



TEMERTY FACULTY OF MEDICINE UNIVERSITY OF TORONTO Rehabilitation Science Research Network for COVID

ABSTRACT BOOKLET

Posters presented at the 2024 International Forum on COVID Rehabilitation Research

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Experiences living with Long COVID among racialized communities in Canada

View poster.

Akbar, N.*, Phadke, S., Mehelay, S., Godinho, A., Fakolade, A., Finlayson, M., Phan, R., Lall, R., & Tough, K. (2024, April 19). Experiences living with Long COVID among racialized communities in Canada [Poster Abstract]. 2024 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada.

Objective: To describe the symptoms, functional experiences, and barriers to accessing rehabilitation among those living with Long COVID, with a particular focus on racialized communities.

Methods: This study used an embedded mixed-methods design. Qualitative interviews were conducted concurrently to quantitative measures. Participants were recruited from across Canada, however most were recruited locally from Toronto.

Results: Data were collected from 49 participants (82% women), 59% of which came from racialized communities (20% South Asian, 16% Black and 22% other race including Indigenous, Latin American, etc.). The mean duration of Long COVID symptoms was 17 months. Large variability in symptom experience was reported, however, the most common were fatigue, brain fog and shortness of breath. Moderate or severe functional limitations were reported by 29% of participants, with 27% not being able to return to full-time work. The strongest themes that emerged from the qualitative data were dismissal by healthcare providers, lack of standardized diagnosis/ assessment process and/or any follow-up rehabilitation leading to the need for self-advocacy and the self-discovery of management strategies. Barriers to treatment and rehabilitation included cost and lack of culturally appropriate care.

Conclusions: Racialized people living with Long COVID need more support by healthcare practitioners. There is also a need for more standardized assessment, education of providers, and greater access to clinics and/or support programs that are culturally sensitive.



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Experiences of Accessing Rehabilitation by People Living with Long COVID

View poster.

Hung, P., Brehon, K., Miciak, M., Brown, D. A., Bostick, G., Brown, C., Churchill, K., Hall, M., Hoddinott, L., Hudon, A., Hunter, S., Perreault, K., Wieler, M., Skolnik, K., Lam, G. Y., Weatherald, J., Gross, D. P.* (2024, April 19). Experiences of Accessing Rehabilitation by People Living with Long COVID [Poster Abstract]. 2024 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada.

Background/Objective: This qualitative study aims to understand the need for, access to, and quality of rehabilitation services for people living with Long COVID. Little is known about the experiences of people living with Long COVID accessing rehabilitation services. Therefore, we explored health concerns leading people living with Long COVID to seek help to address functional concerns and their experiences with accessing and participating in rehabilitation.

Method: Interpretive description guided exploration of participants' experiences with Long COVID rehabilitation in Alberta, Canada. Semistructured interviews were completed with 56 participants recruited from: three publicly funded Long COVID clinics, a specialized private physiotherapy clinic, a telephone-based rehabilitation advice line, and a Workers' Compensation Board-funded Long COVID rehabilitation program. Recruitment through mass media coverage allowed us to include people who did not access rehabilitation services. Data analysis was informed by Braun and Clarke's reflexive thematic analysis.

Results: Four themes were identified: (1) the burden of searching for guidance to address challenges with functioning and disability; (2) supportive relationships promote engagement in rehabilitation; (3) conditions for participation in safe rehabilitation; and (4) looking forward – provision of appropriate interventions at the right time.

Conclusions: Our findings highlight the experiences of accessing rehabilitation services for people living with Long COVID. Our findings suggest that Long COVID rehabilitation approaches should be accessible, multi-disciplinary, flexible, and person-centred.



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Exploring Person- and Family-Centered Stroke Care amid the COVID-19 Pandemic

View poster.

Premnazeer, M.*, Gill, M., Kokorelias, K., Scali, O., Sessford, J., Munce, S., Bayley, M., Cameron, J. I. (2024, April 19). Exploring Person- and Family-Centered Stroke Care amid the COVID-19 Pandemic [Poster Abstract]. 2024 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada.

Background: Worldwide, COVID-19 is known to cause a 7.6-fold increased risk of having a stroke. As a result, people with stroke (PWS) also commonly have COVID-19. This further complicates both recovery and caregiving for PWS. Despite this, healthcare models emphasize patient-centered care. Person- and family-centered care (PFCC) is a model of health service delivery that aims to meet the needs of PWS and their caregiver. To date, there are no models of PFCC across the care continuum for the stroke population and no models have considered the needs of PWS who have had COVID-19.

Objectives: To understand the perspectives and preferences of PWS and caregivers for PFCC across the care continuum within the context of COVID-19.

Methods: Qualitative descriptive methods will be used to elicit the perspectives and preferences of PWS and caregivers for PFCC across the care continuum. The participants will be: caregivers (n=20); PWS (n=20). Equal numbers of PWS who have had COVID-19 and those who have not will be recruited. In-depth interviews will explore context- and COVID-specific considerations of PWS and caregivers for PFCC. Data will be analyzed using reflexive thematic and framework analysis.

Results: The findings will aid in our understanding of PWS and caregivers' perspectives for PFCC across the care continuum. It will address the needs of caregivers who are providing care in the context of COVID-19.

Conclusions: This novel research will contribute to the development of models of PFCC to support recovery and caregiving across the care continuum in the context of a pandemic.



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Family Centered Care in Spinal Cord Injury during COVID-19 Pandemic

View poster.

Scali, O.*, Craven, C., Munce, S., Sessford, J., Premnazeer, M., Gill, M., Cameron, J. I. (2024, April 19). Family Centered Care in Spinal Cord Injury during COVID-19 Pandemic [Poster Abstract]. 2024 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada.

Background & Objective: Family caregivers play a critical role in the wellbeing of individuals with spinal cord injury and disease (SCI/D). Due to limited preparation, caregivers can experience stress, and anxiety, negatively impacting the experiences of individuals with SCI/D. These challenges can be amplified with COVID-19, increasing caregiving stressors, and reducing Quality of Life for both groups. Models of person and family centered care (FCC) are proposed to meet the needs of individuals with SCI/D and caregivers. The aim of this study was to obtain the perspectives of caregivers and individuals with SCI/D related to FCC within the context of COVID-19.

Methods: This study used a qualitative descriptive design. Purposive sampling was used to recruit family caregivers and individuals with SCI with and without COVID-19. Semi-structured interviews were conducted via Microsoft Teams. Interviews examined family caregivers and individuals with SCI/D perceptions of FCC across the care continuum. Data were analyzed using reflective thematic analysis.

Results: Currently 8 people with SCI and 5 family caregivers have been interviewed, with 8 participants (4 people with SCI and 4 caregivers) having had COVID-19. Interviews took an average of 69.4 minutes (SD of 16.94). We identified 4 themes; changes in technology, changes in access to health care, perception of COVID-19 risk; and impacts on social life in the context of COVID-19.

Conclusions: Study findings highlight the needs of people with SCI/D and family caregivers and their perceptions of accessibility, risk, and social engagement in the context of COVID-19. Through obtaining their perspectives of FCC in the context of COVID-19 researchers can work towards creating models of FCC to support their needs.



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Long COVID and Rehabilitation: Experiences of Physical Therapists in Canada

View poster.

Kim, C.*, Lin, C.*, Wong, M.*, Al Hamour Al Jarad, S., Gao, A., Kaufman, N., McDuff, K., Brown, D. A., Cobbing, S., Minor, A., Chan Carusone, S., O'Brien, K. K. (2024, April 19). Long COVID and Rehabilitation: Experiences of Physical Therapists in Canada [Poster Abstract]. 2024 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada.

Objective: To explore experiences of physical therapists (PTs) working with adults living with Long COVID in Canada.

Methods: Cross-sectional descriptive qualitative study involving online semistructured interviews and a demographic questionnaire. We recruited PTs in Canada who self-identified as having clinically treated ≥1 adult(s) living with Long COVID in the past year. Using an interview guide, we inquired about their knowledge, perspectives on roles, clinical practices, and recommendations for Long COVID rehabilitation. Interviews were audio-recorded, transcribed verbatim, and analyzed using a group-based thematic approach.

Results: Thirteen PTs from five provinces participated; most were women (n=8;62%) and practiced in urban settings (n=11;85%). Participants reported variable knowledge of existing guidelines and experiences, having treated 1-25 (n=5;38%), 26-100 (n=4;31%), or >100 patients (n=4;31%) with Long COVID. Participants characterized their clinical experiences as a dynamic process involving: 1) a disruption to the profession (encountering a new population and pivoting to new models of care delivery), followed by 2) a cycle of learning curves and evolving PTs' roles (navigating uncertainty, keeping up with rapidly-emerging evidence, trial-and-error, adapting mindset and rehabilitative approaches, and growing prominence of certain roles). Participants recommended the need for education and training, active openminded listening, interdisciplinary care models, and system-level improvements to increase access to care.

Conclusions: PTs' experiences involved a disruption to the profession followed by a dynamic process of learning curves and evolving roles in Long COVID rehabilitation. Not all participants demonstrated an in-depth understanding of existing guidelines. Results may help inform future Long COVID rehabilitation research and physical therapy education.



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Mental Health of Caregivers to Adults with COVID-19: A Scoping Review

View poster.

Sessford, J.*, Dodwell, A., Elms, K., Gill, M., Premnazeer, M., Scali, O., & Cameron, J. I. (2024, April 19). Mental Health of Caregivers to Adults with COVID-19: A Scoping Review [Poster Abstract]. 2024 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada.

Background and objective(s): Family caregivers (FCGs) to people with COVID-19 can experience mental health strain. This scoping review was conducted to synthesize identified risks and protective factors for mental health of FCGs to adults with COVID-19.

Methods: The review spanned from pandemic onset through January 28, 2023, across Medline, CINAHL, and PsycInfo following the Joanna Briggs Institute methodology. Original quantitative, qualitative, or mixedmethod studies reporting on mental health of FCGs to adults with COVID-19 published in English were included.

Results: Of 2509 identified articles, 15 met inclusion criteria (10 quantitative, four qualitative, and one mixed methods). Most (80%) studies were conducted in Iran. Quantitative studies identified risk factors for poor mental health including demographic variables (e.g., being female, younger, married, employed, over the age of 40 years, having high income), increased caregiving burden, longer durations of COVID-19 infection, and care recipient health complications. Protective factors included accessing support services, coping strategies (e.g., exercise, social support), professional help, and online interventions. Qualitative inductive content analysis yielded two categories: factors associated with (1) negative mental health outcomes (fear of COVID-19, limited support, financial burden, family challenges, nature of COVID-19, inexperience, isolation, unpleasant experiences) and (2) positive mental health outcomes (self-reinforcement, coping strategies, spirituality, social support, access to support services).

Conclusions: Quantitative and qualitative research identified common mental health risk factors (e.g. nature/duration of COVID-19 infection) and protective factors (e.g., online interventions) for FCGs to adults with COVID-19. These factors may inform development of supports and services for FCGs to people with COVID-19.



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Participant Satisfaction with a Virtual Rehabilitation Program in Long COVID

View poster.

Agarwal, K.*, Beauchamp, M., Bourbeau, J., Ross, B., Benedetti, A., Rizk, A., Barreto, L., Sedeno, M., Tansey, C. M., Cloutier, J., Lopez, J., Zucco, R., Janaudis-Ferreira, T. (2024, April 19). Participant Satisfaction with a Virtual Rehabilitation Program in Long COVID [Poster Abstract]. 2024 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada.

Background: Our team has completed a randomized controlled trial of virtual physical rehabilitation in long COVID. With the ongoing debate on the role of exercise for this condition, understanding participants' satisfaction and experience with the program is crucial.

Objective: To explore the satisfaction and experience of individuals living with long COVID with an 8-week virtual rehabilitation program consisting of exercise and education components.

Methods: Participants were randomly assigned to either an 8-week virtual rehabilitation program plus usual care (n=65) or to usual care alone (n=67). After the 8-week program, participants in the intervention group received a satisfaction survey with 15 questions about their satisfaction and experience with the program on a 5-point Likert scale along with an open comment section.

Results: Fifty-seven participants (70% female) completed the survey (response rate 88%). Most respondents (83%) would recommend the program. The majority of the respondents found the program easy to learn (91%), with just the right difficulty (77%), pleasant (80%), and relevant to their needs (82%). Positive comments emphasized lifechanging experiences such as "this program has changed my life". Eight individuals (14%) commented negatively on how the program affected their symptoms: "after most sessions I was unable to be productive later in the day". Four respondents (7%) found the program not suitable. There were suggestions for a longer program to allow for extended recovery periods and a multidisciplinary approach.

Conclusion: The vast majority of participants were highly satisfied with the program. Further adaptations are required for those experiencing post-session symptoms.



Scoping review of race/ethnicity in Long COVID rehabilitation trials

View poster.

Akbar, N., Phadke, S.*, Mehelay, S., Pullattayil, A. K., & Fakolade, A. (2024, April 19). Scoping review of race/ethnicity in Long COVID rehabilitation trials [Poster Abstract]. 2024 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada.

Background: Though there are a growing number of rehabilitation trials for Long COVID/ Post COVID-19 condition, it has yet to be determined the extent to which they may be applicable to racial and ethnic minority populations.

Objective: To determine the extent to which observational studies of Long COVID/ Post COVID-19 condition rehabilitation strategies consider race and/ or ethnicity in defining eligibility criteria, planning recruitment and retention strategies, designing intervention delivery and adherence promoting approaches, selecting outcome measures, and reporting results.

Methods: Scoping review done in accordance with the Joanna Briggs Institute scoping review methodology.

Results: Of the 4845 studies screened, 495 underwent full-text review, with 23 meeting eligibility criteria and undergoing data extraction. The most common reason for study exclusion (n=157) was due to no mention of race or ethnicity within the article. Of the 23 final studies included, eleven studies provided the racial and/or ethnic characteristics of the study sample, with the proportion of under-represented groups (non-Caucasian or non-White) ranging from 0 to 20%. Three studies described using targeted recruitment strategies to promote racial and/or ethnic diversity. Four articles described accounting for race and/or ethnicity during data analysis.

Conclusions: Greater racial and ethnic diversity is needed within rehabilitation trials for Long COVID as there is currently large underrepresentation of racial and/or ethnic minorities. Overall, more Long COVID rehabilitation studies need to incorporate racial and/or ethnic characteristics into their study design as it is not well understood whether existing rehabilitation strategies are effective within these minority communities.



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Virtual Rehabilitation in Long COVID: a Randomized Controlled Trial

View poster.

Janaudis-Ferreira, T.*, Beauchamp, M., Bourbeau, J., Ross, B., Benedetti, A., Rizk, A. K., Barreto, L., Sedeno, M., Tansey, C. M., Lopez, J., Zucco, R., Cloutier, J., & Agarwal, K. (2024, April 19). Virtual Rehabilitation in Long COVID: a Randomized Controlled Trial [Poster Abstract]. 2024 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada.

Objective: To investigate whether an 8-week virtual rehabilitation program improves functional mobility and symptoms compared to usual care in individuals with long COVID.

Methods: Subjects were randomly assigned to either i) tailored virtual rehabilitation plus usual care or ii) usual care. Primary outcome: the Activity Measure for Post-Acute Care (AM-PAC) mobility score. Secondary outcomes: the Transition Dyspnea Index (TDI), 1-minute sitto-stand test (1-MSTS), Timed Up & Go, Fatigue Visual Analog Scale, SF-12, EQ-5D-5L, Hospital Anxiety and Depression scale (HADS), DePaul Symptom Questionnaire and adverse events (AEs).

Results: 132 individuals (48 ± 11.8 years; 75% female) were enrolled. Compared with controls, scores on the TDI (1.5 ±3 (control) vs 2.7 ± 3.6 (intervention); P = .007), EQ-5D-5L Visual Analog Scale (MD 6.8 (95% CI = 0.3; 13.3)) and HADS-anxiety (MD -1.4 (95% CI = -2.5; -0.3)) improved in the intervention group. Per-protocol analysis comparing the control group (n = 67) to participants in the intervention group who were able to progress through the exercise program (n = 40; 61%)) showed improvements in AM-PAC mobility, TDI, 1-MSTS, SF-12 mental score, EQ-5D-5L VAS, Fatigue VAS, HADS-anxiety and depression scores, and the DePaul Questionnaire in favour of the intervention. Thirty-five participants reported 71 mild or moderate AEs and 2 serious AEs (unrelated to the intervention).

Conclusion: An 8-week virtual rehabilitation program improved dyspnea, quality of life and anxiety in individuals with long COVID. Among those who were able to advance the exercise program, improvements were also seen in mobility, fatigue, depression, and postexertional malaise.



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LONG COVID WEB

