by aligning community resources, policies, and organization of care, to offer proactive healthcare service solutions emphasizing client self-management. A program model focusing on providing community based, accessible interdisciplinary care will improve client's disease management and promote improved client functional performance with daily activities.

Unfortunately, one recent example of Canadian Lymphedema program funding reinforced an acute treatment model. A Calgary based outpatient Lymphedema clinic received contract funding between November 2006 and March 2009 from the Alberta Cancer Board. The funding did cover direct client care services, treatment supplies, and a monthly client education session. However, follow-up client care coordination including formal reporting and all subsequent communications with clients and other healthcare providers was not covered. The funding model left the health professionals to complete these services on personal time. This model thereby discouraged both opportunities for valuable interdisciplinary clinical collaboration, and care providers to be accessible to their clients outside of direct care provision. This funding also excluded non-oncology related Lymphedema clients, leaving these clients to pay privately for all services. This resulted in an inequity in client access based on diagnostic history. Clients who elected not to access treatment services are subsequently at a greater risk of other clinical issues,

such as cellulitis infections, resulting in an increasing level of acuity when these individuals inevitably access care from other funded healthcare services.

Growing interest in Lymphedema chronic disease management has been demonstrated outside of Canada. The United Kingdom has taken a leadership initiative to develop a framework for comprehensive based care. The United Kingdom's standards of practice for Lymphedema services (Moffatt, Doherty, & Morgan. 2006), incorporates a chronic disease management service model. One recommended standard is early identification of people at risk of, or with Lymphedema. This standard identifies the need for systems to be designed, implemented, and monitored, to identify people at risk of, or with Lymphedema, regardless of cause. The standard also recognizes the need to support clients 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 of practice acknowledges the necessity for clients to have ready access to trained interdisciplinary healthcare professionals across the healthcare continuum to better manage their complex needs. The practice standard recommends that following comprehensive assessment, any patient at risk of, or with Lymphedema, who requires multi-agency support, will have access to and receive appropriate care from health and social services. This standard recognizes the need for a client centered program, derived from assessment findings, tailored to meet individual's specific needs. Morgan, Moffatt, & Doherty (2006), report that the Lymphedema framework project supports the development and continuous evaluation of integrated Lymphedema services across the United Kingdom. This standard recognizes the importance of integrating quality control mechanisms to emphasize service improvement over time.

The United States is currently considering the Lymphedema Diagnosis and Treatment Cost Saving Act of 2010, HR 4662, introduced to Congress by Larry Kissell (Lymphedema Treatment Act.org, 2010). The successful passing of this Act would offer treatment coverage for U.S. Medicare beneficiaries with Lymphedema from any clinical cause. This coverage would extend funded treatment to all U.S. seniors on Medicare and may be a major step to offering comprehensive Lymphedema treatment to include Americans who receive private employer based health insurance. This outcome would result in funded coverage for the large majority of the American population.

Electronic health records and e-health initiatives offer opportunity to improve quality of care to assist clients with chronic disease Lymphedema management. Throughout their lifespan, clients with Lymphedema may access care in various healthcare settings. Accessible electronic health records will offer healthcare providers' valuable current information on past treatment interventions and frequency, to address Lymphedema related issues and co-morbidities. For instance, a family physician may find a documented history of a treating therapists graduated compression garment recommendations to be helpful when completing follow-up prescriptions. Furthermore, an accessible record offers an important healthcare quality control mechanism to ensure clients are being fitted with appropriate garments to meet their clinical needs. An e-health record will ensure Lymphedema history and treatment will be included in client's clinical record and will be available as needed when being seen for other clinical issues. For instance, a client presenting with documented Lymphedema in an affected limb may help an assessing physician avoid ordering unnecessary and costly diagnostic procedures to rule out other clinical pathologies, and to more expeditiously assess changes in their

client's condition. An e-health record documenting client's history of diagnosis, assessment and treatment, will assist health care organizations to coordinate and expedite Lymphedema treating clinicians as indicated to provide follow-up care. Lymphedema clients with an e-health record may realize improved portability of their treatment records when they move or travel to another region or jurisdiction. Lymphedema clients may utilize electronic communication to complement direct follow-up visits with their healthcare providers. The healthcare provider may subsequently be able to provide direction in a more efficient manner. Clients may have limited ability to access an outpatient clinic service for reasons including: transportation access, other medical issues, distance, and other commitments. These issues may be particularly relevant to Canadians living in rural communities. Electronic communication provides a valuable tool that clinicians could leverage to provide community based follow-up care and support to their clients. Clients, in turn, will have a means to access their clinicians directly and help empower client autonomy as they manage with this chronic condition. Web 2.0 technologies has evolved to offer an increasingly interactive and user friendly platform, providing an opportunity to enhance the client care experience and support our clients in chronic disease management. This technology provides healthcare providers a valuable tool to complement more traditional clinical care service delivery. Web technology, such as Skype, can now potentially enable the clinician to have a real-time remote discussion with clients including the opportunity for direct visual assessment with concurrent verbal interaction.

The Web technology may provide the opportunity to realize system and service efficiencies. Integrating technology would support more efficient community home care

service delivery by potentially reducing provider travel time. Reducing clinician travel can offer greater opportunity for clinicians to increase the support and care utilizing this technology. Healthcare providers would have the flexibility to offer remote support and assistance to complement direct care delivery.

Lymphedema client education, a key component to preparing clients for treatment and learning self-management, may be enhanced through utilizing web 2.0 technologies. Matthews, Bursey, Park, Hodgson, West, & Church (2007) found that public education sessions offered an opportunity to improve both knowledge and attitude of breast cancer clients at risk of developing Lymphedema. Clinicians can meet this need by offering community based informational sessions to inform the public and help manage treatment expectations. Video or online streaming of professional presentations will offer opportunity for clients to access relevant Lymphedema information in a flexible timeframe and location suitable to their needs. As Lymphedema is a chronic, manageable medical condition, providing accessible client education is crucial to developing a client understanding of the critical role of client engagement in learning self-management strategies.

Integrating web technologies into clinical practice face numerous challenges. Policy changes need to be made to support and encourage increased integration of e-health technology into clinical practice. Juzwishin (2009) argues that information system interoperability in the current fragmented healthcare system will not be accomplished until governance, structural, and process barriers are addressed. The potential benefits and operational efficiencies to enhance clinical care warrant continued efforts from

Canadian healthcare leaders and stakeholders to seek resolution for these numerous unresolved issues.

An outpatient interdisciplinary clinic with mobile clinicians to provide homecare services may be one approach to providing an accessible, community based service focusing on chronic disease management. Physician and specialist referrals would be accepted to this Lymphedema outpatient based clinic. An interdisciplinary assessment could provide the framework for developing a comprehensive, client centered interdisciplinary program. Client needs may be appropriately met by one primary treating clinician, or from a more interdisciplinary service. A primary clinician could be assigned to specific files to assist with care coordination as indicated. Clinicians could be dispatched to acute care, homecare, hospice, outpatient assessment/treatment service, or provide online clinical support, based on client needs and their location in the continuum at any point in time. The United Kingdom's standards of practice may offer a model to guide program development here in Canada. This model could be replicated in different Canadian jurisdictions, offering Canadians a relatively consistent, equitable, accessible service wherever they happen to be located.

In conclusion, a chronic disease management approach emphasizing interdisciplinary collaboration and a client centered approach to care is a proactive, logical, and cost effective approach to meeting Lymphedema client lifelong needs. Lymphedema clients will benefit from regular, scheduled follow-up appointments with treating clinicians, and a flexible clinical service that provides a client centered approach to meet client needs through a lifespan. Canadians living with Lymphedema should therefore have access to interdisciplinary, chronic disease management programs, to

proactively help them manage this condition and allow them to regain, maintain, and maximize function in daily living activities.

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