Research Article

Community-based physical activity and wheelchair mobility programs for individuals with spinal cord injury in Canada: Current reflections and future directions

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Rationale: A clear need has been identified to find strategies and opportunities, beyond services provided during rehabilitation, to enhance community-based mobility and leisure-time physical activity (LTPA) participation among members of the spinal cord injury (SCI) population.

Method: This review of existing mobility and LTPA programs that are available for individuals with SCI in Canada reflects the authors' current knowledge of existing evidence-based and community-based programs. The authors aim to highlight the gaps between existing programs and future needs.

Results: The major gaps identified in this brief clinical report include the need for: community-based mobility training programs, patient reported outcomes, assessment of long-term impact of programs, identifying the best approaches for program delivery, and developing researcher-stakeholder partnerships.

Conclusion: Evidence-based mobility programs and community-based LTPA do exist, and the available research shows their promise. Despite the growing research for LTPA and mobility programs among adults with SCI, many gaps remain. Additional partnerships, community engagement practices, service program funding and health policy changes are needed to address the highlighted gaps to optimize community-based programs and enhance the lives of adults with SCI.

KEYWORDS: Spinal cord injury, Leisure-time physical activity, Wheelchair mobility, Community based programs

There is compelling evidence highlighting the increased risk of endocrine-metabolic disease (EMD) including cardiovascular disease, diabetes and osteoporosis among adults living with chronic (> 1 year post-injury) spinal cord injury (SCI).¹⁻³ Rehabilitation-based programs have been implemented with the intent to improve EMD risk-reducing modifiable behaviours over the long term, such as leisure-time physical activity (LTPA), mobility, or diet, but with limited success.⁴ Despite short-term success of inpatient

rehabilitation programs, participation in LTPA and mobility training has proven difficult once adults with SCI are reintegrated into the community. For instance, LTPA participation (defined as physical activities performed during exercise, recreation or any time, but not during occupation, housework, or transportation)⁵ among adults living with chronic SCI is extremely low, with approximately 50% of community-dwelling adults with SCI participating in 0 minutes of LTPA.^{6,7} Moreover, only 12% of a sample of adults with chronic SCI met the SCI-specific physical activity guidelines⁶ that recommend at least two, 20 minute bouts of aerobic activity per week and two strength training activities per week, both of which should be performed at a moderate to vigorous intensity.⁸ Recent studies have

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shown adherence to these guidelines to be feasible, but only with direct (and continual) support,⁹ and with limited improvements in EMD risk outcomes.¹⁰ To facilitate LTPA participation, adults with SCI require the ability to navigate within their physical environment (e.g., overcoming curbs, climbing ramps) with their wheelchair or other gait aid. From a clinical perspective, learning and using just one additional wheelchair skill can have a profound impact. For example, learning to safely perform a transient tip (i.e., popping the casters a few centimeters off the ground) is required to climb a curb, which may ease one's navigation and mobility in the community and enable LTPA participation.¹¹ Although existing wheelchair mobility programs effectively improve wheelchair skills, less than 50% of new wheelchair users receive any formal training during rehabilitation.¹² These low rates of wheelchair training are alarming because ~70% of individuals with SCI require a wheelchair for mobility.¹³ However, given the competing priorities during SCI rehabilitation (bowel and bladder management, sexual function, acceptance of SCI), initial rehabilitation is likely not the best time for training beyond 'beginner' wheelchair skills. Taken together, a clear need exists to find strategies and opportunities, beyond rehabilitation centres, to enhance community-based mobility and LTPA participation among members of the SCI population.

What evidence do we have on community-based rehabilitation programs?

Community-based programs may be an optimal mechanism to promote LTPA and improve mobility among adults with SCI. Community-based programs are defined as programs and/or services that are delivered on an ongoing basis within community settings (both within or outside of the home) and are not mandated and operated by an institutional facility (e.g., hospitals).¹⁴

Unfortunately, community-based mobility training for adults with SCI is not readily available across Canada and the majority of Canadian community-based LTPA programs are offered in metropolitan areas (e.g., VioMax in Montreal, Adaptavie in Quebec, Revved Up in Kingston, MacWheelers in Hamilton, SCI Fitness and Wellness Centre in Calgary, and PARC in Vancouver). To our knowledge, most established programs are provided in urban centres, with little reach to rural towns. Despite the presence of such community-based programs, it is difficult to understand their impact on LTPA participation and wheelchair mobility in adults with chronic SCI, as evaluations of ongoing community program delivery are relatively uncommon. Given the status of the field, we have outlined present

reflections (i.e., where we are now) and future directions (i.e., where we need to move towards to fill existing gaps) for both wheelchair mobility and LTPA programs.

Wheelchair mobility programs

An evidence-based wheelchair skills training program administered in the community has shown moderate success. Three community-based randomized controlled trials (RCTs; samples inclusive of chronic SCI) reported that completion of 3 to 5 hours of a standardized manual Wheelchair Skills Program facilitated by a clinician led to an 18% to 25% improvement in wheelchair skills capacity, compared to a 5% to 9% improvement in a control group who received no training.^{15–17} Recently, wheelchair training programs have adopted theoretical approaches of behaviour change and have measured patient reported outcomes to capture meaningful change to help make the results link to community-related outcomes (e.g., satisfaction with participation in self-selected activities (Wheelchair Outcome Measure).¹⁸ For example, wheelchair use self-efficacy (i.e., one's belief in his or her ability to use a wheelchair) is equally as, if not more important than, wheelchair skills in predicting wheelchair mobility and participation in daily and social activities.¹⁹ Using self-efficacy theory as a guiding framework, Best et al.¹¹ developed and evaluated a 9-hour, peer-led wheelchair skills training program that considered wheelchair skills training and psychological factors impacting wheelchair use (e.g., managing emotions and social situations). In the RCT (n=19 of 28 acute and chronic SCI), participants in the intervention group improved their wheelchair use self-efficacy (24%), wheelchair skills capacity (18%), and performance (30%) and satisfaction with participation in meaningful activities (e.g., LTPA; 25%), compared to -4%, -4%, 3%, and 13% respective improvements in the control group.¹¹ Similar results were found in another RCT (n=15 of 116 acute and chronic SCI) evaluating the effect of 2.5 hours of community-based power wheelchair skills training.²⁰

Gap 1: Outcomes

As illustrated above, wheelchair skills training programs can effectively enhance wheelchair skills when administered in a community setting. However, the intent of such mobility training is to enable community mobility and allow individuals with chronic SCI to increase their participation in meaningful daily (e.g., moving within and outside of their home) and social (e.g., accessing vocation or education training or participating in leisure/recreation activities) activities. To date, these

RCTs have focused on mobility and functional outcomes and satisfaction with participation. Additional studies are needed to assess the impact of mobility programs on participation in meaningful daily and social activities and quality of life.

Gap 2: Long-term impacts

Despite promising findings of the impact of mobility training programs, no wheelchair mobility study to date has evaluated the long-term effects of training on community mobility or participation. It is impossible to know how individuals continue to use their wheelchairs after training, if the studies do not examine key participation outcomes over the long-term.

Gap 3: Community-based

Current mobility skills training programs do not align with our definition of community-based programs, as most of the research funded-programs are initiated in tertiary rehabilitation centres and are neither established nor sustained in the community. Due to programs being predominantly offered in institutional settings, there are very limited opportunities for mobility training in rural areas. It is critical to develop community-university partnerships to identify how to implement and integrate such programs within community recreation programs and to involve other stakeholders to ensure sustainable access for individuals with chronic SCI in all geographic locations.²¹ Future studies may then evaluate sustainability, ecological validity, and impact on community-meaningful outcomes of these community-based mobility programs.

LTPA programs

LTPA promotion efforts have been delivered to adults with chronic SCI using two broad, yet important, methods for fostering behaviour change - LTPA messages and intensive programs. In a recent scoping review examining the quality of Canadian physical activity resources intended for adults with a physical disability, 89 information resources were identified.²² The majority (88%) of these resources were created by non-government organizations. According to the Journal of the American Medical Association quality benchmarks of information on the internet (i.e., details of authorship, attribution, disclosure, and date),²³ the overall quality of resources was generally poor. For example, only 32% of resources were tailored for a specific disability, while no resource provided suggestions for optimal timing to begin LTPA programs post-injury.²² This review highlighted the concerning state of LTPA, sport, and active living resources available online for people with disabilities. Therefore, it is

crucial that newly created informational resources are developed with high quality information to help promote community-based LTPA participation among adults with chronic SCI.

There is growing evidence that community-based LTPA programs for adults with chronic SCI are effective. For instance, two telephone-delivered programs,^{24, 25} along with a 10-week group-based LTPA program,²⁶ and a 4-week home-based strength-training program showed moderate to large effects on LTPA behaviour.²⁷ From a service delivery standpoint, Get in Motion, an evidence and theory-based physical activity counselling service for adults with physical disabilities, demonstrated success in assisting clients to maintain intentions and increase physical activity behaviour.^{24, 28} SCI Action Canada (www.sciactioncanada.ca), a community-university partnership aimed to promote and translate knowledge of physical activity among adults with SCI, has demonstrated that its' initiatives have successfully reached many adults with chronic SCI, but the longevity of these initiatives remains to be examined.²⁹

Gap 1: Long-term impacts

Evidence from RCTs provides early indications that community-based LTPA programs are a viable option to promote LTPA uptake among adults with chronic SCI, although long-term adherence remains a question in the absence of longitudinal evaluations. A more concerted effort among researchers and community partners is needed to understand the impacts of these programs over the long-term.

Gap 2: Researcher-Stakeholder Partnerships

Despite the success of the aforementioned LTPA programs, with the exception of Get in Motion, they remain researcher-initiated initiatives and they do not capture our definition of community-based programs. Unfortunately, true community-based programs (e.g., VioMax, Adaptavie, Revved Up and MacWheelers, SCI Fitness and Wellness Centre, and PARC) are rarely evaluated in a research context. Moreover, these programs are established in urban centres, thus may not reach or address the needs of individuals with SCI living in rural areas. This lack of evaluation makes it relatively difficult to discern how existing programs are currently impacting the lives of adults with SCI. Researchers and administrators from community-based programs need to work as a team in garnering a better understanding of the 'active ingredients' that have been integrated within these programs. In collaboration, researchers and stakeholders in urban and rural communities could maximize scientific and experiential

knowledge to co-develop ideal evaluation methods that would ensure program evaluations are both scientifically sound and practically relevant. Therefore, programs developers should consider community-based participatory research approaches to co-create programs and evaluation tools alongside users and administrators.³⁰

Gap 3: The use of theories

Given the lack of evaluation of community-based programs, it remains unknown whether these programs are grounded in behaviour change theory and which (if any) determinants of behaviour change are integrated within these programs. In contrast, research-initiated programs such as Get in Motion²⁴ and Active Homes²⁷ have utilized the strengths of relevant theories to guide the development and evaluation of these programs. There remains a need to continue to bridge this theoretical gap within existing community-based programs to optimize service delivery models while fostering a set of complex psychosocial variables shown to influence habitual LTPA participation (e.g., autonomy, motivation, self-efficacy).

Gap 4: Method of delivery

The best method to deliver community-based LTPA among adults with SCI is largely unknown. Although tele-health (e.g., telephone-based modality used in Get in Motion;²⁴), group-based,²⁶ structured face-to-face,⁹ and peer-delivered²⁷ programs have shown preliminary success, larger studies comparing modalities within the chronic SCI population would help identify how to best offer community-based LTPA programs in urban and rural areas for individuals with SCI. A recent meta-analysis showed that peer-led self-management programs grounded in theory had a small effect on increasing LTPA duration immediately post program.³¹ Large effects on adherence were also found, but only four studies provided follow-up measures for meta-analyses.³¹ Training peers to encourage LTPA may be an effective method for reaching various clinical and non-clinical populations.

Community-based participatory research initiatives, as previously mentioned,³⁰ may also help to identify which modality or combination of modalities may be best suited for adults with chronic SCI (e.g., a tele-health, group, peer-led programs), and provide further knowledge on other potential modalities not discussed in this paper (e.g., sport participation, high intensity interval training). Overall, our current knowledge of the best method to promote LTPA participation among adults with chronic SCI remains limited.

Limitations

The existing literature and community-based programs discussed in this review predominantly reflect those known by the authors, thus have inherent bias. However, the authors are part of large interdisciplinary research teams across the country who have been conducting mobility and LTPA research in SCI populations for more than 15 years. As such, they are familiar with existing literature and community programming. The opinions presented in this review reflect only those of the authors and do not present potential contrasting perspectives. However, the point of this review is to provide our current reflections of existing programs and recommendations to address some of the research gaps. The programs identified in this review are a representative sample from across the country, and are useful to identify some of the major research gaps. A resource identifying LTPA programs and their quality has been previously published.²³ Finally, the programs discussed in this review are delivered in urban centres and may not reflect the needs of individuals with SCI in rural towns. Future research to address the identified gaps should seek collaborations with stakeholders in rural areas.

Conclusion

Community-based programs promoting LTPA do exist and the available research shows their promise. There is evidence supporting wheelchair mobility training in the community, however, community-based wheelchair mobility programs have not yet been sustained. Despite the growing research of community-based programs aiming to promote LTPA and mobility among adults with SCI, many gaps remain. Additional partnerships, community engagement practices, service program funding and health policy changes are needed to address the highlighted gaps to optimize community-based programs, reduce EMD risk and enhance the lives of adults with SCI. Initiatives such as the Canadian Disability Participation Project (www.cdpp.ca) represent one approach to optimizing access to community-based programs for Canadians with physical disabilities, including SCI.

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