The impact of COVID-19 related restrictions on social and daily activities of parents, people with disabilities and older adults: Protocol for a longitudinal, mixed-methods study.

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Abstract

Methods: and analysis: This project is a longitudinal concurrent mixed-methods study in British Columbia, Canada. Data collection occurred at four time points, between April 2020 and February 2021. The first three data collection time points occurred within phases 1-3 of the Province of British Columbia Restart Plan. The final data collection coincided with the initial distribution of the COVID-19 vaccines. At each time point, participants' socio-demographics, depressive and anxiety symptoms, resilience, boredom, social support, instrumental activities of daily living, and social-media and technology use were collected in an online survey. These data supplemented qualitative videoconference interviews exploring participants' COVID-19 related experiences. Participants were also asked to upload photos representing their experience during the restriction period, which facilitated discussion during the final interview.
We recruited five groups of participants: 1) families with children under the age of 18, 2) adults who have a spinal cord injury (SCI), 3) experienced a stroke or 4) other types of disabilities, and 5) older adults (>64 years) with no self-reported disability. The total sample size is 82. We are limited in the number of participants we could recruit from each group, which may make some sub-group analyses challenging.
Ethics and dissemination: Findings from our study will inform the development and recommendation of a new resource guide for the post-COVID period and for future public health emergencies.

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The impact of COVID-19 related restrictions on social and daily activities of parents, people with disabilities and older adults: Protocol for a longitudinal, mixed-methods study.

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Abstract

Background: The COVID-19 pandemic has led to wide-scale changes in societal organization. This has dramatically altered people's daily activities, especially among families with young children, those living with disabilities such as spinal cord injury (SCI), those who have experienced a stroke,

and older adults.

Objective: We aim to 1) investigate how COVID restrictions influence daily activities 2) track the psychosocial effects of these restrictions over time; and 3) identify strategies to mitigate the potential negative effects of these restrictions.

Methods: This was a longitudinal concurrent mixed-methods study in British Columbia, Canada. Data collection occurred at four time points, between April 2020 and February 2021. The first three data collection time points occurred within phases 1-3 of the Province of British Columbia Restart Plan. The final data collection coincided with the initial distribution of the COVID-19 vaccines. At each time point, participants' socio-demographics, depressive and anxiety symptoms, resilience, boredom, social support, instrumental activities of daily living, and social-media and technology use were collected in an online survey. These data supplemented qualitative videoconference interviews exploring participants' COVID-19 related experiences. Participants were also asked to upload photos representing their experience during the restriction period, which facilitated discussion during the final interview.

Five groups of participants were recruited: 1) families with children under the age of 18, 2) adults who have a spinal cord injury (SCI), 3) experienced a stroke or 4) other types of disabilities, and 5) older adults (>64 years) with no self-reported disability. The total sample size was 81. The number of participants we could recruit from each group was limited, which may impact the validity of some sub-group analyses.

Results: This study was approved by the University of British Columbia Behavioural Research Ethics Board (Approval #: H20-01109) on 2020-04-17. Eighty-one participants were enrolled in this study and data are being analyzed.

Conclusions: Findings from our study will inform the development and recommendation of a new resource guide for the post-COVID period and for future public health emergencies.

Keywords: *Longitudinal study; spinal cord injury; disability; adult; occupational disruption, stroke; older adults*

Introduction

The novel coronavirus 2019 (COVID-19) is the third zoonotic virus to infect humans in as many decades, and was first identified in Wuhan, China near the end of 2010 [1]. The origin of the virus, course of transmission and treatment of infection are still under investigation, but initial understandings of the epidemiology suggest a genome 75 to 80% identical to severe acute respiratory syndrome coronavirus [SARS-CoV] [1]. Once the severity of the virus was realized, the World Health Organization (WHO) characterized COVID-19 as a pandemic on March 11, 2020 [2] and

recommended the implementation of an evolving series of public health and social measures. These included “measures or actions by individuals, institutions, communities, local and national governments and international bodies to slow or stop the spread of COVID-19” [3]. At a community level these measures involve employees working from home where possible, distance learning, avoiding crowding, wearing a mask, closure of non-essential services, re-organization of health care services, and government directed calls to stay at home. For the purpose of this paper, the term restrictions will be used to refer to the abovementioned measures, including physical distancing and limited in-person interactions with others. The first COVID-19 case in Canada was reported on January 25, 2020 [4]. The initial response by the Canadian government included calls for social distancing, which was later clarified to mean keeping physical distance from others [4], although these terms continue to be used interchangeably in many contexts. As health is a provincial responsibility in Canada, the restrictions vary by province and are subject to change depending on the number of COVID-19 cases in the given location.

Concerns have been raised about the unintended negative consequences of the pandemic restrictions among a variety of groups including families with young children, those living with disabilities such as spinal cord injury (SCI) or stroke, and older adults. British Columbia’s Restart Plan [5] consists of four phases calling for varying restrictions primarily related to physical distancing (Table 1), resulting in decreased in-person interactions and disruption of social and daily activities. Easing of restrictions to allow transition between phases is dependent on new developing knowledge about COVID-19, tracking of confirmed and recovered cases,

Table 1. British Columbia’s Restart Plan for COVID-19 Restrictions

Phase start date	Restriction period / phase
March 2020	Phase 1 - Essential services re-open or remain open in compliance with provincial health orders - Declaration of public health emergency - Banned mass gatherings of > 50 people - Restricted visitation in health care facilities
May 18 2020	Phase 2 - Many businesses to re-open with extra precautions and physical distancing measures in place - Child care, hairdressers, gyms, salons and other services re-open - Medical services such as psychology, dentistry, massage, chiropractic, occupational and physical therapies resume
June 24 2020	Phase 3 - Faith-based organizations resume in person gathering up to 50 people - Designated visitors limited to one person for those living in long-term or assisted living care facilities - Limited hours of operation for restaurants, bars, cafes and breweries

	with distancing measures in place
Conditional	Phase 4 - Entering this phase is dependent on community immunity, wide vaccination and broad successful treatments - Once one of the three above factors is met, larger gatherings at concerts, conventions, tourism and events can resume

new outbreaks, and observing how other regions are responding to the pandemic [5]. The restrictions, in place to reduce transmission and ultimately stop the spread of the virus [3], have many unintended consequences such as financial strain along with psychosocial implications. In an attempt to mitigate the financial stressors that many people are experiencing, the BC Recovery Benefit was offered as "a one-time direct deposit payment for eligible families, single parents or individuals" [6]. The Canadian Emergency Response Benefit (CERB) was an additional income support measure that eligible Canadians could claim [7]. These programs offer support for lost income resulting from job loss and ongoing unemployment due to the COVID-19 pandemic, however do not address the psychosocial issues that arise with the loss of employment, changes in routine and overall disruption to social and daily activities which are vital determinants of health [8]. The loss in daily routine combined with physical distancing can lead to increased isolation and loneliness, ultimately reducing mental health and overall well-being [8]. It is important to consider how these psychosocial changes may occur for families with young children, those living with disabilities such as spinal cord injury (SCI), stroke, and older adults.

For parents with school-aged children, COVID-19 responses have led to school closures and home-based online learning which has resulted in an increased need for parental supervision [9]. This has placed additional stressors on parents, who may be dealing with employment changes (e.g., unemployment, reduced hours, working from home), financial pressures and also must respond to changing needs for their children's schooling and daycare needs. Further challenges may arise for single parent families, those who have restricted access to out-of-household familial supports, and those experiencing domestic violence [10]. Early COVID-19 studies indicated that negative mood increased for parents and children and "work disruptions" also increased [11]. These findings suggest that parents and their children are facing unique challenges during the COVID-19 pandemic which are impacting their mood, productivity and are likely contributing to declining mental for the family as a whole [11].

The risks associated with COVID-19 may be further exacerbated in vulnerable populations such as individuals with disabilities who may have compromised immune systems or face mobility challengs. According to the Canadian Survey on Disability, 81.3% of people with disabilities report

using an aid or assistive device such as a wheelchair, or hand and arm supports to facilitate movement [12]. Using mobilty aids or equipment presents additional risks specific to COVID-19, as some prevention strategies maybe more difficult for people with disabilities [3]. For instance, they may not be able to stay 1-2 meters away from others if they rely on a caregiver for personal care, or may not be able to don a mask independently [13].

Additionally, it is important to consider the concerns regarding the reduced well-being among older adults due to physical distancing and isolation resulting from these COVID-19 restrictions [14]. Due to the increased risk of infection and fatality among older adults (aged 65 plus), health officials advise this group “to stay home, and self-isolate.” [15] This has resulted in considerable changes in the daily and social activities for the eight million older Canadians. [5] Furthermore, there are already indications that the well-being of older adults has declined due to physical distancing and isolation resulted from COVID-19 restrictions [14,16].

At this time, there is limited understanding of how prolonged restrictions influence social and daily activities, as well as the health and well-being, particularly among families with children, people with disabilities, SCI or stroke and older adults. It is crucial to consider the unique challenges that COVID-19 restrictions create for those who may not have been considered when these policies were developed [2,5]. Having more inclusive guidance requires a deeper level of understanding of the lived experience of various populations during the shifting and wide-reaching pandemic restriction period. Therefore, the aims of this study are 1) to understand how COVID-19 restrictions change what people do and how they carry out their daily activities 2) to track the psychosocial effects of these restrictions over time; and 3) to identify strategies to mitigate the negative potential effects of these restrictions.

Methods

This study used a longitudinal concurrent mixed-methods design with four data collection time points. Qualitative description was used as the qualitative methodology for this study [17-19]. The Good Reporting of A Mixed-Methods Study [20] (GRAMMS) guideline has been followed for the study protocol and for reporting the results. Quantitative data was collected using an online survey with self-reported questionnaires participants completed seven days prior to each interview. Approval for the study was obtained from the University of British Columbia Behavioural Research Ethics Board (Approval #: H20-01109). This research was unfunded.

Eligibility Criteria

Community dwelling adults over the age of nineteen, living in BC, who self-identified as being comfortable writing and speaking in English were recruited. Participants were excluded if they

reported having moderate to severe cognitive impairment or aphasia.

A heterogeneous sample of 81 adult British Columbians were recruited. This included 1) parents with school aged children (*n = 10)*, 2) people with spinal cord injury (SCI) (*n = 22)*, 3) people who have experienced a stroke (*n = 26)*, 4) individuals with other disabilities (*n = 13)*, and 5) older adults without self-identified disabilities (*n = 10)*.

Recruitment and Consent

Participants were recruited using the following: 1) on-line postings at the International Collaboration on Repair Discovery and Reach BC websites; 2) people who have consented to being contacted again from previous studies; and 3) advertisements on the researchers' social media pages (e.g., Twitter, Facebook). Recruitment took place during the initial phase of restrictions in BC, from March 2020 until May 2020, and the number of participants was ultimately limited by funding. Those interested in participating contacted the research team by phone or email to learn more about the study and determine eligibility. Informed consent was obtained at each study time point.

Patient and Public Involvement

To date, patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research. However, this is a protocol paper and research is not complete. Patients or the public will likely still be included in the dissemination plans of our research as the potential toolkit to be developed from this research will involve input from participants.

Data Collection and Outcome Measures

Data Collection

We used Qualtrics XM (Qualtrics, Provo, United States) to obtain consent, collect demographic information, and administer patient-reported outcome measures (PROMS). PROMS allow us to collect quantitative data on subjective psychosocial constructs [21]. Participants were given the link to the Qualtrics survey and asked to complete the survey within 7 days, and an interview was then scheduled. We used semi-structured interviews via teleconference (Zoom Video Communications, San Jose, United States) to collect qualitative data on participants' experiences with COVID-19 restrictions. The survey was pilot tested with research team members and one participant with a stroke prior to being used with study participants. In order to increase accessibility to the survey, if the person was unable to complete the survey online, it was administered over the telephone.

Demographic Information. Prior to the first interview, we collected data on participants' age, city of residence, country of birth, sex, gender, first language, living situation, education level, income at baseline, employment status, chronic illnesses, and status regarding COVID-19 (asking if

they have tested positive or been exposed to someone who had tested positive).

The measures listed below were captured in the survey which was to be completed one week prior to the interview at each time point. The measures are described in detail in Table 2 which documents the construct(s) measured, number of items, number of sub scales, response range and anchor and scoring.

Table 2. Outcome measures used to collect data at each of the four time points.

Measure	Construct	# of items	# of sub scales	Response range and anchors	Scoring and score range
Connor-Davidson Resilience Scale 25 (CD-RISC-25)	Resilience	25	1	0 (not true at all) to 4 (True nearly all the time)	0 (minimum) to 100 (maximum)
Hospital Anxiety and Depression Scale (HADS)	Generalized anxiety and depression	14	2 - Anxiety - Depression	0 (none) to 4 (extreme)	0 (none/low) to 40 (extreme)
Keele Assessment of Participation (KAP)	Activity participation	11	1	1 (All the time) to 5 (none of the time)	Restricted (some, little, none) and not restricted (all, most)
Life Space Assessment (LSA)	Space mobility	9	1	Life-space level (1–5), the degree of independence (2=no assistance, 1.5=equipment only, 1=personal assistance), and the frequency of movement (1=less than once a week, 2=1–3 times each week, 3=4–6 times each week, and 4=daily)	0 (totally bed-bound) to 120 (moved out of town every day without assistance)
Multidimensional Scale of Perceived Social	Social support	12	3 -Family (4-28) -Friends (4-28)	1 (Very strongly disagree) to 7	12 to 84

Support (MSPSS)			-Significant other (4-28)	(Very strongly agree)	
Multidimensional State Boredom Scale (MSBS)	State boredom	29	5 - Targeting disengagement (10-70) - High arousal (5-35) - Inattention (4-28) - Low arousal (5-35) - Time perception (5-35)	1 (Strongly disagree) to 7 (Strongly agree)	29 to 203
Social Networking Usage Questionnaire	Social networking usage	19	1	1 (Never) to 5 (Always)	19 to 95
Technology Readiness Index 2.0 (TRI 2.0)	Individual's technology readiness	16	4 - Optimism (4-20) -Innovativeness (4-20) -Discomfort (4-20) -Insecurity (4-20)	1 (Strongly disagree) to 5 (Strongly agree)	16 to 80

Anxiety and Depression. The Hospital Anxiety and Depression Scale (HADS) [22] measures anxiety and depression. Evaluation of the HADS among primary care patients and the general public has demonstrated good concordance with clinical diagnoses of anxiety and depression, sensitivity to change and a mean Cronbach's alpha of .83 [23].

Resilience. The Connor-Davidson Resilience Scale 25 (CD-RISK-25) [24] is a self-administered scale that measures resilience and how well people can cope with and bounce back after stressful events and tragedies. The reported Cronbach's alpha for this measure is .93 [24] when used in a sample of adults from the general population.

Boredom. Boredom was assessed with the Multidimensional State Boredom Scale (MSBS) [25]. The Cronbach's alpha for the total measure was .96 [26] upon development of the questionnaire.

Social Support. The Multidimensional Scale of Perceived Social Support (MSPSS) [27] was used to assess perceived social support in three factor groups (Family, Friends or Significant Other).

The Cronbach's coefficient alpha for the total score of the MSPSS was .88 [27] in a sample including adolescents and adults.

Activity Participation. The Keele Assessment of Participation (KAP) [28] measures participation in activities such as work, education, socialization and activities of daily living. The Cronbach's coefficient alpha of this measure has been reported as .93 with a sample of adults aged 50 and older [28].

Space Mobility. The Life Space Assessment (LSA) is an assessment that reports on how frequently and far people have travelled out of the room in which they sleep during the previous four weeks. The LSA is moderately correlated with the Reintegration to Normal Living Index with Spearman's rho correlations ranging from 0.509 – 0.538. The nine day test-retest reliability has been reported to be .876 [29] (intraclass correlational coefficient) among people with SCI.

Social Networking. The Social Networking Usage Questionnaire measures social media usage (academic, entertainment, socialization) in online spaces. Questions regarding academic usage were removed from the questionnaire as these did not apply to our participants. A Cronbach's coefficient alpha of 0.83 has been reported with university students [30].

Technology Use. The Technology Readiness Index 2.0 [31] is used to assess participants' readiness to embrace new technologies. The Cronbach's coefficients for all the dimensions were higher than .60 [32] in a heterogenous sample of adults aged 18 and older.

Substance Use. The demographic questionnaire included five questions related to substance use. For example, "do you use tobacco products" and a clarification question asking, "are you using more or less than you did before COVID-19?" These questions were repeated for marijuana use, alcohol, other drugs and prescription drugs.

Semi-structured Interviews:

Following the completion of the surveys, participants took part in semi-structured interviews on the The University of British Columbia's (UBC) secure Zoom platform to maintain physical distance. Three interview guides were created (Appendix 1), one of which was for the first interview, a guide for interviews at T2 and T3, and a guide for the final interview at T4. Participants were asked about their experiences with daily activities, changes in activity, their feelings about these changes, and strategies they used to cope with the impact of COVID-19 restrictions. Each interview guide was tested in three pilot interviews prior to being used with participants. Each participant was assigned the same interviewer for each of their interviews to facilitate rapport and relevance of follow-up questions based on previous interviews. At the start of the first interview, the interviewer confirmed

any changes to the demographic information collected by the survey at each subsequent interview (e.g., living arrangements, employment status).

Participants were also invited to take pictures during the course of the study that represent their daily and social experiences during the period of COVID restrictions. The photos acted as a catalyst to enrich the sharing, as interviewers prompted participants to share the meaning behind the photos. Participants were invited to send photos to the research coordinator at each time point, which were then combined into a collage by the research team. The interviewer shared the collage with the participant in the final interview and asked participants to choose two-to-three photos from the collage and describe what the photo meant to them in the context of the COVID-19 restrictions.

The interviews were recorded on a password protected Zoom account as well as on a voice recorder as a back up, to ensure accuracy of the transcription, and were then transcribed verbatim. Participants were anonymized with a unique participant ID; the key matching ID with name and contact information is kept in a password-protected and encrypted excel file on a secure UBC server. When transcribing the interviews, the participant's ID was used to refer to them and other proper nouns were replaced with pseudonyms. Participants received a $30.00 honorarium after each interview.

Training

The data collection team consists of 8 interviewers and 17 transcribers. Interviewers were trained 3 times over the course of the project: twice before data collection, and once before the fourth and final interview. The latter session served as a refresher and provided training on new content added to the interview guide. Transcribers used transcription templates for all interviews and timestamped passages to be clarified or verified by the interviewer. Most of the transcription team were experienced and did not require additional training. Novice transcribers received a tutorial from a study team member.

Research Team Characteristics

The research team for this study is a large group of co-investigators who are professors, educators, researchers and other university employees. Interviewers and transcribers included volunteers who are university educated. Information on the positioning of the research team will be reported in further detail as relevant to each publication on study findings.

Data Analysis

Quantitative data analyses:

Before conducting the quantitative analyses, data will be imported from Qualtrics to the Statistical Package for the Social Sciences (SPSS). First univariate statistics will be used to count for

the number and percent of missing data in each measure. Then the patterns of missing values for each measure will be visualized. Missing value patterns will be evaluated carefully to determine missing data mechanism (i.e., completely at random, at random or not at random) [33]. In addition, to determine whether the observed missing value patterns are related to other variables in the study, for each measure that contains missing values, an indicator variable will be developed. The indicator variable will separate the participants who provided complete responses to that measure from the participants who did not complete that measure. Logistic Regression will be used to determine whether other variables in the study including demographic variables can statistically predict the indicator variable. If none of the variables in the logistic regression analyses predicts the indicator variable, it can be concluded that the missing pattern mechanism are completely at random (MCAP) or at random (MAR). If the missing values will be completely at random (MCAP) or at random (MAR), and the percentage of the missing values will be less than 30%, we will impute the missing values using multiple imputation technique. Multiple imputation will result in multiple sets of plausible values for each missing value. In these analyses, the multiple imputation will be used to compute five plausible values for each missing value. Then, the missing values will be replaced by the mean of the five plausible values. Multiple imputation analyses will be run for each measure that contains missing values in each group separately. After imputing the missing values, to test our hypotheses and research questions the following statistical analyses will be used. First, univariate analyses (e.g., mean, sum, standard deviation, variance, range and frequency) will describe the sample. In cross-sectional analyses, Multivariate Analysis of Variance (MANOVA) will be used to test whether there is a statistically significant difference between groups on the outcome variables. Correlational analyses including Pearson's correlation coefficient (R) will be used to test the strength of the associations between different variables. Regression analyses (e.g., linear regression and logistic regression) will be used to estimate the relationship between dependent variables and the outcome variables.

To analyze the longitudinal data, Hierarchical Linear Modeling (HLM) growth curve analysis will be used to investigate the changes in the participants over time [34]. HLM growth curve analysis has several benefits over repeated-measures analysis of variance. First HLM can be used when the interval between the timepoints is not equal and when data contains missing values. In addition, in contrast to the repeated-measures analysis of variance, HLM focuses on individual differences over time by considering each participant initial’s intercept and slope score while repeated-measures analysis of variance stresses on the group differences [35].

Qualitative data analyses:

Transcripts will be analyzed using content analysis to develop a qualitative description [18] of events and experiences of participants within and across the four timepoints. Analyses will be conducted separately for each of the participant groups (families, people with SCI, people with stroke, people with disabilities, older adults) and each time point; then combined if appropriate to examine trends over time or themes across groups. A sub-team of researchers will analyze each group. Because of the large research team, blend of novice and experienced researchers, and five participant groups, a consistent approach to coding will be facilitated by developing coding manuals with notations to explain coding decisions [37]. These coding guides remained flexible to the possibility of adding new codes and recoding previous interviews. For each coding team, two primary coders will read and reread transcripts and code the first two to three interviews and then compare codes and discuss any discrepancies with the coding team. This coding guide will then be applied to subsequent interviews and revised in consultation with the qualitative research team for each participant group. During initial coding the primary analysts assign tentative codes to each idea reflective in the text, recorded in a codebook. The code book and sample quotes supporting codes will be shared with senior researchers. After integrating the comments from the senior researchers, the coders will code the next three to four interviews separately and once again compare their codes to ensure consistency in applying the codebook, updating as needed to reflect new or revised codes. The codebook developed at T1 will be used to code T2 interviews, updated with new codes developed at T2, which will be applied and updated at T3, and then again at T4, that is, updating the codebooks as interviews are conducted throughout the longitudinal study. The coding procedure is applied to each participant group separately, requiring four iterations of five participant group codebooks. Then, codes will be organized into categories representing and interpreting the main topics shared by participants. The final qualitative description is expected to be presented a set of themes and their inter-relationships, supported by illustrative quotes from participants to explain their experiences of pandemic restrictions during the study period.

To integrate quantitative and qualitative data, there are three potential models of integration that may be used. Our primary approach will be to analyze both data sources separately. We will also explore the possibility of sequential analysis in which quantitative or qualitative analysis is used to inform a subsequent analysis using the alternative type of data [37] (e.g., we may identify different types of experiences based on the qualitative data and compare scores on quantitative measures among participants who have similar experiences (or vice versa)).

With regard to trustworthiness [38], an audit trail includes reflexive memos to document research discussions, possible biases, and analytical decisions (dependability, confirmability).

Comparing qualitative themes with numerical results from the PROMs will be used as a form of data triangulation and generate questions to consider in refining qualitative themes. Researcher triangulation occurs within each sub-team (in their analysis of a specific participant group) and in the larger team (all researchers involved across all participant groups). Where available, member checking will further enhance analytical rigor.

Results

This study was approved by the University of British Columbia Behavioural Research Ethics Board (Approval #: H20-01109) on 2020-04-17. Eighty-one participants were enrolled in this study and data are being analyzed.

Discussion

Interviewing and surveying a heterogenous sample of participants during the COVID-19 restrictions presents an opportunity for insight into perceived constraints, barriers and strategies to cope with this unusual period of restrictions. Therefore, our longitudinal investigation into changes in activity, participation and well-being informs recommendations for the post-COVID period and for future public health emergencies. We anticipate this study will provide information to practitioners working in public health with patient groups highlighted in this research by identifying gaps in services. Further, the findings are relevant across disciplines, as mental health is increasingly a priority for health, education and social service sectors, as well as Government portfolios. With a better understanding of the changes and self-management strategies, there is potential for development of a guide that will provide information, resources and strategies for managing periods of isolation. Future research in this area is needed to inform the development and evaluation of such a resource guide.

Our knowledge translation (KT) plan will target families with school-aged children, people with disabilities such as SCI, stroke, and those who are older adults. We will leverage existing communication tools, such as websites (e.g., health authorities in BC), presentations at provincial practice forums; and social media (e.g., Twitter). Building on existing partnerships with the Canadian Association of Occupational Therapists – British Columbia (CAOT-BC), and our research centres (e.g., GF Strong and ICORD), a summary will be prepared for their websites and electronic newsletters to assist us with the implementation of our findings.

Limitations

This study has two main limitations. First, this study relied on online or phone use for data collection, therefore all participants needed access to and familiarity with the required technology. Findings are therefore generalizable to others with similar characteristics and advantages. Second,

funding limitations restricted the number of participants we could recruit for each group, which may make some quantitative sub-group analysis challenging and limit our ability to achieve theoretical sufficiency with our qualitative analysis.

Acknowledgement

We would like to acknowledge the ongoing efforts of the entire research team, especially the extraordinary work of the volunteer- interviewer and transcription teams.

Conflicts of Interest

The authors declare no conflicts of interest.

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Appendix 1: Sample interview guide

Interview guide

Hello, my name is _____ and I would like to start the interview by thanking you for your participation. It is greatly appreciated. The purpose of this interview is to explore and gain a deeper understanding of your experiences and perceptions during the COVID-19 pandemic.

Throughout the interview, you will be asked about your personal experiences. The interview will take approximately 60 minutes. Per the Informed Consent you signed, I just want to remind you that your participation is voluntary. You can stop the interview at any time, if you no longer want to participate. You also do not need to answer any questions which make you feel uncomfortable. During the interview, my main job is to listen to you and your stories. I look forward to hearing about your experiences.

As indicated in the Informed Consent, this session will be video recorded and then transcribed. I will let you know when I will start recording. If your name happens to come up in the interview, it will be removed when the interview is transcribed and replaced with a pseudonym. Do you have any questions for me before we start? I am now going to start recording.

1. Tell me what you've learned over the past month during COVID.
2. What has your experience of COVID been like?

Prompt: Emotionally, physically (exercise), socially.
Prompt: Who, if anyone, do you discuss how you feel about COVID with?

3. What was a typical day like for you before the COVID quarantine?
   Prompt: What does a typical day look like for you now?
   Prompt: What is the most meaningful part of your day?
   Prompt: Which of these changes do you feel are positive?
   Prompt: Which of the changes do you feel are negative?
4. What are you doing more of?
5. What are you doing less of?
6. What activities are you doing to connect with others?
   Prompt: How would you describe your living situation?
7. What activities are you doing to contribute?
   Prompt: To your personal well-being, to society, to the world?
8. What type of restorative activities are you engaging in?
   Prompt: How do you feel when you are doing your daily activities?
9. How, if at all, has the meaning of the activities you do changes with the advent of COVID?
10. What are some of the biggest challenges you have encountered?
11. What are some of the strategies and supports you have used to overcome them?
12. Knowing the ways you've adjusted to the current situation, what would you recommend to others?
13. What ideas do you have about innovations that could facilitate that change?
    Prompt 1. How, if it all, has your use of social media changed during this time?
    Prompt 2: Describe your use of technology currently.
14. What are your future plans?
    Prompt: Today, this week, monthly, before next interview, for the year
15. You will have the option to participate in a "photovoice" part of this study where you take photos of your experiences during quarantine and share them during the next interview, or send them to us online. You will also have the option of giving the research team consent for these photos to be used beyond the interview in the report and in subsequent publications and presentations. Taking and sharing photos is entirely voluntary, and the photos will only be used as a part of this project. Photos will be stored on an encrypted server. Please let us know whether or not you wish to participate in the photovoice in the survey we send to you before our next interview and sign the Photo Release Form if you choose to send and share photos with the research team.

Subsequent interviews

Hi, again! I would like to start the interview by thanking you for your continuing participation. It is greatly appreciated.

Much like our last interview, you will be asked about your personal experiences. The interview will take approximately 60 minutes. Per the Informed Consent you signed, I just want to remind you that your participation is voluntary. You can stop the interview at any time, if you no longer want to participate. You also do not need to answer any questions which make you feel uncomfortable. During the interview, my main job is to listen to you and your stories. I look forward to hearing about how things have gone since we met!

As indicated in the Informed Consent, this session will be video recorded and then transcribed. I will let you know when I will start recording. If your name happens to come up in the interview, it will be removed when the interview is transcribed and replaced with a pseudonym. Do you have any questions for me before we start? I am now going to start recording.

1. Since the last time we talked how have things been going for you?
2. Have you experienced any changes of (e.g., living situation, health, etc.)
3. What is a typical day like for you?
4. How, if at all, has your experience of COVID changed since we last talked?
5. How, if at all, has COVID affected what a typical day is like for you?
6. What activities are you doing to connect with others?
   Prompt: How would you describe your living situation?
7. What activities are you doing to contribute?
8. What type of restorative activities are you engaging in?
   Prompt: How do you feel when you are doing your daily activities?
9. How, if at all, has the meaning of the activities you do changes with the advent of COVID?
10. What are some of the biggest challenges you have encountered?
11. What are some of the strategies and supports you have used to overcome them?
12. What are some potential things that you would think would be helpful for people who are in similar situations as you?
13. What do you think should happen in that regard?
14. What ideas do you have about innovations that could facilitate that change?
    Prompt 1. How, if it all, has your use of social media changed during this time?
    Prompt 2: Describe your use of technology currently?
15. (If consented to photovoice) Please describe each picture you took
    Prompt: Why did you take this picture? What does it convey about your experience?
16. What are your future plans?

Interview 4 guide

Hi, again! I would like to start the interview by thanking you for your continuing participation. It is greatly appreciated.

Much like our last interview, you will be asked about your personal experiences. The interview will take approximately 60 minutes. Per the Informed Consent you signed, I just want to

remind you that your participation is voluntary. You can stop the interview at any time, if you no longer want to participate. You also do not need to answer any questions which make you feel uncomfortable. During the interview, my main job is to listen to you and your stories. I look forward to hearing about how things have gone since we met!

As indicated in the Informed Consent, this session will be video recorded and then transcribed. I will let you know when I will start recording. If your name happens to come up in the interview, it will be removed when the interview is transcribed and replaced with a pseudonym. Do you have any questions for me before we start? I am now going to start recording.

Photovoice: (if provided) open provided slideshow and share with participant. Skip to question 7 if participant has no photos

Note for photovoice: You may make your own comments as well. Perhaps even just describing it visually could get things going.

You could also ask some leading questions if participants aren't digging deep themselves into the content.

Try to be open and not shut people down. Curiosity—learn as you go.

1. Over the several times we interviewed you, you provided pictures. I want to share with you a collage of your pictures. From these pictures I would like to identify a couple that speak about your COVID experience.
2. Tell me about this picture. What does it mean to you? What was going through your mind when you took the picture?
   Prompt: Based on the pictures you identified, can you tell me when you took them and what period of time they represented
3. How have things in your life changed for you since you uploaded this picture?
   Probe: looking at this picture NOW, how does it make you feel?
4. What do you think you're learning as you re-visit these pictures?
5. Since the last time we talked how have things been going for you?
6. What changes have you experienced since we last talked:
   Prompt: living situation, health, etc.
   Prompt: [follow up on notes from last interview, e.g. "last time you also mentioned ..."]
   Prompt: what has remained the same?
7. What is a typical day like for you right now?
   Prompt: What is the most meaningful part of your day?
   Prompt: What are you doing more of?
   Prompt: What are you doing less of?
8. How, if at all, has your experience of COVID changed since we last talked?
   Prompt: What, if any, discrimination have you experienced that you think might be related to COVID?
9. How, if at all, has COVID affected what a typical day is like for you?
10. What activities are you doing to connect with others?
    Prompt: How would you describe your living situation since we last talked?
11. What activities are you doing to contribute since we last talked/currently?
    Prompt: To your personal well-being, to society, to the world?
12. What type of restorative activities are you engaging in since our last interview?
    Prompt: How do you feel when you are doing your daily activities?
13. Is there something that you think is unique about your life that has influenced your COVID experience?
    Prompt: If you identify as an individual with a disability, how do you think your disability has influenced your COVID experience?

14. How, if at all, has the meaning of the activities you do changes with the advent of COVID since we last talked?
15. What are some of the biggest challenges you have encountered since our last interview?
16. What are some of the strategies and supports you have used to overcome them?
17. Have you been admitted to the hospital since the beginning of the COVID pandemic in March 2020?
    Prompt: If yes, do you mind telling me what your experience was like?
    Prompt: Do you mind telling me why you were admitted?
18. How do you feel about the COVID vaccine? Will you be getting one?
19. Having experienced a second wave of the COVID pandemic what suggestions would you provide to help people navigate through this time?
    Prompt: How have you dealt with this lockdown compared to the first time?
    Prompt: Did you prepare at all for another phase of isolation after the first wave?
    Prompt: What did you do to prepare?
20. What, if any, innovations or new technologies are you using to help get by during this pandemic (e.g., for sports, recreation, socializing, mobility)?
    Prompt: What do you like/dislike about these technologies.
    Prompt: What ideas do you have about innovations that could facilitate that change?
    Prompt: How, if it all, has your use of social media changed since we last talked?
    Prompt: Describe your use of technology currently?
21. What are your future plans?
    Prompt: Today, this week, monthly, before next interview, for the year.
    closing thoughts are very interesting so be sure to continue recording. If it is about time to end the interview, let them know and thank them again a final time.