Enhancing primary care for persons with spinal cord injury: More than improving physical accessibility

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In Ontario, Canada, legislation exists that mandates that all medical practices be fully accessible by 2025, in an effort to improve access to primary care for persons with physical disabilities. The simple removal of physical barriers may not guarantee improved access to appropriate care. In this clinical note, members of an interprofessional primary care-based Mobility Clinic reflect on opportunities to improve primary care beyond just better physical accessibility for persons with spinal cord injury (SCI). The importance of collaborations between funders, researchers, and clinicians are examined. Using a participatory action research model, the unique perspective of consumers and consumer networks are incorporated into the Mobility Clinic's clinical and research efforts to improve primary care for persons with SCI.

Keywords: Spinal cord injury, Primary care, Physical disability, Accessibility, Mobility

The problem

There is literature that supports the notion that primary care is not easily accessible for persons with SCI. Reasons include lack of transportation, wheelchair ramps, inadequate space for mobility aids, and inability to transfer to an examination table.^{1–5} Accessibility is a critical step to ensuring persons with SCI can obtain the care they need. Some government legislation such as the Accessibility for Ontarians with Disabilities Act (2005), mandate that all medical practices be fully accessible in the future. While this may ensure that medical practices are physically accessible by wheelchair, patients may still find their care compromised by the lack of appropriate medical equipment such as height-adjustable examination tables, transfer mechanisms such as ceiling lifts, and grab bars.⁶ In a recent study we conducted,³ family physicians reported that without appropriate medical equipment they are unable to properly examine patients resulting in a focus on episodic or acute care rather than preventive care. In some reported cases, patients have been sent to the Emergency Department for

care solely due to accessibility and equipment issues. An initiative that offered funding, through an application process, for adjustable examination tables and overhead lifts was offered to family health teams in Ontario.⁷ Although a very important step toward improving access to care for persons with disabilities, this initiative was limited in that it excluded solo or small group practices. Accessibility in these practice models continues to be a challenge.

Is accessible equipment sufficient to improve access to primary care for persons with SCI? Legislation can mandate physical resources to improve access to care but accessibility is not restricted to physical measures. Other barriers that might be encountered include provider knowledge gaps and attitudinal bias.^{3,8,9} Lack of training on the use of specialized equipment, lack of interprofessional expertise in SCI, lack of easily accessible practice tools, limited remuneration within a publicly funded health system for provision of care that is time consuming, low motivation to build clinical capacity due to low patient volumes, and perceptions of persons with SCI as challenging patients can all contribute to less than optimal primary care.³ For most primary care physicians, management of secondary complications can be challenging and the needs of

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these patients are not limited to issues that can be met solely by physicians.

An innovative solution in primary care

In 2010, the Centre for Family Medicine Family Health Team (CFFM FHT) in Kitchener, Ontario, established an interprofessional Mobility Clinic with the aim of improving access to quality care for persons with severe physical disabilities (in Ontario, FHTs consist of groups of health professionals including physicians, nurses, pharmacists, physiotherapists, occupational therapists and other allied health care providers, working together to provide primary care to patients.).¹⁰ The CFFM FHT is accessible from curb to bedside with accessible parking, ample space within which to manoeuvre wheelchairs and walkers, height adjustable examination tables, ceiling lifts, grab bars, electronic door openers, a wheelchair scale, and other physical resources that help facilitate access to care. While having this type of equipment available in primary care can improve access to care, it may not necessarily improve quality of care. Utilizing the expertise of team members and enhanced training in issues related to persons with SCI has helped to overcome some of the knowledge and attitudinal barriers.

The development of this clinic was a partnership between CFFM FHT, the Schlegel-University of Waterloo Research Institute for Aging, and the Ontario Neurotrauma Foundation, which provided funding for the demonstration and research of this project. Our objectives were to enhance quality of care and improve the health outcomes of adults with mobility impairments (and a particular focus on SCI) by increasing access to care and building capacity among health professionals to provide quality care for these patients within a primary care setting. Initially, given the low volume of patients with SCI in our practice, we began the clinic as an opportunity to improve access to care for all patients whose mobility challenges compromise their ability to get quality health care. The patient-centred team is comprised of a family physician lead, a chiropractor/project manager, a nurse, and an occupational therapist. The clinic is supported by a social worker and pharmacist available when needed, and “virtual” consultation support provided by a rehabilitation specialist via email. It is a shared care model with family physicians referring patients to the clinic to assess and manage mobility-related health issues and treatment either initiated or suggestions made to the referring practitioner. Referrals can be for very specific issues (assess skin, perform pap) or of a more general nature (annual comprehensive examination). Care in this clinic begins with a comprehensive assessment of all

health care needs, with each different health care practitioner offering their expertise, the results of which formulate a holistic plan of care that first and foremost incorporates patient goals and wishes. A more detailed description of this clinic is published elsewhere.^{11,12}

Initial evaluations of the clinic^{11,12} supported our hypotheses that this type of clinic was a viable and effective way of improving access to quality care to patients with SCI and other physical disabilities. Patients in particular were appreciative of a service that understood their needs and could provide preventive care that they could not previously access. Family physicians appreciated the reduced burden of care (gave them support or filled a gap in addressing complex or unknown topics), increased knowledge that was gained from collaboration with the clinic, and welcomed a service within their practice setting that could provide the time and expertise needed to manage complex care issues. Anecdotal evidence we collected suggests that by increasing capacity in primary care to manage and prevent secondary complications, such as bladder infections (which are a common reason persons with SCI attend Emergency Departments), we can serve to reduce reliance on more costly acute care and specialist resources to manage health issues that are within the realm of primary care.

With an emphasis on community-based care and goal to promote the clinic community-wide, outreach initiatives have included presentations, education, and training opportunities for both health professionals and the general public to increase their awareness of the health care issues and management strategies for this patient population. Topics have included secondary complications (bladder management) and psychosocial issues, such as sexuality. Building the team through community connections has been paramount and SCI Ontario (a service and consumer advocacy organization) has become an important collaborator in our outreach efforts. Through this unique relationship, over 20 additional persons with SCI in the region who did not have a primary care provider have been linked to the Mobility Clinic and a family physician.

Consumer participation in designing health care

As the volume of patients with SCI seen in the Mobility Clinic has increased, so has our understanding of the complexity of the care needs of persons with SCI and we have come to realize that the input of consumers is key to truly understanding their health care and overall needs. Using a participatory action research (PAR) model, with an underlying premise that health services informed by patients’ lived experience could

result in multiple positive outcomes, a collaborative relationship between key stakeholders (Mobility Clinic team members, service delivery providers, community agencies, researchers) and consumers helped form a SCI Community Advisory Committee. This committee met on four occasions over 10 months to identify local gaps in care and brainstorm potential solutions. Greater efficiency of health services, an emphasis on preventative health care, fostering self-management over one's health, were some of the topics the SCI Community Advisory Committee explored. A key outcome of the work of this committee was support for shifting ownership of community capacity building to consumers. Consistent with PAR, this "grass roots" approach was viewed an opportunity to facilitate equitable and sustainable health care and service delivery. Building on this premise, a SCI Consumer Network was developed consisting of 22 persons with SCI, whose role is to advise and inform SCI service delivery and research activities. We have learned much from this group, including optimal strategies to prepare persons with SCI for their first visit to their health care providers, the need to improve SCI documentation on electronic health records, and patient desires for information on various health topics. As a result of this group we reviewed the availability of appropriate community-based exercise programs and worked with the local YMCA to deliver an SCI fitness program. Group information sessions were organized with invited guest speakers on topics such as exercise programs for persons with neurologic conditions, management of urinary tract infections and accessibility vehicles, with patients displaying their vehicles in an informal "car show" to demonstrate and share information on accessibility features. Though one might suggest that a "car show" is beyond the scope of usual health care, it could also be argued that adequate transportation is essential for community and social integration, which are important determinants of health.¹³ This group has expanded our understanding of 'accessibility' to also include care that is appropriate and timely, requiring an understanding from all persons within a health care practice (reception, nursing, physicians) to be sensitive and flexible to the needs of the individual. Translating this into practice, we have adopted these recommendations by avoiding early morning appointments that interfere with care, considering telephone consults and home visits, ensuring more timely appointments, dedicating more time for appointments with persons with SCI, and using more standardized assessment tools with greater emphasis on facilitating self-management of health issues.

A sub-group of individuals from this consumer network took on the role of Patient Advisors, working with Mobility Clinic team members to provide consumer perspectives on health care needs for persons with SCI, gaps in services, and potential opportunities for improvement, to serve as strong self-management role models, and to provide input in generating and advancing SCI-related research ideas. As examples, two Patient Advisors reviewed research grant proposals to provide their input on the scope of the research question and the ability of the project to yield outcomes relevant to persons with SCI.

Collaborative research

The collaborative relationship with our patients has raised unique questions and led us down clinical and research paths that otherwise would not have occurred. Through our primary research funder (Ontario Neurotrauma Foundation), we have developed key relationships with researchers, clinicians and organizations provincially, nationally and internationally resulting in the development of a SCI learning collaborative with the objective of developing projects to advance SCI primary care. Examples of current research projects include: (i) the evaluation of an electronic-consultation service aimed at improving the communication between primary care physicians and physiatrists, (ii) the development and evaluation of self-management tools, (iii) a comprehensive needs assessments on SCI primary care, (iv) development a mood and mental health screening template, (v) development, testing, and further refinement of a SCI toolkit for family physicians and patients, and (vi) development and delivery of education programs for health care professionals to build capacity for SCI care and to expand the interprofessional Mobility Clinic care model.

Lessons learned

Our learning curve in the SCI field has been steep and our list of lessons learned long. Our work has been enabled by strong management and leadership support, guided by a clear vision for quality primary care for all our patients and demonstrated with the provision of physically accessible clinic space, specialized equipment, and flexibility in our ability to meet patient needs. Learnings and support from other chronic-disease management clinics (e.g., CFFM Memory Clinic)¹⁴ have helped mold the basic interprofessional structure for the Mobility Clinic.

Sustainability of the Mobility Clinic has been fostered through our outreach activities, our partnership with SCI Ontario, and linking the Mobility Clinic with other initiatives that are pertinent (e.g. Health Links, a focus of the Ministry of Health to address high users of health care).¹⁵ Strong collaborative working relationships

with clinical and research colleagues, and valued input of our consumers has helped our focus and evaluation of the clinic. A close relationship with our primary funder has not only been instrumental for support but also for key relationship building. Our success has not come without challenges. Internally, we have experienced increasing demands for service across a broad range of mobility issues, challenging us to focus our services within existing resources and to sustain a clear overall vision for the clinic. With busy clinical responsibilities outside of the Mobility Clinic, there are time conflicts for research activities. Access to research supports such as research assistants and persons well experienced in grant writing, research methodology, data analysis and interpretation, and project management has been critical to keep us focused on objectives and to ensure projected timelines are maintained. Pervasive health system issues threaten the effectiveness of the clinical service we offer due to community-based home care services that are unable to accommodate or modify treatment recommendations to meet specific patient needs (i.e. care is dispensed as “one-size-fits all”), limited access to private home care services due to cost, and inaccessible laboratories and specialist offices.

Despite these challenges, four years after we established our Mobility Clinic and several research projects later, we celebrate and are buoyed by practice improvements we have experienced, being ever motivated by our ultimate goal of supporting persons with SCI to enable optimal health and wellness to facilitate full community integration and social participation. Although we fully support legislation that mandates the accessibility of all medical practices, we recognize that improved access to care for persons with SCI and physical disabilities goes well beyond ensuring that physical space is accessible. Successful primary care for this population and others with similar complexities will require innovative solutions that will involve strong collaboration and communication in unique ways. Ongoing collaborative relationships among our patients with SCI, fellow clinicians, research colleagues, policy makers, funders, and other key stakeholders will be paramount as we move forward in our quest for high level primary care.

Acknowledgments

The authors are grateful to the Ontario Neurotrauma Foundation for their ongoing support.

Disclaimer statements

Contributors JM—concept, manuscript preparation, final approval. JL—concept, manuscript preparation, final approval.

Funding We wish to acknowledge the Ontario Neurotrauma Foundation for their research funding support and Loretta M. Hillier for her writing assistance and feedback. We have permission for these acknowledgments.

Conflicts of interest The authors report no conflicts of interest.

Ethics approval None.

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