


Impacts of the COVID-19 Pandemic on the Healthcare Provision and Lived Experiences of Patients with Hydrocephalus

Journal of Patient Experience
Volume 9: 1-7
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DOI: 10.1177/23743735221092555
journals.sagepub.com/home/jpx


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Abstract

The emergence of COVID-19 (SARS-CoV-2) led to distancing measures which acutely affected healthcare infrastructure, leading to limited in-person clinical visits and an increased number of virtual appointments. This study aimed to examine the effects this had on adults with hydrocephalus by describing the lived experiences of a cohort of patients at an outpatient hydrocephalus clinic. Between early May and early July of 2020, remote structured interviews were conducted with participants. Interviews were in-depth and open-ended, allowing participants to reflect and expand on the effects of the social distancing mandate on their well-being and quality of care. Three themes emerged: (1) impacts of changes in treatment provision, (2) impacts of changes in mitigating activities, and (3) impacts of changes on personal well-being. The comprehensive understanding of lived experiences may inform the future provision of healthcare services and social policy. Improved approaches to remote care telemedicine have the potential to facilitate high-quality care.

Keywords

COVID-19, hydrocephalus, public health restrictions, patient outcomes, virtual care

Introduction

The emergence of COVID-19 (SARS-CoV-2) as a novel coronavirus has led to a marked disruption in the availability and provision of healthcare. By March of 2020, social distancing measures were put in place by provincial and federal bodies. These restrictions specifically extended to healthcare infrastructure: hospitals were a primary point of contact with those most severely infected with COVID-19, primary care physicians were likely to come into contact with those most at risk for developing complications in their clinics, and elective procedures were deemed to put patients as well as physicians at an unnecessary risk for contagion given the required physical proximity. As a result, in-person physician visits were limited to critical and emergency cases, and physicians began scheduling appointments virtually.

Adult hydrocephalus is a neurological condition broadly characterized by a build-up of cerebrospinal fluid inside the ventricles of the brain, leading to potentially dangerous increased pressure on the surrounding tissues (1). In older populations, hydrocephalus has a largely heterogeneous etiology; it is frequently investigated following persistent symptoms, or presents

secondary to other disorders such as infection, tumour, or intracranial hemorrhage (2,3). With a lack of non-invasive therapies, the most common treatment for hydrocephalus is surgical implantation of a shunt system which allows the drainage of excess fluid (4). However, shunts are associated with potentially damaging complications in elderly patients such as infection and shunt failure, and may not be an ideal way to treat the condition (5). While the global incidence of hydrocephalus is currently estimated

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to be 85/100,000, stratified by age it is estimated at 175/100,000 for adults and 400/100,000 for elderly over the age of 80, with incidence expected to rise in areas with an ageing population (6).

Given the complex nature of the condition and the risk of complications requiring ongoing medical care, patients with adult hydrocephalus are at an increased risk of adverse effects and decreased quality of life in the pandemic climate. While agencies such as the Hydrocephalus Association maintain that hydrocephalus has not itself been identified as a risk factor for contracting COVID-19 (7), many patients have had their surgeries postponed indefinitely and their follow-up appointments cancelled or moved to virtual platforms. The aim of the present study is to examine the effects which the pandemic measures and resulting unavailability of clinical care have had on adults with hydrocephalus and their care partners by describing the lived experiences and perspectives of a cohort of patients at an outpatient hydrocephalus clinic.

Methods

A qualitative approach was used to understand the lived experience of people living with hydrocephalus, with a reflexive thematic approach to data analysis used to iteratively develop descriptive emergent themes grounded in experience. Between 11 May and 14 July 2020, remote in-depth interviews were conducted with persons with adult hydrocephalus (and family care partners if they wished to participate) by telephone. It was important for the interviews to take place in the midst of the pandemic so patients could provide detailed accounts of their experiences while social distancing measures were in place and affecting them directly. Participants were patients who consented to be contacted for research prior to attending the University of Calgary Adult Hydrocephalus Clinic (8) at the Foothills Medical Centre in Calgary, Alberta. In 2019, ~3,000 patients were followed in the Adult Hydrocephalus Clinic, with around 1,500 outpatient assessments and 180 surgical procedures performed. By the end of March 2020, the clinic had suspended in-person specialist appointments and postponed all surgical treatments that were not critical emergencies. Patient contact, recruitment, and data collection were completed by BA, and data analysis was completed by DP and AS, all research staff with experience interacting with patients in this clinical population. Participants had the choice to either sign an online consent form or provide explicit oral consent (which was recorded and transcribed) to participate in the study. The Conjoint Human Research Ethics Board (REB20-0559) at the University of Calgary approved the study. For full details regarding recruitment, data collection, and data analysis, see Subotic et al. (9).

Results

Participant Demographics

A total of 51 potential participants were contacted; of these, 23 patients with non-acute hydrocephalus consented to

participate and completed the interview. Patient characteristics are outlined in Table 1. Interviews ranged in length from 19 m:29 s to 1 h:17 m:25 s (mean length = 34 m:44 s, cumulative length = 13 h:18 m:59 s), with 11 females and 12 males aged 37–86 (mean age = 68.7). All participants chose to complete their interviews over the phone.

Thematic Analysis: Patient Perspectives

Three emergent themes were identified, comprehensively characterizing the COVID-19 pandemic's impact on the lived experiences of patients with hydrocephalus (and their care partners). Descriptive codes isolated in the interview data informed the thematic synthesis, and these branched and were combined as similarities between them were detected. The resulting themes are discussed in the following sections, where direct quotes have been edited grammatically solely to improve readability.

Impacts of Changes in Treatment Provision

Results of Treatment Procedure Postponement. One of the main concerns most patients had while adhering to medical social distancing guidelines was the inability to receive the medical procedures and tests for which they had been previously scheduled (Table 2; Subtheme 2.1). This was especially noted by patients who were awaiting shunt implantation and who felt their symptoms were progressively getting worse (namely that their balance and memory were degrading). Similarly, patients who

Table 1. Characteristics of 23 Interviewed Patients from the Adult Hydrocephalus Clinic.

Characteristic	Value
Age, mean (range)	68.7 (37–86)
FemaleSex (female), n (%)	11 (48%)
Procedure delayed*, n (%)	ELD 3 (13%) ETV 2 (9%) VPS 1 (4%)
	Follow-Up
	Regular 5 (22%)
	1-year 3 (13%)
	3-month 1 (4%)
	Post-op ETV 1 (4%)
	Post-op VPSI 2 (9%)
	Post-op 3-month 2 (9%)
	SDH 1 (4%)
	New patient awaiting consult** 2 (9%)

Abbreviations: ELD, external lumbar drainage; ETV, endoscopic third ventriculostomy; VPS, ventriculoperitoneal shunt; VPSI, ventriculoperitoneal shunt infection; SDH, subdural hematoma.

*Indicates the appointment type that had been rescheduled or temporarily held virtually due to the social distancing measures put in place at the Adult Hydrocephalus Clinic.

**Patients had previously made contact with the Adult Hydrocephalus Clinic and were awaiting consult after neurosurgeon obtained ordered test results.

Table 2. Examples Regarding the Theme of Impacts of Changes in Treatment Provision.

Subtheme	Example Quotes
1.1 Results of treatment procedure postponement	<p>“Oh, it’s pretty hard, pretty hard with this shunt being clogged. It’s hard to walk. My memory is not very good. I keep forgetting things. It’s getting worse and my balance is really bad. I keep forgetting things. I have to be so careful when I’m walking around in the kitchen. I don’t walk an awful lot. I sit in the chair for the better part of the day and the better part of the evening.” (Participant 611)</p> <p>“All the tests that I couldn’t have done - that’s been the hardest part of all this. Some days are better than others, but it’s horrible.” (Participant 635)</p> <p>“Things [symptoms] are all coming back after my surgery and I’m not allowed to be assessed because I’m not a life-or-death situation. So I can’t go in and be reassessed to find out what’s going on in my brain. The surgery didn’t work and I have to wait ‘till this is all over to know what’s going on in my brain. I’m frustrated. I’m, I’m angry. I want to know what’s going on. My health is in jeopardy here, right?” (Participant 616)</p>
1.2 Results of appointment changes	<p>“We do telephone things with our family doctor now, and she can assess us over the telephone. And it was me that was the problem. Because I was having some breathing issues, which had nothing to do with COVID. But I couldn’t get her to listen to my chest or anything. I had an ear infection and she couldn’t look in my ear because she can’t do that over the telephone.” (Participant 634)</p> <p>“They just would phone and ask me some questions, but it wasn’t done where they could see me or I could see them. It was okay to do it that way, other than the fact that they couldn’t see me. So that would be my biggest concern, you know, I’d [like to] see just how much I’ve, um... regressed.” (Participant 609)</p> <p>“Well, I wouldn’t be happy if they couldn’t assess me over the phone in terms of driving, or if they were just to say that I couldn’t drive. The only outcome that I want from a virtual meeting is that yes I can drive.” (Participant 602)</p>

experienced symptoms but were awaiting further testing also expressed their worry at their condition and noted this was exacerbated by the lack of knowing exactly what was wrong. Some patients whose symptoms were deteriorating felt that their concerns were not being taken seriously.

Results of Appointment Changes. Many of the participants had at least one of their regular or follow-up appointments cancelled, and all had experienced at least one telephone appointment with their neurosurgeon. Reactions to virtual appointments were mixed, with patients generally reporting positive experiences if their questions could be answered without a physical examination, and the opposite if they felt the discussion did not thoroughly address their concerns (Table 2; Subtheme 2.2). Patients also seemed concerned that their neurosurgeon may miss important illness cues if they were not assessed in person, and they noted missing the social connection of a face-to-face visit.

Impacts of Changes in Mitigating Activities

Restriction of Access to Physical Activity. Physical activity was mentioned by most participants as either a newly acquired means of dealing with the physical and mental stress of the pandemic, or as something they were no longer able to fully participate in because of closed facilities or deterioration of their physical symptoms (Table 3; Subtheme 3.1). A number of participants used physical exercise as a way to prolong their health, distract from the boredom of being restricted to the home, and spend quality time with a

partner they were living with. Participants whose gait and balance symptoms were worsening and prevented movement were especially motivated to visit their neurosurgeon.

Restriction of Access to Social Supports. The inability to interact with social supports – especially loved ones such as family and friends – was one of the most-often mentioned difficulties of coping with the social distancing measures (Table 3; Subtheme 3.2). This was especially evident in participants who lived alone (did not have a significant other who offered emotional and physical support) or who had persons in their lives that were especially susceptible to COVID-19 (such as elderly parents and immune-compromised friends). Patients were often more willing to disregard social distancing measures to interact with their loved ones than to attend in-person clinical appointments and be exposed to the hospital/clinic setting, or wait in crowded pharmacies for their prescriptions.

Impacts of Changes on Personal Well-being

Concerns About Future State of Diagnosis. One of the acute impacts of social distancing measures was the uncertainty of the future of patients’ diagnoses given the uncertainty of when they would be able to resume their regular care. This seemed to more heavily affect those patients with worsening or untreated symptoms, while other patients recognized the uncertainty but were reassured by remote access to their physicians and the efficacy of their current treatments (Table 4;

Table 3. Examples Regarding the Theme of Impacts of Changes in Mitigating Activities.

Subtheme	Example Quotes
2.1 Restriction of access to physical activity	<p>“Well, we used to go to the gym almost every day. ‘Course, the gym is closed, so we can’t do that. Well, we’re living quite close to [High School]. There’s a large track and playing field there, so we go over to the track daily and trot around it for a mile or so. And then come home and do push-ups; I have some dumbbells and I throw them around, squats, things like that.” (Participant 623)</p> <p>“... I don’t walk very much, but I haven’t been able to maintain any level of fitness that I would have liked to.” (Participant 617)</p> <p>“I noticed that I’m not walking as well as I was before. But, I think that’s because everything has been so limited. Not walking as often and not walking as well.” (Participant 622)</p>
2.2 Restriction of access to social supports	<p>“I’m tired. And I think that’s probably coming from a lot of people because I am working so much, but I am finding that I’m missing that human contact of spending time with people, and having no social activities is definitely affecting me. But I just focus on my family and my work to just try and keep myself pushing through.” (Participant 644)</p> <p>“I can’t have my grandchild come over anymore. And no having your family, immediate family, that’s rough. Mind you that doesn’t stop me from using the telephone.” (Participant 607)</p> <p>“I think just the... the lack of socialization, and sort of the... the fear tactics – and I don’t mean that to sound like they aren’t real. It’s just that... you know that, especially, at first... it was so scary. So that is something we’ve missed, for sure.” (Participant 626; Care Partner)</p>

Subtheme 4.1). Patients were more likely to adapt to virtual healthcare if they were less concerned about their prognosis.

Attitudes About Infection Risk. Generally, participants indicated that they took the risk of infection relatively seriously in their day-to-day lives, and minimized unnecessary interaction as much as possible (Table 4; Subtheme 4.2). Participants with more severe symptoms were more likely to self-isolate; however, they were also more likely to risk exposure in-clinic in the effort to ameliorate their condition. Some patients utilized the help of family and friends to run their errands so they did not have to leave their houses, while other patients related scepticism about infection and self-isolated less overall.

Changes in Mental Health. While there was a spectrum of severity, most participants reported at least some impact on their mental health during social distancing measures (Table 4; Subtheme 4.3). Generally, patients who had a live-in support system (usually their spouse) indicated that they noticed increased irritability and restlessness, while patients who reported feeling more isolated noted a marked decline in their mental health, often through increased anxiety and depression. A number of patients who were already being treated for mental illness mentioned asking for an increase in their medication dosage to alleviate their worsening symptoms. Some patients who experienced worsening of their hydrocephalus symptoms directly attributed this to their deteriorating mental health.

Discussion

This single-centre study presents initial evidence about the effects of the COVID-19 pandemic on adults living with hydrocephalus. In-depth interviews allowed participants to

openly reflect on their lived experiences as patients with non-acute hydrocephalus while also describing the impacts of the pandemic and its restrictions on their well-being and access to healthcare. The importance of qualitative research within the clinical setting during the COVID-19 pandemic has been previously highlighted, along with the efficacy of qualitative data to provide perspectives which may be missed in epidemiological and clinical research and to inform evidence-based public health responses (10). A number of adverse effects were identified by participants, particularly among those who were awaiting surgical procedures, did not yet have a clear diagnosis, and did not have a familial support system they could rely on. The insights gained from this cohort of patients from an urban, ambulatory hydrocephalus clinic may broadly be applied to similar cohorts in other community-based outpatient clinical settings providing equivalent acute and virtual care.

A significant challenge faced by participants while social distancing measures were imposed on clinics and hospitals was their inability to receive treatment in the form of surgery and post-surgical follow-up. Almost all participants who had previously been booked for one of these procedures either had their appointments cancelled or conducted over the phone, as surgical triage has been imposed limiting most elective surgical procedures (11–14). Only acute hydrocephalus has been identified as a high enough triage tier to warrant immediate surgical intervention (15), and emergent cases of hydrocephalus presenting for surgery have not significantly decreased since the start of the pandemic as have other neurological conditions (16). However, this has little impact on patients with chronic hydrocephalus whose condition does not require emergency intervention. Where physicians are not able to provide patients with treatment due to protocols, increasing the frequency of communications with patients could help mitigate the adverse effects of worsening

Table 4. Examples Regarding the Theme of Impacts of Changes on Personal Well-being.

Subtheme	Example Quotes
3.1 Concerns about future state of diagnosis	<p>“I hate to see it keeping on getting too late because I don’t know how urgent my care is. I think at some point I’m going to have to have a spinal tap done, maybe a stent put in. Not looking forward to that, especially as time drags on and my condition gets worse. So far there isn’t much changed.” (Participant 625)</p> <p>“Every three months they’re following me now. He’s gonna call me, see how I’m feeling, and then a month later I have a CT scan or MRI. I forget. But they’re gonna stay on top of me now because that’s how close it was at the last time, to the end. ‘Cause your skull doesn’t expand when the pressure’s getting worse and worse and worse, obviously, so it was really close for me. I’m very lucky.” (Participant 642)</p> <p>“Maybe if I had something really wrong with me, I’d have to go in and see somebody. But [Neurosurgeon] from the hydrocephalus clinic, he phoned, went through it all, and was satisfied with the answers. I think my state of health here right now is pretty even so; maybe if there was something bothering me or coming up, I think it pays to see the doctor once in a while. It makes you feel more confident if you had your shunt just checked.” (Participant 650)</p>
3.2 Attitudes about infection risk	<p>“I guess I’m not sure what to think about it because I’ve got two thoughts in my head that it is a very – uh, disease that can... constrict breathing? I can’t think of the word for it. But, I’m not sure, in the healthier people if it’s as dangerous as they say.” (Participant 619)</p> <p>“Some of the younger people in our cul-de-sac have decided that they would do our shopping for us, so all we do is give them a list and they hop around and get whatever we want and bring it back. And they keep their distance and we’re careful what we touch, and it’s worked great.” (Participant 625)</p> <p>“My husband goes, I was too weary to go. Because I think – if I went – I’m too afraid of getting the virus. I think you feel like your freedom is restricted a bit; there’ll be lots of rules I guess. But, like I said, I’m very careful. I’m not rushing anything, because I want to make sure that they’re safe and I’m safe.” (Participant 622)</p>
3.3 Changes in mental health	<p>“When it first happened, I had a bit of depression. At the start of the pandemic, it was the anxiety and depression that were bad. It was just the number of people that were dying, and worrying about my family.” (Participant 639)</p> <p>“It may have nothing to do with it, but I’ve never really – except for very short periods of time in my life – had one or two nights where I had difficulty sleeping. Now I’m having difficulty getting to sleep, and depression.” (Participant 604)</p> <p>“Well I don’t have a great deal of anxiety and I don’t particularly feel depressed, [to be] honest. I mean, there are days when I think I’m getting tired of this, but it – you know – it’s not a full-blown depression.” (Participant 624)</p>

Abbreviations: CT, computed tomography; MRI, magnetic resonance imaging.

hydrocephalus symptoms by increasing the levels of perceived access to medical support, and may also ameliorate patient anxiety stemming from uncertainty.

The impact of treatment reduction was made more acute by participants’ restrictions in symptom management. Many participants reported a marked decrease in their regular exercise activities, either due to lack of access to facilities or due to their worsening hydrocephalus symptoms while waiting for treatment. Given that cardiovascular diseases are a common recorded complication in patients treated for hydrocephalus (17,18), the benefits of physical activity (19) may be especially crucial to this population. Worsening symptoms such as gait disturbances, as well as memory impairment and difficulty sleeping, appeared to directly influence participants’ concerns about the future state of their diagnosis. These concerns were more likely to be alleviated during virtual appointments for participants who underwent fewer symptom and lifestyle changes. However, the benefits of virtual support (20) and its appreciation by a majority of participants may generally result in more positive outcomes for patients who receive more of

this form of communication from their physicians and health-care teams.

Similarly, due to social distancing measures, participants’ social connections were also affected and they expressed distress at the long periods of time they were unable to interact with their families, their support groups, or their aid workers. Some reported strain on their relationships with partners who were their caregivers, as the social distancing measures restricted their use of other coping mechanisms and limited their partners’ ability to perform self-care. This supports previous evidence showing that caregiver burden is associated with poorer outcomes (21). Participants were much more likely to report flouting social distancing guidelines to interact with friends and family than to interact with healthcare professionals. Although the increased risk of exposure to COVID-19 in clinical facilities was acknowledged, it was usually seen to be mitigated by the perceived benefits of receiving medical care. Given further awareness of the potential of viral exposure to simply anyone outside the home, this likely presents further evidence of the importance of socialization in this population. While these exacerbated participant

experiences align with initial evidence that patients with hydrocephalus require more social support than they currently have access to even outside of pandemic circumstances (22), the impact of socialization on hydrocephalus has not been well-studied, and the physical ramifications of restricted access to support structures remain.

Most participants reported negative changes to their mental health, primarily due to feelings of general isolation (whether they lived alone or were social distancing alongside their care partners) and to exacerbation of symptoms such as difficulty sleeping. These mainly took the form of depressive and anxious episodes, and reflect the documented adverse effects on mental health which have been ascribed to the COVID-19 pandemic (23). However, not all participants reported being negatively affected by this change. It is unclear whether this is due to the apathy previously reported in hydrocephalus patients in similar situations (24), or due to supports available to these participants. While general strategies have been proposed to alleviate the impact of the pandemic on patient mental health (25), the relationship between hydrocephalus and mental health has not been well examined and it is unclear whether they would be helpful to this population. This study presents cursory evidence of enduring comorbidities which should be further explored.

Strengths and Limitations

These findings provide promising avenues for future research, particularly as they have been described by adult patients with hydrocephalus themselves. A strength of this study was the ability to complete the participant interviews and gather data on lived experiences during the height of the public health measures and resulting impacts, while they were being experienced. Participants were able to give details about how they were impacted by pandemic measures as they were occurring, and were able to describe different healthcare experiences, such as telephone appointments, soon after having had them. Conducting semi-structured interviews until theoretical saturation was achieved allowed participants to identify and reflect on their most relevant healthcare and lifestyle experiences, while probing more into the recurring and most challenging factors mentioned by a majority of the participants. As well, while relatively little comparable research has been undertaken, the themes synthesized from the interviews do align with some previous work discussing the impact of various aspects of hydrocephalus treatment and prognosis on patient outcomes and general quality of life (26,27).

A limitation of the study is that, by necessity, only those hydrocephalus patients who were well enough to participate in an interview lasting 30 to 60 min were recruited, excluding those patients who may have been more severely impacted or even hospitalized as a consequence of the pandemic. Similarly, due to the pandemic restrictions, we were unable to perform any clinical evaluations of the participants such as cognitive or gait assessments which, while not within the scope of the present study, would have provided a robust corroborating

dataset. However, virtual adaptations to assessments such as the one utilized in this study may provide useful avenues for future service provision or research participation in which in-person attendance is not possible. Another limitation is that participants were patients recruited from a single specialty outpatient hydrocephalus clinic, which was located in an urban location and funded within a single-payer healthcare system. As a result, findings may not be representative of the experiences of hydrocephalus patients seeking treatment in multi-payer systems or less populous areas with more limited access to specialized treatment. It is worth noting, however, that a number of participants did reside in rural areas which, while still serviced by this outpatient clinic, did routinely face more challenges to their care such as needing to travel a considerable distance to be seen by their specialist, or needing to rely on telehealth for routine appointments.

Clinical Implications

The in-depth understanding of the lived experiences of community-based patients with hydrocephalus limited by decreased social engagement and restricted healthcare access may inform the future provision of healthcare services and information, in addition to social policy. This body of evidence may help mitigate the effect on patients of future pandemics or anticipated future waves of COVID-19, or other major incidents or emergencies, where similar conditions would occur. The reported adverse consequences of the inability to receive surgical treatment and follow-up post-intervention are important for treatment planning and support during social distancing. The underscoring of the negative effects on patient wellbeing of uncertainty (especially with respect to prognosis and treatment planning), isolation, and perceived indifference of the medical system, alongside the willingness to adopt virtual care when it cannot be provided in person, point to a solution which has the potential to be widely implemented. When access to surgical treatment cannot be made possible, improved and innovative approaches to remote care and virtual medicine, with an emphasis on maintaining an open and supportive dialogue between physician and patient, have the potential to facilitate high-quality care which at the very least may alleviate the additional stress and uncertainty felt by the patient.

Ultimately, the identified themes are limited to the impacts of the initial few months of the COVID-19 pandemic. Additional qualitative work documenting how the patient impact changes as the pandemic continues and how the public healthcare response evolves in response to emergent challenges would be beneficial, as would further studying the personal and long-term impacts of living with the condition in its multitude of forms. Relatively little research has been done to date on the acute and enduring impacts on the quality of life of adults with hydrocephalus, especially where it does not relate directly to post-surgery outcomes (8) and specific treatment prognoses. Future research in this area may benefit a more heterogeneous population dealing with the varied aetiology of hydrocephalus.

Acknowledgments

We would like to thank the University of Calgary's Hydrocephalus Clinic – led by Dr Mark Hamilton – for assistance with recruitment for the study, as well as the Brain and Mental Health Research Clinics leadership – Drs Eric Smith, Scott Patten, and Colin Josephson – for their support and provision of in-kind funding.


Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work is supported by an award from the University of Calgary Cumming School of Medicine COVID Rapid Response Clinical Research Fund (grant number CRF-COVID-202003), received by Dr Pamela Roach. Direct and in-kind funding was also provided by the Brain and Mental Health Research Clinics, a part of the Department of Clinical Neurosciences and the Hotchkiss Brain Institute at the University of Calgary (brainandmentalhealthclinics.ca).

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