

Patients' Perceptions and Experiences of the COVIDCare@Home Program: Insights from a Mixed Methods Study

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Abstract

Background

Virtual models of health service delivery are being offered to patients diagnosed and recovering from COVID-19 as a key strategy to minimize the spread of the variants. Although evidence is growing in this area, more is needed to understand the experiences and perceptions of patients and their care partners associated with virtual and telehealth care to inform future care delivery efforts beyond our current pandemic. In this context, a study was undertaken to explore a virtual primary home care program led by a nurse practitioner developed for acute and post-acute COVID-19 patients and their care partners.

Methods

The study employed a mixed methods design that included a cross-sectional patient survey and semi-structured interviews with a sample of COVID-19 patients.

Results

The CC@H program was reported by study participants to have several positive benefits including needs being met and better able to manage their care at home. Qualitative results further elucidated three key themes easing anxiety by providing emotional support and checking in; 2) providing holistic compassionate care to enable self-management; and 3) viewing virtual care as efficient and convenient.

Conclusions

Our study provides interesting insights into the experiences and perceptions of COVID-19 patients receiving care through a primary health care nurse practitioner-lead virtual care program that may be useful to other organizational efforts.

Introduction

Patients diagnosed with COVID-19 appear to have varying symptoms and involve multiple organs^{1,2} Although the majority of patients' symptoms and experiences are mild and resolve, there are cases in which symptoms continue to persist months after diagnosis. With the prolonged impact and multi-system nature of post-acute COVID-19 recovery, a holistic patient perspective is required to manage the clinical, mental, and psychosocial effects.^{3,4,5} As a key strategy to minimize the spread of the COVID-19 variants, many organizations have moved towards virtual models of health service delivery limiting in person contact enabling access to both health and social related services and resources within their communities.^{6,7} Many patients experiencing COVID-19 and post COVID-19 symptoms can be managed

virtually by a primary health team with advice on symptomatic management and psychosocial support.^{4,5,7}

The added virtual component has required clinicians to manage COVID-19 through various sources of information from both patients, and if present, their caregivers. This includes how patients are feeling (subjective) and objective information (e.g. oxygen monitoring) to help guide treatment with a focus on self-management.^{5,7,8} Although evidence is growing in this area, more is needed to understand the experiences and perceptions of patients and their care partners associated with virtual and telehealth care to inform future care delivery efforts beyond our current pandemic. In this context, a study was undertaken to explore a virtual primary home care program (COVIDCare@Home) developed for acute and post-acute COVID-19 patients and their care partners (<https://covidcareathome.ca/>).⁹

Methods

Study Design

The study employed a mixed methods design that included a cross-sectional patient survey and semi-structured interviews with a sample of COVID-19 patients. Research ethics board approval was obtained from Sinai Health.

Study Setting

The COVIDCare@Home program was designed and provided as part of the Mount Sinai Academic Family Health Team (MSAFHT) that provides health and social care (e.g. primary care, obstetrical care and home-based primary care to seniors) to more than 13,000 patients annually. The MSAFHT employs an interdisciplinary model and involves a variety of healthcare workers including diabetes care, social workers, registered nurses, nurse practitioners and dietitian, pharmacist, complex care coordinator, and an in house regional coordinator working in collaboration to provide care to patients in the Greater Toronto Area.

Intervention Description

In response to the evolving COVID-19 pandemic landscape, the MSAFHT adapted the Women's College Hospital COVIDCare@Home (CC@H) program to provide virtual support to COVID-19 positive patients who are in their homes. The program stratified the risk of COVID-19 positive patients based upon a remote assessment program developed in the United Kingdom.^{4,5} An integral component of the program is that a Primary Care Liaison-Nurse Practitioner (PCL-NP) worked in close collaboration with the patient's primary care provider (PCP). Patients were initially assessed for risk by the PCL-NP using a risk assessment tool⁵ in their preferred mode of communication (Zoom, provincial telemedicine program and/or telephone call) and then offered and provided "as-needed" services outlined in Box 1. In addition, the PCL-NP facilitated follow-up visits with the appropriate provider in consultation with the physician, resident, faculty advisor and or nurse practitioner.

Box 1 COVIDCare@Home Program Service Components
Phone calls or video chats to assess and monitor
Patient education, support and self-management resources
Further testing at home or in hospital
A pulse oximeter to self-monitor at home for some patients
Access to consultants and interprofessional healthcare providers
Triage to the urgent care or emergency if needed

Recruitment and Data Collection Methods

An initial email was sent out to patients who received care as part of the CC@H program by the PCL-NP. Follow-up emails were then provided by the PCL-NP for another round of recruitment followed by a PCP for the final reminder during June to November 2021. For those patients who were interested in participating, they were instructed to connect with one of the research staff, who then followed up with the potential participants. As part of the data collection process, potential participants were offered a few options including: 1) completing the survey on-line or as part of the interview process and 2) participating in an interview. Completion of the survey either on-line or in the interview served as implied consent. For those participants who agreed to participate in an interview informed consent was obtained prior to conducting the interview.

A cross-sectional survey was adapted from an existing data collection tool created by another virtual care primary care team (<https://covidcareathome.ca/>). The survey included demographic questions (age, gender, racial and ethnic background, highest level of education, living arrangements, total family income) and overall program utilization (e.g. frequency of visits, ease of access); experience (e.g. needs met and aligned with goals and preferences, effect on anxiety, appropriate amount of time with PCL-NP, doctors and other providers, appropriate referrals, involved in treatment decisions); and program efficacy (e.g. usefulness in managing care and treatment, level of care, appropriate use of emergency services and time saved). Each question was scored on a 5-point Likert scale (strongly agree to strongly disagree) with an 'other' category capturing missing, not stated, not applicable, don't know, prefer not to answer.

The semi-structured interview was derived from a recent COVID-19 study and adjusted accordingly to match the study objectives.¹⁰ Key questions are included in Box 2.

Box 2 Semi-structured Interview Questions

Please describe your overall experience receiving care as part of the COVIDCare@Home program
What care and follow-up care has been provided to you as part of the COVIDCare@Home program.
What parts of COVIDCare@Home were most helpful to you?
What parts of COVIDCare@Home were least useful?
What supports do you wish you had from COVIDCare@Home or areas you feel are missing that you would have benefitted from?
What recommendations do you have to improve COVIDCare@Home?

Data Analysis

Quantitative data from the surveys was analyzed using descriptive statistics including frequency counts, and mean, median, and mode where appropriate.¹¹ Interview responses were recorded and transcribed verbatim into word documents. Thematic analysis was performed, with a coding schema developed iteratively to guide and categorize the narratives.^{12,13,14} Five research team members coded the transcripts line-by-line independently and then through a series of analytical meetings developed a codebook with codes and categories through consensus across between July 2021 to December 2021.^{12,13,14} These codes and categories were then developed into key themes and sub-themes until saturation was reached.^{12,15}

Results

Sample Characteristics

The total sample size was 16 participants who completed the survey and participated in the interviews from July to November 2021. This included 13 females and 3 males ranging between the ages of 30–79 enrolled in the Mount Sinai Family Health Team. There were 15 interviews conducted over phone calls with one conducted using Zoom. Interviews ranged from 15 minutes to 45 minutes in length.

Quantitative Results

The CC@H program was reported by study participants to have several positive benefits. Percentages include the sum of those participants who reported they agree or strongly agree with the statements. Overall, 94% of respondents reported they would recommend the program to both patients with COVID-19 and other patient populations with a lot of health issues. The majority of respondents reported that the program eased their anxiety (87%); that their needs were being met (81%), the care provided was aligned with their goals and preferences (81%), and their condition was being appropriately treated (81%). Study participants also reported that seeing a healthcare provider was easier following their COVID-19 diagnosis (81%); information provided was useful in managing care and treatment (81%); and they were better able to manage their health and medical needs (81%). The level of care received through the program was reported to be at least equivalent to the care prior for 75% of the study participants. Participants also reported that there were minimal technical difficulties (88%) and the scheduling of remote visits were easy (75%).

To a lesser extent, study participants shared that without this program they would not have gotten the care they needed (69%). Further, respondents reported that the program provided appropriate referrals (69%); sufficient time with care providers (63% with physicians and 57% with other providers – nurses, social workers). 63% of participants shared that the program helped them to decide to go or avoid going to the emergency department.

Qualitative Results

Themes emerging from the narrative further elucidated the benefits that patients perceived and experienced from receiving care within the PHL-NP CC@H program. Specifically, the following three key themes emerged: 1) easing anxiety by providing emotional support and checking in; 2) providing holistic compassionate care to enable self-management; and 3) viewing virtual care as efficient and convenient. Recommendations for improvement also emerged.

Easing anxiety by providing emotional support and checking in

Similar to the quantitative results, participants shared that the CC@H program helped to alleviate and ease the anxiety they were experiencing associated with contracting COVID-19. Being connected with the PHL-NP provided them with answers to their questions and addressed their concerns, and provided emotional supported normalized their experience and eased their anxiety. Study participants also acknowledged how appreciative they were with the follow up and checking in with them, as one participant described *“answering the questions reassured me that I am doing well, I’m glad someone is checking in on me as I am essentially living alone”* (Patient 1). Some participants also shared that their anxiety was also alleviated by the physicians associated with the primary care setting the CC@H program was offered in. The following narrative quotes illustrate this theme.

“She (nurse practitioner) provided great emotional support and was phenomenal. I was just so happy that existed during that time for me. She called me up, introduced her role, gave me a number I could call 24/7. She was very personable and down to earth, and provided a lot of reassurance. Definitely provided a lot of emotional support. With the good will and love of the nurse practitioner, I don’t know what I would’ve done without her. She would always check in with my symptoms, she’d always return calls promptly. It was just such a wonderful service offered.” (Patient 3)

“I got a call that day and that really helped, she was mostly just reassuring me and giving me an understanding what to look out for regarding fever, my blood oxygen. That really helped quell the anxiety which probably was the biggest thing at the outset after receiving the diagnosis. I was very pleased, and she kept following up, she spoke to my wife for a little while as well because she had questions. She was following up to make sure I was on the right track, and not get worse and I was very appreciative.” (Patient 2)

“At one point I did call them again because I was panicking a little bit but I just wanted to get some reassurance and somebody from the office called me back a few hours later, so they were pretty good with follow up... I think just the reassurance from the doctors and knowing that somebody was there if you had questions.” (Patient 12)

“She (nurse practitioner) was very reassuring. She made me feel moralized, she said I have 2 cohorts of patients and a lot of my patients this group are feeling very much the same as you or have had these symptoms. I felt like okay, what I’m experiencing is normal. I think the most important thing was I was

really worried about the asthma and the breathing. How accessible the nurse practitioner was and being able to get reassurance.” (Patient 4)

Providing holistic compassionate care to enable managing care

Closely aligned with the first theme, the holistic, compassionate care provided by the PCL-NP lead of the CC@H program was viewed as valuable in study participants’ efforts to manage their care and care of their family which, in some situations had become infected, or in isolation to avoid acquiring COVID-19. Study participants described the PCL-NP as *“calm”, ‘a rock’, and ‘a life line’* as she helped patients to monitor and manage their symptoms and problem solve by providing information on what to look for and triggers to seek emergency and urgent care services and return home. As one participant shared *“she was literally helping me triage my entire family while I’m still going through it myself. She was helpful to me in helping me manage symptoms, dry mouth at the beginning. Helping me problem solve as acute issues arose with each family member at the same time.”* (Patient 2) Further quotes that exemplify this theme include:

“She helped me self-manage, she encouraged me to get an oximeter and get the necessary equipment to manage, what the cut offs are for a low oxygen or high heart rate or when it was truly time to seek medical assistance, and just giving me very black and white clinical advice on when it’s time to act and what more I could for myself and how so just providing appropriate self-management support.” (Patient 3)

“It was the hard facts, the thresholds to be mindful of in terms of myself and my symptoms. In a situation where you can’t just walk into a hospital and get care, that I think helped because I was allowed to self-monitor with confidence. She told me what to look out for and she said if it (e.g. blood oxygen) ever went below, I think it was 91% or something, I should call an ambulance. At only one point did it do that but I retested about 30 seconds after and it bounced right back.” (Patient 2)

“The nurse practitioner was, just amazing. I’ve never seen her, we’ve only spoke on the phone, so if you have the opportunity to pass along from me personally that she was just a lifeline.” (Patient 8)

“I’m here alone - what if I had a really bad accident. When I told her that I’m crying, and she was super calm and she was like okay so this is what we need to do. We need to get a pulse oximeter and you’re going to read it and if it’s below 90, you’re going to call 911 and you’re going to the hospital.” (Patient 4)

Viewing virtual care as efficient and convenient

Similar to survey findings, several of the study participants described the efficiency of home-based virtual care and telehealth. Specifically, they shared that appointments were on time and more efficient than going to a doctor’s office. Further, the time saved by not having to go the primary care setting or emergency services located in a busy downtown area and the convenience, particularly during episodes

where they were experiencing symptoms, was also beneficial to study participants, as noted in the following narrative:

“The idea that somebody could talk to you rather than lug your ass down to their office and be sitting in a room where there’s other people that may have other things when you’re already immunocompromised, I’m quite happy to talk to somebody on the phone. I think it’s a really – it’s that kind of care I think we’re going to see because of COVID, more at home care being delivered. There’s a lot you can do by sending photographs or if you’re facetimeing, it’s something they can see.” (Patient 7)

“If someone’s checking in on you on a daily basis there’s less of a chance of things going the wrong way quickly. It can let you say okay it’s time to go to the hospital or you’re doing fine at home. It keeps people out of emergency because they’ve got somebody to talk to.” (Patient 10)

“Everything was always on time. If an appointment was booked for a specific time then the calls were always on time. It was very different from waiting at a doctor’s office where it could go on for a little bit later. Everything was always very efficient, it felt like more efficient than going into the doctor’s office.” (Patient 6)

“They were all over the phone, and that was really convenient because we were self-isolating too so we didn’t want to leave the house and we didn’t have to go to the hospital. Everything was over the phone.” (Patient 11)

Study participants also identified a few gaps and areas for improvement including variation in follow ups and check ins from the CC@H program. Variation ranged from consistent while others reported sporadic check ins with some reporting no check ins at all. Further, some participants were confused about whether they were oriented to the program at the beginning, thus causing confusion of their participation within the CC@H program. Finally, expanding the program to include other disciplines (e.g. psychology, social work) was suggested. The following quotes illustrate the suggested areas for improvement:

“Reassurance of maybe access to a counsellor at the time or a social worker at the time. Just to talk about the illness and how it affects people’s everyday life and all that stuff. Just maybe knowledge, offering of extra resources, or reassurance maybe that—I have no idea. Just someone to check in I guess just to see how I was doing, if I was improving or whatever.” (Patient 5)

“It was not as regular as I would’ve liked it to be, people had days off. There also wasn’t as rigid of a pattern that I could rely on so I sometimes wondered what’s happening? Had there been a consistent person checking with me that would’ve been good. There was a nurse practitioner initially and then she was gone for a week, so one of the other doctors in the team took care of it. Then it dissipated rather than ended. I didn’t get a sense of completion of this is over. The one doctor I remember saying ‘I think you’re doing fine.’ But I didn’t get the impression that there wouldn’t be any more calls. I think closure needs to be more intentional or more clear or reasons that you’re now at this degree of wellness and therefore we’re not going to be calling you anymore.” (Patient 1)

“I’m just wondering though for people who didn’t have access as a frontline staff to a psychologist. Because the nurse practitioner had her hands full. If perhaps with COVID, there was a psychologist at home because a lot of times easing your mind can maybe ease how you’re physically feeling to some extent. I think if there was a psychologist working with her in some cases because it’s a real head game, this illness.” (Patient 3)

“I’m not sure exactly what the program was. I mean I did speak with my doctor a couple of times, 2–3 times as I was going through the COVID. She’s the one who had mentioned the relapse. My symptoms weren’t bad enough, I didn’t get any sort of prescription medication from her, I just used Tylenol and that was it and maybe the decongestant. Just over the counter stuff. There was no prescription.” (Patient 13)

Discussion

Although there is growing evidence on the benefits of remote virtual care during the pandemic,^{16–22} this is the first study to our knowledge to share COVID-19 patients’ perceptions and experiences associated with a nurse practitioner led CC@H program. Collectively, our study findings demonstrated promising outcomes with the COVID-19 patients sharing that without the CC@H program, they would not have gotten the care they needed and that they recommend the program to continue and scale to other complex patient populations. In addition, our COVID-19 patients also predominately reported that the care received in the CC@H program was at least equivalent to the care prior to the advent of the pandemic. These findings also add to the evidence base of the effectiveness of nurse-led clinics and programs.^{23–25}

Our study elucidates the integral role the PCL-NP had in easing the COVID-19 patients’ anxiety and enhancing their capabilities in managing their care at home by providing emotional support and the holistic, compassionate care. Referring to the PCL-NP as ‘a rock’ and ‘a life line’ are powerful metaphors that our study participants shared to describe how appreciative they were in being provided information and answers to their questions to help them monitor their symptoms, manage their care, and understand triggers for seeking acute care services. These metaphors also reflected how the PCL-NP normalized their experience by acknowledging that what they were asking questions around were to be expected and sharing that other patients were experiencing some of the same symptoms. Further, the PCL-NP’s checking in and following up with the COVID-19 patients in our study was viewed as valuable. Collectively, the PCL-NP likely also impacted their responses around having appropriate care provided that met their needs and was aligned with their goals and preferences and being able to better manage their care and treatment at their homes. This is consistent with what is known around the navigation role that primary health care nurse practitioners play, enabling access to care, particularly chronic disease patients.^{26,27}

Although concerns that the pivot from in-person to virtual may jeopardize the care experience by minimizing human interactions have been raised,²⁰ our study findings offer a different view. Specifically, the valuable role that the PCL-NP had within the CC@H program exemplifies the provision of “virtual”^{16–18, 28} and “digital” empathy^{18,29–31} that is focused on a person-centred approach that integrates relational

aspects of care with care for physical and psychosocial needs.^{32–35} Enacting humanistic practices including virtual and digital empathy requires adapting verbal and non-verbal (body language) cues to establish and sustain meaningful connections and a trusting relationship with patients virtually.^{18,29–31,36,37} Similar to our study findings, providing empathetic, compassionate, person-centred care has been linked to improved health outcomes perceived to impact.^{18,35} Specifically, by responding with compassion and empathy, the PCL-NP was able to provide a safe space for participants to express their concerns and anxieties associated with their COVID-19 diagnosis and prognosis that contributed to their overall experience and well-being.

Clearly, future efforts to continue to offer and adapt this type of model grounded in virtual and digital empathy to COVID-19 patients are called for.^{18,29–31,36,37} These efforts can draw from and incorporate from existing resources for virtual humanistic practices^{36,37} and the Academy of Communication in Healthcare's training videos that includes sharing practical tips and to be present, identify a patient's needs, listen, respond with empathy, and share information during virtual visits.³⁸

Our study findings around how our COVID-19 patients viewed the virtual care provided as part of the CC@H program to be efficient and convenient adds to what has been described previously with virtual care.^{18,20,21,38,40} For example, a recent study exploring oncology patients' views on virtual care amid the COVID-19 pandemic included that the virtual appointments were predominately positive experiences including easy to schedule and connect with their healthcare provider.¹⁸ Study participants also shared other benefits including it being convenient and saving time and money due to not having to travel to virtual care appointments.¹⁸ Nurses reported that they believed virtual care improved access to health care by eliminating barriers and reducing costs associated with travel to appointments and having to balance appointments with work schedules.²¹ In our study, virtual care also was viewed as efficient as it was keeping patients out of the hospital that enabled resources to be used more for acutely ill patients. Similar to our study findings, the oncology patients receiving virtual care also expressed being less anxious not having to travel to their appointments amid the pandemic landscape. Another study reported that virtual mental health counseling with veterans may be as effective as in-person visits.³⁸ However, future research needs to examine and explore the various virtual care approaches to respond to the evolving COVID-19 pandemic and post-pandemic landscapes.

While the PCL-NP led CC@H program was perceived to have positive impact on COVID-19 patients, several participants offered areas for improvement. A clearer, more structured approach that outlines what the program entails and expectations around virtual care and follow-up care and access to resources. This approach can draw from what has been suggested in another study to create a virtual care preparation checklist that could be personalized by patients to set their expectations for the appointment, organize their information, and plan their questions.¹⁸ Additionally, integration of other health disciplines including a psychologist and social work to address mental and social health issues within the CC@H program is an important recommendation to address. While the nurse practitioner lead of the program provided the much-needed emotional support to participants, the involvement of these

health disciplines would have been helpful in aiding in the navigation of anxieties, depression, stigma, and social isolation associated with contracting COVID-19 our study participants experienced.

Study Limitations

The homogenous sample consisting predominately of well-educated, high-income, Caucasian women in one primary care setting limits the transferability of our study findings. Despite this limitation, our study findings emerged through a rigorous analytical process.

Conclusion

Our study findings demonstrated promising outcomes with the COVID-19 patients including that they received at least equivalent, efficient, and convenient care and treatment virtually compared to in person appointments. Underpinning these outcomes was the valuable role the PCL-NP had in easing the COVID-19 patients' anxiety and enhancing their capabilities in managing their care at home. Core to the care provided virtually by the PCL-NP within the CC@H program was providing holistic, compassionate care and emotional support demonstrating virtual and digital empathy. Collectively, our study provides interesting insights into the experiences and perceptions of COVID-19 patients receiving care through a PCL-NP lead virtual care program that may be useful to other organizational efforts. Future efforts to continue to implement and adapt this type of care model with COVID-19 patients and to other patient populations where virtual care is beneficial to and preferred by the patients are called for.

Declarations

Ethics Approval and Consent to Participate: As part of the informed consent process, participants consented to participate in an interview and survey. Ethics approval was obtained through Sinai Health Research Ethics Board. All methods were carried out in accordance with relevant guidelines and regulations.

Consent to Publish: As part of the informed consent process, participants provided consent to publish.

Availability of data and materials: The datasets used and/or analyzed during this study available from the corresponding author on reasonable request.

Competing Interests: The authors have no competing interests.

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Authors Contribution: LJ, TA and ML conceptualized the study. RZ, NS, TA and MO analyzed the data with LJ, TA and ML. All contributed to the publication.

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