

Chronic disease patients' experience with telehealth interventions and self-care strategies during the first wave of the COVID-19 pandemic

Marie-Eve Poitras, RN, PhD*, Department of Family Medicine and Emergency Medicine/Nursing School, Faculty of Medicine and Health Sciences, Université de Sherbrooke, Saguenay, Canada

Yves Couturier, PhD, Centre de recherche Charles LeMoine Saguenay-Lac-Saint-Jean sur les innovations en santé, École de travail social, Université de Sherbrooke, Sherbrooke, Canada
Mélicha Lavoie, RN PhD, Département des sciences de la santé, Université du Québec à Chicoutimi, Saguenay, Canada

Noémie Bouchard, MD (c), Department of Family Medicine and Emergency Medicine, Faculty of Medicine and Health Sciences, Université de Sherbrooke, Saguenay, Canada

Megan Pépin, MD (c), Department of Family Medicine and Emergency Medicine, Faculty of Medicine and Health Sciences, Université de Sherbrooke, Saguenay, Canada

Jessica Bernier, MSc, Department of Family Medicine and Emergency Medicine, Faculty of Medicine and Health Sciences, Université de Sherbrooke, Saguenay, Canada

Monica McGraw, RN, MSc, Department of nursing sciences, Moncton University, Moncton, Canada

Mohamed Ag Ali Ahmed, MD, PhD, Department of Family Medicine and Emergency Medicine School, Faculty of Medicine and Health Sciences, Université de Sherbrooke, Saguenay, Canada

Vanessa T. Vaillancourt, MSc, Research coordinator, Department of Family Medicine and Emergency Medicine, Faculty of Medicine and Health Sciences, Université de Sherbrooke, Saguenay, Canada

Caroline Cormier, M. Ps. Éd. Research professional, Department of Family Medicine and Emergency Medicine, Faculty of Medicine and Health Sciences, Université de Sherbrooke, Saguenay, Canada

Gilles Gauthier, Patient-partner, Centre intégré universitaire de santé et de services sociaux du Saguenay Lac Saint Jean, Saguenay, Canada

Marie-Dominique Poirier, Patient-partner, Centre intégré universitaire de santé et de services sociaux du Saguenay-Lac-Saint-Jean, Saguenay, Canada

Emmanuelle Doucet, RN, MSc, Project manager, Department of Family Medicine and Emergency Medicine, Faculty of Medicine and Health Sciences, Université de Sherbrooke, Saguenay, Canada

*Corresponding author
Department of Family Medicine and Emergency Medicine
Faculty of Medicine and Health Sciences
Université de Sherbrooke
Campus Saguenay
305 Rue Saint Vallier, Chicoutimi,
QC, Canada G7H 5H6
418-541-1234, ext. 3249
Marie-eve.poitras@usherbrooke.ca

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Abstract

Purpose. During the COVID-19 pandemic, the Québec Public Health Agency asked Family Medicine Groups (FMGs) to prioritize telehealth interventions over face-to-face consultations. Telehealth interventions may increase stress and anxiety among patients with physical and/or mental chronic diseases (PCDs) and have a negative impact on patient-centered care. This study aimed to explore how PCDs coped with their healthcare needs through the use of telehealth services provided by FMGs during the first wave of the COVID-19 pandemic, between march and august 2020.

Methods. We conducted a qualitative descriptive study in FMGs in three regions of the province of Québec, Canada (metropolitan, semi-urban and rural). Forty-nine PCDs participated in this study. We carried out semi-structured interviews with 40 of these patients. We explored their satisfaction with telehealth services received in FMGs, their healthcare needs and emerging coping strategies related to self-care. We also investigated frequency of appointments in primary care. We used the transactional theory of stress and coping to inform our data collection and analysis, according to the COREQ appraisal grid.

Results. All PCDs were satisfied with their telehealth experience. They reported quick and easy access to their family physician or other healthcare providers. Participants thought telehealth was less appropriate for follow-ups with social workers or with any healthcare provider with whom no trust relationship had been established. Furthermore, several PCDs mentioned having visited primary care settings less frequently during the pandemic than before, as most of them tried to cope on their own before making an appointment for an in-person consultation. PCDs developed coping strategies primarily aimed at maintaining their health status, others aimed at reducing their stress. Consistent with the transactional model, many participants demonstrated the use of strategies that promote resilience in a pandemic context.

Conclusion. PCDs appreciated the telehealth interventions received but believe follow-ups could be improved. PCDs developed coping strategies to face the pandemic but they were not all optimal for their health. Combined with pandemic side effects, this could lead to a negative impact on PCDs' health and self-management abilities.

Keywords

Family medicine groups, telehealth, patient perception, chronic disease, coping strategies, COVID-19

Abbreviations

FMG: Family Medicine Group PCD: Patient with chronic disease (physical and/or mental)

Introduction

The COVID-19 pandemic has disrupted all areas of healthcare in Canada and primary care settings are no exception.¹ During the first wave of the pandemic, in Quebec, the mortality rate per million people was 683, which is the third highest rate in the world (245 for Canada).² In response, the Quebec government focused their efforts on the availability of material and services in hospitals.³ As a primary care setting, Family Medicine Groups (FMGs), which serve 85% of the population, had to adapt their services to the public health crisis in regard to the follow-up of patients living with chronic physical and/or mental diseases (PCDs).⁴ In response to the COVID-19 pandemic, the Quebec Public Health Agency asked FMGs to make major changes to their services offer, including switching from face-to-face appointments to telehealth interventions, such as by telephone or videoconference, for patients for whom an in-person visit was not essential.⁵ The pandemic modified patients' needs in term of their health management and the way the primary care settings deliver services, even more so for those living with chronic physical and/or mental diseases who are recognized as frequent users of these services.^{7,8} These changes may increase stress and anxiety⁹⁻¹¹ and therefore interfere with their self-care. According to Lazarus and Folkman (1984), stress is “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (p. 19).¹¹ In response to stress, in this case caused by the COVID-19 pandemic, the patient then evaluates his or her personal resources and those of his or her environment (for example healthcare services) to identify coping strategies.¹² If the patient's and environmental strategies are not sufficient for him or her to adapt to stress, he or she will develop new ones to cope with the situation. This stress and its responses could promote or inhibit self-care behaviours and influence PCDs' motivation and capacity to maintain appropriate self-care.^{11,14-16} For PCDs,

positive coping strategies are essential to maintaining appropriate self-care and preventing a deterioration in their health condition. ^{5,17,18}

The objective of this study was to explore how PCDs experienced telehealth interventions and used coping strategies to manage their self-care during the first wave of the Covid-19 pandemic, more specifically between march and august 2020.

Methods

We conducted a qualitative descriptive study ¹⁹⁻²¹ in six FMGs in three regions of the Province of Québec, Canada (metropolitan, semi-urban and rural). We used the transactional theory of stress and coping¹² to inform the data collection and analysis and the COREQ appraisal grid for qualitative studies to report project rigor and methods. We used a convenience sample of 49 patients with chronic disease registered with the six FMGs participating in a research project, named Formation des formateurs en première ligne (F2PL), conducted by the principal investigators MEP (junior), YC (senior), SM (senior), FRQS #PCIBL-2 .²⁰ These patients suffered from chronic disease and/or mental conditions and had follow-ups with a physician and either a social worker or a family practice nurse. Two patient partners (GG and MDP) were involved in the study and were trained by the professionals of the Patient Partner's Office at the Centre intégré universitaire de Santé et de Services sociaux du Saguenay–Lac-Saint-Jean (CIUSSS-SLSJ) and by the principal investigators to standardize the interview methods. Two medical students (MP and NB) were also involved in the data collection and were supported by the principal investigators to conduct the interviews and analyze the data to build conceptual maps. Patient partners and students reached participants by telephone between July and August 2020 and conducted short semi-structured telephone interviews¹⁸ (Appendix 1: Interview guide

about the healthcare needs of PCDs during the COVID-19 pandemic of PCDs participating in the F2PL project). They audio recorded the interviews and wrote fieldnotes to help the analysis, according to three concurrent flows: condensation, presentation and verifying conclusions.¹⁹ Two team members (one patient partner and one student) explored the following themes: PCDs' needs and experience with primary care during the first wave of the COVID-19 pandemic, emerging and determinants of coping strategies related to self-care, and gaps between PCDs' needs and health and social services provided by FMGs. Researchers, patient partners and students validated the themes through interprofessional (social work, nursing, and medicine) discussion. For each PCD, the students illustrated the interview themes in a concept map²¹, which have been revised by at least one research team member according to the transactional theory of stress and coping.¹² The project obtained ethics approval from the CIUSSS-SLSJ and all participants provided informed verbal consent which was recorded.

Results

Of the 49 patients with chronic disease identified for our sample, seven were unreachable, two refused to participate. Among the forty who agreed to answer our questions, 27 % mentioned that they did not require health services between March and August 2020 “*I didn't really have any special needs [regarding my health] during the pandemic*” (Pt #202-5-002). On the other hand, 72% received care by telehealth intervention and 5% said their health had deteriorated because of the impacts of the pandemic. Factors that had contributed to the deterioration of their health were the decrease in social contacts, difficulty in balancing work and family, or the burden of being pregnant during this period of crisis “*Being pregnant is a situation that can be a cause for concern. I had a miscarriage before, so the first month I was a little more nervous. Then you have the*

pandemic coming which adds a layer of nervousness with that. (Pt #101-5-002) ” Table 1 presents participants’ sociodemographic data (collected during the previous study²²). Table 2 presents the physical and psychosocial conditions of the participants.

PCDs’ perception of telehealth in FMGs in the context of a pandemic

In our sample, 37% to 60% of patients who had an experience of telehealth during the first wave of the COVID-19 pandemic referred to a consultation with a family physician. All PCDs who received telehealth care mentioned that they were satisfied with the consultation. They mentioned having quick and easy access to their family physician, which never happened before the pandemic. *“When I need an appointment, I get it right away [...] I find it's even quicker than before [the pandemic]”* (Pt #302-5-003). Many of them had an appointment on the same day (rural and semi-urban) or the day after (urban) requesting an appointment.

PCDs appreciated telehealth for several reasons. First, PCDs were pleased with avoiding the pitfalls associated with travel, particularly in terms of saving time, not having to find a parking space and avoiding potentially difficult driving conditions. *“I like it [telehealth], yes. I don't need to move around, the street is a construction site, it's a mess going there. I didn't need to drive around in the street all crooked.”* (Pt #202-5-007). In addition, as no traveling was required, accessibility was easier for PCDs with limited mobility. In general, PCDs have been resilient and had accepted telehealth interventions imposed by government authorities. Some of them reported, *“having no other choice”* since the FMGs restricted access to in-person services. According to PCDs, telehealth was less appropriate for follow-ups with social workers and professionals with whom they didn’t have an established trust relationship. *“I started having consultations with him during the pandemic. I never had face-to-face consultations with him. There is definitely a proximity at this level that I will feel less than if I had seen him in person”* (Pt #302-5-001).

Several PCDs mentioned having visited primary care settings less frequently during the pandemic than before. They indicated having consulted their healthcare provider when it was perceived as essential and they had no alternative options. Most of them mentioned having tried to cope on their own and engaging in self-care before trying to make an appointment as opposed to before *“I don't think we have the choice to adapt, everything changed overnight [...] we had to adapt, I took it positively”* (Pt #202-5-007).

Emerging coping strategies related to self-care

With the lockdown order and the decrease of face-to-face healthcare follow-ups, PCDs had to develop coping strategies to deal with this new reality. The coping strategies implemented by the PCDs were aimed at maintaining their health status and their social participation, including family and social relationships, hobbies, and work. We observed that PCDs with children at home, or who had to maintain their professional obligations, had more difficulty coping with the pandemic and the lockdown because they had less time for themselves *“It's difficult when you're at home with children, with a destabilized routine [caused by the pandemic], to take time for yourself”* (Pt #101-5-002). Several PCDs also mentioned having modified their eating habits. Some made positive changes to get healthier while others resorted to eating more or increased their consumption of fast food to relieve stress. The latter having negative impacts on blood sugar control, in diabetic patients, for example. Others increased their physical activity (walks, home training) and had acquired sports equipment to workout at home. Some PCDs mentioned not having changed anything in their behaviours, especially for those who were living in a remote area. *“It hasn't changed anything in my life. I live in the country, I wasn't too confined. I take advantage of the woods on my land and it hasn't changed anything in my life”* (Pt #301-5-010). We also found that

some patients opted for strategies that would not necessarily have been prioritized by the PCD and its care team in a non-pandemic context. Two PCDs increased their use of antidepressant drugs to cope with an increase in anxiety. *“Just before the pandemic, my mother-in-law died in a nursing home and 4 days before the closing of the nursing home, my father-in-law was admitted, without knowing that we would no longer be allowed to see him. It was quite difficult [...]. It was a period of teeth grinding and anxiety for several weeks. My wife and I had been on antidepressants for a year and a half [...] We increased our dose of antidepressants and then we lowered it, it's going better now”* (Pt #201-5-001).

Through theme analysis, we produced an integrative scheme (Figure 1) by classifying the determinants (barriers and facilitators) of coping strategies according to what they were related to (environment, healthcare providers and PCDs themselves). Barriers represent the obstacles encountered by PCDs in deploying optimal coping strategies, while facilitators simplified them. We also included coping strategies used by PCDs for emotional regulation or problem resolving.

Discussion

In this study, we described PCDs' experience with telehealth services in FMGs, and emerging coping strategies related to self-care. Overall, we found that PCDs appreciated telehealth and even perceived several benefits. They also reported that healthcare accessibility was increased. PCDs developed coping strategies mainly focused on their diet and physical activity. We also observed a link between the deployment of coping strategies and patients' concern about leaving medical services for others in this time of crisis. These results led us to make the following observations.

First, based on PCDs' perceptions, telehealth interventions are meeting most of their needs. All those who received telehealth services were satisfied and even perceived several benefits. When

referring to their satisfaction with telehealth, patients immediately mentioned accessibility and time saved. A recent systematic review by Flodgren and colleagues showed that patients using telemedicine were as satisfied or more satisfied than the ones receiving usual care.²⁵ The most frequently reported advantage was a decrease in waiting time, which is an indicator of patient-reported experience measures (PREM)²⁴ and often used by patients to assess their satisfaction.²⁷⁻²⁹ PCDs with low mobility also appreciated the ease of telehealth as reported by Turner and al.²⁸ The only inconvenience raised by PCDs regarding telehealth was the difficulty in creating a trust relationship, especially with social workers and other professionals when meeting with them for the first time. This is consistent with the literature as telehealth may create a physical and emotional distance between the patient and the healthcare provider.^{27,28} Telehealth can also reduce the quality of interpersonal relationships through poor communication or misinterpretation, making a psychosocial intervention more difficult as it requires a special decorum to establish a trusting relationship.³¹ The therapeutic relationship is at the heart of the quality and effectiveness of services offered in mental healthcare.²⁸

Second, our study indicated that PCDs perceived accessibility as improved during the COVID-19 pandemic compared to before. This improved accessibility illustrates that the FMGs properly adjusted their operations to respect government directives. It also indicates that PCDs were more able to use coping strategies and consulted the physician only when necessary, as many reported.⁵ PCDs perceived this increased accessibility positively and it seemed to influence their satisfaction assessment regarding their care. This goes along with the fact that accessibility is also an indicator of PREM and is considered important for patients.^{24,27} However, we cannot assess the quality of the services provided by the healthcare providers and their consistency with professional practice guidelines, such as patient-centered care and interdisciplinary collaboration.³⁰ Nonetheless, our

study highlights that it was difficult for PCDs to describe the quality of the services received by healthcare providers since their main reference in regards to this was access. This is an important aspect to document in further studies as access and rapidity is not a guarantee for quality nor a confirmation that professional practices are embedded in best practice guidelines and scientific evidence. Healthcare in a pandemic context requires providers of primary healthcare to develop their practice in line with the best scientific evidence, including patient-centered care and interdisciplinary collaboration within a physical and social perspective.³³ From health professionals' perspective, this decrease in the number of appointments, which is consistent with the literature during a pandemic period,³⁴⁻³⁸ is preoccupying, as it may indicate a lack of timely and appropriate care for vulnerable people.³⁷ Even in a pandemic situation, patients' health and social needs remain and primary healthcare providers have to fulfill them. Even more so, knowing that the COVID-19 pandemic discouraged some patients from getting services, as they feared being infected with the virus,³⁴⁻³⁸ and that health measures (lockdowns, quarantines) had an impact on mental and physical health.⁴⁰⁻⁴² It is clear that the pandemic increased the healthcare needs of patients which are not directly related to COVID-19 and this represents an important issue for maintaining the social safety net and the adequate follow-up of patients.

Third, we observed that the coping strategies developed by the PCDs, during the first wave of the Covid-19 pandemic, were primarily aimed at maintaining their health status by adopting health-promoting behaviours, as well as maintaining their social roles and responsibilities (work, family relations, social relations), i.e., their social participation.⁴¹ Lazarus and Folkman¹² consider these outcomes to be coping strategies aimed at adherence, emotional well-being and functional status. The coping strategies mentioned by PCDs are similar to those reported by Sign et al. (2020), the main ones being social and family support and staying in touch with family and friends using

different media.⁴² Sign et al (2010) also reported that spirituality was an important coping mechanism, but this strategy was not raised by any of the participants in our study. ⁴²

In some cases, even though coping seemed to be a positive response, it may be inadequate. Indeed, without the expertise and support from healthcare providers during the pandemic, coping can also be harmful, and patients can make choices or adopt habits that are detrimental to their long-term health.^{33,60-63} With good reason, they were not prepared to deal with their condition and health issues, on their own.⁴⁷ This highlights the need for healthcare providers, especially those in primary care, to be present for patients, especially when certain services are absent. One study showed that patients, for whom a cardiac rehabilitation program was unavailable, tended to develop self-care strategies to adapt their behaviour instead of going through a rehabilitation program with their healthcare provider . This decreases their quality of life while increasing their risk of suffering from a second (or third) cardiac event.⁶⁵ This issue demonstrates that coping, without guidance from healthcare providers is not always positive for patients. For PCDs, interprofessional teams could have a positive impact on patient-related outcomes.⁴⁷ This is even more important during a pandemic episode when it is expected to decrease the population's health.^{43,65,66} Therefore, during data collection, 57% reported receiving services from the physician only while being followed by an interdisciplinary team prior to the pandemic.

This study presents several strengths, such a highly competent patient-oriented research team and expertise in primary care. . As the PCDs were involved in another project with the research team and had established a trust relationship, this facilitated the carrying out of the in-depth interviews. Co-coding and rigorous analysis of the data with the Lazarus model led us to make links between existing evidence-based research and our field data. The involvement of patient partners in the

collection and analysis of the data indicates potential for transferability of the results to other patient populations.

This article also presents some limits that should be discussed. Since physicians referred certain PCDs, it is possible that some of them only referred PCDs with whom they had a positive relationship. This can partly explain PCDs' high level of satisfaction and the authors wanted to highlight this point. In addition, coping strategies used by the patients were not differentiated according to their health condition. It would have been interesting to analyze the strategies used by patients with mental health problems, compared to those with physical problems or both.

This study highlights important findings and issues that primary care providers need to consider. Telehealth interventions are viewed positively by primary care patients in terms of accessibility. This is an important part of the patient care experience and this can have a positive impact on health. Decision makers of primary care services need to consider strategies to support the continuation of this practice in a post-pandemic environment. However, these strategies must be appropriate for the needs of patients and support interprofessional management as recommended for primary care.

Regarding the needs of patients during the pandemic and in relation to changes in primary care consultation modality, further studies should be conducted in order to fully understand whether the coping strategies used by patients are related to emotional regulation or problem solving. For example, future research could find a way to maintain PCDs' motivation to put forward coping strategies as a first resort, rather than automatically making an appointment for in-person consultation at the clinic. This could contribute to relieving healthcare services congestion in order to improve access to primary care.

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Table 1 Sociodemographic characteristics of the PCDs participating in the study

Characteristic	Patients (N=40) n (%)
Sex	
Male	17 (42.5)
Female	23 (57.5)
Age (mean=60.5)	
< 30	3 (7.5)
31-40	1 (2.5)
41-50	2 (5)
51-65	19 (47.5)
65 +	15 (37.5)
Marital status*	
Married/Common-law partner	33 (82.5)
Single	2 (5)
Separated/Divorced	4 (10)
Highest level of education*	
Primary/High school	12 (30)
Professional/College	16 (39)
University	11 (27)
Employment status[†]	
Working	11 (27.5)
Work interruption	5 (12.5)
Retired	18 (45)
Other	2 (5)
Income (\$)‡	
[0 – 29 999]	8 (20)
[30 000 – 59 999]	15 (37.5)
[60 000 – 99 999]	7 (17.5)
≥100 000	5 (12.5)
City	
Metropole	9 (22.5)
Rural	15 (37.5)
Urban	16 (40)
Healthcare provider before COVID-19	
Family physician	10 (25)
Family physician and nurse	14 (35)
Family physician and social worker	10 (25)
Family physician, nurse and social worker	6 (15)

- * Data is missing for 1 patient
- † Data are missing for 4 patients
- ‡ Data are missing for 5 patients

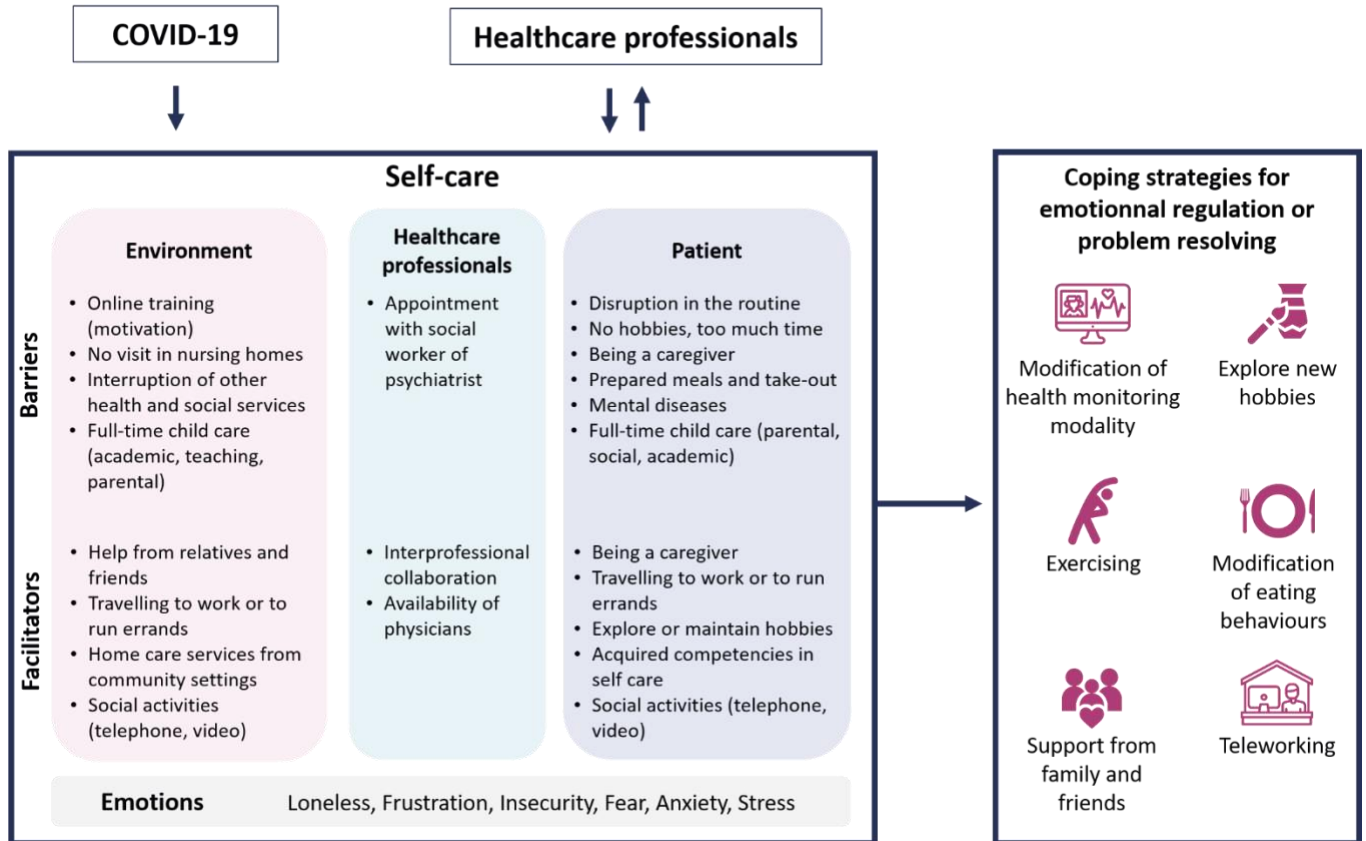
Table 2 Medical and psychosocial conditions of the PCDs participating in the study

Medical and psychosocial conditions	Patients (N=40) n (%)
Type*	
Diabetes	15 (37.5)
Arterial hypertension	11 (27.5)
Personal difficulties	7 (17.5)
Difficulties in adapting to situations	6 (15)
Mental health difficulties	6 (15)
Coronary artery disease (CAD)	5 (12.5)
Cancer	4 (10)
Asthma	3 (7.5)
Relationship difficulties	3 (7.5)
Suicidal thoughts	2 (5)
Bereavement	1 (2.5)
Chronic obstructive pulmonary disease	1 (2.5)
Heart failure	1 (2.5)
Neurodegenerative disease	1 (2.5)
Professional difficulties	1 (2.5)
Other	16 (40)
Number of conditions	
1	16 (40)
2-3	18 (45)
4-5≤	6 (15)

**not mutually exclusive*

Figure 1

Barriers, facilitators and coping strategies for self-care reported by the PCDs participating in the study



Appendix

Interview guide about the healthcare needs of PCDs during the COVID-19 pandemic

INTRODUCTION

Hello M. or Mrs. (name of patient), how are you?

My name is ...

I am

1. Trainee on F2PL project, a medicine student
or
2. Patient researcher on F2PL project

I am part of the team of the F2PL research project in which you are participating and which aims to better understand how FMC professionals meet the needs of patients. Our team did a first group or phone interview with you and other patients in the fall of 2019, do you remember?

M. or Mrs. (name of patient), is it a good time for me to talk to you?

1. No: Can we schedule an appointment at a time that suits you better? (Make an appointment and tell the patient that we will contact him at that time, thank him and hung up.)
2. Yes : pursue

If I'm calling you today, it's to hear from you and tell you where the F2PL project is at.

We had to contact you this winter to do a second interview, but the COVID-19 situation changed plans and we had to postpone several stages of the project. As it is not possible to immediately assess the impact of the F2PL project on your clinic, we will get back to you in further months to organize the next interview.

However, the research team wants to take advantage of the current situation to verify how FMC patients experienced COVID-19 and whether it influenced the service they needed.

Do you agree if I ask you a few questions and if I record our call?

The interview lasts 20 minutes.

1. Patient refused: no problem, thank you. Our team will contact you again when it is time to do a next interview for the F2PL project to assess the impact of our intervention
2. Patient agreed: Thank you. I will now record the interview.

Interview's question

1. Since the start of the COVID-19 pandemic last March, how has it been for you in your FMC?

(Suggestion for reformulation of the question if necessary):

- *How are you?*
- *Have you had any health problems or needs?*
- *Has your FMC's service offer changed?*
- *Were you able to join your FMC and tell them about your health problems?*
- *Did you feel welcomed?*
- *Have you consulted a physician, a nurse or a social worker in your FMC? If so, was it a face-to-face or a telemeeting?*
- *Did these meetings meet your needs and expectations?*

2. Since the start of the pandemic, have there been any changes in the services offered by your FMC and how have you adapted to these changes?

(Suggestion for reformulation of the question if necessary):

- *How did you adapt to the situation?*
- *What have you done to take care of yourself and your condition?*

3. In which consideration were you able or unable to adapt yourself to the COVID-19 pandemic?

(Suggestion for reformulation of the question if necessary):

- *What made your adjustment easier or more difficult?*
- *Did you feel accompanied in this period of time?*

4. In the things you changed to take care of your health, what will be left after the pandemic?

(Suggestion for reformulation of the question if necessary):

- *What have you learned about your ability to manage your disease during this pandemic?*
- *Did you feel like you are better at taking care of your health?*

5. What would you like to say to the professionals at your FMC so that they better understand your experience of care during the COVID-19 pandemic?

CONCLUSION

Thanks a lot, M. or Mrs. (name of patient).

If you agree, we will call you back in a month to discuss again in the same format.

In addition, if it's possible, we would like to organize a new group meeting with all the patients in your clinic in the fall of 2020. Depending on how the COVID-19 situation in Quebec is going, do you agree to be contacted by phone again about this topic ?

Good bye and have a nice day.