

# Survey of the Impact of COVID-19 on Chronic Liver Disease Patient Care Experiences and Outcomes

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## Abstract

**Background:** The COVID-19 pandemic has a secondary impact on the health of patients with chronic liver disease (CLD). Our objective was to study this impact on care provision, telemedicine, and health behaviours in CLD patients.

**Methods:** CLD patients of an urban gastroenterology clinic who attended a telemedicine appointment between March 17, 2020 and September 17, 2020, completed an online survey on care delays, health behaviours, and experience with telemedicine. Chart review was conducted in 400 randomly selected patients: 200 charts from during the pandemic were compared to 200 charts the previous year. Data were extracted for clinicodemographic variables, laboratory investigations, and clinical outcomes.

**Results:** Of 399 patients invited to participate, 135 (34%) completed the online survey. Fifty (39%) patients reported 83 care delays due to the COVID-19 pandemic, with the majority (71%) of delays persisting beyond 2 months. Ninety-five (75%) patients were satisfied with telemedicine appointments. There was a longer delay between lab work and appointments in patients seen during the pandemic compared to 2019 ( $P = 0.01$ ). Compared to the year prior, during the COVID pandemic, there was a similar number of cases of cirrhosis decompensation ( $n = 26$ , 13% versus  $n = 22$ , 11%) and hospitalization ( $n = 12$ , 6% versus  $n = 5$ , 3%).

**Conclusion:** The COVID-19 pandemic has led to care delays for CLD outpatients, with most delays on the scale of months. These patient-reported experiences and clinical observations can direct optimization of CLD care as effects from the pandemic evolve.

**Keywords:** Care delays; Chronic liver disease; COVID-19 pandemic; Patient survey

## INTRODUCTION

Despite the advent of COVID-19 vaccines, the global pandemic continues to have a secondary impact by disrupting health care systems and patient behaviours. Multiple studies have demonstrated care delays and resulting negatively associated health outcomes (1–7). Patients have also reported worsened mental health (8–10), decreased medication adherence (11), and reduced care-seeking due to fear of contracting COVID-19 (12,13).

Particularly vulnerable are patients with chronic liver diseases (CLD), which includes viral hepatitis, non-alcoholic fatty liver disease (NAFLD), alcoholic liver disease (ALD), autoimmune hepatitis (AIH), and cholestatic liver disease. As CLD demands a high level of consistent care to prevent disease progression and complications, these patients are especially susceptible to interruptions in medical care (14).

Emerging literature predicts that the pandemic will increase the burden of CLD (15). Patients with cirrhosis are anticipated to have worse outcomes due to delayed HCC screening, medication non-adherence, and more sedentary lifestyles (16). Delays in diagnosis, treatment, and lack of monitoring of viral hepatitis could increase the incidence of hepatitis flares, fibrosis progression, HCC, and

associated mortality (17–19). The rate of hospitalization for liver disease has declined during the pandemic, implying undertreatment of sick patients (20,21). To address these care disruptions and outcomes, health care providers are prioritizing acute disease (22–24) and increasing the utilization of telemedicine (25).

Telemedicine is an emerging solution to ensure consistent care for CLD patients amidst pandemic restrictions (26–28). Previous studies had shown that telemedicine has high acceptance rates by both patients (29,30) and physicians (31,32). However, this solution is not perfect as access can be affected by rural residence, socioeconomic status, lack of internet access or lack of familiarity with technology (33). Clarifying how these factors interact with the delivery of telemedicine could further optimize care during the pandemic and beyond.

While literature exists on care delays and health outcomes in hospitals and endoscopy units (34–39), little is known in the outpatient hepatology setting. Outpatient CLD care has adapted to the COVID-19 pandemic with modified guidelines (22,23) and an abrupt shift toward telemedicine. To our knowledge, no Canadian study in CLD outpatients currently exists. Our objective was to study the impact of the pandemic on care disruptions, subsequent health outcomes,

and experiences with telemedicine from the perspective of patients.

## METHODS

### Patient Population and Study Setting

This study was approved by the University of British Columbia institutional research ethics board. Subjects were outpatients with chronic liver disease followed at Pacific Gastroenterology Associates, a clinic located in Vancouver, Canada. For the chart review, 200 records were selected by random number generator from all patients seen between March 17, 2020 and September 17, 2020 (designated the 'COVID' group); another 200 records were selected from March 17, 2019 to September 17, 2019 (the 'control' group). The sample size was chosen to detect a 10% increase in decompensation rate, for an alpha of 0.05 and beta of 0.08. March 17, 2020 was selected as it is when British Columbia declared a public health emergency and commenced pandemic measures (40). For the survey study, all patients seen for liver disease by one hepatologist (H.H.K.) between March 17, 2020 and September 17, 2020, with available contact information, were invited to participate in an online survey. Patients with previous liver transplant were excluded.

### Patient Survey Methods

Participants were invited to complete an anonymous online survey through a mailed letter, up to two e-mails, and one phone call (by S.J. and K.S.) between November 9, 2020 and January 1, 2021. The survey was on Qualtrics and required a mean of 7 minutes to complete. Participants consented verbally by phone or online before proceeding to the survey. The survey collected information on demographics, care delays, experiences with the pandemic, and telemedicine (Supplementary Figure 1).

### Chart Review Methods

Clinical data were extracted from medical records, including most recent date of appointment, lab work or imaging, hospitalization for liver disease, and decompensation events that occurred within the time periods of interest. As patients are asked to complete testing just before their appointment, duration in days between lab work or imaging to appointment date was calculated to approximate delays. We recorded relevant lab measures and new suspicious liver lesions, defined as requiring further imaging to rule out HCC. Hospitalizations and decompensation events were extracted from data available from patient charts and not obtained from hospital databases.

### Statistical Analysis

Descriptive summary statistics were reported for survey and chart review data. Baseline characteristics were reported using means and standard deviation for continuous data; for nominal data, counts and proportions were reported. Fisher's exact test was used to assess for clinicodemographic factors associated with care delays. To assess for significant differences between the COVID and control group, Wilcoxon rank sum test and *T*-test were used for continuous variables, and Fisher's exact test was used for categorical variables. Odds ratio with 95% confidence interval was calculated for the difference in clinic outcomes between COVID and control

groups. Statistical significance was defined as  $P < 0.05$  with a two-tailed *P* test.

## RESULTS

### Survey Participant Characteristics

Of 399 participants who were invited to participate, 135 (34%) completed the survey (Supplementary Table 1). Participants' median age was 40 to 59 years, 60 (49%) were female, and 67 (54%) were of East Asian ethnicity. The median household income of respondents was \$50 to 100,000/year and 53 (43%) had a university or college degree. The self-reported liver diagnosis was viral hepatitis (41%), NAFLD (24%), ALD (4%), and AIH (1%).

Of all respondents, 51 (38%) reported a care delay. Having fewer self-reported care delays was associated with having a university/college degree ( $P < 0.01$ ) or being East Asian ( $P = 0.02$ ). All other clinicodemographic factors were similar between patients with and without care delays (Table 1).

### Patient-reported Care Delays

There were 83 total delays in the form of delayed appointments (40%), imaging (33%), laboratory investigations (26%), and liver biopsy (1%). Most delays were over 2 months in duration: 17% (14) were delayed for <1 month, 12% (10) were delayed 1 to 2 months, 30% (25) were delayed 2 to 4 months, and 41% (34) were delayed for >4 months. This trend was also seen within care types (Figure 1). Reasons for care delay included challenges with taking time off work, difficulty with COVID-19 precautions, travel, and childcare arrangements (Table 2). Narrative responses are reported in Supplementary Table 2.

More instances of health care avoidance were reported by those who experienced care delays: 54 avoidances were reported by 27 patients with care delays, compared to 29 avoidances reported by 20 patients without care delay (Figure 2).

### Patient-reported Medication Adherence

Three patients (6%) reported medication non-adherence due to expiring prescriptions ( $n = 2$ ) and the medication not being available at the pharmacy ( $n = 1$ ). The high adherence rate is attributed to having extra refills ( $n = 28$ , 58%), receiving help from family or friends ( $n = 10$ , 21%), and email prescriptions ( $n = 7$ , 15%). Narrative responses are reported in Supplementary Table 2.

### Patient-reported Impact of the COVID-19 Pandemic on Personal Life

Of all respondents, the most frequently reported impacts were: decreased social support (64%), worse mental health (39%), financial strain (17%), loss of employment (10%), increased substance use (7%), and sedentary lifestyle (4%) (Figure 3).

### Perceptions of Telemedicine

The majority of patients reported being satisfied with their phone appointment, comfortable with technology, and not requiring assistance. These trends were seen across all age groups. Nevertheless, 68% of patients still preferred an in-person appointment rather than telemedicine (Figure 4). Narrative responses centred around the preference for video

**Table 1.** Clinicodemographic information

Variable	Self-reported categories	Total N (%)	Care delays, N (%)	No care delays, N (%)	P-value <sup>a</sup>
		135	51	79	
Age (years)					0.09
	20–39	21 (16)	7 (14)	14 (18)	
	40–59	52 (40)	27 (53)	25 (32)	
	60–79	52 (40)	15 (29)	37 (47)	
	>80	5 (4)	2 (4)	3 (4)	
Sex					0.95
	Female	60 (49)	25 (50)	35 (49)	
	Male	62 (51)	25 (50)	37 (51)	
Ethnicity					0.02
	East Asian	67 (54)	18 (38)	49 (64)	
	Caucasian	27 (22)	12 (26)	15 (20)	
	South Asian	17 (14)	11 (23)	6 (8)	
	Other	13 (10)	6 (13)	7 (9)	
Annual household income (\$)					0.76
	<20,000	10 (8)	4 (8)	6 (8)	
	20–50,000	26 (21)	8 (17)	18 (24)	
	50–100,000	41 (34)	18 (38)	23 (31)	
	>100,000	45 (37)	18 (38)	27 (36)	
Education level					<0.01
	High school or less	32 (26)	12 (24)	20 (26)	
	Vocational	15 (12)	6 (12)	9 (12)	
	University/College	53 (43)	14 (29)	39 (52)	
	Post-graduate	24 (19)	17 (35)	7 (9)	
Location (from clinic)					0.14
	<30 km	106 (84)	38 (78)	68 (88)	
	>30 km	20 (16)	11 (22)	9 (11)	
Liver diagnosis					0.74
	Cirrhosis	12 (8)	4 (7)	8 (9)	
	Alcoholic liver disease	6 (4)	3 (5)	3 (3)	
	Non-alcoholic fatty liver disease	36 (24)	15 (25)	21 (23)	
	Viral hepatitis	63 (41)	24 (39)	39 (42)	
	Other <sup>a</sup>	36 (24)	15 (25)	21 (23)	

<sup>a</sup>Using Fisher's exact test

<sup>b</sup>Includes autoimmune hepatitis ( $n = 2$ ), elevated liver enzymes not yet diagnosed ( $n = 2$ ), medication induced liver injury ( $n = 1$ ).

over phone appointments ( $n = 6$ ), lack of physical exam ( $n = 2$ ), and concerns with security of personal information ( $n = 2$ ). Further narrative responses are reported in [Supplementary Table 2](#).

### Chart Review Patient Characteristics

There were no differences in clinicodemographic factors between the COVID and control groups. There were similar rates of smoking and alcohol consumption, though there were slightly numerically more patients drinking in excess of the Canadian Low-Risk Alcohol Limits (41) during the pandemic ( $n = 11$  versus  $n = 6$  in 2019). Liver diagnosis and reason for clinical encounter were similar between groups ([Table 3](#)).

### Care Delays During the Pandemic

Time between completing lab work and appointment was significantly greater in the COVID group (mean 67 days) compared to the control group (mean 46 days,  $P = 0.01$ ;

[Figure 5](#)). There was no statistically significant difference for completion of imaging before appointments between the COVID group (mean 107 days) compared to the control group (mean 87 days,  $P = 0.18$ ; [Table 4](#)).

### Clinical Outcomes During the Pandemic

The number of patients with cirrhosis was similar between groups. The COVID group had a similar rate of cirrhosis decompensation ( $n = 26$ , 13%) compared to the control ( $n = 22$ , 11% OR 1.21, 95% CI [0.63, 2.33]). The number of hospitalizations for cirrhosis was also similar between the COVID group ( $n = 12$ , 6%) and the control ( $n = 5$ , 3% patients, OR 2.48, 95% CI [0.80, 9.18]; [Table 4](#)). Ascites was the main reason for hospitalization in COVID group (nine versus one patient in the control group). The number of admissions for variceal bleeding (two in the COVID group versus four in the control group) and hepatic encephalopathy (two in the COVID group versus three in the control group) were similar.

The COVID and control groups had similar levels of ALT, bilirubin, HBV DNA level and MELD score (Table 4).

There was no statistically significant difference in the number of suspicious liver lesions identified during the COVID pandemic ( $n = 10$  versus  $n = 6$  in 2019,  $P = 0.31$ ). Of all liver lesions identified during the pandemic, four were considered definitely or highly suspicious for HCC on subsequent imaging, while all lesions identified in 2019 were benign.

## DISCUSSION

Across Canada, there has been decreased care-seeking and system-wide redistribution of resources during the COVID-19 pandemic, leading to reduced treatment across diverse areas of medicine (2,5,6). As the first Canadian study in hepatology patients, we found that 38% of outpatients with chronic liver disease reported care delays, the majority of which were on the scale of months. Similarly, our chart review found more delays in completion of lab work but there was no clear impact on clinical events including hospitalizations, cirrhosis decompensations, and HCC diagnoses. Our findings provide an outpatient counterpart to the care delays observed in hospitalized patients with cirrhosis and endoscopy units (20,36,37). Our results also reflect predictions of rising

CLD burden from interruptions in health care provision and changes in patient behaviour due to the pandemic (15,16).

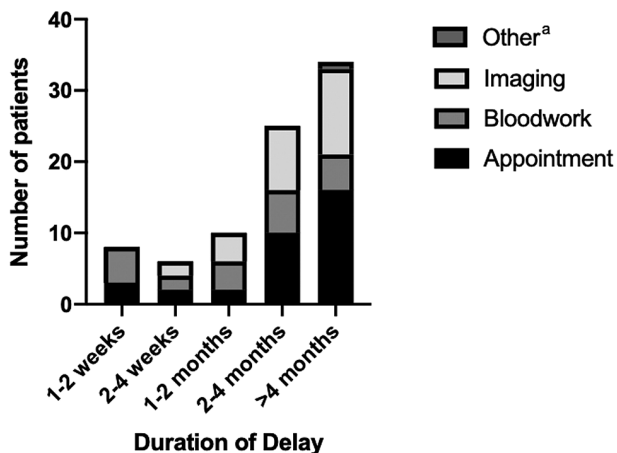
We observed numerical differences in chart review of clinical outcomes during the COVID-19 pandemic, including more hospitalizations, and increased rates of decompensation, though these findings were not statistically significant. While no definitive conclusions can be made, this may suggest the onset of rising CLD needs. At the beginning of the pandemic, hospital-based studies observed a 4.5% decline in admissions for cirrhosis during the pandemic (21,42), though the average admission MELD was higher (20). In contrast, we observed slightly more hospitalizations during the pandemic; this may be explained by our study being conducted months after the onset of pandemic measures, at which time hospital presentation could not be delayed further. In our study, more admissions were attributed to ascites, compared to HE and variceal bleeding. Given patient anecdotes of difficulty accessing primary care physicians who normally oversee diuretic regimens, these patients might more likely to present themselves to the hospital for paracentesis instead.

In our survey, health behaviours were driven by fear of contracting COVID-19. We found that patients with care delays also reported more instances of avoiding care. Similarly, Canadian studies of patients with stroke (2,5) and myocardial infarction (4) have shown decreased health care utilization due to patient reluctance to present to hospitals. As patient decision-making is an important factor in receiving timely care, this highlights an opportunity for patient education on infection control measures and importance of maintenance health care visits. Similar initiatives have been implemented in US emergency departments to encourage patient presentation during the pandemic (43). Patient behaviours extend to medication adherence, which remained high during the pandemic. As patients reported satisfaction with obtaining prescriptions by phone to prevent in-person visits, this further demonstrates that patients are motivated to improve their health if fears of infection can be addressed.

The pandemic has multiple impacts on personal life that are relevant to CLD. Patients reported decreased physical activity and poor dietary habits similar to surveys of large Canadian populations (44–46), presenting a unique challenge to NAFLD management. Further, there was more excessive alcohol consumption, which may reflect increased stress and social isolation incurred by the pandemic, and local availability of alcoholic beverages (47,48). This may lead to higher rates of alcoholic liver disease to come.

Our findings on the acceptability of telemedicine are congruent with the broader Canadian experience. Like our survey respondents, patients in other areas of medicine also

**Care delays by type and duration**



<sup>a</sup>Other delays include: liver biopsy

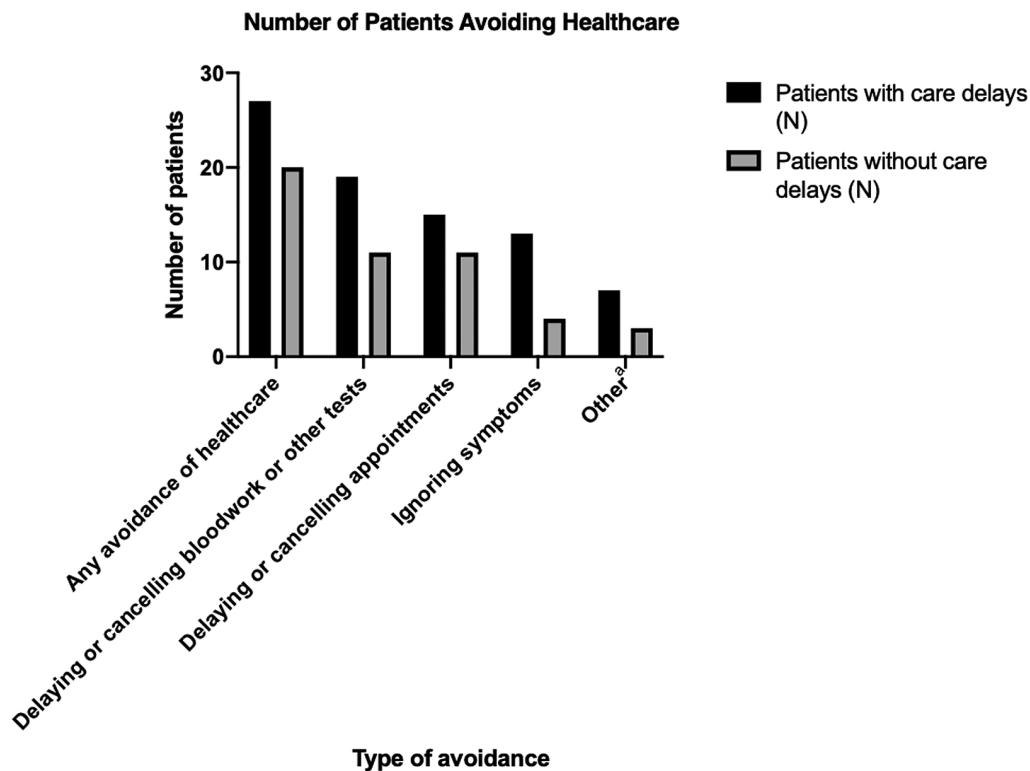
**Figure 1.** Care delays by type and duration.

**Table 2.** Reason for care delays

Care delays	Total N	Appointment N	Bloodwork N	Imaging N	Other <sup>a</sup> N
Needed to travel further	7	1	2	3	1
Needed to take time off work	13	3	2	7	1
Needed to make childcare arrangements	3	1	1	1	0
Difficulties with COVID precautions	8	3	2	2	1
Other reason <sup>b</sup>	20	5	7	7	1

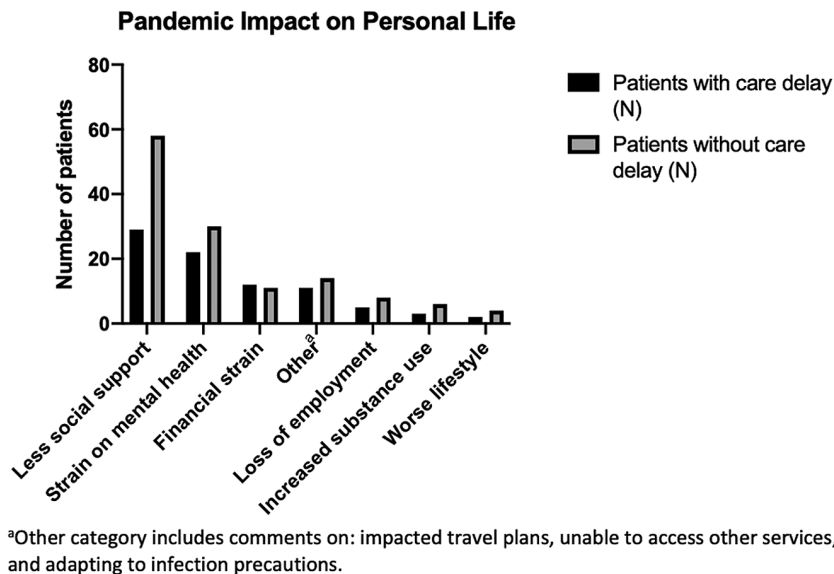
<sup>a</sup>Includes liver biopsy

<sup>b</sup>See Supplementary Table 2 for narrative reasons for care delays.



<sup>a</sup>Other types of avoidance include comments on: avoiding scheduled treatments such as phlebotomy, avoiding urban centres in general, avoiding leaving the home.

**Figure 2.** Number of patients avoiding health care, by presence of reported care delay.



**Figure 3.** Impact of COVID-19 pandemic on personal life.

found telemedicine to be acceptable (49,50), though there is a preference for in-person appointments outside of the pandemic (51,52). Some patients preferred video over phone appointments (53), while others had concerns about data security and privacy (54), and perceived less rapport with their physician at virtual appointments (55). Older patients (>80 years) reported the same acceptability of telemedicine as younger patients. We identified challenges with telemedicine

for patients with hearing impairments, living in rural areas, and requiring translation. Other factors impacting telecare may include areas of higher COVID-19 prevalence (56), medically underserved communities (57), and social isolation (23). As telemedicine opens up a new avenue of practice, understanding how these factors impact care delivery would allow for more directed interventions for vulnerable populations.

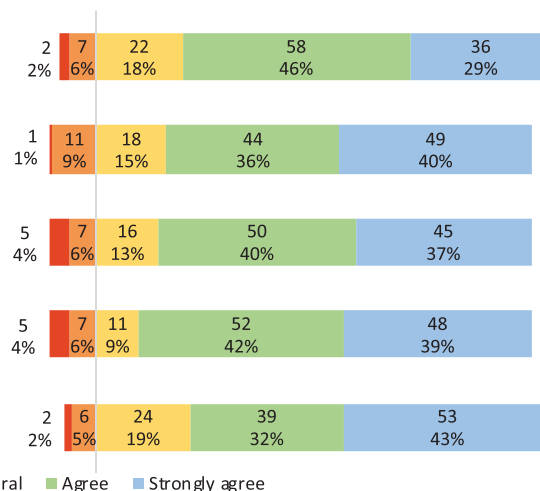
**I was satisfied with my phone/video appointment.**

**I am very comfortable with using technology.**

**I did not have any difficulties with my phone/video appointment.**

**I did not need help from friends or family during my phone/video appointment.**

**I prefer an in-person appointment to phone/video.**



**Figure 4.** Patients Preferences Toward Telemedicine.

**Table 3.** Clinicodemographic data of chart review patients

Characteristic	Control group (n, %)	COVID group (n, %)	P-value <sup>a</sup>
Total	200	200	
Age mean ± SD	59.1 ± 14.4	56.9 ± 14.6	0.13
Gender - female	115	102	0.23
Social supports present	165	173	0.46
Tobacco smoking	7	8	0.53
Alcohol use	37	39	0.50
Within low-risk drinking limits <sup>b</sup>	31	28	
Excess of drinking guidelines	6	11	
Distance from clinic			
<30km	124	120	0.65
>30km	19	25	
Charlson comorbidity score <sup>c</sup> (mean ± SD)	3.1 ± 2.1	3.0 ± 2.2	0.54
Liver diagnosis			
Cirrhosis	42	53	0.18
Non-alcoholic fatty liver disease	83	76	
Viral hepatitis	92	72	
Autoimmune hepatitis	5	7	
Alcohol liver disease	23	26	
Other <sup>d</sup>	29	44	
Reason for clinic encounter			
New patient	47	50	0.62
Active treatment	56	48	
Follow-up appointment	95	102	

<sup>a</sup>For continuous variables, unpaired T-test was used; for categorical variables Fisher's exact test was used to calculate P-value.

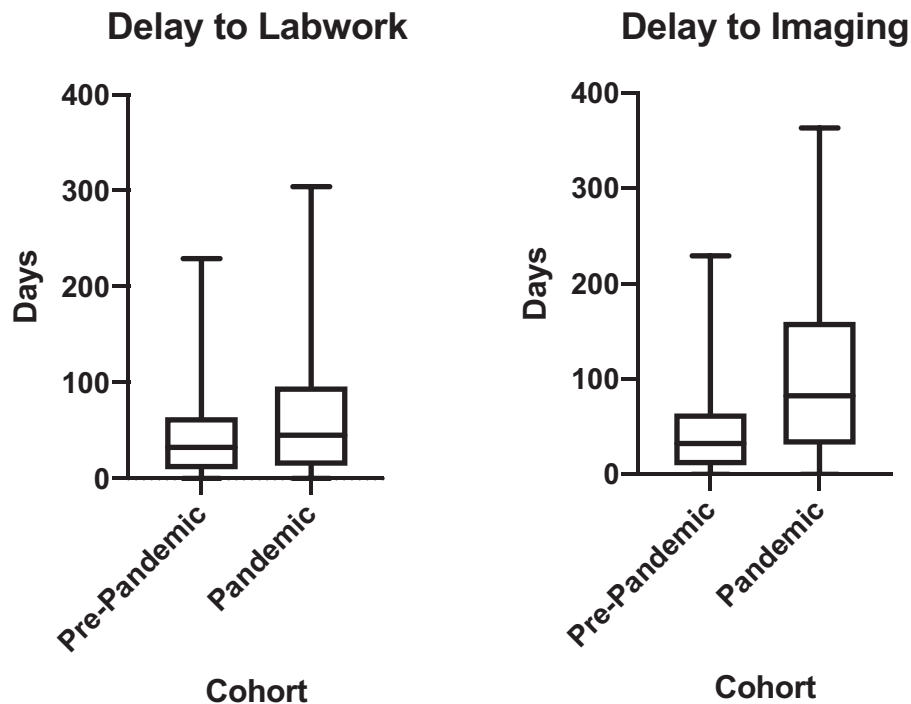
<sup>b</sup>Defined as 0-2 standard drinks per day, no more than 10 per week for women; 0-3 standard drinks per day, no more than 15 per week for men (41)

<sup>c</sup>A score calculating comorbidity level by assessing the number and severity of 19 pre-defined comorbid conditions.

<sup>d</sup>Other liver diseases included: liver lesions, liver enzyme elevation not yet diagnosed, drug-induced liver injury, Wilson disease, hemochromatosis, biliary cancer, and Caroli disease.

There are several limitations in this study. Despite using modalities of phone calls, emails, and mail invitation, our response rate was only 35%, which could lead to significant response bias. To address this, we have compared clinicodemographic characteristics between respondents and all patients eligible for the survey, which were largely similar. As a single-centre study of a hepatology clinic situated in an urban centre, the generalizability of our results may

be limited. However, our survey did capture rural patients and those with language barriers. Our local experience may not reflect other areas with different COVID-19 prevalence as burden of disease has been associated with care delays (56,58). The online survey is prone to selection bias as only those with access to technology could complete the survey. To mitigate this, all eligible participants were called with the option to complete the survey by phone. It is also



**Figure 5.** Box plot of care delays.

**Table 4.** Liver outpatient clinical status

Clinical Characteristic	Control patients	COVID patients	P-value <sup>a</sup> OR [95% CI]
Care delays (days)			
Lab work <sup>3</sup>	46 ± 47	67 ± 69	0.01
Imaging <sup>3</sup>	87 ± 76	107 ± 96	0.18
Cirrhosis (n)	42	53	
Decompensated cirrhosis	22	26	0.64 OR 1.21 [0.63, 2.33]
Ascites	18	26	0.26 OR 1.50 [0.76, 3.02]
Hepatic encephalopathy	7	7	
Variceal bleed	6	5	0.77 OR 0.71 [0.17, 2.64]
Hepatorenal syndrome	0	0	
Hospitalizations for cirrhosis	5	12	0.13 OR 2.48 [0.80, 9.18]
Labwork (value, mean ± SD)			
ALT (IU/L)	44 ± 54	58 ± 91	0.13
Bilirubin (µmol/L)	15 ± 15	23 ± 41	0.13
HBV DNA level (log <sub>10</sub> IU/mL)	2.2 ± 1.2	2.8 ± 2.0	0.06
MELD score (cirrhosis patients only)	14 ± 5.6	15 ± 7.4	0.69 <sup>b</sup>
Imaging			
New liver lesion found <sup>c</sup>	6	10	0.31

<sup>a</sup>Wilcoxon rank sum test for non-parametric data, Fisher's exact test for categorical data.

<sup>b</sup>As calculated by number of days between appointment date and lab work/imaging date.

important to note that while we found numerical trends in outcomes, we were unable to demonstrate statistical significance at times. This could be due to a low overall rate of clinical outcomes, small sample size or relatively short

duration of study. Further, as our data were obtained from chart review in the clinic rather than a provincial electronic database, this may not capture all hospitalizations and decompensation events. Care delays were also patient-reported

and not verified on chart review as the surveys were done anonymously. Some may argue that the pandemic is going to end shortly since vaccinations are global however, there are still significant concerns about COVID-19 variants and other future pandemics therefore, issues like telehealth and various precautions such as masking may be slow to be abandoned. Finally, our chart review was retrospective and cannot establish causal relationships. Future studies with larger sample sizes and longer observation time could provide more definitive results on how the pandemic is affecting care of CLD patients.

In conclusion, we found that the COVID-19 pandemic has caused care delays in a large proportion of outpatients with chronic liver disease, which could have negative impacts on their health outcomes. Patient behaviours are strongly impacted by their fears of contracting COVID-19, leading to an opportunity for patient education where possible. Telemedicine has evolved as an alternative solution to in-person visits but still requires optimization. Additional research is needed to investigate the care and outcomes of patients with chronic liver disease, in both inpatient and outpatient settings, to inform care delivery as the secondary impacts of the pandemic continue to unfold.

## SUPPLEMENTARY DATA

Supplementary data are available at Journal of the Canadian Association of Gastroenterology online.

## FUNDING

There was no funding for this study.

## CONFLICT OF INTEREST

The authors have no conflicts of interest.

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