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Co-creating, implementing, and evaluating a community-based peer-run physical activity program to enhance sport and exercise participation for adults with moderate to severe traumatic brain injury

Project Summary

Traumatic brain injury (TBI) is a leading cause of disability and moderate to severe (m-s) TBI frequently results in long-term physical, cognitive, and psychosocial impairments – a major social problem that leads to significant reductions in employment, interpersonal relationships, and leisure activities. Exercise and sport participation are proposed for the management of TBI-related impairments and positively influence community participation, mood, and quality of life. However, adults with m-s TBI face many barriers to physical activity (PA) after injury. Therefore, PA-based programs need to be specifically tailored. The purpose of this participatory action research (PAR) was to co-create, implement, and evaluate a community-based peer-led PA program that supports exercise and sport participation for adults with m-s TBI.

A qualitative exploration of a promising community-based peer-assisted program established in Montreal between the YMCAs of Quebec and the Quebec TBI Association identified themes about the collective experiences of program participants, mentors, and employees. Results subsequently informed program components across a PAR partnership established to co-create a revised version of the program for a larger group of users and explore the perceived experiences involved. We identified considerations for supporting optimal PA participation after m-s TBI through the development of the formal *TBI-Health* program. Findings can help inform strategies to continue supporting sport and exercise participation community-dwelling adults with m-s TBI.

Research Methods

The co-creation was guided by a community-based PAR design and interpretive case study methods helped develop the program and provide an in-depth exploration of the participants' experiences. First, a subgroup of program mentors (n=4) was actively engaged in knowledge generation and transfer through nine monthly participatory workgroups focused on tailoring the program as it was being delivered. Second, a purposeful sample of 15 adults with moderate to severe TBI (participants n=11; mentors n=4) were involved with six audio-recorded 60–90-minute semi-structured focus groups after each phase of the nine-month program to further modify delivery and identify the

perceived experiences involved. Third, the principal investigator included observations and field notes during 72/80 program sessions (over 108 hours) to gain entry to participants' everyday program experiences. Integrated knowledge transfer from the workgroups, focus groups, and field notes enabled the parallel development and delivery of the formal *TBI-Health* program. Reflexive thematic analyses of the focus groups identified themes about the participants' transformative experiences.

Research Results

Three higher-order themes were generated from inter-analyses across program phases, representing 10 lower-order themes developed from intra-analyses within each program phase.

Program Participation – “it’s motivating to see people like us with traumatic brain injuries who are empowered to do more.” The *Program Participation* theme identified barriers, facilitators, sources of motivation, and suggested modifications related to optimizing program success and PA participation. *Program Barriers* included the internal and external factors that negatively affect program accessibility, experiences, and participation. *Program Facilitators* revealed the external factors (e.g., structure and technology aids) that positively affect program participation and experiences. *Program Motivation* involved the incentives for participating in the program ranging from biopsychosocial outcomes to increased interest in PA and pushing limits through a sport challenge. *Program Modifications* discussed suggestions about adapting program structure, clearly defining phases, and maintaining program length.

Biopsychosocial Changes – “When I walk, I have more confidence in myself because I am more stable. I lose my balance less.” The *Biopsychosocial Changes* theme reflected perceived changes, by self and others, related to the physical, cognitive, psychological, and social outcomes that resulted from the 9-month program. *Physical Outcomes* identified improved physical strength, endurance, balance, mobility, and management of TBI impairments, whereas *Cognitive Outcomes* included perceived improvements with concentration and memory that began in the second phase of the program. *Psychological Outcomes* involved perceptions about positive feelings of confidence, joy, pride, privilege, value, and empowerment related to accomplishing a community sport challenge. *Social Outcomes* discussed developing social skills, increased confidence, and the positive, inclusive, and supportive social experiences with people in the YMCA and the outdoor community sport challenge.

PA Autonomy – “I realized that I have more autonomy in my training, I know more where I am going. So, I can do my things and I can adapt them.” The *PA Autonomy* theme highlighted development in knowledge, abilities, and sex- and gender-related beliefs about exercise and sport participation within and outside the gym. *PA Capability* included abilities as a gym-goer and PA knowledge that developed from self-discipline, freedom, and confidence as an exerciser to appreciation for outdoor PA and wanting to create a sports team. *Sex and Gender* included preconceived sex- and gender-related beliefs about PA preferences and intensity that transitioned to challenging their own and others' beliefs through a newfound appreciation for different PA modalities.

Study results may be delimited by the adults with m-s TBI involved with the *TBI-Health initiative* and the YMCA fitness centre where the program was run. Ongoing methods were upheld for study rigour and the transferability of the findings such as 1) prolonged engagement and persistent observation in the field; 2) peer-debriefing and reflexivity throughout data collection and analysis; as well as 3) data and analyst triangulation.

Policy and Program Implications

Research findings about co-creating and participating in the *TBI-Health* program addressed three broad goals of the Canadian Sport Policy. 1) *Introduction to Sport*: program participants learned about and created a program manual that focuses on the fundamental skills, knowledge and attitudes required to exercise safely, independently, and for a sport challenge. 2) *Recreational Sport*: program participants were involved with and created a program about the associated health and social benefits of community-based exercise and sport for adults with m-s TBI. 3) *Sport for Development*: program participants had the opportunity to use their exercise and sport participation as a tool for their social and economic development through volunteerism, advocacy, and leadership. Across our PAR methods, we increased the number and diversity of Canadians who participate in sport by involving community members in the development of a program that introduces basic skills and peer leadership, while engaging, and financially supporting participants with these meaningful activities. This research supports the development of athletes who live with a disability by providing them with an opportunity to participate in community-based exercise and sport for fun, health, and social interaction.

Next Steps

Due to COVID-19, the YMCA facility where the program was run closed, so the anticipated feasibility study and evaluation of the program in 2020 was not possible. We therefore ran a qualitative needs analysis with past program participants to determine pandemic's impact and how their PA could be supported. Surprisingly, preliminary results suggest that participants transferred PA knowledge from the program to the COVID-19 context. A pressing need was also established for an adapted outdoor version of the program based on positive findings related to the outdoor running/walking groups to prepare for the community sport challenge. Future results about the feasibility and acceptability of an adapted version of the program are forthcoming.

Knowledge Translation

Completed Strategies:

- YMCAs of Quebec community sport challenge (2017):
https://www.youtube.com/watch?v=64ZbPv_VGsl
- YMCAs of Quebec community sport challenge (2018):
https://www.youtube.com/watch?v=y1_LJDTaO2s
- SSHRC Storyteller competition entry (2019):
https://www.youtube.com/watch?v=xYa_JIEZaEk&t=9s
- SSHRC Storyteller competition winning presentation (2019):
<https://www.youtube.com/watch?v=yZaKdORBE8A&t=1s>

- YMCAs of Quebec promotional video for Quebec TBI Associations (2021):
<https://www.youtube.com/watch?v=KJFuhEtkYxs&t=5s>
- Infographic about *Community-Based Physical Activity Interventions after Moderate to Severe Traumatic Brain Injury* (2021).

Planned Strategies:

- Publication of *TBI-Health Program Manual and Implementation Model* (2022).
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