Physical activity and chronic disease prevention: Where is the research on people living with disabilities?

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■ Cite as: *CMAJ* 2022 March 7;194:E338-40. doi: 10.1503/cmaj.211699

More than 1 billion people, 15% of the world's population, live with some form of disability.[1] Disability is not merely the presence of a medical condition. Rather, disability occurs when impairments (physical, mental, sensory, intellectual) interact with personal and environmental barriers to impede a person's ability to fully participate in society.[1] For instance, a patient who has arthritis is not necessarily "disabled," but if they have impaired physical functioning, and architectural (e.g., stairs instead of elevators) or policy (e.g., mobility scooters banned from public transit) barriers restrict their ability to work or move freely in their community, this person would be considered disabled.[1]

People living with disabilities are at greater risk for developing chronic diseases than the general population.[1] For the general population, extensive high-quality evidence from population-level observational studies and randomized controlled trials (RCTs) has shown that physical activity is associated with lower risk of developing chronic diseases, including cardiovascular disease, type 2 diabetes and site-specific cancers.[2,3] This evidence has been put into practice around the world in the form of physical activity policies, programs and clinical practice guidelines. In contrast, virtually no research exists on the role of physical activity for preventing chronic diseases in people living with disabilities.[2–4]

In separate development processes for physical activity guidelines, scientists from the United States Department of Health and Human Services[3] and the World Health Organization (WHO)[5,6] reviewed research on 9 common disabling conditions: osteoarthritis, intellectual disabilities, multiple sclerosis, Parkinson disease, history of stroke, major clinical depression, attention-deficit/hyperactivity disorder, schizophrenia and spinal cord injury. Each organization found insufficient research to determine the relation between physical activity and the risk of developing chronic diseases for people with any of these conditions.[3,5,6] In our search of articles published from 1999 to 2019 in 5 high-impact medical journals (*The BMJ, The Lancet, JAMA, JAMA Internal Medicine and The New England Journal of Medicine*), using search terms for 55 conditions (e.g., chronic pain, autism spectrum disorder, epilepsy) and impairments (e.g., hearing, visual, intellectual) that could lead to disability, just 0.3% of nearly 27 000 articles addressed chronic disease prevention, health promotion or health factors in people with these conditions or impairments[4] and fewer than 0.001% addressed physical activity.

It is clear that insufficient research (population-level observational studies, RCTs) is evaluating physical activity for preventing chronic diseases in people living with disabilities. Without data, evidence-based physical activity policies, programs and guidelines cannot be developed to address health differences and disparities experienced by these vulnerable populations. What is the solution?

Coordinated efforts are needed to collect population-level data on physical activity and chronic disease among people living with disabilities. Currently, no existing international, population-level surveillance system monitors and assesses physical activity and chronic disease in people living with disabilities, unlike for the general population. In most national health surveillance systems, disability is either an exclusion criterion or is not measured.[4] This limitation can be overcome by

Key points

- For the general population, extensive high-quality research has established the link between physical activity and reduced risk for chronic diseases, and has been used to formulate physical activity policies, programs and clinical practice guidelines worldwide.
- Virtually no research has evaluated physical activity and chronic disease prevention among people living with disabilities, hindering development of best practices to address health differences and disparities in this vulnerable population.
- Research on physical activity and chronic disease prevention in people living with disabilities can be advanced by engaging coordinated international efforts to collect and disaggregate population-level data from people with disabilities, ending exclusionary scientific practices and fostering scientific and clinical appreciation of differences and disparities.

implementing standardized, valid measures of disability (e.g., the WHO Disability Assessment Schedule, which measures disability as the impact of health conditions on functioning in 6 life domains) into ongoing population-level data collection systems[4] and disaggregating data on disability status. Resources must be devoted to purposely enrol people living with disabilities into these systems to ensure adequate statistical power for analyses. Population-level assessment of the physical activity of people living with disabilities requires greater attention and effort. Scientists must develop better measures of physical activity that are valid and reliable for people with different impairment types.[4]

Moreover, scientific practices that exclude people living with disabilities from participating in research on physical activity and chronic-disease outcomes must stop. For instance, impairments in walking, mental health and communication were exclusion criteria in landmark clinical trials evaluating the efficacy of physical activity to reduce risk factors for type 2 diabetes and cardiovascular disease,[7,8] trials that informed recommendations on physical activity to prevent and treat type 2 diabetes. Exclusion of people living with disabilities in such studies violates the fundamental principle of justice in research ethics[9] that no segment of the population should be denied the benefits of research, and is a human rights issue. The United Nations' *Convention on the Rights of Persons with Disabilities* legally obligates countries to collect data to formulate policies that ensure the rights of people living with disabilities, such as the rights to enjoy the highest attainable standard of health and to participate on an equal basis with others in physical activities.[10]

Scientific gatekeepers (e.g., funding agencies, journal editors, ethics boards) should implement policies to uphold these rights, such as mandating representative numbers of people living with disabilities in study samples, measures of disability and disaggregation of disability data, research methods that incorporate accessible research design[11] (e.g., providing study consent forms and surveys in Braille, sign language and plain language; fitness testing using adaptive exercise equipment) and meaningful engagement of people living with disabilities throughout the research process.[4] These actions will stretch limited resources. However, resource limitations cannot justify continued ethical and human rights violations in science.

Scientists and clinicians should also be educated regarding the differences and disparities between people with and without disabilities. The WHO recently formulated physical activity guidelines for people living with disabilities based almost entirely on evidence from people without disabilities.[6] Yet, accumulating research shows people with certain physical impairments (especially neurologic and limb) have attenuated cardiometabolic responses to physical activity and, thus, may not derive the same health benefits from a particular dose of physical activity as people without impairments.[12] Therefore, we cannot assume that physical activity recommendations for reducing risk of chronic disease in the general population are applicable to people living with disabilities.[12] Population-level observational studies and RCTs involving people living with disabilities are needed to formulate evidence-based recommendations regarding the amount of physical activity required to reduce chronic disease risk in this population.

Furthermore, people living with disabilities face greater barriers to meeting physical activity recommendations and participating in physical activity programs than the general population.[4] Health systems and behavioural research are needed to inform policies and interventions, and to educate health care providers on how to improve physical activity and prevent chronic diseases in people living with disabilities. Of note, physicians typically receive very little training in disability assessment or management, partly because of a lack of research evidence.

People living with disabilities urgently need advances in health science and practice. Addressing the lack of research on physical activity and chronic disease prevention in people living with disabilities has profound implications for developing evidence-informed best practices in health service delivery, decreasing health care costs and enhancing the well-being of more than 1 billion adults and children worldwide.

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Competing interests: Kathleen Martin Ginis currently holds funding for research on physical activity and disability from the Canadian Institutes of Health Research, the Social Sciences and Humanities Research Council, the Canadian Tire Jumpstart Foundation and Praxis Spinal Cord Institute. No other competing interests were declared.

This article has been peer reviewed.

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Contributors: All of the authors contributed to the conception and design of the work. Ritu Sharma conducted the literature search, and Kathleen Martin Ginis and Ritu Sharma analyzed the data. Kathleen Martin Ginis drafted the manuscript, and Ritu Sharma and Sarah Brears revised it critically for important intellectual content. All of the authors gave final approval of the version to be published and agreed to be accountable for all aspects of the work.

Funding: Kathleen Martin Ginis is supported through the Reichwald Family UBC Southern Medical Program Chair in Preventive Medicine.

Acknowledgement: The authors thank Adrienne Sinden for support with data analysis and manuscript preparation.

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