



Clinical Research

Examining the impacts of the COVID-19 pandemic on the well-being and virtual care of patients with epilepsy

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ABSTRACT

Objective: The emergence of SARS-CoV-2 (COVID-19) as a novel coronavirus resulted in a global pandemic that necessitated the implementation of social distancing measures. These public health measures may have affected the provision of care for patients with epilepsy. Social isolation may have also adversely affected well-being and quality of life due to informal and formal support networks becoming less accessible. The purpose of this qualitative study was to examine the lived experiences of patients with epilepsy and to see how their quality of life and healthcare has been affected by the COVID-19 pandemic.

Methods: From April 27 to May 15, 2020 we performed remote interviews with 18 participants who had virtual appointments with their healthcare providers and were enrolled in the Calgary Comprehensive Epilepsy Program registry. Interviews were recorded and transcribed, after which transcripts were analyzed and coded into relevant themes using NVivo 12.

Results: Three broad themes emerged throughout the interviews: 1) impact of pandemic on informal and formal support systems; 2) impact of pandemic on healthcare provision; and 3) concerns about the impact of the pandemic on personal situations and society in the future. Participants reported anxiety and stress about decreased social engagement and activity cessations. Although face-to-face appointments were preferred, virtual care was well-received. Common concerns about the future included securing employment and burnout from balancing family responsibilities. Some patients also feared they would be stigmatized as society adapted to the situation.

Significance: This study highlights the need for additional research in anticipation of the implementation of remote medicine in the management and treatment of epilepsy. It also highlights the tenacity of those living with epilepsy during difficult periods despite social and familial pressures. Raising awareness during this time about the lives and experiences of epilepsy patients can help challenge misconceptions and stigma in the workplace and wider society.

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1. Introduction

Social support provides an important buffer against harmful physical and mental health impacts of stress exposure [1]. Epilepsy

is often characterized by negative psychosocial ramifications beyond the immediate physical manifestations in the form of epileptic seizures [2]. It has been associated with limitations in independent living [3], unemployment [4] and social stigma [5], which can contribute to serious psychological burden and a decreased sense of self [6]. As a result of these factors, persons with epilepsy may experience feelings of social isolation and diminished treatment outcomes.

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In late 2019, SARS-CoV-2 (COVID-19) emerged as a novel coronavirus. The resulting global pandemic led to the implementation of various degrees of social interventions aimed at limiting the spread of the virus. In Mid-March of 2020, the Government of Alberta implemented widespread social distancing measures which limited public gatherings of people. Further requirements were subsequently put in place which limited the provision of non-urgent in-person clinical care. Given the importance of psychological distress, loneliness, and the ability to adjust and cope to the quality of life of persons with epilepsy [7], these measures may have had unintended consequences on their – and their caregivers' – physical and mental well-being by affecting essential activities and rendering them unable to engage in-person with healthcare providers and personal networks. The move to virtual-based care may have also impacted how and when patients receive treatment from specialist providers, as well as the quality of care provided.

The aim of the present study is to contribute to the base of evidence describing how the COVID-19 pandemic is impacting the well-being and quality of life in persons with epilepsy. We conducted a qualitative study of persons with epilepsy and care partners who have had virtual appointments with their physician at an outpatient Epilepsy specialty clinic. This qualitative approach utilized in-depth interviews to collect detailed information about both attitudes and lived experiences of this patient population in the midst of the social distancing environment resulting from the COVID-19 pandemic.

2. Methods

2.1. Recruitment

Over a three-week period spanning late-April to mid-May 2020, we conducted in-depth interviews with persons with epilepsy over the phone and via Zoom (online video conferencing) [8]. We purposely recruited participants who had attended the Calgary Comprehensive Epilepsy Program (CEP) in Calgary, Alberta Canada, since April 23, 2020; had a diagnosis of Epilepsy or experienced periodic seizures verified by an epileptologist working in the clinic; had agreed to participate in the CEP registry, and had previously provided written consent to be potentially contacted for future research. The CEP is an ambulatory specialist clinic that is located at a large tertiary care centre in Calgary, Alberta. Created as a means to improve patient outcomes and facilitate clinical research within the CEP, the registry comprises a breadth of patient information, with patients' records updated after every clinic appointment. Currently, the CEP registry has a database of over 6000 participants. By the end of March 2020, the CEP had suspended in-person clinic appointments to comply with Public Health

restrictions, and had transitioned exclusively to remote medicine (telephone or Zoom).

Potential participants were informed about the project and given two options for connecting with the interviewer, in adherence with social distancing guidelines: by telephone or online via the videoconferencing software Zoom [8]. Information sheets and consent forms were then emailed to interested participants, who were given a minimum of 24 hours to discuss the project with their care providers and their family members. If the patients consented to participate in the study, they signed an online consent form and were then contacted again to schedule the interview. Consent was obtained online using Qualtrics® software [9]. Additionally, in cases in which it was difficult to obtain consent over email (e.g. if there was disability or lack of access, preventing the use of a device connected to the internet) we obtained explicit oral consent over the phone before the start of the interview, which was later transcribed and archived. This allowed us to ethically include a larger and more diverse patient population. Over the duration of the study, process consent [10] was used each time there was an interaction between interviewer and participant (e.g. at initial contact, during scheduling, before the start of the interview) to ensure participants were comfortable with the day and time of the interview. The Conjoint Human Research Ethics Board (REB20-0559) at the University of Calgary approved the study.

2.2. Data collection

In-depth interviews were conducted in a manner in which participants and their care partners were able to explore and reflect on the pandemic and how it had altered their well-being and quality of life. An interview guide was used by the interviewer to guide the conversation through the topics of interest. We asked what participants' experiences had been with the healthcare system during the pandemic, and how this differed from their pre-pandemic experience. We also asked questions pertaining to how participants' regular activities and social supports were impacted by the pandemic, what coping mechanisms were being utilized to mitigate this, and overall attitudes towards life under these circumstances and the public and institutional response to the pandemic. Interviews were digitally audio recorded and field notes were taken during the session to capture relevant themes and impressions about the participants' thoughts and opinions, with reflexive field notes also being recorded immediately after the interviews. Participant demographic data was collected from the CEP database, and participants were additionally asked whether they had been diagnosed with COVID-19 or were under self-quarantine recommended to them by a healthcare authority.

Theoretical saturation of participant experience was anticipated to occur after the completion of up to 20 interviews, and subsequently a target of 15–20 recruited participants was determined.

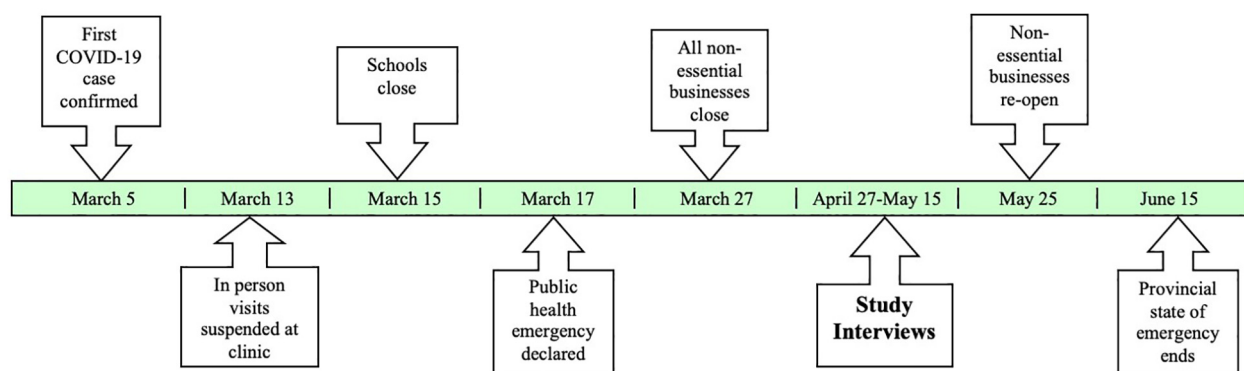


Fig. 1. Timeline of COVID-19 Public Health Response in Alberta, Canada.

All interviews were scheduled and conducted between April 27 and May 15, 2020. During this time, the pandemic was at the height of its first wave, and social distancing measures were strictly enforced both in public and in clinic. A timeline of these measures, as implemented by the Government of Alberta, is shown in Fig. 1. Recruitment, data collection, and data analysis were completed by AS and DP, both research staff with experience interacting with and recruiting persons with epilepsy for various studies in the CEP. The interviewers and participants were unknown to each other at the time of initial contact, but introduced themselves and developed a rapport during the interview process.

2.3. Data analysis

Audio recordings were transcribed verbatim using a professional transcribing service, after which files were anonymized and checked for accuracy by the interviewers. Data management and qualitative analysis were completed using NVivo 12 [11]. Interview transcribing occurred while data collection was ongoing in order to facilitate iterative analysis of relevant themes and inclusion at subsequent interviews to reach theoretical saturation. The first step of analysis was immersion in the qualitative data, during which transcripts were read and re-read while the interview recordings were replayed. We used reflexive thematic analysis [12] which relies on positioning the researcher as the driver in the analysis process, to analyze the field note and interview data. Annotations were used to capture iterative analyses and analytical thoughts during this process. Disagreements concerning the analysis and emergent themes were resolved through discussions with the research team.

3. Results

3.1. Participant demographics

In total, 18/52 (35%) of potential participants consented and completed the interview. Data from 17 of these participants were used in the analysis, as one of the patients had received a diagnosis of non-epileptic seizures. Characteristics of patients analyzed are shown in Table 1. Interviews ranged in length from 20 m:23 s to 1 h:33 m:54 s (mean length = 37 m:26 s). Telephone interviews were completed for 13 of the 17 participants, and 4 interviews were completed with Zoom. Participants comprised 9 females and 8 males aged 23–87 (mean age = 37.2).

None of the participants (patients or care partners) reported a diagnosis of COVID-19 for any members of their household. One participant had been tested for COVID-19 following a brief hospital stay, and seven participants had been advised to self-isolate due to risk of contracting COVID-19. One participant reported they were “not sure” when asked if they had symptoms that might have been COVID-19-related.

3.2. Thematic analysis: impact of COVID-19 pandemic on patient experiences

Thematic coding was completed by AS and DP, and directed by PR (Principal Investigator and qualitative methods expert). We were able to identify three emergent main themes, which comprehensively described the impact of the COVID-19 pandemic on the lives of patients with epilepsy and their care partners. The themes were synthesized from descriptive codes identified in the interview data which branched and were aggregated as similarities between them arose. These resulting main themes are described in more detail in the following sections; direct quotes have been edited only for grammar and spelling to improve readability. The

Table 1

Characteristics of the seventeen patients with epilepsy who were interviewed.

Characteristic	Value
Age, y, mean (range)	37.2 (23–87)
Female, n	9
Diagnosis, n	Focal (OE) 11 Focal (OE/Encephalopathy) 1 Encephalopathy (Developmental) 1 Focal (Presumed Genetic) 2 Generalized (Presumed Genetic) 1 Generalized (OE) 1
Localization (Hemisphere), n	Left 7 Right 2 Generalized 3 Unknown 5
Localization (Lobe), n	Frontal 1 Frontal/Temporal 1 Temporal 6 Generalized 3 Parietal 1 Unknown 5
Seizure Frequency (#/unit time), n	1/Day 1 2/Day 1 1/Week 4 1/Month 1 1/Year 4 2/Year 2 4/Year 1 6/Year 1 Unknown 1
# of Medications (current), n	0 1 1 13 2 1 4 1 5 1
Epilepsy Surgery, n	Yes 1 No 11 Unknown 5

Abbreviations: OE, Other Etiology.

themes are broadly grouped into three domains: impact of the pandemic on informal and formal support systems, impact of the pandemic on health care provision, and concerns about the impact of the pandemic on personal situations and society going into the future.

3.3. Impact of pandemic on informal and formal support systems

3.3.1. Family dynamics

Due to the public health measures put in place, a disruption in normal social support was noted by participants. This was mainly through changes in family dynamics, which had a negative impact on family communication and patient and care partner well-being (Table 2; Subtheme 2.1a). Despite the disruption in normal family life, participants and caregivers who experienced anxiety or fear of leaving the house reported that immediate family members were still able to support them in essential activities and comfort them, thereby alleviating some of the burden and daily stressors that they were experiencing as a result of the pandemic (Table 2; Subtheme 2.1b).

3.3.2. Activity changes and coping mechanisms

Many participants reported drastic changes in their lives with respect to their social and physical activities, resulting in higher levels of stress and leading to a number of different coping

Table 2
Impact of pandemic on informal and formal support systems of patients.

Theme	Subtheme	Example Quotes
2.1 Family Dynamics	2.1a Negative Experiences	"We have a very big family and there are always birthdays or anniversaries and I think that you do miss seeing family." (Participant 234) "I can't hug my son. And my son is desperate for a hug. Every time he would come over the last thing he did before he left our home, he'd hug his sister and he'd hug me. We can't do that." (Participant 239; Care Partner)
	2.1b Positive Experiences	"But my son, he's been really good about it. He'll actually ask if we need anything if he's heading out. There's a grocery store for his own stuff, he'll text me and ask if we need anything, so it's been good for that." (Participant 239; Care Partner) "They've been supportive of helping me. My family keeps me going, 'cause otherwise, I'd be in a really rough spot." (Participant 241)
2.2 Activity Changes and Coping Mechanisms	2.2a Activity Changes	"Sometimes I would do yoga with a friend of mine, and we haven't been able to do that in the last little while." (Participant 235) "Definitely a negative thing for me is that I do feel lonely because I've been definitely trying to find a girlfriend. And since I haven't been able to go out, that's been kind of hard." (Participant 221) "All I would say is that, as I mentioned before, my ability to function and my cognitive functioning skills have declined because I am no longer able to get out and interact with people in the real world, or be able to provide positive encouragement in different situations like tutoring." (Participant 253)
	2.2b Coping Mechanisms	"I think I've been drinking more just because I'm bored." (Participant 235) "But, over this past month, I started smoking cigars again. So that was one downfall." (Participant 245) "Weight lifting, body weight exercises, riding a spin bike. . . That's kind of the important thing for me, is to try and stay in shape and healthy because I am still sitting around a lot." (Participant 238) "There's a lot of free time. I'm taking a lot of online courses and just kind of going back and taking the time to read the books that I thought I never had time to, and learn some new skills." (Participant 217) "I'm a little bit more musically inclined, so I've had opportunities to do that as something to supplement some of the other areas I can't do as much in." (Participant 249)

strategies. Alcohol usage was reported to have increased among some participants (Table 2; Subtheme 2.2a). Despite being socially isolated and unable to engage in many of their usual routines outside of home, many participants noted that they were coping by engaging in activities which they valued before the pandemic. In addition, a common thread in discussions was a greater sense of freedom to pursue activities that participants did not have a chance to do before the pandemic started (Table 2; Subtheme 2.2b).

3.4. Impact of pandemic on healthcare provision

3.4.1. Healthcare support: opinions on healthcare response and concerns about the unknown

When asked about their situation regarding healthcare support, participants generally reported that they understood public health measures were put in place for the greater good of the community, and that the healthcare community was doing its best to navigate the situation (Table 3; Subtheme 3.1a). However at the same time,

Table 3
Impact of pandemic on healthcare provision.

Theme	Subtheme	Example Quotes
3.1 Healthcare Support	3.1a Opinions on Healthcare Response	"I definitely noticed that they are trying their best with the circumstance, and just trying to accommodate everybody's needs and stuff like that." (Participant 221) "I guess the main degree of support is in terms of the medical community. So my family doctor, my psychiatrist, and my neurologist. And the continuity of healthcare support has been maintained." (Participant 249)
	3.1b Concerns about the Unknown	"The last time I refilled my medications, they had limited me to a smaller amount at a time to pick up. And so I'm a little bit nervous, am I going to get my meds every time? Because I obviously require them." (Participant 203) "I know that I'm probably going to go in for brain surgery here, but part of the unknown is when? How do I prepare for that? Is it going to be safe?" (Participant 217) "I guess the biggest would be the unknowns. You could feel that focus shift, or I guess you're kind of afraid that you'll be kind of lost in the mix and then your issues would be pushed aside for the greater good for the local pandemic." (Participant 217) "She wanted me to go do a heart test. And the diagnostic company called me, and they said they'd have to postpone it until the end of the summer. So, I'm a little bit stressed about that." (Participant 240)
3.2 Virtual Care	3.2a Facilitators of Good Care	"I feel like we had a good conversation, and she listened to what was going on. She didn't judge me over the phone, and we got everything sorted out, and I felt like I was being listened to." (Participant 245) "I love having the phone appointments. To go to the neurologist, it's three and a half hours for me to drive there and drive back, to sit there for five minutes in their room when I can talk on the phone or do like we're doing now. It just doesn't make sense. The lung specialist, he does the telehealth and has done it for years. And it's great." (Participant 216; Care Partner) "I think the video calls definitely help, because it doesn't give you the complete picture but you're able to hear those slight changes in intonation, and in their expressions and gestures." (Participant 217)
	3.1b Barriers and Concerns	"But not everybody has access to a computer system, internet system, an iPhone, and where they could have that. We're lucky that we do. And usually patients that are disabled have high need. . . They don't have the money to pay for broadband." (Participant 239; Care Partner) "My concern is with telehealth; where is the data going? We're talking about a secure network within AHS. That I think has the benefit. But if we're talking about third party companies bidding, doing health data management, or going to Babylon health or things along those lines, then that wouldn't interest me at all." (Participant 249)

a global sense of altruism was expressed while feelings of anxiety with regards to certain aspects of healthcare were present. Participants expressed concerns about the delay of elective surgeries and general treatment, and the unknown consequences this could have on their health (Table 3; Subtheme 3.1b).

3.4.2. Virtual care: facilitators and barriers

With the rapid transition to virtual appointments as a result of social distancing measures put in place, both patients and healthcare providers had to quickly transition to new modes of communication and treatment provision. Overall, while many participants did express that face-to-face appointments were preferred, most reported being able to effectively communicate their concerns with their providers during phone appointments and did not perceive any decrease in quality of care (Table 3; Subtheme 3.2a).

When discussing challenges and barriers to the implementation of virtual care, some participants pointed out that while they themselves did not have trouble accessing virtual means of communication, virtual appointments in the future could prevent others from accessing it more readily. Additionally, one participant noted that they were unsure about how privacy could be secured and maintained going into the future if third-party online software was a necessity for virtual care (Table 3; Subtheme 3.2b).

3.5. Concerns about pandemic impact on personal situations and society in the future

3.5.1. Concerns about the future: personal and societal impacts

Due to the uncertainty of the situation, many participants reported anxiety and concerns regarding their condition going into the future, especially relating to education and finances. A common theme that was identified was balancing family accountabilities, both as a parent with childcare responsibilities and as the child of aging parents who require assistance (Table 4; Subtheme 4.1a). When asked about the future, a sentiment that the pandemic could change the lens through which society views work was observed. The possibility that people may remain wary of interacting with others was cited as a potential repercussion of the pandemic, and that this could exacerbate the stigma and differential treatment already experienced by persons with epilepsy and marginalized populations in the workforce and wider society (Table 4; Subtheme 4.1b).

3.5.2. Opinions on societal response

Participants noted that while they thought the healthcare system had dealt with the pandemic situation in a competent manner overall, a frustration that other people may not have taken the situation seriously was expressed, particularly with regards to risks to vulnerable populations (Table 4; Theme 4.2).

4. Discussion

This study has provided early evidence about the impact of the COVID-19 pandemic on the wellbeing of persons with epilepsy. It was important to complete participant interviews during the height of implemented public health measures in order to collect accurate details regarding patients' experiences with virtual healthcare and experiences managing epilepsy while socially isolated and restricted from regular care and services. Positive experiences included the perception that family was supportive, free time to pursue new activities, as well as an overall satisfaction with the quality of virtual care. Negative experiences comprised disruptions in family dynamics, increased social isolation, and anxiety concerning the future regarding treatment and employment. Interestingly, no concerns about access to medication prescriptions emerged from the data. Our findings are in line with quality of life concerns that have been examined in persons with epilepsy in previous studies [13,14].

So far, few data have been collected examining the lived experiences of persons with epilepsy during the COVID-19 pandemic. In one recently published study, authors provided guidelines on how clinical care should be modified and provided general advice on navigating the current circumstances [15]. However, no direct perspectives from persons with epilepsy were included. Another study examined the risk of contracting COVID-19 among those with epilepsy, highlighting that pre-existing comorbidities could put persons with epilepsy at risk, but did not include perspectives on the situation from patients themselves [16]. Another study did conduct telemedicine visits with the aim of elucidating the impact of ketogenic diet therapy [17], but did not collect in-depth information regarding quality of life. Our study complements prior work by directly interviewing persons living with epilepsy to extract themes on coping with social distancing and remote healthcare imposed by the public health response to the COVID-19 pandemic.

Table 4

Concerns about the impact of the pandemic on personal situations and society going into the future.

Theme	Subtheme	Example Quotes
4.1 Concerns about the Future	4.1a Personal Impacts	<p>"I'm gonna be honest with you. Not like that crazy fear, but I was just a little bit afraid, because recently my seizures have started." (Participant 247)</p> <p>"Well, I was job hunting. I'm supposed to go back to work July 1st and I have to find a different job. So I've been looking. But now it's hard to; now is a weird time to apply for something because everything's closed. So I guess after my disability I might have to go on EI, I don't know." (Participant 235)</p> <p>"Does that mean my daughter isn't gonna go back in the fall too? So then I have to juggle her schooling and my schooling at the same time?" (Participant 245)</p> <p>"So, that certainly is a big concern for me because my parents ... I don't want them going anywhere unless they've got gloves and a mask. And we just don't have those supplies right now." (Participant 240)</p>
	4.1b Societal Impacts	<p>"I think there's not a lot of balance to work-life in some care, especially if you're two working parents and have children. And I really think there needs to be a shake-up in the way people can work. Whether that be sometimes remotely, or I don't know..." (Participant 243)</p> <p>"Then, I have had people talk to me like I'm a baby, and it's like, 'Guys, just don't.'" (Participant 239)</p> <p>"They're going to be so cautious. They don't want somebody to get sick, they don't want the liability of an employee getting sick, and so they are going to push the disabled, the immune-compromised, the aged people... They're going to push us aside." (Participant 239; Care Partner)</p>
4.2 Societal Response Opinion		<p>"I don't feel sorry for people who are, like, 'Reopen the golf courses'. I don't know, that's not what's important right now. So I don't have much sympathy for people that complain about that, because there's some really sick people..." (Participant 243)</p> <p>"Maybe if I say something negative, it's more a disappointment in how other people maybe are not taking it seriously or maybe buy into that it's a conspiracy" (Participant 249)</p>

Adverse impacts on the well-being of persons with epilepsy and their family/care-partners were identified. Negative coping strategies, passive and emotionally focussed in nature, were seen through instances of increased alcohol consumption. Participants expressed feelings of loneliness and a decline in general functioning as a result of activity suspensions. In those suffering from epilepsy, social engagement and support have been found to positively affect self-efficacy and improve feelings of being interpersonally connected [18,19]. Additional distress was identified regarding concerns about the future, such as finding employment due to the economic situation, as well as the concern that there would be an unconscious discrimination against those deemed 'at risk'. This is consistent with previous studies which have shown that concerns related to working have an adverse impact on the quality of life in persons with epilepsy [20,21], and have been a part of epilepsy-related stigma throughout history. Although negative attitudes toward epilepsy have lessened over time, misconceptions such as inaccurate beliefs regarding the causes, treatment, and prognosis remain [22]. To prevent misconceptions and further stigmatization, public awareness campaigns aimed at improving understanding, social inclusion, and reducing stigma can be undertaken [22]. To facilitate the spread of information, it may be prudent to target a broader audience utilizing communication technologies such as social media. Additionally focusing on constructive information [23], such as highlighting persons with epilepsy as living a full and engaged life, could also help counter negative stereotypes and lead to greater inclusion in the workplace and other areas. Through our study, discovered that patients' lives were fulfilled and engaged. We observed that many had diverse hobbies, engaged in leisure activities and attended school, were active community members, and were ultimately leading active and accomplished lives. We also learned that many participants were actively engaging in positive coping mechanisms - such as exercise and music - as a means of dealing with social isolation and cessation of regular activities. Overall these findings demonstrate that, as a whole, persons with epilepsy were responding in a resilient manner and effectively countering stigma which may still be present.

In terms of socialization, participants indicated that they kept in touch with their friends and family through social media and virtual hangouts. This is consistent with previous studies which found persons with epilepsy overcoming social barriers via phone and social media [24]. However, participants did report stress and anxiety due to increased demands of family responsibilities. Many participants were middle-aged and needed to spend more time taking care of children at home while maintaining support for aging parents, some of whom were immunocompromised. The literature so far has focused on persons with epilepsy as care-receivers, and less attention has been given to their role in maintaining family obligations. These findings again highlight the active and engaged nature of the lives of persons with epilepsy, ones in which they often serve as social anchors. With further research, these findings could pave the way for further de-stigmatizing epilepsy as socially and interpersonally limiting.

Concerning virtual appointments, participants expressed that they were useful and efficient, and provided an outlet to talk about fears and concerns regarding general treatment. Although face-to-face meetings were still preferred, participants welcomed virtual care, citing that it helps those who live far avoid travel and reduces waiting times in general. With recent announcements that virtual care will be permanently implemented in Alberta, it is likely that some patients will choose this method of service delivery. In light of this, it is important to also consider the limitations of

telemedicine compared to in person visits. As our study found, participants still preferred face-to-face meetings. Meeting in person is beneficial for the development of the patient-physician therapeutic alliance, which can affect patient activation by influencing their comfort and confidence in seeking knowledge about their condition and their degree of adherence to treatment plans [25]. Additionally, sequential physical examinations are important for the diagnosis certain types of epilepsy and anti-seizure medication adverse effects, which can be difficult to perform through telemedicine [26–28]. In addition, existing and potential infrastructure challenges for patients should also be addressed. As mentioned by one participant, some patients may experience issues accessing telemedicine due to the quality of their internet connection, which can be affected by factors such as location of residence and finances. Obtaining the necessary devices required for video conferencing, as well as addressing the needs of patients who may be hard of hearing or are blind or have low vision, are also important. To overcome these barriers, health care providers should aim to customize healthcare delivery and have accommodations in place to prevent potential participants from being excluded. Educating patients in the use of technology, as well as providing the necessary devices and internet technology (IT) support, could improve patient-readiness and make virtual care more accessible. The development of national standards for patient health information access and a concrete framework for regulating safety and quality of care [29] will also be instrumental in helping patients understand the use of virtual care and that privacy and security risks will be mitigated [30]. This would facilitate the provision of necessary support to persons with epilepsy, including regular contact with healthcare providers and access to mental health resources [15], and possibly a comprehensive online effort from the wider community to reduce stigma [24].

A strength of this study is that it utilized a prospective clinic registry which allowed us to quickly identify and recruit and interview participants who were experiencing the impacts of the public health measures - including virtual appointments - while they were happening. We also had the opportunity to speak with participants and care givers who lived in communities requiring substantial travel time to receive care at a tertiary centre, therefore allowing us to capture their perspectives concerning virtual care and remote interviewing in our study. A limitation of the study is that this clinic population tend to uniquely be of higher SES, well-educated, and engaged in research. In addition, most of the study participants reported a relatively stable condition. Our study may not fully reflect the experience of patients who may arguably be at higher risk of poorer outcomes. Future work should aim to incorporate the perspectives of patients who are in acute care or from communities which may have more tenuous access to specialist care.

In conclusion, this study provides some of the first evidence of the impact of the COVID-19 pandemic on the quality of life and healthcare of persons with epilepsy. The pandemic was found to exacerbate feelings of social isolation and anxiety concerning the future. The study highlighted the importance of continued social support in persons with epilepsy, the acceptance of virtual-based care in the treatment and management of epilepsy, and the reduction of misinformation-based stigma, going forward.

5. Ethical publication statement

We confirm that we have read the Journal's position on issues involved in ethical publication and confirm that this publication is in accordance with those guidelines.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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