“I’ve Already Lived like There’s a Pandemic”:

A Grounded Theory Study on the Experiences of People with a Mobility Disability

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Abstract

Background: It is widely documented that people with a mobility disability are at increased risk of severe illness, morbidity, or mortality following a disaster. However, disaster risk is multifactorial and not simply a result of underlying conditions. There is a need to examine contributors to dis- ability experiences during a pandemic, and strategies to account for these in pandemic response.

Methods: Using grounded theory methodology, we employed iterative, inductive coding and constant comparative methods. Sixteen people with a mobility disability from Ontario and Quebec, Canada, participated in 1-hour qualitative interviews (ages 20-86). Participants' disability etiology included stroke, multiple sclerosis, amputations, and other.

Results: The pandemic was a source of dis-ability for the whole population, making disability disparities more noticeable and highlighting the role of adaptive capacity in disaster resilience. Although COVID-19 compounded existing barriers faced by people with a mobility disability, participants were able to mobilize their assets (i.e., individual capacity, mobility assists, etc.), empowering them to take action to maintain autonomy. When the general population experienced barriers to social connection, adaptations to support resilience were at the forefront of policy decisions. New solutions, including digital infrastructure, demonstrated the potential to diminish existing barriers by providing accommodations to meet the accessibility needs of people with disability, especially for regular healthcare provider contact.

Conclusion: The COVID-19 pandemic is an opportunity to break the cycle perpetuating health- related inequities. Pandemic planning, response, and recovery can be reformed toward disability- inclusiveness with systemic changes focused on human rights, and physical and psychosocial needs of people with a mobility disability.

Résumé

Contexte: Il est largement reconnu que les personnes à mobilité réduite courent un risque accru de maladie grave, de morbidité ou de mortalité à la suite d'une catastrophe. Cependant, le risque de catastrophe est multifactoriel et ne résulte pas simplement de conditions sous-jacentes. Il est nécessaire d'examiner les facteurs qui contribuent aux expériences de handicap pendant une pandémie, et les stratégies pour en tenir compte dans la réponse à la pandémie.

Méthodes: En utilisant la méthodologie de la théorie ancrée, nous avons employé un codage inductif itératif et des méthodes de comparaison constante. Seize personnes à mobilité réduite de l'Ontario et du Québec, Canada, ont participé à des entretiens qualitatifs d'une heure (âgées de 20 à 86 ans). L'étiologie de l'incapacité des participants comprenait les accidents vasculaires cérébraux, la sclérose en plaques, les amputations, et d'autres conditions.

Résultats: La pandémie a été une source de handicap pour l'ensemble de la population, rendant les disparités liées au handicap plus visibles et mettant en évidence le rôle de la capacité d'adaptation dans la résilience aux catastrophes. Bien que la COVID-19 ait aggravé les obstacles existants auxquels sont confrontées les personnes handicapées, les participants ont pu mobiliser leurs atouts (c.-à-d. capacité individuelle, aides à la mobilité, etc.), ce qui leur a permis de prendre des mesures pour maintenir leur autonomie. Lorsque la population générale a rencontré des obstacles à la connexion sociale, les adaptations visant à soutenir la résilience étaient au premier plan des décisions politiques. De nouvelles solutions, y compris l'infrastructure numérique, ont démontré le potentiel de réduire les obstacles existants en offrant des aménagements pour répondre aux besoins d'accessibilité des personnes handicapées, notamment pour les contacts réguliers avec les prestataires de soins de santé.

Conclusions: La pandémie de COVID-19 est l'occasion de briser le cycle qui perpétue les inégalités en matière de santé. La planification, la réponse et le rétablissement en cas de pandémie peuvent être réformés pour inclure les personnes grâce à des changements systémiques axés sur les droits de la personne et les besoins physiques et psychosociaux des personnes à mobilité réduite.

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This thesis is dedicated to my parents, who have been my first and constant example of resilience.

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CHAPTER 1: INTRODUCTION

Globally, more than 538 million people have been infected by SARS-CoV-2, more commonly known as COVID-19, by June 2022 (World Health Organization, 2022). The World Health Organization (WHO) declared this coronavirus outbreak a serious public health concern and pandemic in March 2020 (World Health Organization, 2020a). In Canada alone, by June 2022, approximately 3,897,879 total cases and 41,363 deaths had been reported (Government of Canada, 2022), reflecting the virus' strong rate of transmission and its detrimental effects on population health. During the Severe Acute Respiratory Syndrome (SARS) outbreak in in 2003 and the H1N1 ("swine flu") influenza pandemic in 2009, public health measures were directed at protecting all members of the population, but especially people most at-risk for medical complications from disease outbreaks (O'Sullivan & Bourgoin, 2010). However, there are segments of the population who are at heightened risk for negative impacts of a pandemic due to intersectional variables, including their socio-economic status and health conditions (Croft & Fraser, 2022). These variables can determine the pandemic experiences of people with disability and their ability to manage the societal impacts of a disaster (O'Sullivan & Bourgoin, 2010; Umucu & Lee, 2020).

People with disability are a heterogenous group with diverse abilities (Elisala et al., 2020). Disasters impact their abilities and can contribute to how they perceive and respond to a pandemic. Intersectional determinants of health, including their socio-economic status and age, coupled with a health condition or existing disability-related barriers, affect disaster risk (Croft & Fraser, 2022). For people with a mobility disability, loss of autonomy, limited financial resources, movement restrictions, and social isolation are among the factors that can increase their risk during an emergency (O'Sullivan & Bourgoin, 2010). In addition, the need for personal care or assistance with mobility are inadequately addressed in most emergency plans (Wingate et al., 2007). This has

contributed to the historically higher rates of morbidity and mortality in the disability population during pandemics (Harrison et al., 2020). Like in previous disasters, the COVID-19 pandemic response has been inequitable due to insufficient preparation to meet the intersectional needs of people with a mobility disability (Bambra et al., 2020; Kiple, 2007; Summers et al., 2014).

In previous physical disasters, the specific needs of people with disability were not sufficiently considered in evacuation protocols; this included mobility assistance, accessible evacuation shelters, and reliable power sources to run equipment, such as power wheelchairs (Quail, 2018). Currently, people with a mobility disability continue to have specific, unmet needs related to access, safety, and inclusion which have not been adequately addressed in lockdown protocols and other pandemic measures (Croft & Fraser, 2022). To understand what these are and how they may be addressed through policy, COVID-19-related disparities must be explored so structural disadvantages are not further exacerbated (Jesus et al., 2021).

A global crisis like the COVID-19 pandemic has not occurred since the 1918 influenza pandemic (Morens et al., 2010). The health, psychological, and social impacts of COVID-19 are expected to be more sustained and longer-lasting than immediate impacts of natural disasters, such as the 2010 earthquake in Haiti (Fahim et al., 2015), or the Acquired Immunodeficiency Syndrome (AIDS) epidemic (Suárez Fernández, 2011). Therefore, there is more to do to understand how mobility needs intersect with the pandemic environment to influence vulnerability to COVID-19 and its social impacts.

To our knowledge, there is no existing model to describe how people with a mobility disability are experiencing the COVID-19 pandemic in Canada. Furthermore, strategies to address inequities and to promote adaptive capacity have yet to be established. To address this gap in literature, the purpose of this Master's thesis was to explore the lived experiences of people with

a mobility disability in the context of the COVID-19 pandemic.

CHAPTER 2: LITERATURE REVIEW

Disability and Disasters

The 2017 Canadian Survey on Disability (CSD) found that 22% of the Canadian population aged 15 years or older had at least one disability (Statistics Canada, 2017). The most common disabilities among adults are related to pain (15%), flexibility (10%), and mobility (10%) (Statistics Canada, 2017). The World Health Organization (WHO) states that "disability" is an umbrella term covering impairments, activity limitations, and participation restriction (World Health Organization, 2021) Related to disability is 'functioning', defined as a synthesis of the biological, psychological, social, and environmental aspects of health by the International Classification of Functioning, Disability, and Health, or ICF (Kostanjsek, 2011).

The Government of Canada recognizes disability is a complex interaction between features of people's bodies and features of society. As such, there is no harmonized "operational" definition of disability across federal programs (*Federal Disability Reference Guide*, 2013). However, some research attempted to operationalize 'disability' by exploring it in terms of constructs of self-rated health, activity limitations due to physical, mental, or emotional problems, the need for special equipment, and self-identification of disability (Adams et al., 2019). Similarly, the World Report on Disability outlines an interactive model of disability, referring to disability as the negative aspects of the interaction between individuals with a health condition (such as Cerebral Palsy or Down Syndrome) and personal or environmental factors (contextual factors: such as negative attitudes, inaccessible infrastructure, and limited social supports) (Kostanjsek, 2011). This perspective reflects the Social Model of Disability, which distinguishes between physical diagnoses (i.e., functional factors) and dis-ability (i.e., contextual factors).

The Social Model of Disability

In recent years, disability was explored as a determinant of social vulnerability, with research becoming increasingly grounded in the Social Model of Disability (Phillips et al., 2021). This model is an alternative to the Medical Model of Disability, which views disease, injury, or corporal limitations as the primary causes of inequity and social challenges (Bampi et al., 2010). In contrast, the Social Model of Disability states that disability is experienced when society fails to accommodate for varying degrees of functional abilities and functional needs that support independent living (Oliver, 1984; Phillips et al., 2021). Following this approach, the ICF characterizes disability not only in terms of impairments, but as well, activity limitations and restrictions in the involvement of life situations (World Health Organization, 2001). This conceptualization of disability by the ICF has been used for decision-making purposes, including disaster research applications (Adams et al., 2019; World Health Organization, 2001).

In disaster research, it is necessary to consider both the subject-independent dimensions (such as etiology) and subject-dependent dimensions (such as experiences of social contributors) of disability and how they contribute to functional needs in an emergency (Sabatello, Landes, et al., 2020). Awareness through both lenses contributes to the body of knowledge of the challenges faced by people with disability living through disasters (Elisala et al., 2020). For example, people with disability previously identified the subject-dependent attitudinal, physical, programmatic, and transportation barriers as restrictive to their disaster preparation and recovery (Elisala et al., 2020; Stough et al., 2016). In addition, identifying types of subject-independent factors, such as physical impairment types, has helped public health groups, including the Centers for Disease Control and Prevention (CDC), pinpoint groups of persons with disability who are at higher risk for negative outcomes during a pandemic to strengthen health protection efforts (Boyle et al., 2020).

Mobility Disability

Mobility is a functional need recognized as a key category of disability in Canada (Morris, 2017; Statistics Canada, 2017). In 2010, Canada ratified the United Nations Convention on the Rights of Persons with Disabilities and developed the *Disability Screening Questions* (DSQ), a set of identifiers of disability. Through this, the Canadian Survey on Disability defined mobility disability as having difficulties with the ability to move around, limiting daily activities (Statistics Canada, 2017). Therefore, '*people with a mobility disability*' experience movement limitations, which interact with contextual factors, affecting their daily functioning and social participation (Cieza et al., 2018; Jesus, Kamalakannan, et al., 2020).

The 2017 Canadian Survey on Disability confirmed over 2,676,000 Canadians over the age of 15 had a mobility disability (Statistics Canada, 2017). Mobility disability is one of the most widespread and impactful consequences of multiple sclerosis, stroke, and a variety of orthopedic, neuromuscular, and other conditions (Baird et al., 2018; Saunders et al., 2016). All mobility impairments range in severity from stamina limitations to paralysis. Certain conditions may be congenital, such as cerebral palsy or congenital heart defects. Other conditions may be a result of acquired injury, for example, by stroke or substance abuse (Samokhvalov et al., 2010; Simondson et al., 2003). The degree to which individuals experience mobility disability varies tremendously. There is no consensus on which abilities and functionalities characterize disabilities (Finkelstein & Finkelstein, 2020), and not all who have a functional limitation identify as being a person with a mobility disability (Goering, 2015).

Risks during Disasters

In previous disasters, it was evident that risk for people with disability was exacerbated by existing barriers (Van Willigen et al., 2002). In the wake of Hurricanes Bonnie (August, 1998), Floyd (September, 1999), and Dennis (July, 2005), households with people with disability reported

fewer or delayed evacuations due to a lack of accommodating transportation or access to shelter facilities (Van Willigen et al., 2002). Similarly, Christensen et al. (2007) determined that building designs create evacuation barriers for people with physical disabilities. This places them at a disadvantage during earthquakes since the built environment exposes them to higher risk than the general population (Christensen et al., 2007; Stough et al., 2016).

Risk was exacerbated by physical-distancing measures and a lack of vaccination plans for people with disability during influenza pandemics (Campbell et al., 2009). Additionally, when caregivers were given low priority for vaccines and antiviral medications, they were at risk for reduced or no ability to provide care to people with disability (Campbell, 2007; *HHS Pandemic Influenza Plan*, 2005). As a result of these factors, post-disaster impacts were significantly greater for the disability group than the able- bodied group experiencing the same outcomes of a disaster (Van Willigen et al., 2002). These impacts can affect the ability for people with disability to live independently during and well after the disaster (Stough et al., 2016).

The United Nations Office for Disaster Risk Reduction (UNDRR) supported risk reduction amongst people with disability by implementing the Sendai Framework for Disaster Risk Reduction (UNDRR, 2015). The Sendai Framework advocates that disaster risk reduction activities are required to empower people who are disproportionately affected by disasters, including people with disability. Capacity preparedness is empowering and crucial for reducing disaster risk, such as through evaluation drills and developing plans for people with disability (Elisala et al., 2020). In the event that vital caregivers cannot provide assistance, capacity preparedness entails pre-pandemic planning to maintain essential services (Campbell, 2007).

Social Determinants of Health

The social determinants of health perspective on vulnerability considers resilience to be

based on the intersection between determinants of health and the effects of a disaster (Garoon & Duggan, 2008; International Centre for Infectious Diseases, 2010). As such, the interplay between different determinants of health creates a social gradient of risk for the effects of a pandemic (O'Sullivan & Bourgoin, 2010).

Without addressing the clustering of people with disability's social determinants of health, there may be a lack of community disaster relief plans, inadequate infrastructure, or difficulties returning to daily routines after disasters (Sabatello, Landes et al., 2020). This relates to intersectional factors influencing disaster risk, as people with disability were found to be more likely to have fewer financial resources (in terms of education, employment, and socio-economic status), social resources (such as personal and professional networks), and psychological resources (such as mental health support) (Finkelstein & Finkelstein, 2020). Because these resources are necessary for coping with disasters, people with disability were found to be at higher risk of developing post-traumatic stress symptoms in the aftermath of emergencies (Shpigelman & Gelkopf, 2019).

People with disability are marginalized in health care, compared to the general population (Sabatello, Landes et al., 2020). Policies in many regions have not accounted for people with disability being less likely to have private or employer-funded health insurance, more likely to have unmet health care needs, and lower scores on social determinants of health (Yee et al., 2018). Furthermore, people with disability have experienced stigma and discrimination in public and professional settings, de-prioritization of health resources, and ableist triage approaches for health system resources, such as intensive care unit (ICU) beds and ventilators (Ndumbe-Eyoh et al., 2021). Healthcare access and quality is a social determinant of health; the inequitable experiences of people with disability in healthcare access, healthcare quality, and health outcomes place them

at a disproportionality greater risk of being overlooked by the medical system during an emergency (Healthy People 2030). When socially disadvantaged populations experience exacerbation of existing health and social inequities created by a pandemic, they are exposed to greater risks of severe health consequences if infected (Perera et al., 2020; Peterson-Besse et al., 2014). Furthermore, beyond heightened medical risks from infection, these inequities can cause disproportional social impacts from physical-distancing mandates (Jesus et al., 2021).

In the event of viral pandemics, there is a focus on implementing healthcare policies enforcing mandatory separation from others (Selgelid, 2008). During the 2003 SARS pandemic, citywide quarantines were imposed in areas of China and Canada, and during the 2014 Ebola outbreak, entire villages in several West African countries were under lockdown (Brooks et al., 2020). During the COVID-19 pandemic, physical-distancing mandates required keeping a distance of at least two meters from others, avoiding crowded gatherings, and limiting contact with people at higher risk (Health Canada, 2020; Centers for Disease Control and Prevention, 2019). Since 2020, COVID-19 physical-distancing measures in Canada included stay-at-home orders, curfews, and cancellation of indoor work and educational activities, dining, and entertainment (Global News, 2021; Government of Canada, 2021). These measures are crucial for reducing the spread of COVID-19 (Ghoreishi et al., 2020). However, protocols prohibiting in-person contact can negatively impact people experiencing disability, especially those with mobility needs based on the clustering of the social determinants of health in this population. For example, people with a mobility disability are more likely to require close-contact assistance and in-person services to manage their conditions (Middleton et al., 2020; Aldrich & Benson, 2008; Quail, 2018).

Economic Stability and *Social and Community Context* are categories of risk that intersect with other determinants of health to increase vulnerability during a pandemic (Healthy People 2030). People with disability are more likely to have socio-economic disadvantages, compared to

the general population, as functional needs can limit their ability to work or sustain sufficient resources (Bettger et al., 2014; Falvey et al., 2021). Factors that influence this are: increased costs of living, inaccessibility of certain employment, and necessary but expensive health treatments (Lund, 2020; Sabatello, Landes, et al., 2020). In a pandemic, this may lead to increased exposure and illness, less access to support, separation from one's social safety net, and decreased health-seeking behavior (O'Sullivan & Bourgoin, 2010; Uscher-Pines et al., 2007). Therefore, when a disaster spurs an economic crisis, it is likely to exacerbate financial disparities between disabled and able-bodied populations (Goggin & Ellis, 2020).

Many guidelines developed to enhance access and functional abilities during emergencies have not addressed the needs of people with disability (Sakellariou et al., 2020). There is a push to shift emergency strategies towards interventions targeting social determinants of health to sufficiently address long-standing systemic health disparities (Levine & Jansson, 2021). Novel disaster approaches must look beyond the medical needs of at-risk groups and place additional focus on addressing the underlying determinants of health (Levine & Jansson, 2021).

Assets and Resilience

Assets are the social, financial, physical, environmental, or human resources that function as protective or promoting factors to buffer against negative life events (Harrison, 2004; Morgan & Ziglio, 2007). Assets enhance individuals' abilities to maintain and sustain wellbeing and adaptive capacity (Morgan & Ziglio, 2007; Moser & Satterthwaite, 2008). When facing negative impacts from disasters, assets motivate an adaptive shift from awareness to action; this helps individuals develop a sense of self-efficacy (Morgan & Ziglio, 2007; O'Sullivan et al., 2014). It is important to acknowledge and foster the assets of people with disability during disasters as this will influence their disaster preparedness and response (Adams et al., 2019).

Adaptive capacity is defined as the ability to modify characteristics or behaviors to better cope with existing or anticipated external stressors (Jakku & Lynam, 2010). Adaptive capacity and resilience have different purposes (Colombi & Smith, 2012). Resilience refers to a state or condition, whereas adaptive capacity is the ability to change one's state or condition (Jakku & Lynam, 2010). Therefore, adaptive capacity can be framed in terms of a cultural process related to adjusting to adverse situations to achieve resilience (Colombi & Smith, 2012).

Healthy adaptation to disasters is linked to knowledge about hazards, knowledge of protective action, social support resources, community membership, sociocultural frameworks, and risk perception (Mishra & Mazumdar, 2015). When individuals, especially those at heightened risk, can build on these to respond to the perceived threat of disasters, their capacity for adaptive strategies and disaster preparedness increases (Mishra & Mazumdar, 2015).

Physical assets (i.e., ramps, assistive devices) support resilience by increasing accessibility. For example, people who had a spinal cord injury reported physical assets can promote independence in activities and decrease mobility restrictions, which in turn, supported a higher quality of life and levels of resilience (Peter et al., 2012). Stroke survivors similarly identified assistive devices, including mobility assists, as important for resilience because they promoted autonomy in daily living and capacity to be independent (O'Sullivan et al., 2017). Moreover, assistive devices were also found to be able to mitigate the sense of being a burden when there were architectural barriers to evacuation during physical disasters (Pakjouei et al., 2018).

Other than external assets, personal characteristics were found to contribute to resilience (O'Sullivan et al., 2017). Positive attitudes helped people with disability accept things out of their control after and during a disaster (Umucu & Lee, 2020). Determination, motivation, self- efficacy, and patience are other personal characteristics that are important in a disaster context because they

help adaptation to unfamiliar settings (O'Sullivan et al., 2017). In addition to managing existing health conditions, coping with the stress related to COVID-19 is thought to be more challenging for people with disability (World Health Organization, 2020b). However, adaptive coping strategies may play a role in buffering negative emotions associated with pandemic stressors (Umucu & Lee, 2020).

Discourse and Resilience

Although supports, such as mobility devices, were found to be assets in both every day and disaster settings, there are unfair attributions of people who use assistive technology as being "different" in Canadian media (Fraser et al., 2016). Stereotypes around group differences in society are not only damaging, but can lead to reduced willingness to adopt external assistance due to fears of being categorized (Anastasiou & Kauffman, 2013; Fraser et al., 2016). Therefore, asset literacy is needed instead to view people in terms of their unique asset profiles, to promote and accept the assets important for their resilience (O'Sullivan & Phillips, 2019).

The social risk of people with disability is increased when people are viewed solely through deficit-oriented lens. In emergency management, it is recommended to change from deficit-oriented labelling to recognizing capabilities people bring to an event (O'Sullivan & Phillips, 2019). Person-first language is recommended, as this directs focus to the person themselves and their abilities, before any limitations. Through a shift in discourse, the disability community can have their risk profile recognized in disaster management whilst not being labelled "vulnerable" (O'Sullivan et al., 2014).

The Supreme Court of Canada states that having a "handicap" refers to the experiences of functional limitations of the person rather than the person themselves (Ontario Human Rights Commission). Referring to a person with disability as "a disabled person" is stigmatizing; instead,

"person with disability" is a term that puts the individual before the condition (Bampi et al., 2010; Crocker & Smith, 2019). On the national broadcasting level, 'disabled' or 'handicapped' are only recommended for use when describing a particular condition or environmental barrier (Canadian Association of Broadcasters). When detailing the story of the individual, it should be inclusive of the person in society, rather than emphasize a person's barriers to inclusion (Ontario Human Rights Commission). Patston et al. propose using the *functional diversity* view of disability, which recognizes that all people function in diverse ways and encourages acceptance of the complex array of human function and strengths (Patston, 2007).

Summary

In the literature, people with a mobility disability are often defined in terms of their functional limitations rather than their assets. However, both can equally shape and contribute to their experiences of a disaster. Although disability is among the risk factors that exacerbate the impacts of a disaster (Garoon & Duggan, 2008), being-at risk does not imply vulnerability if appropriate supports are accessible (O'Sullivan et al., 2017).

Much of the existing literature on disasters and disability focuses on how disability worsens disaster outcomes, or how disasters exacerbate existing medical impairments (Stough et al., 2016). There is a lack of research on lived experiences of people with disability during a pandemic. Furthermore, few studies have explored capabilities, assets, and resilience of people with mobility needs during a pandemic disaster.

This qualitative study aimed to fill the gaps in knowledge on: (a) the needs of people with a mobility disability during the COVID-19 pandemic, (b) societal determinants that impact their abilities, and (c) what is needed in the recovery period from this pandemic and future disasters to reduce disparities. Hearing, exploring, and understanding the experiences of people with a mobility

disability will facilitate a more inclusive decision-making process for pandemic response. This knowledge may also bring awareness of the implications of current public health decisions on different marginalized groups.

The Social Model of Disability acknowledges that the first experts of the phenomenon of disability are people with disability themselves who may speak from lived experiences of disparities in existing systems (Abberley, 1987; Anastasiou & Kauffman, 2013). Therefore, this study honors the perspectives of people with disability by using their authentic voices to inform a grounded theory on their pandemic experiences.

The overarching research question for this study is: What are the experiences of people with a mobility disability in the context of the COVID-19 pandemic? Specifically, we explored key areas within people's experiences that were shaped by the pandemic and share their recommendations for a more inclusive future.

CHAPTER 3: MANUSCRIPT I: Grounded Theory Study

"I've Already Lived Like There's a Pandemic":

A Grounded Theory Study on the Experiences of People with a Mobility Disability

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ABSTRACT

Introduction: Disability intersects with other social determinants of health to heighten the risk of negative impacts from disaster. For people with mobility limitations, disasters present unique consequences, impacting ways to adaptively cope with resulting societal changes. This study aimed to capture the unique experiences of people with a mobility disability during the COVID-19 pandemic. The purpose was to explore how various social determinants of health intersected with COVID-related restrictions to create a gradient of social risk.

Methods: We applied grounded theory methodology, which instructed our sampling, data collection, and analysis. Data for the study was generated through one-hour virtual interviews with 16 participants, aged 20-86 years, with varying mobility disabilities who live in Ontario and Quebec, Canada.

Results: Through qualitative analysis of participants' experiences of the first four waves of the COVID-19 pandemic, we developed our theory: *Adaptation is Not a Choice, It's a Way of Life*. We found six themes to substantiate this grounded theory: Exacerbated Disability Challenges, Assets Enhance Resilience, Taking Calculated Risks, Common Experience, The Role of Increased Innovation, and Social Justice. The participants described the ways restrictions imposed by the pandemic resembled everyday barriers faced by persons with a mobility disability. Although this could increase risk, participants reported not being dis-abled when they had internal and external assets to support adaptive capacity. Adaptive capacity supports the resilience needed to manage disability challenges from restrictions in the environment. People with disability took calculated risks to maintain quality of life during the pandemic. Although they shared a common dis-ability experience with the general population, the ways in which innovation flourished during the

pandemic provided solutions to mitigate experiences of dis-ability. The tipping point for change is social justice, to support resilience.

Conclusion: Planning, for both daily living and pandemic response, must be disability-inclusive. Assets that support resilience every day, such as stable transportations systems, can minimize risk for people with a mobility disability during pandemics.

Keywords: mobility, disability, pandemic response, grounded theory, resilience, disaster preparedness

1. Introduction

COVID-19 emerged in 2019 and resulted in a global pandemic (World Health Organization, 2020). Over 3.8 million Canadians have had at least one case of COVID-19 as of June, 2022 (Government of Canada, 2022). However, the impact of the pandemic was not experienced equally across population groups. Certain peoples, including those with a mobility disability, experienced disproportionate negative functional and social outcomes of the COVID-19 pandemic, related to impairments from the coronavirus and other social factors (Jesus et al., 2021).

During previous respiratory outbreaks, certain populations were recognized as being at increased risk of serious illness, such as older adults, immunocompromised individuals, and pregnant women (O'Sullivan & Phillips, 2019). While age and existing health issues have been used to identify people as 'vulnerable', or at a greater risk of severe illness, less emphasis has been placed on vulnerability related to clustering of the social determinants of health (O'Sullivan & Bourgoin, 2010; Senjam & Singh, 2020). For people with disability, intersectional factors affect their ability to respond to environmental changes following a disaster (Croft & Fraser, 2022). For example, because people with mobility needs are more likely to rely on others for personal care or support for daily living, socio-economic impacts of a pandemic present significant challenges to this group to secure health resources (Campbell et al., 2009; Croft & Fraser, 2022). Living in congregate settings or receiving caregiving may also place people with disability at increased risk of viral transmission (Glynn et al., 2020). Further, having chronic conditions may raise the risk for serious medical complications from a coronavirus, which increases stress and decreases perceived well-being (Umucu & Lee, 2020).

Beyond medical risk to the coronavirus, reliance on external assistance or services impacts

the social risk of people with disability when restrictive physical-distancing measures are enforced (Glynn et al., 2020). People with disability often require routine health and rehabilitative care to maintain or recover their functional abilities. However, during lockdowns, many services may be forced to close, or operate with limited human and physical resources (Boldrini, Kiekens, et al., 2020). A United Kingdom (UK) survey found social impacts of the pandemic, such as policies restricting services, caused people with disability to experience increased levels of psychological distress, social isolation, lack of social support, discrimination, food poverty, and unequal access to health care (Glasgow Disability Alliance, 2020). Reductions in the range and quality of services —or changes in eligibility criteria to access services— especially affect people with a mobility disability unable to work or who have lower socio-economic status (Glasby et al., 2020; Shakespeare, Watson, et al., 2021).

Mobility is a functional need that impacts the ability to manage consequences of a disaster (Pakjouei et al., 2018; Stough et al., 2016) and has been recognized as a key category of disability in Canada (Morris, 2017; Statistics Canada, 2017). Previous research found people with a mobility disability were at increased risk of displacement, injury and illness, and mortality when disaster preparedness lacked inclusiveness to meet mobility needs (Dunn et al., 2017; Pakjouei et al., 2018). Inaccessible infrastructure was a barrier during physical disasters when those with mobility needs had challenges evacuating buildings that lacked accessible exit routes or ramps (Pakjouei et al., 2018).

Globally, societies and organizations have shared insights on the impact of the COVID-19 pandemic on people with disability. For example, in Italy, the Italian PRM Society (SIMFER) organized weekly webinars (“Covinars”), allowing professionals to discuss social protection measures and initiatives to mitigate effects of physical- distancing on people with disability and

their families (Boldrini, Garcea, et al., 2020). However, to actualize plans, it is important to listen to the voices of those who are facing the situation first-hand to understand how experiential knowledge can be used in decision-making (Boldrini, Garcea, et al., 2020; Elisala et al., 2020).

Pandemic preparedness planning and response must recognize the intersectionality of the social determinants of health and their collective contributions to disaster risk (O'Sullivan & Phillips, 2019). New insight on people with a mobility disability's experiences during the current pandemic provides an opportunity to re-shape care systems and stimulate innovation in how to include and support this population during a disaster. It is an area that can be improved upon according to the principles of dignity for persons living with disability (Armitage & Nellums, 2020; Boldrini, Garcea, et al., 2020). In this study, to address this gap in the literature, we asked the following research question: What are the experiences of people with a mobility disability in the context of the COVID-19 pandemic? In this paper, we presented the grounded theory developed in response to that question.

2. Methods

2.1 Research Design

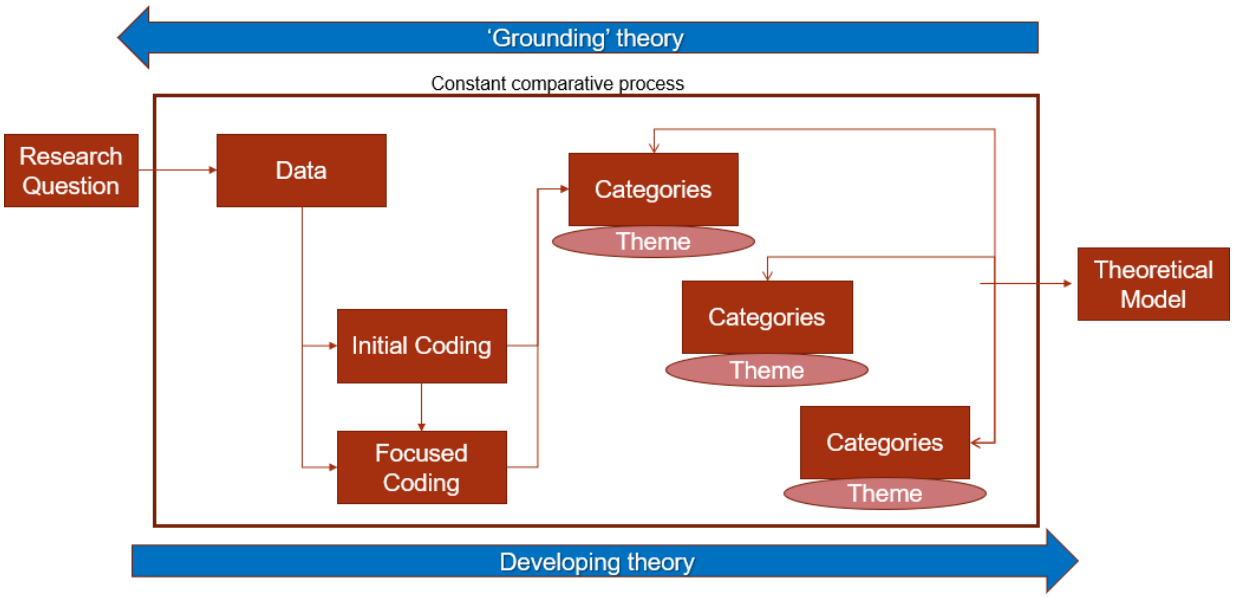
We employed grounded theory as a methodology for understanding the COVID-19 pandemic experiences of people with a mobility disability in Canada (Figure 1). This methodology is characterized by constant comparative methods at each stage of the inquiry and iterative model building (Charmaz, 2014). As such, each stage of data collection and analysis informed the next.

Following Charmaz's qualitative grounded theory approaches, we used virtual semi-structured interviews as the primary data collection method. Analysis relied on initial and focused coding to sort the data, categorization to find meaningful themes within and across interviews, and

theoretical coding to summarize the overall theory. Given the limited research on the lived experiences of people with a mobility disability during COVID-19, this approach is appropriate for this new area of inquiry. We incorporated the analytical strategies of Miles et al. (2014) and Hennink et al. (2020) as tools to tell a coherent analytic story. We followed the COnsolidated criteria for REporting Qualitative research (COREQ) Checklist (Tong et al., 2007), which can be found in Appendix I.

Figure 1

Grounded theory methodology (adapted from Charmaz, 2006)



2.2 Data Collection

Participants and Recruitment

Prior to data collection, we obtained ethics approval from the Health Sciences and Science Research Ethics Board of the University of Ottawa (REB) (see Certificate of REB Approval: Appendix II). First contact was initiated by the participants, who could obtain our contact information from recruitment flyers. We obtained oral or written consent from eligible participants

before each interview began. Beyond consent to participate in the study, participants had the voluntary option to consent to being quoted (see Consent form: Appendix III).

Participants were eligible to take part in this study if they met the following inclusion criteria: 1) Have a mobility disability 2) live in Canada 3) age 18+ years, 4) proficiency in English, 5) ability to comprehend their role in the study, and 6) capacity to provide written or verbal consent, including consent to having their interview audio recorded. Participants could self- identify as having a mobility disability based on a definition provided by the Canadian Survey on Disability (CSD): "Identifying as a person whose daily activities are limited because of difficulties with their ability to move around, including walking or using stairs" (Canadian Survey on Disability, 2018). Additionally, for participants who inquired further about their eligibility based on their functional abilities, we described mobility using terminology from the CSD: 'dexterity, balance, walking, physically maneuvering, or other'.

Participants were recruited through Canadian non-profit and community organizations that support people living with disability or a chronic condition. These included Ottawa Independent Living Resource Centre, March of Dimes, Multiple Sclerosis Society of Canada, Perley Health, and other. Organizations distributed notices about the study within their networks, using listservs/newsletters or posting flyers in their centers. Recruitment took place between September and December 2021. Recruitment material provided an overview of the study's goals but did not include any personal details about the researchers (see Recruitment Material: Appendix IV).

Sampling

We used purposeful sampling to identify participants who met inclusion criteria and could speak about their lived experiences of the phenomenon (Mack et al., 2005; Trochim & Donnelly, 2008). This strategy allows sample size to be determined based on theoretical saturation rather

than a set number (Mack et al., 2005). Additionally, we employed snowball sampling, with individuals spreading news of the study to those in their social circles. This approach is less systematic than purposeful sampling but carries the value of recruiting groups not easily accessible to researchers (Mack et al., 2005).

Interviews

Data for this study came from semi-structured interviews ranging between 60–80-minutes and conducted over the phone or on the video-conferencing app, Zoom, depending on the participant's preference. During the interviews, we explored participants' experiences with COVID-19, their lifestyles and activities, social connections, assets, and perspectives on public health measures and pandemic responses. We also asked how the pandemic changed various aspects of their experiences of mobility disability, such as effects of the pandemic on their resources, ability to maintain mobility, quality of life, and outlook on the future (see Semi-Structured Interview Guide: Appendix V). In addition to written transcripts, memos or "field notes" served as a data source. The interview guide did not undergo pilot-testing.

The primary investigator (PI), a female MSc candidate (MY), conducted the interviews. Only the participants and the PI were present during virtual interviews. There were no relationships established between the interviewer and participants prior to study commencement. All participants completed at least one full interview.

Our interviewing techniques were based on constructivist interviewing practices where questions or comments serve to "keep a story coming when a participant can and wants to tell it" (Charmaz, 2014, p. 151). Hence, we strived for a balance between focusing on relevance to the interview guide and making the interview open-ended (Charmaz, 2006).

As interviews progressed and categories became increasingly defined, questions within the interview guide evolved. We added new questions when multiple participants reported the same incident had an impact on their pandemic experiences (i.e., experience with a certain infrastructure), or if a salient topic had a place within the emergent theory.

Constructivist grounded theory recommends multiple interviews with participants to obtain information about the development of a process, or changes in how they understand the phenomena (Charmaz, 2014). We conducted follow-up interviews with some participants (n = 3) to clarify meanings or elaborate on a previously discussed topic. Like initial interviews, follow-up interviews were guided by theoretical saturation.

Theoretical saturation is demonstrated when no new categories emerge and when new incidences described in interviews fall into existing categories without changing the meaning of the category (Holmgren et al., 2019; Holton, 2010). When categories are saturated, new information ceases to add to the built framework and the model is considered to adequately capture the phenomenon experienced by a given group (Charmaz, 2006). Through consensus, we agreed theoretical saturation was reached after 16 initial interviews and 3 follow-up interviews.

Following each interview, we transcribed audio-recordings verbatim to preserve the context of participants' original statements. We identified participants by an arbitrary numeric participant code at this stage; these codes were also included with participants' quotes in the written report. Transcripts were not returned to participants for comments.

Constant Comparative Process

As grounded theory is an inductive method, codes and themes were not identified in advance. Instead, our model was built through the constant comparative process, which requires data collection, coding, transcribing, and model building to occur in tandem, to achieve saturation

(Charmaz, 2006). We employed the constant comparative process to identify repeatedly present and relevant topics. These provided analytic direction for following interviewing and analysis (Charmaz, 2014).

2.3 Data Analysis

The stages of analysis undertaken to form this grounded theory are presented in Table 1.

Coding

The process of coding fits segments of data into constructed foundations of a grounded theory (Charmaz, 2006). This inductive process was necessary to maintaining consistency between the original data and our findings. In our analysis, the lead author (MY) completed initial coding using NVivo 11. The resulting codebook was checked by all authors (MY; SF; TO) to ensure reliability in how codes were defined and applied. Additionally, we increased rigor in coding by having multiple authors code the same data for comparison. These processes support *credibility*, a feature of qualitative analysis that confirms the quality of analytic conclusions (Miles et al., 2014).

Code development is an iterative process. Therefore, our process of new codes being added, code descriptions being refined, or combining or dividing codes continuously evolved throughout the analysis stage.

Table 1

Stages in Analysis

Stage	Definition	Processes
Coding		
Initial coding	Incident-by-incident coding through assigning relevant segments of text a symbolic label	Descriptive codes: summarizing short text In-Vivo codes: participants' special terms Gerunds ("-ing" words): describing processes "+" and "-" code tags: adding a positive or negative evaluation to a code
Focused coding	Condensing initial codes through finding patterns that capture larger chunks of data	Timepoint matrix: focused codes formed through finding patterns between pre-pandemic and pandemic incidences
Theory Formulation		
Categorizing	Moving from codes to broader categories representing higher-order groupings of data	Group focused codes with similar attributes into meaningful categories related to the research question Categories become saturated when new data that falls under it does not add new information about the category
Conceptualization	Considering the relationship between categories	Form analytic ideas on how categories relate to each other Move from describing data to explaining data
Theoretical coding	Identifying and elaborating on the core theory	Create an overarching "story" from links between categories Identify a core theme throughout the data and integrate existing literature into a single substantive theory

Initial Coding

Charmaz's grounded theory rules prescribe conducting initial coding without preconceived concepts in mind (Charmaz, 2014). We adopted this inductive procedure, as well as "First-Cycle" coding approaches from Miles et al. (2014), in our first stage of analysis. The incident-to-incident coding process determined the amount of data to incorporate into one code (Charmaz, 2014); we used this strategy to compare incidents to previously coded incidents to identify properties of a concept that could be captured by a code. In this style of coding, the unit of coding varies (Charmaz, 2014). We chose full sentences or complete phrases as our unit to code data.

Focused Coding

Focused coding is a method of assessing and going forward with initial codes most important to the emerging analysis (Charmaz, 2014). Forming focused codes is a process described by Miles et al. (2014) as generating "pattern" codes (p. 90). To condense material into "at-a-glance" patterns (Miles et al., 2014, p. 94), we developed a timepoint matrix (adapted from *Checklist Matrix,* Miles et al., 2014, p. 134). Since grounded theory methodology places an emphasis on processes, this strategy helps to link events that might otherwise seem unrelated (Charmaz, 2014). Matrices make data synthesis systematic, enables verifications, encourages comparability, and may permit simple quantification (Miles et al., 2014).

2.4 Theory Formulation

Hennink et al. (2020) describe the next task in the *analytic cycle* as moving beyond the codes to consider the data as a whole. During this process, we constructed a final model that meets criteria for grounded theory studies: Credibility, Originality, Resonance, and Usefulness (Charmaz, 2006; Charmaz, 2014). Our categories satisfied these criteria by covering a wide range of empirical

observations across interviews, offering new insight, portraying the fullness of the lived experience, and providing interpretations that people can use in their everyday worlds (Charmaz, 2006).

Categorizing data is a higher-level process involving grouping codes with similar attributes into meaningful categories (Corbin & Strauss, 1990; Hennink et al., 2020). We developed categories until we reached saturation, indicated when we no longer identified meaningful themes. Consecutively, conceptualizing involves considering the relationship between categories (Hennink et al., 2020). This process is described as moving up the *analytic spiral* from describing data to explaining data in theory development (Dey, 1993; Hennink et al., 2020).

Theoretical coding takes conceptualizations of the categories as hypotheses to be integrated into a theory (Charmaz, 2014). At this stage, we created our "story" through identification and elaboration of a core theme, and integration of existing literature into a single substantive theory (Charmaz, 2014). Literature related to lifestyle drift, community resilience, and asset literacy were consulted to gain deeper understanding of the core phenomenon of the study.

Participants were not solicited to provide feedback on the findings. Previous studies found that *member-checks*, or the act of returning aggregated data to participants to check for accuracy, may be useful for confirming validity of reports from stakeholders in collaborative research (Birt et al., 2016; Thomas, 2017). However, member-checks have less utility in research focused on theory development and generalization, as they often do not result in changes to a theory founded on inductive and reflexive methods, such as grounded theory (Birt et al., 2016; Thomas, 2017).

2.5 Personal Reflexive Statement

Constructivist grounded theory posits a researcher's prior assumptions and interactions influence theory construction (Charmaz, 2006). Positionality statements represent a reflexive approach to the research process recognizing the researcher "affects the social processes

constituting each stage of inquiry" (Charmaz, 2006, p. 132). Here, I provide a brief description of my positionality and how my life experiences informed my understanding of the study results.

I volunteered in the field of disability services and advocacy for several years, first by providing companionship to people who are blind, and later as part of a team advocating to the provincial government to make services more accessible. This project is particularly meaningful in the COVID pandemic era when pathways to accessing social and health services changed. I witnessed many people with disability struggle to meet basic needs and lose their independence as a result. Moreover, in my personal life, I witnessed loved ones experience delays in accessing crucial health treatments during the pandemic, impacting their functional abilities.

I have employment experiences providing workplace accommodations to people with a disability, injury, or illness. Through this work, I learned about the organizational duty to accommodate (DTA) on the grounds of human rights laws. My position is that duty to accommodate places the onus on the organization responsible for accommodations for those with diverse needs.

Finally, my personal experiences inform my interpretation of this grounded theory. While I have physical conditions impacting my mobility, I do not identify as a person with a mobility disability. I am fortunate to have received physical and programmatic accommodations from institutions to meet my needs. Due to this, I believe it is more meaningful to discuss barriers and needs rather than limitations. This shapes my perspective on dis-ability in the current study; my position is that disability and ability are functions of both the body and the support received from society.

As an investigator for this study, I do not claim to fully understand the lived experienced of people with a mobility disability. However, I acknowledge disability is complex; to attempt to

build a framework of understanding, investigation of the social context is needed. In the context of the most far-reaching disaster during my lifetime, I believe it is worthwhile to listen to people with a mobility disability to understand the factors that shape their experiences. This reflexive statement is intended to contextualize my position as a researcher, graduate student, and community member.

3. Results

3.1 Demographics

We conducted 19 interviews with 16 people with a mobility disability. The age range was 20 to 86 years. Participants lived in six cities across Ontario and one city in Quebec, Canada. Eight participants identified as male and eight identified as female; none identified as another gender. Fourteen participants identified as heterosexual, and two identified as being lesbian and gay, respectively. Predominantly, participants lived in a house, and some were receiving care in a long-term care facility. There was heterogeneity in disability etiology. Conditions included stroke, multiple sclerosis (MS), cerebral palsy (CP), neuropathic conditions, quadriplegia, spinal cord injury, osteogenic conditions, diabetes, arthritis, cancer, or were related to amputation (see Table 2).

Table 2

Demographic Information

Age in Years (Range=20-86):	***52, 53, 65, 72, 67, 74, 57, 78, 68, 65, 66, 32, 77, 20, 60, 86***
City	Ottawa, ON: 8 Toronto, ON: 3 Chelsea, QC: 1 Niagara Falls, ON:1 St. Catharine's, ON: 1 Windsor, ON: 1 Kitchener, ON: 1
Gender Identity	Male: 8 Female: 8 Other: 0
Sexual Orientation	Heterosexual: 14 Lesbian: 1 Gay: 1 Other: 0
Race or Ethnicity	Caucasian (Canada, UK, Australia): 15 Mixed (Caucasian and West Indian): 1
Type of Residence	House: 6 Bungalow: 2 Long-term care home: 3 Condominium: 2 Apartment: 2 Town house: 1
Who They Live With	With family (more than just partner or other than partner): 3 With partner: 6 Alone: 7
Occupation Status	In school: 1 Working: 2 Retired: 12 Neither: 1
Disability Etiology	Stroke: 6 Multiple Sclerosis: 2 Cerebral Palsey: 1 Neuropathic condition:2 Amputation: 2 Quadriplegia: 1 Spinal Cord Injury: 1 Osteogenic condition: 1 Diabetes: 1 Arthritis: 1 Cancer: 1

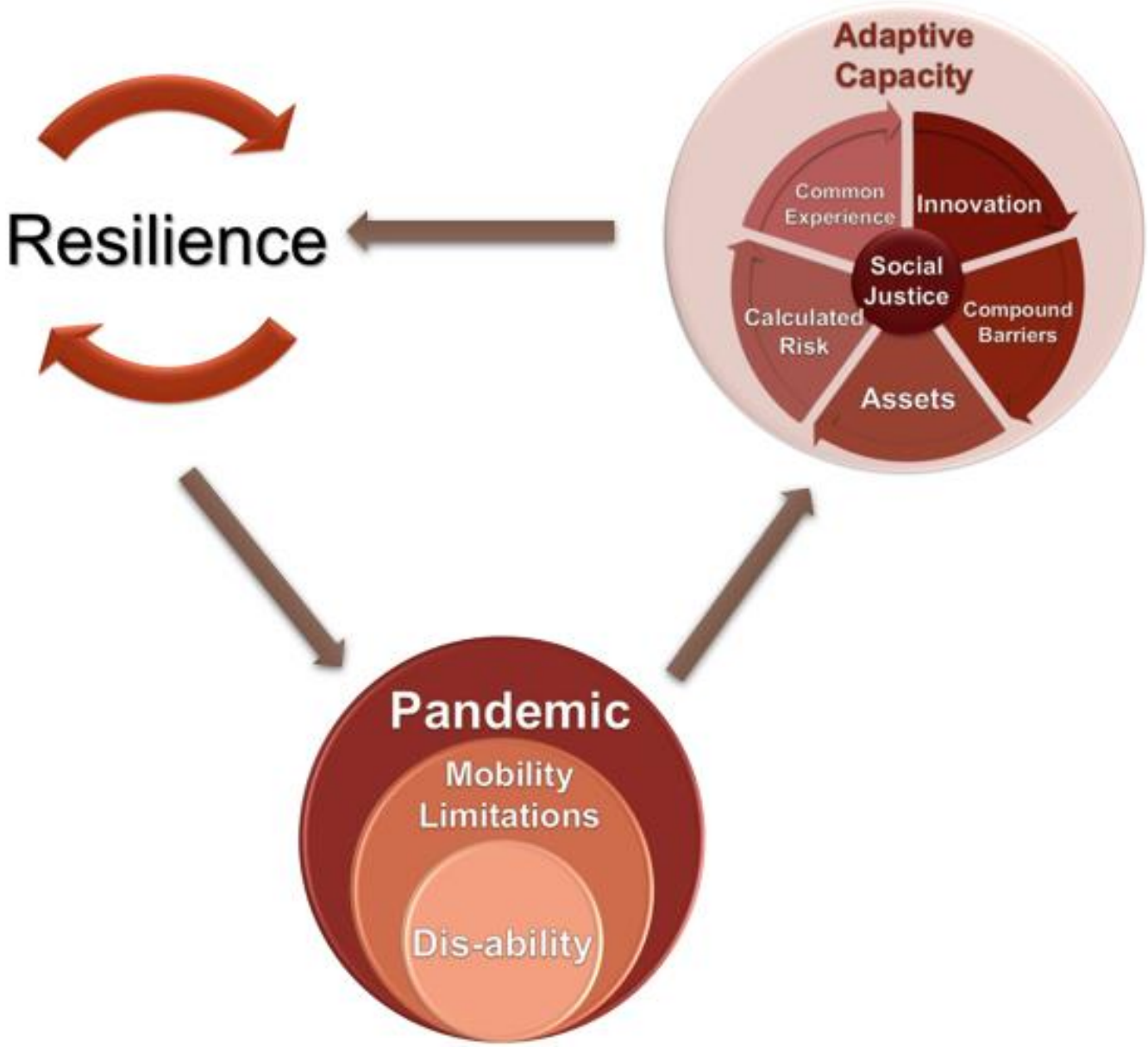
Abbreviations: ON, *Ontario*; QC, *Quebec*; UK, *United Kingdom*

The following six themes comprise the theoretical framework and lend evidence to the central theory, entitled: Adaptation is Not a Choice, It's a Way of Life. An explanation of how these categories

were interpreted is included within each section. The relationship between the theory and themes are displayed in Figure 2.

Figure 2

Adaptive capacity supports the ongoing process of resilience



3.2 Exacerbated Disability Challenges

For people with a mobility disability, social, physical, and economic impacts of COVID-19 exaggerated existing barriers that physical disability and social environments impose.

The Pandemic as Another Layer of Dis-ability

The pandemic was a dis-abling event for the whole-of-society. As such, COVID-19 compounded disparities people with disability experienced in their pre-pandemic lives. The barriers, magnified by dis-abling impacts of the pandemic, were described as a "double whammy" by some participants. One participant mentioned the impact of the pandemic on their recovery from amputations:

> My life going forward at that point, not only with an adjustment to what was now my new life but layered on top of that was the impacts of the pandemic and all of what it didn't allow me to do. Now there were also extenuating aspects of life, which were denied to me because of the pandemic. [P13]

The pandemic compounded the disabling and isolating experiences of another person:

> I do feel a bit isolated. Which is a fairly commonplace when you have a disability from stroke... from having a stroke to COVID coming- that just added to the dilemma. Because a lot of the rehab places were somewhat closed, and it was quite restrictive. So, for me as a disabled person, it was a double whammy. [P16]

Restriction to Care and Services

When public health restrictions impeded access to usual services, it increased challenges to managing mobility disability. Physical therapy was an important service; one participant explained

why it was essential to their life: “So I stand a chance of walking” [P2]. The pandemic increased difficulties in finding such support, and participants who could not secure services reported worsening of outcomes. One stroke survivor said:

> [Restriction to services] affected me because I do have achiness in my left side. And the physio[therapy] that I was doing was directed towards trying to gain that mobility back and get rid of the tenseness and all that kind of stuff. So yeah, COVID definitely played a part in not being able to get back to where we were heading. [P3]

COVID-19 heightened this sense of neglect; another participant described their experiences being denied critical post-stroke care: “In a really critical time of recuperation -it was a critical window- so I did as much as I could at home with intermittent help. But there was no one-on-one. [P16].

People with a mobility disability had heightened risk when they faced an increased lack of healthcare prioritization:

> I had a port and I needed it flushed. Well, when my nurse couldn't flush it, then what? And so I would go months where I would have to go to the emergency room to get it flushed. So I was raising my risk level of catching something because there was no alternative. And there was no alternative because they were locking everything down so that COVID didn't take over… So when [doctor] doesn't see her patients [with chronic conditions], who does she prioritize? [P8]

Some participants reported their options for healthcare locations were limited pre-pandemic as some labs or clinics lacked ramps, lifts, or other accessible features. This was mirrored during the pandemic, when participants saw a lack of universal design, limiting access to testing or vaccination centers. One person described an issue with the built environment that prevented

people with mobility needs from accessing preventative care:

> When I went in, I used my mobility scooter to go in [COVID-19 vaccination facility] and all on the levels, the paddle at the front door was very good when you went in. But when you were leaving, they wanted you to go out a different entrance or an exit from when you came into, and that exit- it was a heavy door, and it didn't have a paddle…. So in that case, they allowed me to out the 'in"-door, but they hadn't thought about that. I was surprised they didn't think about that. [P1]

Barriers to Participation

Changes made on the grounds of physical- distancing reduced the number of Para Transport buses, passenger capacity, or routes. People with a mobility disability commented how these restrictions kept them from participating in ways the general population could. One participant said: “It was an issue before the pandemic and definitely is still an issue. But when the pandemic hit, it became even worse- and I can't imagine that, but it did.” [P5]. They described how this increased exclusion:

> Let's say I want to do something that's just sort of fun, like take my girls out for supper- they aren't allowed on the bus. It's like, not happening. Honestly, that needs to be looked at. That's something really serious in our society that needs to be addressed. And through COVID, it's been awful, it's been non-existent. [P5]

Environmental Changes Compound Dis-ability

The pandemic affected mobility in indirect ways. Navigating new environments while managing disability was described as “hitting a wall” [P15], as stress from the pandemic had physical consequences. One participant shared how stress from navigating a virtual learning

environment without support had a cascade effect:

> It's not enough time. Because the amount of tasks you have to do is constantly piling. And since you're having issues that are related to yourself and your physical life, there's more and more there, and nothing's ever going to get accomplished…You have things to do and your health just ends up suffering. [P15]

For many participants, the closure of indoor environments, including pools, impacted the ability to maintain mobility. Although outdoor activities were an alternative, outdoor environments are not always a suitable option for people with disability. For some participants, inaccessible terrain or cold weather conditions were barriers. One participant who previously supported their mobility through programs at the YMCA said:

> I couldn't exercise because in the winter, you can only exercise indoors. And I could lift some cans or something like that, but as far as walking and that, that was pretty much zero for that because either the fitness places were closed or there was no way I can even step outside the door. When it's winter- I'm completely disabled. I don't trust myself to walk on the ground. [P5]

The economic environment created by the pandemic reduced access to places to support mobility. This participant described impacts of financial hardships from the pandemic:

> Going to that gym was excellent. I stopped about two years ago, about the time of the pandemic. I no longer go to the gym because of the costs associated with it. And I wish I could win a lottery so I could go back. [P2]

3.3 Assets Enhance Resilience

Although social restrictions during the pandemic were barriers to supporting health, some

people with disability did not experience barriers when they had the internal and external assets they need to support functioning and resilience.

External Assets

One person described how the Para Transport system in their city was an asset that supported their mobility during the pandemic:

> So on your app, you can do bookings. They accommodate your wheelchair or your walker, and they take you to a place and they make sure you're set and able to get inside. That's been great. Basically, you can do anything you need to do, really. [P16]

Participants also identified mobility devices as assets for overcoming transportation barriers resulting from pandemic restrictions. One participant described how their mobility device reduced risk of exposure through supporting independent living:

> [My scooter] has kept me off buses more. And I have a big issue with- every bus I should go on- on the side of it is a sign saying that masks are mandatory, but it's not enforced… [my scooter] does give me the freedom to go on my own, to do my own thing without relying on other people. [P4]

Similarly, access to Personal Protective Equipment (PPE) prevented participants from losing vital personal support services. One person living in a care home said:

> So extra care for wearing the mask, and especially for service providers and suppliers. And we have all kinds of people that come to us- pharmacy people, maintenance people, Personal Support Workers (PSWs), there's a whole group of different people that come here, so they have to take extra precaution and [PPEs] are what's keeping us safe and in good health. [P11]

Another safety measure was the COVID-19 vaccination. This similarly ensured one participant had consistent caregiving: “I had the same girls come in for years, so they were comfortable to begin with. And I knew they were vaccinated. They came in with super solid equipment on and I felt safe. There's no difference [in caregiving].” [P6].

Internal Assets

One person related the life-altering impacts of the pandemic to the life-changing event of having a stroke. They spoke about how resilience from managing their physical condition aided in their adjustment to the pandemic:

> I was able to relate my experience to the point in time where I had my stroke…I think my fondest recollection was when I walked into my psychologist’s office and introduced myself as [Me]-two because [Me]-one isn't coming back. And she just basically looked at me at that point in time and said, “you got it”. And that's basically what I've been able to carry forward. [P3]

Similarly, acceptance was a strategy another person used to cope with changes coming from both COVID-19 and multiple sclerosis (MS):

> The Friday group that I do with the MS society- it runs on the 12-step program. But I've changed it for MS. In other words- we have MS, we can't change that, but there are things we can do about it, but we have to accept it. It's all about acceptance. If I find myself getting anxious and stuff like that, then I just think- 'God grant me the serenity to accept the things I cannot change, change the things I can, and give me the wisdom to know the difference. And the wisdom that I know is that I cannot control that there is a pandemic, but I can control how I react to the pandemic. [P9]

Participants identified assets that made them feel empowered. Feelings of empowerment reduced fear during the pandemic and encouraged participants to continue engaging in health promoting activities. One participant said:

> That particular gym has a lot of people with mobility issues. So, it's always encouraging because of the little bit of socializing in the change room. Obviously, co-socializing with my trainer is not the same as it used to be, we wear masks and so on. But it's empowering. [P1]

Finally, having bravery was an empowering asset that reduced burdens of the pandemic. One participant described a phrase that helped them deal with the pandemic:

> Don't try to be a hero. Asking for help is brave. It's brave, it's smart, it's good for your family. It takes the pressure off them and it improves your lifestyle. So especially with MS, it would help people with fatigue, with worrying about having a shower and falling or not having proper nutrition. Giving up that little piece of independence is very small. It's more empowering to ask for help. [P9]

Virtual Connection and Remote Services

Online modes of ordering groceries, refilling prescriptions, or shopping were assets. For one participant, a remote service that delivered meals was supportive when they faced challenges accessing groceries and making meals independently during the pandemic:

> I'm tired at night. I can't stand. It's so hard to cook. And [family members] found this thing called 'WeCook' and six meals come fresh once a week, three minutes in the microwave and they are healthy and they're delicious. I'm now eating every night. [P9]

Strategies to continue activities remotely were assets for coping with changes in activities

and lifestyle. One participant shared how a disability organization kept members active during the pandemic:

> I get the calendar [from the organization] and then one of the months, it said that they would deliver it to the house with the supplies if we wanted to participate. I signed up and every month they bring me a canvas and a ceramic just to paint. And they have Zoom classes. Once a month I have an art project… there was no way that I was going to learn another art form until they sent this out and said, “Hey, we'll do it by Zoom. And you can do it”. [P8]

Contextual Factors

The context in which a resource or infrastructure was considered an asset depended on its ability to support equity. For example, Para Transport was both an asset and barrier during the pandemic. One participant described the context in which the Para Transport system (often referred to as ‘Wheel-Trans’) in their city could help them overcome restrictions:

> They don't discriminate on what the task is at hand. They're just interested in getting to the place that you need to be…I use Wheel-Trans for five hospital appointments per week, which is really mostly rehab…if I was to go to a mall, have a coffee or something, or Starbucks, I would feel guilty. And I said that to the lady when I had the assessment, I said, “I use them mainly for a medical appointment”. Oh, she said, "We don't discriminate what you use them for. It's there for you to use, whatever you need to use them for because there's no other way to get there”. [P16]

In contrast, the Para Transport system was not an asset for a participant in a different city. They shared their Para Transport system, which was heavily restricted during the pandemic, was

discriminatory of what individuals needed the service for did not as it did not prioritize the social needs of people with disability:

> They would only go to the hospital. If you call and you were going somewhere else, they would make a judgment on whether that was important enough because they had other patients that needed to go to the hospital, so that takes priority over everything else…They need to take people on things that are enjoyable too. Disabled people need to see movies occasionally, disabled people need to get out and go see their favorite local act or something like that. [P5]

Continued Care

Participants indicated having continued services throughout the pandemic was an asset to overcome restrictions to maintaining health. Moreover, the support from organizations or government social services to ensure the continuation of such services was impactful:

> The PSW's are from Care Partners. And the therapy is March of Dimes. I don't pay for it… it's a service provided by the government. It was just for range of motion to keep the muscles that I don't use- which is my left arm and my leg- just to keep the muscle moving so it doesn't get passive. [P6]

A continuum of care was vital to people with a mobility disability for maintaining health and protecting their quality of life. Two participants described what it meant for them to have continued physical therapy during the pandemic:

> No changes [with physiotherapy]. Otherwise, I would stop moving completely…my health will go down drastically, and I will not be able to live independently. So whatever care I get here, it is essential to my wellbeing. [P12]. [Physiotherapist] is a superwoman and very

encouraging, very wise. So, I always feel like she's not just working on our bodies. She's working on our spirit too. It’s great. [P1]

3.4 Taking Calculated Risks

Participants took calculated risks during the pandemic to protect their quality of life. This showed they were not the most vulnerable nor scared segment of the population during the COVID-19 pandemic, which was a common media stereotype further marginalizing people with disability.

One participant expressed that taking calculated risks meant they did not stop “living” during the pandemic just because there were restrictions. They shared their volunteering experiences:

> The other [volunteers] are afraid to come back into the hospital environment to do what we do and I feel bad for them. I've tried talking to them, letting them know that if you do all the precautions, you're safe. Patients are safe. But some people are so negative now because of the pandemic and they’re overcautious, I feel. And that they're missing out on a lot by not living. [P4]

Don’t Label me as Vulnerable

Some participants stated that they had policies made for them when they were seen as incapable. Some measures put in place to protect ‘vulnerable’ populations inadvertently made people more vulnerable. This included rigid distancing measures at long-term care homes:

> If you live in a facility and you stop all of the activities, what's left? You've stopped visitation by my family so I have no one to talk to. I have nowhere to go or nothing to do. And you want to keep me in my room so I don't spread the disease. So what am I supposed

to do for days and days and days and days, because that's essentially what it was? [P13]

All participants acknowledged their health condition contributed to increased risk of clinical complications; however, they did not want to be defined through their risk. In fact, almost all participants reported being healthy during the pandemic and shared their capability to reduce risk. One participant wanted to focus on their abilities during the pandemic rather than their disability:

> I find most people in my age category feel sorry for themselves and stay home and wallow in their pity. And I'm not like that. I like to be out in the community. I like to be sharing. I like to be very active. And my serious health issues have never held me back. [COVID-19] may change my schedule a little but never held me back. [P4]

Participants voiced that they were able to protect themselves when they had access to tools. One participant said that their ability to keep themself safe protected against feeling vulnerable:

> I don't think [I'm more at risk for COVID-19] because I'm careful, I follow the rules. I've had my two vaccines so if I do get it, I probably won't get it as badly as I would if I didn't have my vaccines. No, I don't worry about it because I follow the rules and I listen to the science and I'm careful about who I see and what I do. And if I get COVID, then I do. But I could get the flu. I could get a cold. I could get anything. I don't worry about that. [P9]

Weighing the Pros and Cons

Participants took calculated risks and were not afraid during the pandemic because there was more weight in losing other aspects of life. Many shared how they continued doing things that were important to their lives during the pandemic; for one participant, this was to see their family:

> Well, when COVID was at its worst…at Christmas, we made a little exception. What

> happened was we sat at opposite walls and then we put the garbage can in the middle and we threw our paper in there. And we all wear masks the whole time. But there's a slight risk with that for sure, but what sort of events do they think a disabled person can do? There's only so much that we can do, and you don't have those things anymore. [P5]

For another participant, this was to maintain mobility through physiotherapy: “I weighed the pros and cons. The pro was getting the back pain under control. The con was -because of the location of this place- I had to walk through all the sick people waiting for bloodwork.” [P2].

Another person emphasized the value they place on their mobility: “From not being able to stand 10 years ago to be able to walk is a great achievement as far as I'm concerned.” [P7]. They described why they did not let the pandemic hinder them from working towards their goals: “No, I’m not vulnerable. I can do anything anybody else can do.” [P7].

Mental health was important to many participants. One person expressed how taking certain risks during the pandemic protected their emotional wellbeing:

> When I'm not active, I have to be very, very careful of depression. Being active saves me from that… [My family] said, "Mom, you shouldn't be there [volunteering at the hospital], you're taking a chance". I said, "No, I don't feel I am because I use all the precautions I need". I know that I'm higher risk. But I feel very confident because I'm very protective of my own health. I have to weigh my mental health along with my physical health. And my mental health would have suffered greatly if I had stayed any longer at home. And [volunteering] is a big part of my life and I get great satisfaction from it. [P4]

Disability Rights

One person stated that having a condition, being an older adult, or being seen as more

vulnerable than the general population did not justify rigid lockdown measures that did not take people with disability into account:

> As a society, we should be disgusted that we allowed it to happen. I don't care how robust an infection is out there, how robust a pandemic is out there. You have to find a better way. We cannot ever repeat that history because it was inhumane. We have prisoners in the penal system that we treat better than we treated the seniors during the pandemic. [P13]

Participants chose to take calculated risks because they expressed it was their right to maintain a quality of life during the pandemic. Some said taking risks was necessary because pandemic measures were more "crippling" than the threat of the virus itself. One participant said:

> My extracurricular is very low as it is. This pandemic has taken my social life and threw it out. There's no family, there's no friends' support…And sometimes you just need help. You need to get through it. But the government has failed to realize that there are a whole lot of people who would choose this risk than this fallout from [pandemic restrictions]. [P8]

The "medical perspective" that drove many public health decisions did not consider the rights of people with disability and how they would be impacted. For one participant, public health decisions took away their opportunity for rehabilitation, which would have increased their quality of life:

> The pandemic impacted my rehabilitation, and my rehabilitation was not the same as someone who would've experienced it six months before that. They would've had a much more robust, much more widespread experience of very different activities, of different opportunities that would've been available to them that just weren't available to me because things were closed. The infectious control restrictions were very prohibitive in the early stages of COVID so they aired on the side of caution, which from a medical perspective is

a great place to be. From a lived perspective, it's the worst place to be. [P13]

3.5 Common Experience

In some ways, the pandemic exacerbated the differences between people with disability and able-bodied people caused by existing barriers. However, living under pandemic restrictions meant that the general population and people with disability also shared similar experiences.

Not a Separate Group

People with disability expressed they are equal members of society who had the same needs as the general population during the pandemic. One participant described the whole population's struggle during quarantines:

> We're all going through a lot. And I think we all needed a little bit more help than we led on and I think it all goes back to that conversation we had earlier about humans being social creatures and we need that social contact. [P13]

Recognizing this common experience may increase understanding for dis-ability experiences:

> If the pandemic was finished today… the 'new normal' would be awareness, for sure. Awareness of other people…so more than ever, we need to be there for one another and to be able to reach out to people who are somewhat isolated, disability or none. Just to help you get through that and realize that we're still connected. [P16]

Reducing the Difference

Because people with disability were not a separate group experiencing restrictions, participants stated that stigmatizing language needs to be addressed to reduce the difference:

> You'll get instructors and physiotherapists talking about [horseback]riders, they refer to

> them by their diagnosis or their disability…the term, "disabled person", will not pass my lips, so it will be "a person with a disability"…I really see it as important. We need to educate people. It does reflect an attitude. We know that, and the attitude can extend from a benign disregard to absolute violence, and history has proven that. [P1]

Societal changes affected attitudes towards people with disability during the pandemic. This includes attitudes around different abilities, such as mobility to put on face masks:

> I don't have the ability to put on a mask myself nor do I have the ability to take it off myself. So, if I want to go out somewhere, I need to ask and say, “Can you put on a mask for me?”. [P11]

This affected the general public’s perception of people with mobility limitations: “It's more of a challenge because I cannot put on my mask. But people tolerate me because and I've had two shots and I'm being very careful.” [P12].

Despite this, participants believed the pandemic was an opportunity to recognize people with disability were not that different from the rest of society, as everyone faced emotional hardships from the fallout of the pandemic. They suggested that all of society needs to be supported during a time of dis-ability, irrespective of functional abilities:

> If you're home and you're not out and you can't do things because of your disability, the media should be spreading good news and making people feel better, provide different ways or different places that they can go where they feel safe. I've seen so many of my friends -not disabled- that are so mentally… their mood and their depression is increased. Because they haven't stepped out of their homes. [P4]

3.6 The Role of Increased Innovation

Innovation that helped the population overcome limitations imposed by COVID-19 indicates there are solutions to the accessibility problems that people with a mobility disability have traditionally faced.

Filling the Gap

People with disability are used to the "huge gap" [P4] in access to reliable healthcare as compared to the general population. During the pandemic, innovation proved to reduce some of those gaps. For example, telehealth was an important innovation that reduced usual burdens of travelling for those with mobility limitations:

> [Para Transport] either comes extremely early or extremely late, and I end up being stuck for hours if I have to get to an appointment. And in some ways, once we got the telephone thing figured out this year, we finally have the portal to write to [doctor] and she writes me back. Or I phone and ask for an appointment and she calls. That way, I don't have to go to her. [P8]

People with disability pointed out that they should be solicited for their input to understand what is important to their health that can be addressed through innovation. For example, advancements in information systems provided the public with rapid updates on the virus; a stroke survivor and transplant patient noted as this is needed for the general population, it is needed for people with disability for them to make informed health decisions:

> I want statistics for disabled people. So, I want to know how many transplant recipients are there in Canada?... just break it down for the disabled people, how many people have gone? And how many have died? How many are recovering? Because that would really make a difference as to how serious I take it in terms of what sort of precautions and what sorts of things I do and don't do. [P5]

Some participants indicated innovation can fill the gap in disability inclusion. One person described how new methods for meeting needs during quarantine can increase inclusion:

> So if you ask the question, just in terms of mobility challenges-are there solutions that were enhanced by the pandemic? Then I would say I think that the pandemic has helped in that regard, has helped us realize that we can have some of those services delivered to our door, that we can take advantage of working from home. I think that the pandemic has been very good to us that way. [P13]

Implementing Change

Participants shared instances where the pandemic showed new solutions, such as funding, are possible and can be implemented to support those facing restrictions, whether from health conditions or the environment:

> People just have this idea that [people with disability] are inconvenient and it's too expensive to accommodate them… But now suddenly everyone can't go to the restaurant 'cause of its financial difficulties during the pandemic. They found the money to save it. But I'm thinking like, are they going to use any of that $50,000 to make that place accessible? [P1]

Other than funding to increase the accessibility of infrastructure, the pandemic made it possible to implement more accessible modes of professional or social participation. One person spoke about remote conferences and how such innovation should be sustainable:

> This year for the first time, we had an online virtual symposium, and it was great…when we were viewing the live presentations, there was a real sense of connection, and you could ask questions, there's a little thing where you can type in your question…in a situation like

this [pandemic], where we haven't been able to travel as freely, [the pandemic] just allowed us to do something that we otherwise couldn't do. So I think it may continue like this. [P1]

This shows that innovation is not only be possible but should be maintained post-pandemic to increase the accessibility of usual structures.

Despite experiencing challenges, many participants believed the pandemic could be "a good thing", as it could encourage collaborative implementation of solutions:

So, to me, this situation that we've been involved in for the last 18 months or whatever could be a good thing. Once everything's back out of it, people that were involved can open up their eyes a bit more to be able to be more inclusive. [P3]

3.7 Social Justice

Participants' narratives indicated innovation that enabled access was only spurred by the pandemic when it was needed for everyone. As such, participants' experiences highlighted instances of pandemic-induced social justice as well as areas that continue to lack social justice.

A Global State of Dis-ability

During the pandemic, societal adjustments were made to increase access when the whole population needed it. One person who benefited from online work shared that this was the normative attitude during the pandemic and may be the norm after it:

The pandemic has proven to employers that you can trust your employee to be at home and still give you an honest day's work. It's forced that mindset change, so I think that's good. And it's a win-win because they think of the money that businesses can save, not having to pay for rent for hundreds of office spaces in downtown. [P13]

Another participant explained that having a disability is something that “makes us sick”, which the population has not focused on until the whole-of-society became at risk of becoming dis-abled:

> I've already lived my life like there's a pandemic because I have to be so careful to wipe everything down, even if I go to the grocery store. After all, there are a lot of other things that make us sick that we're not focused on. And so, I've always had to wipe down my groceries. I've had to sanitize my hands. I've had to wipe down the table when we go to sit down somewhere. So not much changed in that way for me, except that other people were more hyper-focused on it. [P8]

They shared that their disability experiences had not changed during the pandemic because they were used to a lack of accommodations; it was able-bodied people who were new to dis-ability.

Other than behavioral changes that the whole-of-society had to adopt during the pandemic, adoption of innovation to overcome physical-distancing barriers became the norm. However, there were still instances where innovation proved to be solutions to the majority, leaving out people with disability, whose needs were not considered in the implementation of innovation. One participant spoke about challenges they faced in the context of new technology for distanced learning:

> So the onus again is on you to give feedback to who? The school? The owning school of that technology? The manufacturer? The mental health stress, the emotional stress, with the pandemic… the onus again is on [people with disability] to insert themselves somehow into the lives of people who don't have time for them. [P16]

3.8 Theory: Adaptation is Not a Choice, It’s a Way of Life

People with disability's experiences of barriers, assets, inclusion, and social justice indicate they have "*already lived like there's a pandemic*". This supports the theory that *Adaptation is Not a Choice, It's a Way of Life* for people with a mobility disability to remain resilient when faced with dis-abling circumstances. Many participants spoke about the parallel between everyday restrictions and pandemic restrictions: "[Pandemic restrictions] don't impact me very much because I've cut back quite a bit already. Like, I'm limited in where I can go on my scooter. So, I don't think [the pandemic] is going to change that much for me." [P4]. Therefore, we theorize that people with a mobility disability are constantly adapting in their everyday lives and in a disaster setting.

Participants' experiences indicate the pandemic was a tipping point that underscored the role of adaptive capacity. Universal impacts of the pandemic, such as isolation, were an opportunity to understand the importance of adaptive capacity in managing dis-ability. One person's adaptive capacity was seen in their ability to "multi-task"; they described how this strength helped them to adjust to negative life situations:

> I'm disciplined, so that helps me a lot. Because if you're not so disciplined, or able to focus on the positives in life, or be able to understand what is happening- you can get very depressed…so that discipline has been very beneficial. And it's very important to keep that in check. And therefore, it comes back to isolation. Because if a person is more isolated due to the pandemic, people can get trapped in one's own thoughts. And sometimes that's not always a good place. So, I think those things help you in your everyday life and the pandemic because you can multitask, you can have a few things going on. Keeps your mind active when you're busy- when you're trying to operate life as much as you can in some level of normalcy within the confines of your disability. [P16]

Other participants similarly showed that "operating life" with a disability and navigating life during the pandemic are not so different; they require the same resources and adaptive capacity. In one person's narrative, they have "*already lived like there's a pandemic*" because pandemic restrictions exacerbated usual challenges to securing personal support workers: "I've done so much in my life and I've seen so much that everything is just like, "yeah, whatever, I'll take care of it" [P11]. At the same time, they dealt with these pandemic challenges using the same resources they have for maintaining everyday resilience:

> My entire life was, you need something, you go and get it, or you make it.…the thought process is still ingrained in me that if I need something, I need to go and get it. [During the pandemic], I helped a few folks to find information. There was all the big hype about finding PPEs, few people can find PPEs. So, I pointed them in directions where you could find PPE, that kind of stuff… [this outlook] has helped me throughout my entire life. [P11]

Strength from disability supported the adaptive capacity of other participants as well. This was true of both those with lifelong conditions and those who acquired a condition close to the beginning of the COVID-19 pandemic. One participant who had amputations before the pandemic started spoke about learning to manage the impacts of disability coupled with the pandemic through adaptive capacity:

> I shared some of that concern about being that person that stuck out, and a little bit about what I described to you earlier about fumbling for my wallet and fumbling for my bank card and stuff... And the psychologist said, "But maybe they're thinking, "oh my God, look at how wonderful that is. That person is comfortable enough and capable and confident to be out and about in society and doing all of those things and being independent". And I thought, "you're right". It may be- how I will deal with [disability] has more to do with me

than it does to do with how society is receiving me. It's a mindset I'm working on. [P13]

Their adaptive capacity experiences resemble other people with disabilities', whether newly disabled by a condition or not, who voiced "Failure is not an option, right?" [P11].

As the pandemic reflected exiting inequities that contribute to dis-ability, it consequentially revealed the phenomenon that *adaptation is not a choice, it's a way of life*. As such, COVID-19 was a magnifying glass through which people with a mobility disability's usual experiences of adaptive capacity could be viewed: "I had medical professionals tell me that I helped them just because they said, "If you can go through what you went through on top of a pandemic, then I can go through a little bit more myself"." [P13].

4. Discussion

Changes during the pandemic magnified settings of inequities where people with a mobility disability experienced restriction, causing dis-ability. However, changes also brought awareness of the capabilities of people with disability and assets that can reduce barriers. Experiences of dis-ability during the pandemic revealed how the pandemic compounded existing barriers. They also uncovered important assets that enhance resilience and raised awareness on true risks and vulnerabilities people with disability experienced. Common dis-ability at a societal level shaped views on disability and innovation, and emphasized socially just measures to mitigate dis-ability. In aggregate, these factors shaped the adaptive capacity of those with a mobility disability. This in turn stimulated a cycle of resilience employed to lower societal barriers to inclusion, both in everyday settings, as well as that experienced during the COVID-19 disaster (Figure 2).

Adaptive capacity is the ability to adaptively respond to external stressors through active coping (Jakku & Lynam, 2010). The ability to modify characteristics or behaviors to cope better

to changes supported an ongoing process of resilience. While adaptive capacity is a cultural process of those who experience disability, resilience is a personal, unique experience to the individual. We found resilience was seen in each person's unique asset profile and how they mobilized their assets to reduce dis-ability and disaster risk. Disaster resilience was also shaped by each participant's individual way of life and they ways they adapted it to meet their needs during the pandemic. Their ability to withstand adverse impacts and embrace positive changes spurred by COVID-19 showed resilience was not static but was ever-evolving to prepare people with disability for unprecedented situations. People with a mobility disability showed that living with disability meant there is no choice but to work towards resiliency every day; *it's a way of life* when faced with restrictions to preserve quality of life.

Restrictions during the pandemic magnified existing accessibility challenges contributing to experiences of mobility disability. Pre-pandemic, people with a mobility disability faced health inequities in securing services to meet their needs. Accessible facilities to support mobility, specialized services, and consistent caregiving services were sometimes inaccessible, either physically or financially.

People with a mobility disability are disproportionately impacted by the socio-economic and health consequences of a disaster when environmental changes compound inclusivity barriers (Croft & Fraser, 2022; United Nations, 2020). During COVID-19, this was apparent when the rearrangement and reprioritization of the public health system impeded access to Personal Support Workers (PSWs), health services (i.e., rehabilitation), or environments to support mobility (i.e., fitness centers or pools).

Furthermore, disruption from the pandemic affected the ability for people with a mobility disability to participate in society. Being denied timely health services, such as rehabilitation, can

have lasting impacts on the functional abilities and occupational health of people with mobility limitations. Changes to the public transportation system during the pandemic compounded existing systemic issues with Para Transport in certain cities, which further hindered people with disability from social participation opportunities.

Our findings that the pandemic compounded disability challenges is consistent with previous studies reporting people with disability experience negative disaster-related consequences because of disparities in the existing socio-economic system; this is caused by an interplay between people with disability's social determinants of health and the built environment (Campbell et al., 2009; Pakjouei et al., 2018). Therefore, groups become 'high-risk' based on disadvantages resulting from the aggregated cultural, economic, and societal factors shaped by a disaster (Stough et al., 2016).

People with disability are also disadvantaged in crisis settings when there is a lack of preparation, planning, or recovery efforts that recognize the need for accessibility (Quail et al., 2018). In some cases, there is discrimination on the basis of disability when resources are limited or people with disability are perceived as needing complex services (King et al., 2019). This may place people with disability at an increased risk for being further dis-abled during a disaster.

Disruptions from the COVID-19 pandemic increased dis-ability when it exacerbated barriers. However, when supports were in place to support resilience, people with a mobility disability did not identify as being dis-abled. This shows that an 'assets approach' can be used to understand the disaster risk of people with a mobility disability during a pandemic, which focuses on salutogenic resources of individuals, communities, organizations, and systems, rather than on deficits (Antonovsky, 1996; Morgan & Ziglio, 2007). Rather than emphasizing on the causes of disease (pathogenic approach), focusing on salutogenic resources emphasizes factors that promote

health.

Asset literacy is defined as an understanding of what one's assets are and how to mobilize or access them (O'Sullivan et al., 2014). In a study exploring the assets stroke survivors and caregivers deemed useful when responding to a disaster, O'Sullivan et al. (2017) proposed interventions to enhance asset literacy support an all-of-society approach to disaster risk reduction. In the current study, people with a mobility disability similarly identified assets, described how they facilitated empowerment, and shared how they could mobilize them in the face of pandemic restrictions. Understanding how these protective factors shape adaptive capacity will have utility in informing future pandemic interventions that increase the availability of assets and promote their use in an emergency context.

Securing a continuum of care, even during restrictive phases of the pandemic, was an asset protecting against mobility and health declines. Assets to reduce risk increased the access of people with a mobility disability to sustained services; this included personal protective equipment, vaccinations, and face masks. Acceptance of the pandemic empowered people with disability to continue health promoting activities and supported adaptive coping.

The pandemic highlighted the role of infrastructure in decreasing barriers. This is in line with other work that has specifically examined Para Transport during COVID-19 (Ashour et al., 2021). Stable and available Para Transport systems during the pandemic enhanced individuals' mobility, independence, and ability to meet needs. Remote platforms, such as remote delivery services, were other infrastructures that allowed people with disability to access resources whilst reducing risk of exposure.

Fraser et al. (2016) found a prominent policy stereotype in the media to be vulnerability, whereby those with a health condition are portrayed as consistently needing help. This affects

legislation as it frames “vulnerable” individuals as needing protection, which can comprise their autonomy (Fraser et al., 2016; Lagacé et al., 2021). All participants respected stay-at-home orders and understood they were necessary. However, it was when their disability rights were not acknowledged that protection from the virus became damaging.

People with a mobility disability did not want to suffer a loss in their quality of life by being protected as a ‘vulnerable’ segment of the population. Despite media portrayal, people with disability did not perceive themselves to be the most vulnerable group to COVID-19 just because they have a disability. As such, people with disability took calculated risks to continue activities that are important to their lives. This included volunteering, seeing loved ones, and maintaining activities to support mobility.

The American Psychological Association (APA) cautioned against conflating health status with disability, as many people with disability are healthy (American Psychological Association, 2020). Although many people with mobility limitations have underlying acute or chronic health conditions increasing their risk of severe symptoms associated with COVID-19 infection, the International Center for Infectious Diseases (ICID) made an important distinction between *medically at-risk* and *functionally at-risk* during a pandemic (International Centre for Infectious Diseases, 2010). Disability is not the sole determinant of health, nor should it be the sole determinant of disaster risk.

Public health decisions do not protect every segment of the population when the general population does not understand the true risks of people with disability. As a consequence of this, many people with disability, especially those living in long-term care homes, lost access to vital services, assistance, or loved ones, due to closure of in-person activities or travel restrictions. Beyond risk to the coronavirus, people with disability were at increased risk of physical, social,

and mental health declines when limitations restricted their quality of life. This aligns quite closely with negative health outcomes experienced by older adults during the pandemic who were labelled "vulnerable" and were socially isolated (Fraser et al., 2020; Simard & Volicer, 2020).

The pandemic highlighted the differences between people with a mobility disability and the general population driven by systemic barriers. At the same time, it brought awareness to the similarities between their pandemic experiences. Common experiences shared by both groups included social isolation, health concerns, and lack of access. The solutions to these problems were also the same, innovation to overcome barriers (Croft & Fraser, 2022; Shakespeare, Ndagire, et al., 2021).

Digital transformation was a particular innovation that expanded universal design during the pandemic. COVID-19 incentivized policy makers and leaders to move from the slow "reimagining" of healthcare to rapid "recreation" of entire health systems (Hollander & Sites, 2020). This includes development in virtual telemedicine platforms, digitalization methods for therapy, and infrastructure to improve remote patient care.

Furthermore, advances to combat social isolation increased inclusion for people with mobility needs. COVID-19 prompted communities and programs to rethink effective solutions for "distanced connectivity" (Smith et al., 2020). The goal of distanced connectivity is to maintain and repair the qualities and functions of physical social connectedness through novel telephone, computer, or smart device methods. The impact remote tools made on people with a mobility disability indicate that during and post-COVID-19, societies should embrace technology as a tool for social change.

Pre-pandemic, the lack of progress made in reducing the health inequities can be explained by a trend known as 'lifestyle drift'. This occurs when initiatives for tackling inequities in health

start off with a social determinants ('upstream') approach and then are reconfigured 'downstream' as a matter of individual behavior change (Carey et al., 2017; Williams & Fullagar, 2019).

Lifestyle drift places the responsibility of accommodations on the person who has the disability. However, the global state of dis-ability during the COVID-19 pandemic resulted in systemic, upstream changes. Innovation allowing the population to overcome barriers removed the often-burdensome task for people with mobility limitations to travel to receive healthcare, attend meetings, or engage with peers. Moreover, programmatic accommodations for people with health concerns or illness were normalized, as managing health conditions was recognized as being a public health concern rather than a personal problem. The changes in attitudes and strategies increased the adaptive capacity of people with disability during the pandemic, contributing to risk reduction and empowerment. Social justice is the tipping point for change to ensure inclusive strategies continue to be developed to meet the accessibility needs of all people.

People with a mobility disability have criticized the normative assumption that functional limitations can be managed through sufficient personal motivation (Finkelstein & Finkelstein, 2020). This is a view that disregards the social and physical barriers that they must cope with daily. While people with disability have adaptive capacity to cope with the impacts of dis-ability, they should not need to be resilient through personal resources. The pandemic emphasized the need to shift the onus for change to support systems to safeguard the safety and inclusion of people with disability.

Community resilience is a concept that shifts responsibility for resilience to the systems that keep people physically and psychological healthy during minor crises and major disasters (Wulff et al., 2015). As compared to the tradition preparedness approach, community resilience encourages the action of stakeholders to build preparedness while addressing underlying social

determinants of health (Wulff et al., 2015). This perspective avoids categorizing disability populations as inherently vulnerable or at-risk, but rather, considers the factors that comprise their adaptive capacity during a disaster (U.S. Department of Health & Human Services, 2020).

Many people with a mobility disability voiced that the pandemic could bring positive social change. COVID-19- as it illuminated disabling social circumstances (such as barriers to health care) as well as increased accessibility of services (such as telehealth or virtual learning)- has inadvertently been an opportunity to foster inclusion and expand the definition of 'dis-ability' beyond the wheelchair, cane, or crutches. Disablement from existing structures was met with accommodations on the population-level during the pandemic. Moreover, it was met with a humanitarian resolve to take timely action to increase the quality of life of those living under restrictions. The experiences of people with disability show that such systemic action can make significant impacts on the lives of those living with disability or chronic conditions; embracing community resilience and an assets-approach supports population-health, disaster preparedness, and equitable disaster responses.

5. Limitations and Future Directions

This study consisted of a convenient sample of participants with self-reported mobility disability. This may have excluded individuals who are less comfortable disclosing their functional abilities. Data was collected from 16 participants, most of whom were Caucasian. Our theoretical framework may not directly apply to people from non-western cultures. Due to the virtual nature of data collection, this research may have left out those who are unable to or do not have access to virtual communication platforms (i.e., computer) or a telephone. Conducting the interviews in English may have limited our sample diversity.

While we aimed to capture the narratives of people with disability across Canada, we

conducted recruitment mainly in Eastern regions; therefore, we may have missed the experiences of those in other parts of the country. As such, future research should expand sampling to refine our understanding of experiences of people with a mobility disability with health and social systems during disasters. It would be of value to explore the experiences of those with intersecting identities, to understand intersectional factors impacting adaptive capacity.

6. Conclusion

Following a grounded theory approach, we constructed a model to explain the way people with a mobility disability have experienced the COVID-19 pandemic: *Adaptation is Not a Choice, It's a Way of Life*. During the pandemic, physical, social, and economic outcomes of the pandemic reduced access for the whole-of-society, introducing dis-ability to the population and exacerbating existing challenges for people with disability. At the same time, when people with a mobility disability had internal and external assets, they had the ability to reduce their risk, were empowered to continue health promoting activities, and maintained their quality of life. These experiences of navigating pandemic life under social restrictions and utilizing assets to lower barriers was common to both the general population and people with disability. The role of adaptive capacity in overcoming dis-ability barriers was acknowledged when the whole-of-society faced novel challenges.

To plan an inclusive disaster response for future waves of the current or future pandemics, society must consider systemic barriers contributing to the risk of people with disability, assets for resilience, and the role of adaptive capacity. The COVID-19 pandemic demonstrated solutions to people with a mobility disability's usual accessibility challenges are possible. Moreover, implementing strategies to reduce health inequities should be made on the ground of social justice to promote both every day and disaster resilience.

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CHAPTER 4: MANUSCRIPT II: Recommendations Paper

Recommendations to Support Pandemic Resilience Among Persons With Mobility Disabilities

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ABSTRACT

Introduction: Globally, the COVID-19 pandemic underscored barriers faced by people with a mobility disability and how these barriers affect their adaptive capacity during disasters. There is a need to examine disaster risk and resilience of this population, as it intersected with the social determinants of health during the COVID-19 pandemic. People with disability are often an afterthought in disaster preparedness, response, and recovery planning; therefore, the aim of this research was to explore potential strategies to support resilience among people with a mobility disability, based on their lived experiences.

Methods: We conducted semi-structured interviews with 16 people with a mobility disability in Canada. Following inductive grounded theory methods, we mapped thematic findings of the recommendations onto the responsible sector that would implement improved strategies.

Results: Concerted pandemic response efforts from public health and government are crucial during a pandemic to maintain standardized policies, monitor the demand for health care resources, and strengthen adaptive health systems. Unified action from stakeholders can ensure persons with disabilities are prioritized in rollout plans, such as mass vaccination efforts or implementation of emergency response benefits. People with a mobility disability recommend public health authorities consider accessible formats of risk communication and continued collaborative care, to ensure pandemic measures are inclusive. Organizations similarly have the responsibility for ensuring a continuum of personal support services and recognizing true essential needs. This necessitates pre-pandemic planning to address provisions for adequate staffing during a crisis and allocation of resources (such as personal protective equipment) to people with disability and their caregivers. Additionally, providers and staff should be trained on accessible digital infrastructure (such as telehealth), the needs of high-risk groups during infection outbreak,

and how to maintain their own wellbeing to enhance disaster preparedness. In the future, building hybrid models for health services would balance in-person and virtual opportunities for healthcare, education, work, and activities.

Conclusion: Inclusive systems are needed to support accessibility needs, pandemic resilience, and adaptive capacity. The government, healthcare sector, and organizations must work collaboratively to ensure the sustainability of innovation during the pandemic, and accessibility needs of people with a mobility disability are met in future pandemic response.

Keywords: health systems, disability, COVID-19, disaster preparedness, emergency response, recommendations

1. Introduction

Adaptation of various aspects of life during the COVID-19 pandemic created a shift in society, often referred to as the "*new normal*" (Goggin & Ellis, 2020). For people with a mobility disability, *new normal* is shaped by the adoption of behavioral changes (such as physical-distancing or hygienic measures), as well as broader economic, social, and public health impacts (Senjam & Singh, 2020). The capacity of people with disability to adapt to unprecedented changes must be viewed through an intersectional lens (O'Sullivan and Bourgoin, 2010). Adaptation, and hence resilience, is influenced by disability etiology, personal capabilities, accessibility within society, and preparation for disaster-related changes (Finkelstein & Finkelstein, 2020).

More than 2.7 million Canadians over the age of 15 had a mobility disability in 2017 (Statistics Canada, 2020). The COVID-19 pandemic underscored the barriers that people with a mobility disability experience daily. For example, people with a mobility disability in Canada reported they face a lack of workplace accommodations and accessible transportation, and have unmet needs for physiotherapy (Statistics Canada, 2020). These inequities were compounded by pandemic impacts, including physical-distancing policies (Yang et al., 2022). However, for pandemic response measures, such as lockdown-protocols, to be disability-inclusive, they must consider the specific needs of people with a mobility disability. In particular, the intersectional factors include employment-related disparities, the need for mobility assists, and reliance on personal assistance to meet daily needs (Quail et al., 2018; Croft & Fraser, 2022).

In many jurisdictions, the barriers, preferences, and experiences of people with a mobility disability were not factored into previous disaster preparedness, response and recovery planning (Pakjouei et al., 2018). When there was a lack of consultation by planners and policymakers, people with disability experienced more negative outcomes of disasters than the general population

(Pakjouei et al., 2018; Sakellariou et al., 2020). Being at increased risk to the negative impacts of a disaster is in part due to knowledge gaps among public health and safety emergency planning and response personnel, including frontline responders (Wolf-Fordham et al., 2014). For example, people with disability in Pacific Island Countries were found to have lower rates of employment, socio-economic status, and education. Consequently, without sufficient financial supports for this group, they were not able to buy food, water, and other essential items to prepare for physical disasters. In the context of emergency quarantines, the lower employment rates and greater systemic barriers to managing health conditions of people with disability exacerbated their risk when there was lack of support for resources (Croft & Fraser, 2022). Moreover, marginalization and discrimination can cause people with disability to be excluded from community decision-making, which consequentially affects their adaptive capacity during disasters (Elisala et al., 2020).

Pandemics and other disasters magnify the limited capacities of social care systems (Ruhr University Bochum Institute for International Law of Peace and Armed Conflict, 2021). Inadequate preparedness upstream —and disaster impacts downstream— combine to influence adaptive capacity, the ability to modify characteristics or behaviors to cope better with existing or anticipated external stressors (Jakku & Lynam, 2010). Recent studies found that many social care systems have been broken for some time, and the COVID-19 pandemic exposed their vulnerabilities (Shakespeare, Watson, et al., 2021). A framework of insufficient measures and repeated cuts to social care, in turn, harms the ability to respond to a pandemic adaptively.

In contrast, a social and health system that is sufficiently prepared to scale up social protection rapidly to meet increased disaster-related needs offers protection against vulnerability. An example is a Columbian transnational project with the purpose of ensuring public services were

adapted for people with disability (Gabel, 2021). Upstream effects of this social project enabled downstream effects of improved access to social programs and to the training and labor market. Having established measures strengthened the resilience of people with disability in preparation for a disaster, enhancing their adaptive capacity during the COVID-19 pandemic (Gabel, 2021). Implemented and established measures such as these can ensure people with disability meet their needs through inclusive COVID- 19 interventions, including food support. A system that places the individual and their care at the center of disaster response is responsive and humane (Shakespeare, Watson, et al., 2021).

Policymakers and care providers have been urged to investigate the challenges people with disability face during a disaster and develop strategies to reduce their impact in the recovery phase (Shakespeare, Watson, et al., 2021). Historically, developing new supports to reduce barriers during disasters promoted social justice and prevented some groups from becoming socially disadvantaged based on their risk profiles (Ruhr University Bochum Institute for International Law of Peace and Armed Conflict, 2021). Therefore, post-pandemic social change may require upstream investment for inclusive and just disaster management (O'Sullivan et al., 2014). Such social change should be made on the grounds of social justice, recognizing that the onus for change should not be on the person requiring accommodations to have equitable experiences (Yang et al., 2022).

The first step toward strengthening adaptive capacity is awareness of disability issues during a pandemic. We attempted to address this step by exploring the personal narratives of people with a mobility disability to understand their experiences during the first four waves of the COVID-19 pandemic in Canada (Yang et al., 2022). Here, we present recommendations for action needed during the pandemic recovery phase, from people who have a mobility disability.

2. Methods

Sixteen people with a mobility disability participated in individual 1-hour virtual semi-structured interviews, sharing their experiences with changes that occurred during the pandemic, lifestyle, health, and perspectives on pandemic response. Following approval from the University research ethics committee, participants were recruited from Canadian non-profit and community organizations that support people with a disability or a chronic condition(s). Participants were from six cities across Ontario and Quebec, Canada, with ages ranging from 20 – 86 years old. Eight people identified as male, and eight identified as female; no participants identified as another gender.

We followed traditional grounded theory approaches, outlined by Charmaz (2014), which guided the interviewing, analysis, and model building stages. Grounded theory as a method consists of flexible guidelines for collecting and analyzing qualitative data (Charmaz, 2014). This approach facilitates exploration of links and themes within a specific population's experience with a phenomenon. Grounded theory methods offer sets of principles and strategies, rather than formulaic prescriptions that instruct how researchers proceed from gathered data to constructed categories. Our analysis consisted of inductive coding using NVivo 11 and a constant comparative process to yield themes from individuals' description of their lived experiences.

The overarching theory we built was *Adaptation is a Not a Choice, It's a Way of Life,* which explains how people with a mobility disability experienced the COVID-19 pandemic in Canada (Yang et al., 2022). In the current article, we present suggestions participants made to support their adaptive capacity and enhance disaster response. We also present recommendations for a post-pandemic context, as innovation triggered by the pandemic will have lasting consequences.

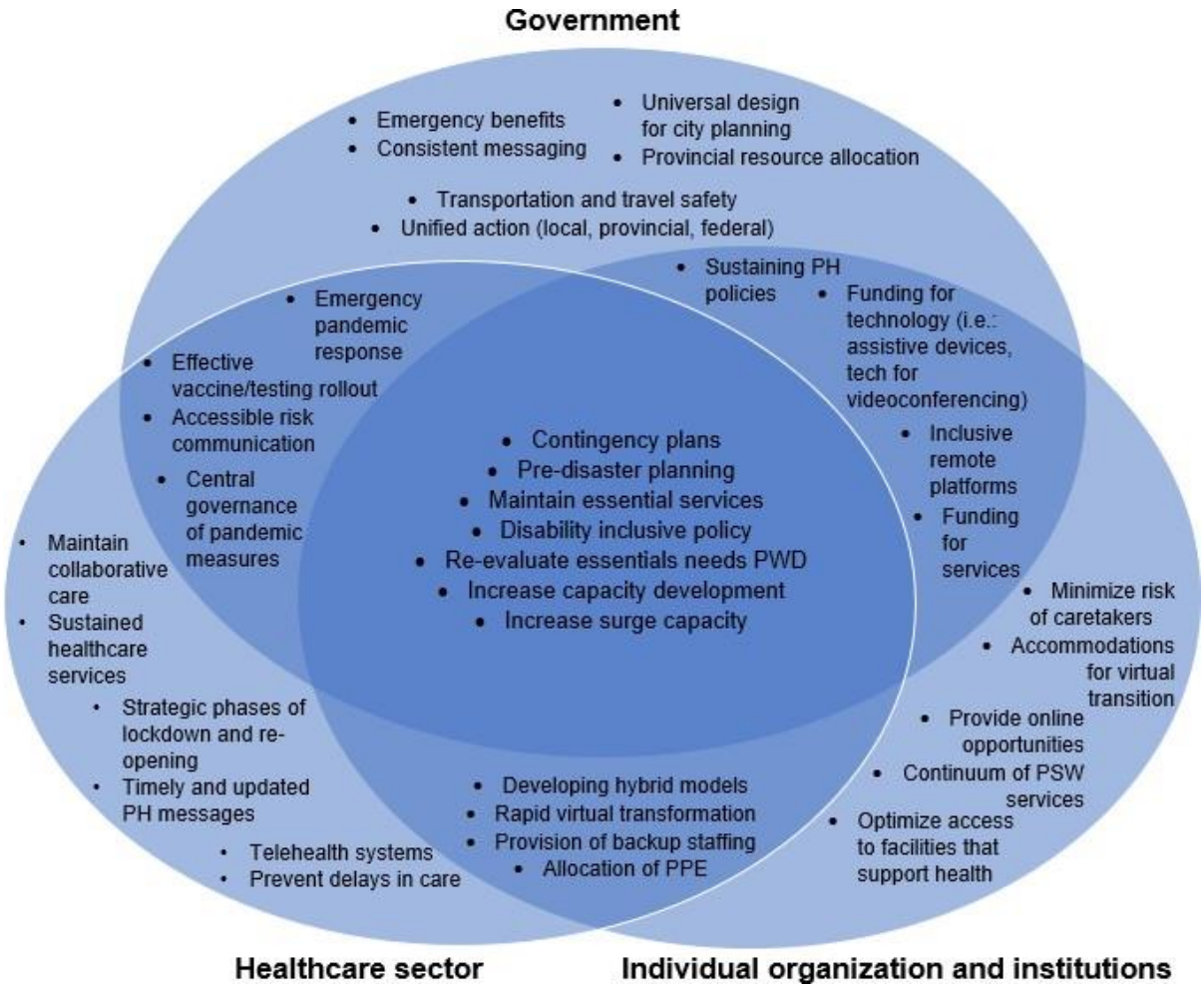
3. Recommendations

Four salient recommendations emerged from our data. These recommendations are oriented toward increasing the disability-inclusiveness of the COVID-19 pandemic response and recovery. Participants expressed the need for concerted public health and government efforts, an inclusive virtual transition, hybrid models to meet accessibility needs, and awareness for disability rights and needs.

Thematic findings of the recommendations are mapped onto the responsible body or sector that would implement the suggested recommendations (Figure 3). Figure 3 also illustrates the relationship between responsible stakeholders, and the cohesion needed to build a more inclusive pandemic response. Resilient systems are built through efforts of these responsible bodies; our participants' suggestions demonstrate the need for their reform and synergistic efforts.

Figure 3

Levels of Implementation of Recommendations



Abbreviations: PH, *Public Health*; PSW, *Personal Support Worker*; PPE, *Personal Protective Equipment*; PWD, *People With Disability;* Tech, *Technology*

3.1 Concerted Efforts

Maintain Collaborative Health Care

During the pandemic, public health priority was directed towards the emergency sector. Different divisions of the healthcare sector were overstretched, not only reducing the individual

health services of people with a mobility disability, but as well, their strategic care plans. When resources are constrained, multidisciplinary efforts must be adapted to continue to meet the needs of people with disability. These efforts are paramount, as mobility disability is heterogeneous in etiology and functional outcomes. For example, many people with disability relied on the combined efforts of multiple providers, including physiotherapists, nurses, general practitioners (family doctor), and or specialists.

A reorganization of the health care system to prioritize COVID-19 response disrupted people with disability's physical therapy, occupational therapy, rehabilitation, and other services needed to maintain mobility. The reorganization also prioritized 'best practices' during the pandemic, which included minimizing physical contact and delaying treatments, unless they were deemed critical. However, people with disability expressed collaborative patient care should be recognized as critical. To continue collaborative care throughout a disaster, contingency plans must be in place when health resources are diverted. This way, the healthcare network (i.e., remote, community, and private services, etc.) can continue to collaborate on an individual's care to assist in complex cases. One participant spoke about interdisciplinary action to reform rehabilitation services during COVID-19:

> Well, the biggest problem was you couldn't have all those [different health care providers] in the same room…Make [physiotherapy center] a rehab center, where you have all the different disciplines in the same place working together for a common outlook. So that would mean you have your occupational therapists (OT)'s there for fine motor skills, you have your physio's there for gross motor skills, you have your speech pathologists there for communication skills, you have the psychologists there just for 'mind-bent-out-of-shape' skills. All those disciplines in an area, and it doesn't just have to be for stroke, because your

> patients that have heart problems can also benefit from that kind of stuff. There are people there who have vehicular accidents. [P3]

Concerted Government Response is Protective

The health of people with disability was not only compromised by a divided public health system, but a lack of concerted government response; this affected their safety, mobility, and quality of life. People with disability reported variance among government bodies (i.e., federal, provincial, and regional) which often had different directives and messages, increasing confusion- especially regarding pandemic safety. Disorganization in pandemic response impacted the allocation of health resources, causing some people with disability to be denied early access to vaccines due to confusion over whether they met eligibility criteria in certain regions. Additionally, it impacted their eligibility for elective health procedures, as some were canceled because provincial rules on healthcare prioritization took precedence over decisions at the local public health level. People with a mobility disability stated that there should be "collective agreement" so they can know which steps to take and how and where they could access help to increase their emergency preparedness:

> For a while we were told at the beginning that our family doctors were going to give us the [COVID-19] shots, but that never happened…And this [vaccination] passport thing that they're talking about, they don't tell you how to download it or where to get it. I find that the information part should be more strategic, clear, and maybe not just on the news- we all have city Councilors. Why aren't we getting letters from our Councilors telling us what to do? And all this stuff about getting any vaccine that you can- then there was a problem of who's accepting it and who's not, and the federal government seems to be doing one thing and then leaves the rest of the provinces. I think it should be standardized. And I think

> it should be a collective agreement across the country instead of just willy-nilly, 'everybody doing their own thing'. [P9]

Participants expressed how government unification was needed to strengthen pandemic response, yet governments were divided. People with disability found that the 2021 Canadian elections exacerbated dissention. They expressed how the needs of citizens, including people with disability, must come first before different governments' "personal gain" [P12]. One person described the importance of a person-centered pandemic response:

> There was a lot of confusion and I think the governments weren't working together, whether it was regional, provincial, or federally, and that causes conflict. And then verbally taking pokes at each other is very demeaning to the people that have to listen to it. Like, get on the same page, support the opposition instead of fighting…help resolve issues in the province…[politician] stood up for the people, he really did and tried to make it as good as he could make it. I think the main [lesson] is the governments have to work together. [P4]

A lack of coordination to rapidly enforce protective health guidelines raised the risk for people with a mobility disability. Weak implementation of regulations for masks, social-distancing, and stay-at-home orders compromised safety (as many had immunocompromising conditions). It also affected their quality of life, as it exacerbated lockdowns, further reduced services, and extended social isolation. One person living in a long-term care facility described the negative effects of an extended and repeated lockdown:

> I think [masks] should be mandatory. Otherwise, we are never going get out of this pandemic. I think the policy should have been- go to a store or somewhere- wear a mask. Make the mask and social distancing mandatory. I think they were afraid of losing votes, losing power. [P14]

Consistent Messaging to Reduce Risk

In a public health crisis, concerted efforts to provide clear information becomes more important than ever, especially for people with disability who are at higher risk to a negative health outcome from a coronavirus. Mixed messaging from the government and public health led to low confidence in public health messaging, lack of awareness of protective activities, and stress from uncertainty of the situation, consequentially decreasing adaptive capacity. One person shared:

> There were a lot of things that were kept open that I was thinking, 'well, this is serious?'. Why aren't these other shops like LCBO closed? I mean, is beer really an essential service? Are we not supposed to be staying home? And if we are, then why is this not controlled better? I mean, does that sound like a lockdown to you? I thought we got mixed messages. [P11]

Another person similarly described how precise and consistent messaging impacts their own abilities to keep safe and respond adaptively:

> [Consistent messaging] would really make a difference as to how serious I take it in terms of what sort of precautions and what sorts of things I do and don't do. So, can [people with disability] have a boyfriend or girlfriend during the time of COVID? What sorts of things can they do and can't they do? [P5]

People with a mobility disability recommend Canadian provinces be more unified in their pandemic response to ensure organized rollout of plans, such as mass vaccinations. Pandemic response plans should be in place to describe the responsibilities of different governments in terms of infection control. These directives can be useful to delegate critical duties and to safeguard effective integration of accommodations for people with disability; the recommended accommodations include specific messaging and communication formats for people with

disability, prioritization for resources and services, and maintaining an accessible transportation system. Importantly, strategies should be standardized across all levels of government so people with disability from all regions, including those living in rural areas, can be included and informed.

The participants indicated that the healthcare and government sectors have the responsibility for multidisciplinary action to build adaptive health systems. Different levels of government organization should realize that no one organization can or should control the pandemic response. Positive leadership must take a person-first approach and invite collaboration among stakeholders from the government, healthcare, and organization sectors to meet the whole population's diverse health, social, and community needs. People with disability indicated *systems thinking* may be fundamental to strategic planning for future disasters. Systems thinking in public health involves building a comprehensive infrastructure for knowledge transfer between stakeholders, multidisciplinary communication and collaboration to solve problems, and analyzing complex systems through modelling behaviors and their consequences (Leischow et al., 2008). Especially when an unprecedented crisis emerges, a systems approach is needed to ensure disaster response maintains health in the most inclusive and fastest way (Leischow et al., 2008).

3.2 Supporting an Inclusive Virtual Transition

Ensure Accessibility and Usability in Virtual Designs

The virtual platform benefits people with disability by allowing them to maintain personal, health, and occupational commitments without the risk of COVID-19. However, a digital transformation of services is only accessible if it considers the barriers to remote connection and increasing strategies for inclusion. One person spoke about a potential barrier: "If you were taking physiotherapy, it went online. If you didn't have a computer, your therapy ended because the therapist couldn't come into your home." [P4].

Other than access to technological devices (such as computers) barriers to technology use hindered some people with a mobility disability from online participation. Organizations should consider sensory, cognitive, and manual dexterity restrictions that some people with disability have to digital connection during a time of lockdown. One participant shared experiences with the virtual transition of a stroke support group: “We meet on Zoom but it's just not the same. Some [stroke survivors] don't have any computer skills and they won't share in it. So that has been a huge difference for us stroke survivors.” [P4].

Some people with a mobility disability have conditions precluding them from traditional technology use. Therefore, institutions must recognize these limitations and put measures into place to accommodate a diverse array of abilities. For example, people with mobility limitations expressed their need for adaptive or supportive devices; this included headsets, specialized typing tools, hands-free devices, or ergonomic workspace equipment. More institutions- including workplaces and schools- must be prepared to provide such accommodations to increase access to remote connectivity, such as through lending programs or direct financing. One participant’s personal experience is an example of what such an organization can do: “Muscular Dystrophy Society of Canada -they have been very supportive of financing of equipment. And hosting Zoom meetings.” [P12].

Accommodations should not only be given to the person requiring accessibility; organizations have the responsibility of building systems accessible by design so people with special needs are automatically included. Additionally, organizations should ensure all providers or staff are trained on virtual inclusion guidelines. An example is for workplaces to provide the entire group with tools that increase the accessibility of the programming as a whole:

I have had the opportunity to attempt to have to attend a meeting virtually where

> everyone else is in-person…Primarily the problem is with the audio, in that, if you have a speaker pod that you can place in the middle of where everyone that's physically in the building or physically at the meeting… I knew who the speaker was, but I couldn't make out what they were saying because [speaker pod] wasn't picking up their voices well enough on top of the ambient noise that it was picking up. I don't know what the solution is, for everyone to have some speaker headset or something? [P13]

Remote platforms not only increase participation in society but have the vital role of keeping people with disability safe during a disaster. An inclusive virtual transition is vital during lockdown phases to support adaptive capacity. One participant described flaws in the systems that affected their ability to book vaccinations and access updated public health information:

> I felt that I've been neglected… Especially people with disabilities, who computers can be confusing. And if you have brain fog, to try and navigate the systems and where to find the vaccines and where to go, I don't think they were clear at all. They didn't take into consideration the people that aren't clear in their heads, just ignored them and left them at home. [P9]

People with a mobility disability recommend the government, public health, and organizations increase capacity development when a virtual transition is needed. Capacity development has been important for people with disability during previous emergencies requiring evacuation; it increased evacuation knowledge and preparedness within people with disability as well as communities assisting them (Elisala et al., 2020). In the current context, capacity development for virtual transitions entails building virtual infrastructure with accessibility and usability in mind. Not unlike preparedness for evacuations, preparedness for lockdowns necessitating virtual transitions requires public health and organizations to have an in-depth

knowledge of different types of disabilities, disability needs, and strategies to empower people through enhancing access. As a first step, there must be increased awareness and adoption of tools to meet individuals' sensory, cognitive, physical, or social needs when designing a digital shift. For example, tools to enhance resilience include accessible formats of text and audio, adaptive devices, and technical or financial support through the company or organization. Alternate ways of accessing services (i.e., telephone or teletypewriter (TTY)) should also remain available for people with disability who have difficulties using online forms or web pages.

Filling the Gap with Virtual Connection

The virtual transition must be prepared to meet novel needs spurred by the disaster. People with disability recommended government services and organizations consider the importance of social support during periods of quarantine and ensure that virtual transitions are prepared to fill the gap. People with disability recommended this could be done through organizing accessible get-togethers on platforms such as Zoom, Google Hangouts, or Facebook. Moreover, organizations should prepare to support the same frequency of remote meetings or activities as pre-pandemic- if not more- as stress from the pandemic may cause some individuals to require more support than usual. This was especially important for people with disability, a group that disproportionately experiences mental health impacts from social isolation during a pandemic (Croft & Fraser, 2022). Some participants indicated that to actualize this, the government and groups need to increase capacity development. One person described how increasing the capacity of inclusive virtual transitions is needed to build resilience:

> Not that the government could have done more, but I would love to have had more opportunities to have people in other groups that you connect to online- that sort of virtual help or assistance. But I realized they can't do everything. But you know, it's on my wish

> list. If there was anything particular that I'd bring attention to- it's that, because there are so many people with disabilities in our world… So maybe in the future pandemics- and we're aware now, like there's something [the government] can do that helps mitigate or helps balance it out so people out there can be a bit more resilient. [P16]

In the early phases of lockdown, people with a mobility disability experienced a lag in digital alternatives that could meet their needs. Many faced difficulties reaching their usual physicians or service providers, as telehealth platforms were not yet developed or not implemented on a wide enough scale. In the event of future waves of the pandemic that necessitate a lockdown, people with a mobility disability recommend that their services, such as for physical therapy or primary care, make a rapid transition to avoid delays that could result in poor health consequences. New solutions must fill in the gap when a disaster puts stress on the healthcare system or economy. For example, people with disability suggested that virtual group activities, such as for physical therapy, take the place of one-on-one activities if there are less professionals accessible to provide individual services.

To support a timely virtual transition, emergency preparedness plans must be established by public health and organizations to reduce bottlenecks and provide direction for the development and updating of virtual tools. Policies and protocols for handling physical-distancing challenges should be decided on pre-disaster; this includes healthcare prioritization decisions, so people with disability are not neglected. The phases of implementation should also be prepared pre-disaster, so plans are executed with minimal disruption. This includes standardizing patient portals or telehealth systems across communities or healthcare systems, which streamlines health services. Finally, all sectors must make timely and intermittent evaluations of remote workflow structures (whether for hospitals or for remote work) to ensure virtual infrastructure is not leaving any group

out.

3.3 Building Hybrid Models

There have been positive developments for people with disability during the pandemic. Remote advancement largely overcame physical barriers, as work, leisure, shopping, education, and healthcare were driven online. Despite this, there are inequities not yet addressed relating to the accessibility of remote participation. As such, people with a mobility disability made suggestions for how new models for participation can be improved and sustainable in the future.

Models for Comprehensive Healthcare

Remote healthcare facilitated people with disability receiving services, such as medication prescription, functional assessments, and general checkups without the traditional challenges that mobility disability poses on accessing health facilities. In addition, new platforms for mHealth helped individuals with self-management of their conditions from home, and videoconferencing allowed for visual inspection of conditions that cannot be assessed through telephone-based appointments. One person mentioned:

> It is easier because [my neuropsychiatrist] is across the city, it's a way to go, and I only see him for 15 minutes. To talk on the phone is easy…they always say, 'I'm here, if you want anything, you just call'. [P9]

Although remote care could overcome limitations to travelling, some people with disability reported telehealth cannot meet all their needs. People with a mobility disability often had underlying conditions; they voiced it is important to them to receive individualized, person-centered care, which can be supported by in-person attention. One participant shared:

> There's only so much you could do over a phone. And [doctor] could ask me questions and

> questions and questions, but sometimes it's good to assess live. So [telehealth] is a good start, but I don't think it's a complete service. [P11]

People with a mobility disability recommend that organizations and health systems sustain the hybrid model in the future to provide a "complete service". Remote care would allow healthcare providers to be involved through allowing rapid exchanges, such as through email or patient portals. In-person care could complement this as providers can be involved through more personalized support and easier rapport. Depending on the needs of people with disability, both options should be available to facilitate comprehensive patient care. Most participants were hopeful that hybrid systems could and should be a sustainable model for the future.

Increasing Participation through Hybrid Models

A hybrid model may be incorporated in academic, employment, and leisure environments since this model supports accessibility. People with a mobility disability expressed remote interactions should continue, but can only be sustainable if it is balanced with in-person social opportunities:

> I'm active on many panels and task forces and meeting face-to-face via Zoom. So, that participation would never have been available to me before. Most of the people on the task force are in Toronto. I couldn't get to Toronto for meetings…but if I was still working full-time [remotely], I think that it's not sustainable. Full-time- I do think there's benefit in physically being together. And I think that there is benefit in not being alone at home all the time. I think we all need social interaction. [P13]

The needs of people with disability must be kept at the forefront of discussions when modelling post- pandemic systems. People with a mobility disability suggested hybrid models

were “the way of the future” [P16, P13]; a hybrid model is a way to a more inclusive future, as it expands opportunities, and supports acceptance of diversity in society. In fact, acceptance of hybrid systems could lower discrimination, creating more accessible environments for people with a mobility disability to meet their needs without barriers.

People with disability have indicated they do not want a return to the pre-pandemic status quo, which was a societal framework filled with complex barriers to inclusion (Shakespeare, Ndagire, et al., 2021). Strategic thinking is needed so social inclusion and public health can better reach people with disability (Wulff et al., 2015). Implementing a hybrid model to accommodate to all people’s needs is an investment that can withstand predictable and novel threats to society. Upstream efforts to sustain this model are needed to strengthen day-to-day systems to improve community resilience.

3.4 Defining Essential Needs

For policy purposes, it is imperative to define what is essential to people with a mobility disability to understand their true risks, barriers, and how they can be sufficiently protected during pandemic response.

Acknowledging Essential Assistance

Some people with a mobility disability living in long term care homes or receiving in-home care were denied access to usual volunteers, informal caregivers, and or formal caregivers during the pandemic. This resulted in people with disability losing essential supports and facing isolation, which had detrimental mental and physical effects. All types of caregivers or service providers play an integral role in the overall health, rehabilitation, mobility, and psychological wellbeing of people with a mobility disability. In fact, many participants described the mandatory changes to

their essential support as “inhumane”, as the role of others in supporting their quality of life was taken for granted in public health decisions. One person stated that these decisions undermined their human rights:

> The pandemic "allowed" -and I used the word "allowed" in quotation marks- "allowed" society to remove all those rights of an individual upon saying, "you cannot have access, you cannot have these people come into your home, they cannot come into your home. You cannot have contact with those people for fear of spreading the disease". And as a person who might have been living in a society with a disability, it's like, I'm sorry, but my ability to live my life in society depends on the assistance of a certain amount of people, of a certain amount of help. And you can't deny me that. [P13]

Furthermore, people with disability shared that the consequences of being denied access to essential support could have been avoided through having a more defined and inclusive governance:

> What I'm hearing rumblings around is, "Oh, that's not what we said. We, the ministry, we didn't say 'you couldn't have'. We said, 'it's a recommendation that you do not have visitors' or, 'we recommend that you not have open access to family' or whatever". It's almost laughable where everyone is now denying accountability in the absolute. I think that if there's a pandemic again, I think that there needs to be a clearly defined body governance and they need to issue clearly defined rules, [otherwise] I think you'd have had a lot more serious consequences. [P13]

Providing Resources to Ensure Safety

The COVID-19 pandemic profoundly affected national economies and government

budgets. This forced organizations and local public health to reduce service provision when it was in greatest demand. Further, supply chain issues increased challenges people with disability had to securing both usual supports for everyday mobility, as well as tools to reduce risk to COVID-19. One person recounted how reduced provincial health and social services, coupled with the scarcity of resources, created challenges to accessing mobility assists:

> Recently I needed to replace a pair of crutches. In Quebec, through [organization] in Gatineau, they will provide a pair of crutches free of charge... But I noticed that in one of my crutches- there's a bolt that had broken and I realized I better replace them. And I called the guy and he hasn't called me back. [People with disability] are having difficulty getting stuff. If you want something specialized, there can be supply issues…So we don't know when [mobility devices] will be in, but this type of thing is happening, I think with a lot of stuff. [P1]

Economic outcomes during COVID similarly limited access to Personal Protective Equipment (PPE). These were scarce and expensive for both individuals and organizations. Personal Protective Equipment minimizes risk of infection; for many people with a mobility disability, continuity of care during the pandemic was contingent on having such protective resources. Some people with disability who could not secure PPE themselves discontinued receiving in-person care or cancelled outside appointments. For some others, losing personal support was not an option even when personal support workers (PSWs) were not supplied enough or any PPE from their organizations; they inadvertently raised their risk by continuing to receive care under riskier circumstances. One participant described the protective role of PPE:

> I had PSWs around, and they put little covers on their shoes when they come in, shields, and all the different things. It's fine. I understand why. But you can get that level of care when

they're not too scared to touch you or things like that. So PSWs did a good job, they worked around it. Which does make a difference to the level of personal care. [P16]

The issue of resource prioritization and dissemination directly relates to the safety of people with mobility limitations during an outbreak. Policies and financial resources to ensure safety during the pandemic are essential for people with disability yet were not prioritized in many cases. Even when participants could locate PPE themselves, they were an added financial burden, compounding existing financial disparities some people with disability face (Yang et al., 2022). Therefore, participants voiced it is imperative to their health that they are allocated enough PPE through their organizations or local public health. Not only does it have a direct impact on medical risk, but social risk, as a lack of protection limited their social access, ability to work, and options for healthcare to improve functional abilities.

COVID-19 placed immense pressure on health and social services- some already overburdened- highlighting the need for more resilient social infrastructure. During a crisis, emergency managers have the responsibility of ensuring personal assistance organizations have provisions for adequate staffing, and that staff and people with disability are supplied with enough vaccines and or protective equipment in a timely fashion. Due to insufficient planning in these areas, some participants' PSWs were fired if they were deemed unsafe to provide care (i.e., they lived with others), or simply due to funding cuts. Other participants experienced disrupted health services, as their usual health care providers or physical therapists were moved out of the community and into hospitals. To mitigate or prevent these outcomes, people with disability indicated they need infrastructure capable of minimizing disruption during infection control, prepared through pre-emptive scenario planning, and prioritizes accessibility to their services. To prevent negative outcomes of separation from services, all sectors should be prepared to set higher

targets for surge capacity in preparation for a disaster that can disrupt the functioning of entire systems.

People with disability indicate the support of public health and individual organizations for their caregivers is essential to their care. Some people with disability had changes to their care due to the reluctance of some staff to work in settings of potential exposure- when they, themselves, could not secure PPE or early vaccination. Health systems and organizations must support caregivers in feeling safe and protected during emergencies. A strategy is to provide resources for caregivers' own physical and mental health to minimize burnout during a crisis. Additionally, before a disaster, organizations must provide personnel with training on disaster protocol to enhance their own sense of emergency preparedness. Importantly, in the case of a pandemic or epidemic, these trainings should prepare caregivers for protocols during infection control and lockdown, as well as training on the unique needs of high-risk populations in those circumstances.

Meeting Infrastructure Needs

The built environment is paramount to promoting access during a pandemic. When public health restrictions are imposed for the population, it is essential to consider how these may compound the existing barriers people with disability have to health promotion or social activities. Outdoor options for supporting mobility or social interaction must be accessible when indoor facilities close. Municipalities have the responsibility of enhancing the universal design of sidewalks, trails, and outdoor facilities or dining spaces. Accommodating infrastructure also has a protective role during pandemic response. Public health must consider the accessibility of building designs when planning for testing or vaccination centers (this includes having accessible doors, lineup systems, lifts, or shorter routes).

Another element of infrastructure that must be stable during a pandemic is public

transportation. In particular, Para Transport is a “safety net” for people who, because of their disabilities, require ramps or lifts (to accommodate mobility devices), have service animals, and or require audible and visual announcements for stops (RTS Access; Sitter & Mitchell, 2019). People with disability indicated their essential needs must be considered during the redesign of transportation services during a pandemic, as this system is an asset that enhances mobility and adaptive capacity.

Transportation guidelines must balance public health needs with the needs of people with disability. For example, Para Transport must not be limited to the point that people with a mobility disability struggle to find a way to travel or cannot have timely transportation. At the same time, all levels of transportation ministries must consider enforcing sanitizing and masking safety protocols to protect those with varying conditions to allow them to safely travel to meet their needs. To support stable infrastructure, especially during a pandemic, stakeholders must increase funding to support internal resources. One person, who was further restricted when Para Transport services were limited during the pandemic, described systemic issues that have been ignored:

> To count on that mobility system, I'd have like 10% faith that I could take that [during the pandemic]. It’s a broken system. I think maybe a computer could schedule the appointments better… A lot of money must be put into that. Something has got to change, and they got to get some good ones working on it. And I’d do it as a volunteer. I've offered that, I said, “as a disability [person], I volunteer, I'll work in that office and I can schedule people on that bus better than you can. Because it’s not working right now”. [P5]

Providing Essential Financial Support

Some people with a mobility disability were left out of emergency response benefits. This occurred in the case that they did not meet previous employment criteria or if they received care

at-home rather than in a congregate setting. This issue especially affected those who were retired or unable to work due to having a health condition. Therefore, it is important that the federal government as well and individual organizations provide benefits people with disability are eligible for according to their disability needs. This includes essential supplementary funding for assistive devices (which were scarce during the pandemic), resources for virtual connection (such as Zoom licenses or mobile devices), and home equipment to maintain mobility or rehabilitation.

Moreover, it is important that different agencies recognize how general emergency response benefits may affect the disability group. One person spoke about how benefits to the general Canadian population inadvertently harmed them:

> The federal government has been giving compensation money for pretty much everybody that wasn't able to work. So, it's like an order of $2,000 a month to people who just sit at home because they couldn't find work during the pandemic… Well, I don't usually pay my [personal support workers] $2,000 a month. A lot of people that work for these [personal support organizations], they just decided, "well, you're not giving me enough money, and Trudeau will give me a bunch of money and we'll just stay home". So, there was a big shortage of staff. It's extremely, extremely, extremely difficult to find staff. So, for the past two years, I've had staff that I would not normally hire but if I don't hire them, then I'm stuck. [P11]

Other than losing staff due to inequities caused by emergency benefit rollouts, some people with disability lost staff due to increased hesitation of workers to provide close-contact care. As such, a 'pandemic premium' provided by government or organizations can serve as an incentive for support workers to work in riskier settings and to honor their contribution during the pandemic.

Living under pandemic restrictions has highlighted the need to redefine vulnerability

(Savin & Guidry-Grimes, 2020). The experiences of people with disability show that vulnerability is related to policies and social structures, rather than individual capacity, autonomy, and physical ability. Vulnerability occurs when policy dismisses the essential needs of groups and their quality of life, when addressing the needs of the majority (Ahmad et al., 2020). During the COVID-19 pandemic, the participants' experiences of being made and being treated as a vulnerable group in society indicate their essential needs were not known nor sufficiently addressed in pandemic protocol. However, this knowledge must have a role in disaster response, such as in triage protocols to reduce health disparities and protect against discrimination.

4. Discussion

In this qualitative study, 16 participants with a mobility disability made recommendations for how people with disability can be included in emergency pandemic protocols as well as in disaster planning pre-pandemic. While people with disability appreciated the need for evolving policies and healthcare services, they offered suggestions for how their barriers and assets can be taken into consideration in the rapid transformation of society. Inviting individuals to speak on socially determined disparities that influence their dis-ability experience and disaster risk was important for people with a mobility disability. Opportunities for participation are essential for disability-inclusive pandemic planning, including guidance for risk communication, lockdowns, a digital shift, hybrid consultation models, and public health and funding systems.

Recognition of individuals' true mental, physical, and social needs as well as their capabilities, is important for implementing systemic accommodations. Systemic accommodations recommended by people with a mobility disability themselves can support people with disability in receiving timely and appropriate health care, financial support, and participation in society during a pandemic, and can be implemented at different levels involving multiple stakeholders and

players.

5. Conclusion

Disability-inclusive strategies can enhance disaster preparedness for people with a mobility disability and their communities, and may be sustained through multidisciplinary efforts. Therefore, the experiential knowledge of people with a mobility disability is an asset for decision-making and can bolster community resilience. Through collaborative efforts, we are hopeful the recommendations from this study will be implemented at different governmental and organizational levels, to build adaptive capacity for resilience through the pandemic recovery period and in advance of the next disaster.

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CHAPTER 5: GENERAL DISCUSSION

The purpose of this research was to understand how people with a mobility disability experienced the COVID-19 pandemic. Our objective was to build a framework of their experiences which may inform future development of pandemic planning, mitigation, and recovery strategies. Following traditional grounded theory methodology, we built a theoretical model: *Adaptation is Not a Choice, It's a Way of Life*; this illustrates the role of adaptive capacity in supporting resiliency in managing dis-ability challenges. "*I've already lived like there's a pandemic*" summarized this theme within the lived experiences of participants. It also serves as a call for action to enhance equity and social justice in both daily planning and disaster response.

Universal pandemic restrictions magnified the everyday restrictions of those living a mobility disability. As such, *adaptation was not a choice* for people with disability, as they have consistently needed to adapt and work towards resiliency to decrease social barriers. They described already living "*like there's a pandemic*" since lack of access during the pandemic was a normal part of the disability experience. This includes access to treatment for rare disease or ways to participate in certain events. Because the risk of becoming dis-abled was not rare anymore, upstream emphasis was finally given to implementing changes.

Systemic Vulnerabilities in Social Protection

A central promise of the 2030 Agenda for Sustainable Development was to realize the rights of persons with disabilities to 'leave no one behind' (United Nations, 2015). This has been a priority for institutions worldwide, including the United Nations, especially in times of crises. However, the COVID-19 pandemic saw more people with disability excluded because of societal impacts magnifying barriers (United Nations, 2020). Barriers to inclusion hinder a disability-

inclusive response to COVID-19.

Impacts of exacerbated exclusion revealed insufficiencies in the preparedness of societies to managing social care for people with disability. However, resilient societies must be sufficiently prepared to respond to mass emergencies to mitigate negative effects of a disaster on all segments of the population (Finkelstein & Finkelstein, 2020). As such, resilient societies must be able to prevent barriers to accessing social benefits before disasters emerge. This is a responsibility that can be addressed in the emergency planning stages.

Gaps in social protection make individuals susceptible to crises, raising their disaster risk. This has resulted in exacerbated poverty, deepened inequities, and weakened resilience to future crises for some populations (Ruhr University Bochum Institute for International Law of Peace and Armed Conflict, 2021). Risk factors related to their social determinants of health may have caused people with disability to experience the COVID-19 pandemic as a *syndemic,* whereby the pandemic becomes magnified by pre-existing inequities, co-morbidities and gaps in social protection (Bambra et al., 2020; Singer, 2009).

One of the key obstacles to equitable disaster response is the assumption that there is no need to implement 'special' social supports for people with disability (Goggin & Ellis, 2020). However, COVID-19 has shown that treating the disability population the same as the rest of the population is a systemic vulnerability. The lack of attention to unique needs precludes adequate support and inclusion of people with disability.

Despite devastating repercussions, disasters bring light to disability issues (Goggin & Ellis, 2020; Quigley & Nadar, 2020). Mainstreaming disability into emergency responses and preparedness, such as after the Haiti earthquake in 2010, can cause a paradigm shift whereby national and international actions and policies can protect the human rights of all people (Danquah

et al., 2015). In Canada, the COVID-19 pandemic has sparked debate on social justice and disability. This raised questions on whether 'Canada has gone far enough to make sure all Canadians have equal rights' (Quigley & Nadar, 2020, p. 6). Research attempting to address this found that measures and policies implemented have still fallen short of what is required in certain areas (Croft & Fraser, 2022). To reduce vulnerability through policy changes, it is recommended that planning for response strategies shift from deficit-oriented lens to viewing people with disability through their asset profiles so that measures can enhance their resilience when there is a disaster (O'Sullivan & Phillips, 2019).

Asset-Oriented Approach to Disaster Resilience

COVID-19 illuminated discriminatory beliefs about people with disability embedded in our society (Public Health Agency of Canada, 2020). Ableism fundamentally devalues and neglects the lives and contributions of many individuals (United Nations Human Rights Council, 2020). However, an asset model can re-shape the way society thinks and acts to promote a positive and inclusive approach to tackling health inequities (Morgan & Ziglio, 2007). Bayen et al. (2020) suggest the pandemic has been an opportunity to invert our usual perspectives of capacity. In this way, adaptive capacity can be acknowledged as the capacity to consistently develop adaptive behaviors to cope and lower the social and physical barriers encountered in a dis-abling environment (Bayen et al., 2020; Van Bortel et al., 2019).

Assets have demonstrated a supportive role under usual circumstances (Middleton et al., 2020); we found they are also essential resources during disasters that disrupt health systems as well as day-to-day activities. Although they experienced structural barriers imposed by the pandemic, participants shared systemic assets could help to overcome these.

A critical infrastructure that supports adaptive disaster response is accessible public

transportation (Stough et al., 2016). In the aftermath of Hurricane Katrina, accessible transportation alternatives (often referred to as 'Para Transport' or 'Wheel-Trans') were limited, compounding challenges people with disability had to living independently, participating in community life, and seeking employment and medical services (Stough et al., 2016). In our current study, stable transportation methods within certain cities were assets that protected against these consequences. Stable Para Transport could enhance mobility, as it allowed people with disability to meet their needs, even during the most restrictive phases of the pandemic.

Other assets to enhance disaster resilience include maintaining the capacity of usual health services or personal support services. Our findings were consistent with other literature, which found preserving access to rehabilitation services during lockdowns mitigates the negative impact of social isolation on physical functioning (Middleton et al., 2020). Infrastructure that enhances access also increases social participation for people with disability (Campbell et al., 2009). People with a mobility disability found that remote support groups, virtual transition of usual activities or health services, and systems that prioritize the needs of people with disability, were assets. Finally, acceptance of the disaster was an asset that helped people with disability adjust to the 'new normal', supporting their disaster resilience.

Equitable Measures

A lack of universal design during pandemic response measures caused people with disability to experience lockdown-related disparities. Stay-at-home orders implemented at the height of each wave of COVID-19 in Canada magnified existing burdens of receiving timely and adequate healthcare. Social isolation compounded isolating effects of disability, which are often the result of stigma, discrimination, or lack of institutional accommodations. Consistent with recent literature, we found a unique vulnerability (for social and health risk) among those living in

long-term care facilities (Jesus et al., 2021). Rigid measures deprived some people with disability of their right to live independently through reducing assistance, opportunities, and recognition.

When people with a mobility disability were put in the 'vulnerable' category, they were seen through their risk factors rather than assets and abilities. However, the experiences of people with disability during lockdowns show there is more that could make one vulnerable than just an underlying condition. In fact, surveys have found that a substantially lower percentage of persons with disabilities than able-bodied persons report their health to be excellent or very good (U.S. Department of Health & Human Services, 2005).

Disability is not equated with poor health status nor is it the sole determinant of health. As such, people with a mobility disability recommended public health not only focus on preventing disability from illnesses. Instead, health indicators should measure the degree to which society promotes all dimensions of wellness for all groups and eliminates health inequities (Becker, 2006; U.S. Department of Health & Human Services, 2005).

When public health is aimed at maximal disease burden reduction across the population, there is historically less attention given to equitable responses for specific groups, such as people with disability, and their human rights during a pandemic (Selgelid, 2008). Although pandemic restrictions to prevent exposure are necessary, they need to address the health, social participation, and socio- economic disparities of people with disability in tandem protect their disability rights. Moreover, policy planners should ensure essential needs to one's quality of life are addressed through inclusive health, social, and financial systems. This includes specific pandemic benefits for people with disability, their caretakers, or organizations.

When lockdown measures are needed, they must be equitably enforced, considering disability rights. People with a mobility disability voiced that there must be concerted efforts in

the planning of public health interventions and coordination across all sectors to address the wide range of lockdown-related disparities. Moreover, the disadvantages people with disability experience must be compensated for with accommodations, additional supports, and availability of alternative methods of carrying out daily activities (Goggin & Ellis, 2020); this includes hybrid models, which increases accessibility, and prioritization for personal protective equipment. In fact, Qi and Hu (2020) criticize the "one-size-fits-all" approach that was adapted in global pandemic responses; a lack of specific and humane adjustments places the disability community at greater risk as compared to the general population. Even in Canada, people with disability expressed there is a need to re-examine pre-established frameworks for ethical decision making in health crises that exclude people with disability due to preconceived notions on their quality of life (Kuper et al., 2020; Levine & Jansson, 2021; Qi & Hu, 2020).

Many major disasters and conflicts have historically resulted in breakthroughs due to the need to accelerate development (Bambra et al., 2020; Sheth et al., 2020). Sheth et al. (2020) hypothesized the result of "World War COVID" to be a reinvention of healthcare delivery and systems of care. The rapid transformations that the health care system has had to undertake due to the pandemic prove that in "peacetime" (pre- and post-disaster situations), society can do a better job at accelerating the development of healthcare delivery models to overcome the systemic issues affecting people with chronic conditions (Sheth et al., 2020).

The necessary virtual transition during the COVID-19 pandemic was a means for people with a mobility disability to meet health needs. Although telemedicine is recognized as an effective clinical method, outside of disaster settings, the overall uptake of telemedicine or the hybrid model has been slow and fragmented (Smith et al., 2020). However, during the SARS epidemic in 2003 in China, telehealth, or "e-health" was constructed as a public health strategy to deploy regional

collaborative medical services (Zhao et al., 2010). In the current pandemic, telemedicine has also been exponentially transformed as it was harnessed to overcome enforced distancing challenges (Ben-Pazi et al., 2020).

Prior to the COVID-19 pandemic, many medical services limited reimbursement to people with disability based upon site of service or geography (Sheth et al., 2020). Since the COVID-19 outbreak, telemedicine is covered by more federal governments and commercial payers (Hollander & Sites, 2020). This is beneficial since people with disability across all socio-economic circumstances have traditionally faced challenges receiving federal compensation and inclusive care and rehabilitation (World Bank and World Health Organization, 2011). To maintain newly established infrastructure of services, people with disability indicated funding is needed to accelerate development or repairs to patient portals, online communications with providers, and virtual physical therapy.

Preventing Lifestyle Drift through Enhancing Community Resilience

Responding to the COVID-19 pandemic sparked a conversation around "what does it mean to be vulnerable?" (Ahmad et al., 2020). Jesus et al. (2021) suggest social risk results from socially-determined disparities that people with disability have been experiencing for long time before COVID-19. These disparities have caused people with disability to be commonly referred to as a minority group, frequently vulnerable to stigma, discrimination, marginalization, and socially determined disadvantages (D'Cruz & Banerjee, 2020; Sabatello, Burke, et al., 2020). However, pandemic outcomes, such as the lockdown, allowed the general population to share the lived experience of necessary confinement. This shift triggered a realization that systemic change is needed to reduce vulnerability and to prevent against being disadvantaged by social restrictions.

Previously, Hopf and McLeod (2015) identified "drivers of change" as needed innovation

for service development for people with disability. Macro-level drivers included development of disability-inclusive legislation and policy, and micro-level changes included changes in the perceptions of disability within the general community (Hopf & McLeod, 2015).

People with mobility limitations expressed that they are traditionally thought of as being too difficult to accommodate. However, a micro-level change that occurred during the pandemic was a shift in attitudes; COVID-19 showed it is not impossible to accommodate in some areas, including funding to increase access to health services and public infrastructure. A macro-level change that came out of the pandemic was society's acceptance and implementation of different ways for inclusion; virtual innovation challenged previous notions of participation.

Rosso et al. (2013) found that lower mobility was associated with decreased opportunities to participate in community social activities. This causes disability, which limits individuals' autonomy, making engagement with others more difficult (Rosso et al., 2013). Fortunately, virtual opportunities during the pandemic increased the autonomy of some people with mobility needs, empowering them to maintain social connection and integrate in society. Moreover, current mass adoption of remote or hybrid healthcare, work, education, and leisure has expanded employment, health services, and physical activity opportunities for people with disability (Croft & Fraser, 2022; Hollander & Sites, 2020). People with disability found that these advancements should be sustainable, as they will support more diverse workforces, institutions, and overall societies.

Carey et al. (2017) state that *lifestyle drift* occurs when 'whole of society' problems are reduced to the personal problems occurring at the fringes of society. The COVID-19 pandemic is a case where problems emerging from societal processes, such as pandemic responses, were addressed when they affected dominant values and interests (Carey et al., 2017). Because dis-ability problems were no longer occurring at the fringes of society, what were previously thought

of as complex interventions could now be implemented.

The pandemic is an opportunity to re-evaluate and rebuild systems to accommodate to the needs of people with a mobility disability through multiple novel strategies. Hollander & Sites (2020) provided insights into the perceived impediments that have led to previously slow adoption of certain innovation, such as telemedicine, that came with the current pandemic. For example, COVID-19 addressed the long-time myth that "telemedicine is too hard". However, providers in the U.S. possessed the technology needed to conduct a telemedicine visit (i.e., phone, computer); they were already doing telemedicine, just not with their patients. When the fear of catching a potentially fatal disease arose, telemedicine was no longer "too hard" (Hollander & Sites, 2020).

In addition to the actions to address ramifications of COVID-19, pandemic responses should be supplemented by more systemic changes for universal design and specific accommodations. Since problems are systemic, solutions must be too. While new platforms, including telehealth or tele-work, greatly supported people with disability in overcoming restrictions, innovation still did not spare some people with disability from structural exclusion (Pineda & Corburn, 2020). This has been a problem prior to the pandemic, and for some, became more challenging during- as society needed to rely heavier on the remote access (Annaswamy et al., 2020; Jesus, Landry, et al., 2020).

It has been overlooked that many people, such as those with cerebral palsy, require mediators for remote services to be accessible (Ben-Pazi et al., 2020). Similarly, in our study, some people with disability criticized the lack of accessible and user-friendly design in new technology methods, as digital designs were barriers for those who have physical dexterity or sensory needs. While innovation during the pandemic 'filled the gap' that previously hindered people with disability from opportunities, more work needs to be done to prevent lifestyle drift. Institutions,

manufacturers, and governments must develop disability-inclusive, digital networks that increase the quality of life, mobility, and social inclusion of people with disability for the 'new normal' after the COVID-19 pandemic.

Mladenov (2016) argued that the disability perspective is essential for understanding and promoting social justice, although it is often disregarded. In the pandemic context, the perspectives and lived experiences of people with disability should inform integrative development of social and health policies, improving access for those with mobility- or other functional- needs. Recent literature suggests a need for research on the needs and disparities faced by people with disabilities, told through their own voices (D'Cruz & Banerjee, 2020; Eskytė et al., 2020; Pineda & Corburn, 2020). Research that highlights lived experiences during a crisis can promote the inclusion of people with a mobility disability in the design of robust pre-disaster preparedness plans and subsequent pandemic responses. Capacity development is founded on experiential knowledge of different types of disabilities —and disability needs— informing preparation for future disasters.

Another component of inclusive disaster planning is participation. Like previous planning for physical disasters, people with a mobility disability must be included in community, public health, and government decision-making bodies, such as different disaster management departments (Elisala et al., 2020). Positive work has already been done in Canada; the Minister of Employment, Workforce Development and Disability Inclusion formed the Disability Advisory Group at the onset of the pandemic, with the involvement of leaders from the disability community (Government of Canada, 2020). The goal of this national initiative was to consider the real-time lived experiences of Canadians with disabilities to make sure people with disability received supports needed during the COVID-19 pandemic, and to prepare for future ones.

People with disability who were members of the Advisory Group made meaningful

differences in the Government's pandemic responses through discussions on important issues, such as financial support to cover extraordinary expenses incurred by persons with disabilities, and visitor policies for hospitals (Government of Canada, 2020). However, data from our study suggest there is still work to be done to improve the actual day-to-day experiences of people with disability around the country, as they navigate pandemic environments.

Traditional resilience-building initiatives focus on the infrastructure and environmental sectors of preparedness plans and frameworks. However, there is often a lack of focus on the lives of the people served by the infrastructure (Wulff et al., 2015). In contrast, the Community Health Resilience Approach is more appropriate in a pandemic situation and may be relevant to the Canadian context. This framework states that commitment to bolstering human resilience should be at the forefront of any workable model of disaster resilience. Adaptive capacity to withstand impacts of a disaster, recovery, and maintain a quality of life should not be a 'personal problem' resulting from lifestyle drift (Carey et al., 2017, Mladenov, 2016). Instead, it should be the outcome of everyday community health resilience, supporting people with disability as they face everyday challenges as well as emergency situations.

Limitations and Future Work

Limitations of this study include the convenient sampling strategy, which may have excluded people who are less comfortable disclosing disability identity. The participant sample lacked ethnic and racial diversity. Therefore, our grounded theory and recommendations may not reflect the true lived experiences and needs of those from non-western cultures. We found through this study that virtual connection should not be assumed to be accessible to all peoples; this applies to our own study, as the remote nature of our interviews may have left out those who do not have access to physical devices (i.e., computer) or stable internet connection, or those who are unable

to navigate digital platforms independently.

Future work should expand sampling to include people with a mobility disability across Canada to capture an array of experiences. It would be of value to explore the experiences of those with intersecting identities, to understand intersectional factors that impact adaptive capacity. This includes people with disability from rural areas, who may have different experiences of access to community resources.

Finally, although we highlight the recommendations people with disability made to public health officials and politicians to reduce the identified disparities, here we do not address actional, internal plans that could be actualized to increase disability-inclusive pandemic preparedness and responses. Future work should include stakeholders to understand strategies to implement these recommendations into the systems that support the wellbeing of persons with disabilities.

CHAPTER 6: CONCLUSION

Using the traditional grounded theory approach, we built the theory *Adaptation Is Not a Choice, It's a Way of Life* to explain how people with a mobility disability in Canada have experienced the COVID-19 pandemic. Furthermore, we expanded on the themes to account for recommendations people with disability made to improve disability-inclusiveness in pandemic response.

People living with disabilities have been widely documented to be at increased risk of morbidity, mortality or severe illness following a disaster. However, due to the pandemic, there has been increased awareness that risk is shaped by the social context of a disaster. This lent evidence to the adaptive capacity of people with disability which supports their resilience in managing limitations from the environment. *Adaptation is Not a Choice, It's a Way of Life* because people with a mobility disability employed resilience to continuously lower societal barriers to inclusion, used assets to enhance adaptive capacity, and were advocates for the need to receive accommodations for equitable experiences- both in and out of a pandemic context.

Participants' narratives on their adaptive capacity during the pandemic show that structural exclusion during the pandemic mirrors everyday experiences of exclusion. They have "*already lived like there's a pandemic*", because the COVID-19 disaster illuminated pre-established frameworks for city planning, social infrastructure, and public health decision-making during and prior to a disaster that have left people with disability out. This applies to public transportation, education, employment, public health, and funding systems. Where before the disability experience was commonly minimized, life reconstructed under the pandemic made dis-ability disparities more apparent, helping to mainstream conversations around systemic action to reduce the risks of marginalized groups. With increased understanding of the true physical and

psychosocial needs of people with disability, as well as disability rights, dis-ability inclusion can be brought even closer to the frontline of public health decisions, and planning. It is important to let people with disability's own experiences be the drivers of change that leave lasting impacts on public health and pandemic response interventions.

The COVID-19 pandemic is an opportunity to revert the normative that the onus for change to reduce health-related inequities is on the person requiring accommodations. Ensuring that systems can be accessed by all members of society is a safeguard for resilience because it preserves independence and ability to reduce risk. It is the role of the government, healthcare sector, and individual organizations to provide supportive structures that empower people with disability to maintain their health and safety during a pandemic. The ultimate goal of developing more adequate support, policies, and services is to redesign social justice in our systems.

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Appendices

Appendix I: COREQ Checklist

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	23
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	23
Occupation	3	What was their occupation at the time of the study?	23
Gender	4	Was the researcher male or female?	23
Experience and training	5	What experience or training did the researcher have?	N/A
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	23
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	22
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	28
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	20
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	22
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	21
Sample size	12	How many participants were in the study?	30
Non-participation	13	How many people refused to participate or dropped out? Reasons?	23
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	23
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	23
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	31
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	23
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	24
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	22
Field notes	20	Were field notes made during and/or after the inter view or focus group?	23
Duration	21	What was the duration of the inter views or focus group?	23
Data saturation	22	Was data saturation discussed?	24
Transcripts returned	23	Were transcripts returned to participants for comment and/or	24

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	25
Description of the coding tree	25	Did authors provide a description of the coding tree?	26
Derivation of themes	26	Were themes identified in advance or derived from the data?	24
Software	27	What software, if applicable, was used to manage the data?	25
Participant checking	28	Did participants provide feedback on the findings?	28
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	24
Data and findings consistent	30	Was there consistency between the data presented and the findings?	25
Clarity of major themes	31	Were major themes clearly presented in the findings?	31
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	N/A

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix II: Certificate of Research Ethics Board Approval

06/08/2021

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE | CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number	H-03-21-6652
Titre du projet / Project Title	COVID-19 Pandemic Experiences of People with Mobility Disability: A Grounded Theory Study
Type de projet / Project Type	Thèse de maîtrise / Master's thesis
Statut du projet / Project Status	Approuvé / Approved
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	06/08/2021
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	05/08/2022

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Michelle YANG	École interdisciplinaire des sciences de la santé / Interdisciplinary School of Health Sciences	Chercheur Principal / Principal Investigator
Tracey O'SULLIVAN	École interdisciplinaire des sciences de la santé / Interdisciplinary School of Health Sciences	Superviseur / Supervisor
Sarah FRASER	École interdisciplinaire des sciences de la santé / Interdisciplinary School of Health Sciences	Co-superviseur / Co-supervisor

Conditions spéciales ou commentaires / Special conditions or comments

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Appendix III: Consent Form

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Faculté des sciences de la santé
Faculty of Health Sciences

Participant Consent Form

Principal Investigator:
Michelle Yang
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Email: [redacted]

Supervisors:
Dr. Tracey O'Sullivan
Phone: [redacted]
Email: [redacted]

Dr. Sarah Fraser
Phone: [redacted]
Email: [redacted]

Invitation to participate: participants are invited to contribute to a research study entitled *Experiences of the COVID-19 Pandemic of People with a Mobility Disability.* Participants can confirm that they i) are 18 years or older ii) live in Canada iii) can meet virtually over Zoom or by phone iv) can provide written or verbal consent for their own participation v) identify as having a mobility disability

Purpose of study: the purpose of this research is to:

1) Give individuals an opportunity to share lived experiences of managing changes related to COVID-19
2) Identify important assets and capabilities in their lives that support their resilience in pandemic
3) Examine existing systems that address pertinent issues to a disability population during a disaster

Participation: we are recruiting 15-20 individuals who identify as having a mobility disability to participate in 1-2 phone or Zoom interviews, lasting 60-80 minutes each. Participants are invited to *one* interview, with the possibility of a follow-up interview at a later date, if they are interested. Interviews will be audio-recorded. Topics that will be discussed during the interviews will include daily activities, relationships with others, caregiving, physical and mental health, physical activity, social connectedness, the news reporting about COVID-19 and personal views on the pandemic situation. We will accept participants on a first-come first-serve basis in the study. The interviews will be scheduled at a time convenient for participants.

Voluntary participation: participants are under no obligation to participate and if they choose to participate, they may withdraw from the study at any time and/or refuse to answer any questions. If a participant chooses to withdraw, all data gathered until the time of withdrawal will be deleted and not be used in the study.

Benefits: participation in this study will contribute to awareness about the experiences and impacts of the pandemic on people living with mobility disability. In particular, this study will highlight the voices of those with mobility impairments and their experiences and suggestions to inform public health interventions and policy strategies.

Confidentiality and Anonymity: This study is being conducted as part of Michelle Yang's Master of Science thesis. Identifying information will only be accessed by Michelle Yang and any researchers working under Dr. O'Sullivan's or Dr. Fraser's supervision for this project. Names will be disguised in written reports, presentations, and publications. All researchers with access to identifying information will sign a privacy and confidentiality form.

Conservation of data: All information and discussions will remain strictly confidential. The contents will be used only for this study. Recordings and transcripts of the interviews will be password protected and stored on a secure computer. Only Michelle Yang, Dr. O'Sullivan, and Dr. Fraser will have access to data files. The data will be conserved for 10 years.

Risks: It is possible that during the interview participants may find themselves uncomfortable with discussing their experiences of the pandemic and the structures of their lives relating to mobility impairments.

The following list of resources may be helpful if participants require support:

- Ontario Disability Support Program (ODSP) 613-787-3951; https://www.mcss.gov.on.ca/en/mcss/programs/social/odsp/index.aspx
- Council of Canadians with Disabilities:

http://www.ccdonline.ca/en/socialpolicy/disabilitysupports

- Ottawa Public Health (Mental Health and COVID-19) https://www.ottawapublichealth.ca/en/public-health-topics/mental-health-and-substance-use-services-and-resources.aspx

Quotations:

Participants may be quoted in the research study reports, presentations and publications, but no names or identifying information will be used.

It is the participant's choice whether to be quoted. Participants can change this permission at any time.

Please initial beside your choice:

- *I agree to be quoted, but all personal identifying information shall be removed or altered and contents of the quotation shall not be revelatory of my identity _____.*
- *I do not wish to be quoted from my interviews _____.*

Signatures:

My participation is voluntary and there is no financial compensation provided for my participation in this study. I understand I am free to withdraw from the study at any time.

Participants are invited to contact the principal investigator for more information about this study.

Michelle Yang: [redacted] or [redacted]

Note: If you have any questions concerning your rights as a participant in this research, please contact The Protocol Officer for Ethics in Research at the University of Ottawa at the following address, phone number or email:

Mailing address: Protocol Officer for Ethics in Research

uOttawa
Faculté des sciences de la santé
Faculty of Health Sciences
Office of Research Ethics and Integrity
University of Ottawa
Tabaret Hall (154)
Ottawa, ON K1N 6N5

Phone: 613-562-5387 Email: ethics@uottawa.ca

Participant Consent: I have read this consent form and I have been given the opportunity to ask questions. I consent to participating in a phone or videoconferencing interview for this study.

Participant name (please print): _____

Participant signature: _____

Date: _____

Researcher Signature:

Researcher signature (please print): _____

Researcher signature: _____ Date: _____

Please sign and date this letter and return to Michelle Yang [redacted] before the first interview. Alternatively, you may read this form together at the interview and provide verbal consent. **Participants should print a copy of the consent form to keep for their personal records.**

Thank you for your interest and contribution to this project.

Appendix IV: Recruitment Material

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Research Study

Pandemic experiences of people with a mobility disability

People living with disability related to mobility have experienced unique situations and challenges during the COVID-19 pandemic. Our research team is conducting a research study exploring the experiences of people with mobility impairments in the context of the COVID-19 pandemic.

What is the study about?

- What has your life been like during the pandemic?
- How has COVID-19 impacted you?

Where and when?

- Participants may choose to meet with us over Zoom or over the phone
- Interviews will be scheduled at a time that is convenient for you

What will you be asked to do?

- Participants are invited to *one* interview with the possibility of a follow-up interview at a later date, if they are interested
- The interviews will last a maximum of 60-80 minutes

Who can participate?

- Identify as having a **mobility disability**
- 18 years or older
- English speaking
- Live in Canada
- Can consent to have their interview *audio recorded* in a confidential manner

How do you get involved?

- We are recruiting 15-20 participants (we will use a first-come first-serve basis to enrol people in the study)

If you would like to get involved, please contact: **Michelle Yang** at [redacted] to book a time for the interview. Do not hesitate to get in touch if you have any questions or would like to learn more about the study!

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Appendix V: Semi-Structured Interview Guide

Introduction

PURPOSE

The purpose of the interview today is for our research group to learn about the lived experiences of people with a mobility disability in the context of the COVID-19 pandemic. The goal is that knowledge produced here provides an opportunity to re-shape care systems and stimulate innovation in how to address pertinent issues to people with a mobility disability during a disaster.

BACKGROUND

I'd like to start by asking you a few demographic questions – a little bit of information about your background and living situation:

- Age
- Where in Canada do you live?
- What is your sexual orientation?
- What gender do you identify with?
- What is your race?
- Do you live with somebody (partner/children)? In what type of residence (i.e., house, care home)?
- Work, in school, retired?
- General perception of health
- Do you identify as having a disability related to mobility?

Experiences with COVID-19

I'd like to ask you about your experiences with COVID-19

- In general, how have you felt during the pandemic?
    - Is there any difference from how you saw your own health before the pandemic?
- How would you define "health"?
    - What does "healthy" look like to you?
- Can you describe any experiences you may have had with the COVID-19 virus (i.e., illness, getting preventatively tested, receiving the diagnosis/any treatment, etc.)?
    - How have you managed or coped with this?
- When you think of COVID-19, what comes to mind?
- How do you perceive your risk in terms of the virus?
- Can you tell me about any things/people that might have affected your perception of the risk of the virus? (i.e., the news, people you live with, your health specialists)?

Changes in lifestyle or activities

I'm interested in finding out how you experience the changes that came along with the pandemic.

- Has the pandemic changed anything in your life?
    - Probes: *activities, education, employment, health (including mental health), leisure*
- How has the pandemic changed or affected how you are able to do these activities?
    - What feelings do you have around these changes?
    - Can you tell me about any strategies you have used to cope with changes resulting from the pandemic?
- Can you describe any barriers/things that have made life more difficult with the pandemic?
- Which things have made life easier or have provided support for you?
- Did these activities hold a certain type of meaning to you? (previously or currently)
- Is there something you valued about these activities? Or a reason why you chose to participate in these activities?
- Are there any activities that would you like to be doing now, that you are not?
    - What would it take for you do these activit(ies)?
- *(To end this section off) Are there any other activities you used to or currently participate in that have been impacted by the pandemic?*

Contact and connection

Now I want to ask you about how you experience changes in your relationships or connections with others.

- Can you describe the connection you had with others before the pandemic started?
    - Can you tell me about any groups or communities you were a part of?
- Has the pandemic impacted the ways you connect with others?
    - If so, how?
- What are your relationships with these people/groups like now?
    - What have been the barriers to maintaining this relationship throughout the pandemic?
    - What have been the things that helped to maintain your relationships throughout the pandemic?
- Other than those in your social circle, how has the pandemic affected your ability to connect or get in touch with other important people in your life? (this includes those who you may work with, receive services from, are involved with, etc.)

Assets and contribution

I'd like to discuss the ways you have been going about meeting your needs during this pandemic - and if you are helping others, how you have managed this during the pandemic.

- Can you describe your own strengths or abilities that help you in your everyday life?
- Are there other things/people/services supported you in meeting your needs?
    - If so, how?
- Can you describe any ways that the pandemic changed or impacted your strengths or abilities?
    - What barriers have you faced?
    - What types of things have supported you or allowed you to continue to meet your needs?
- Can you tell me about any things that you might have done to support or help others during the pandemic?
    - If so, who?
    - How does this make you feel?
    - What are your strengths or abilities that allow you to support or help others?

- How was the pandemic impacted how you feel about giving or receiving support?
    - What kinds of support? (i.e., health, daily living, work, etc.)

Future

We don't know what the future holds in terms of the COVID-19 pandemic, but we're interested in how you feel about what will come.

- When the restrictions lift, is there anything you are looking forward to?
    - What will you do?
    - Where will you go?
- What do you now define as the new "normal"? Do you think this will remain "normal" after the pandemic?
- What would you like to see happen in the future?
- In a future pandemic, what would you like to see happen?
    - Anything same or different?
- What would you like public health practitioners and politicians to know about your experience with this pandemic?

Closing

Thank you very much for sharing your experiences with me today.

- Is there anything that I have not ask asked you that I should have asked in order to understand your experiences of the pandemic?
    - If I need further clarification on anything that we talked about today, is it ok if I contact you?
- Thank you very much for your participation and time.
- Please feel free to contact me at the number/email given in the consent form if you have any questions regarding this study or your participation today.