

Going home positive: a qualitative study of the experiences of care for patients with COVID-19 who are not hospitalized

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Abstract

Background: Most Canadians diagnosed with COVID-19 have had mild symptoms not requiring hospitalization. We sought to understand the patient experience of care while being isolated at home after testing positive for SARS-CoV-2 infection.

Methods: We conducted a phenomenologically informed qualitative descriptive study using in-depth semistructured interviews to identify common themes of experience for patients sent home from hospital with a positive COVID-19 diagnosis. Between July and December 2020, we conducted interviews with patients who were followed by the North York General Hospital COVID Follow-Up Clinic. Patients with mild to moderate symptoms were interviewed 4 weeks after their COVID-19 diagnosis. We conducted the interviews and performed a thematic analysis of the data concurrently, in keeping with the iterative process of qualitative methodology.

Results: We conducted interviews with 26 patients. From our analysis, 3 themes were developed regarding participants’ overall experience: lack of adequate communication, inconsistency of information from various sources, and the social implications of a COVID-19 diagnosis. The implications of a positive test for SARS-CoV-2 infection are substantial, even when symptoms are mild and patients self-isolate as recommended. Participants noted communication challenges and inconsistent information, leading to exacerbated stress.

Interpretation: Participants shared their experiences of the stigma of testing positive and the frustration of poor communication structures and inconsistent information. Experiencing care during self-isolation at home is an area of increasing importance, and these findings can inform improved support, ensuring access to equitable and safe COVID-19 care for these patients.

More than 4.5 million Canadians had been diagnosed with SARS-CoV-2 infection as of Jan. 30, 2023.¹ However, only a very small minority of diagnosed patients have been hospitalized (1.2%) or died (1.1%),² and therefore, most patients with COVID-19 can be categorized as having mild to moderate disease that does not require hospitalization. In Ontario, patients presenting to the emergency department of most hospitals with symptoms suggestive of mild COVID-19 (or with confirmed diagnosis who are seeking medical advice) are discharged home with instructions on how to view their test results online, how to manage symptoms and indications to seek further medical care. At the time the current study was completed, patients with positive polymerase chain reaction (PCR) testing for SARS-CoV-2 were then contacted by local public health units to discuss their symptoms, discuss recent contacts and develop a quarantine plan. To provide additional support for patients seen in the emergency department or COVID-19 assessment centre who tested positive for SARS-CoV-2 infection, or for whom the clinical team felt there was a need for close follow-up during assessment, North York General Hospital implemented a primary care physician-led virtual call-back system (known as the COVID Follow Up Clinic).

To date there has been considerable focus in the scientific literature on severe illness and long COVID syndrome.³ However, given that many people do not experience severe illness⁴ and the increasing likelihood that COVID-19 will transition to an endemic disease,⁵ it is important to understand the experiences of patients with mild or asymptomatic conditions who are isolating at home after testing positive and the perceived value of virtual follow-up systems. Further waves of the pandemic are inevitable,⁶ and improvements in the design of follow-up systems to better meet the needs of the full spectrum of patients will be beneficial. Therefore, we sought to understand the patient experience of care while being isolated at home after testing positive for SARS-CoV-2 infection.

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Methods

During the early period of the COVID-19 pandemic, patients who came to the North York General Hospital Emergency Department or COVID-19 assessment centre with symptoms of COVID-19 or possible exposures to SARS-CoV-2 and were not admitted to the hospital were sent home to await their test results. In general, people attended the emergency department or the assessment centre for similar symptoms such as cough, shortness of breath or fever; the COVID-19 assessment centre also conducted preoperative screening and would conduct SARS-CoV-2 tests for asymptomatic individuals who had been exposed to the virus in community settings. These individuals accessed their test results online, and if they subsequently received a positive diagnosis, they then received a follow-up telephone call from a family physician working with the hospital's COVID Follow Up Clinic. Both the COVID-19 assessment centre (now called the North York Cough, Cold and Covid Clinic) and the process by which patients receive a telephone call from a physician after a positive SARS-CoV-2 test are ongoing. Patients who were considered to be at high risk for complications or would have challenges accessing results online were also referred to the follow-up program. The clinic is still functional in 2023.

This manuscript was prepared in accordance with the Consolidated Criteria for Reporting Qualitative Research checklist.¹⁵

Study design

We conducted a phenomenologically informed qualitative descriptive study using in-depth semistructured interviews to understand the experience of patients sent home from an emergency department with a positive COVID-19 diagnosis. Phenomenological research attempts to understand the lived experience of people from their perspective as “insiders” who perceive, derive meaning and form understandings of particular phenomena.⁷ This approach seeks to generate in-depth knowledge of what it is like to experience a particular thing or situation by focusing on the aspects that are most salient to those who have lived through/with it.⁸ It is a useful approach for health-related quality-of-life research, and the approach supported our goal of understanding relevant experiences and perceptions expressed by patients accessing health care in this unique pandemic situation. This study was designed to explore the experiences (including the experience of the North York General Hospital COVID Follow-up Clinic) of this unique group of patients testing positive for SARS-CoV-2 infection as this has not been well-described in the literature.

Patients were interviewed approximately 4 weeks after their COVID-19 diagnosis, and all had sufficiently mild-moderate symptoms of COVID-19 that they were able to self-manage those symptoms in a home-based, outpatient setting, with support from the COVID Follow Up Clinic.

Participant recruitment

We used purposive sampling to recruit adult patients who experienced this process and were followed by the COVID Follow-up Clinic. All of these participants also received calls

from local public health organizations, whose activities were independent of the COVID Follow Up Clinic. Eligible patients were identified by a team of primary care physicians working at the clinic and provided consent to be contacted by our research team to learn more about the study. Patients who subsequently agreed to participate in this research were given an opportunity to review the letter of information and consent form, ask questions and provide verbal consent before starting the interviews.

Data collection

Data for this study were collected between July and December of 2020. Interviews were conducted by a PhD-trained female research coordinator with extensive experience in qualitative methods (M.B.S.). The interviewer had no prior relationship with the study participants. Our team developed an interview guide focused on 3 domains: recent experiences accessing health care for SARS-CoV-2 testing and follow up, impact of the condition, and additional questions and knowledge needs (Appendix 1, available at www.cmajopen.ca/content/11/6/E1041/suppl/DC1). To facilitate the generation of participant-led accounts, the selection of follow-up probing questions, question order and phrasing of the questions varied according to each patient's narrative as in standard practice in qualitative interviews.

The interviews were conducted by telephone, digitally recorded and transcribed verbatim by an external transcription service. We continued to conduct interviews until our research team determined through discussion, review and comparison of the transcripts that we had reached the point of thematic saturation and assessed no further insights would be gleaned from interviewing additional patients.^{9,10}

Data analysis

We used an iterative approach, conducting the interviews while concurrently performing a phenomenologically informed thematic analysis of the data.¹¹ Team members K.N.D. and M.B.S. reviewed and coded the interview transcripts independently, compared the codes to develop a final coding scheme, and then analyzed the data according to standard thematic analysis techniques.¹² We attached descriptive emergent codes to segments of the text in each transcript and grouped the codes into broad topic-oriented categories that reflected overarching subthemes, and then compared all text segments that belonged in the same category. Subthemes that express similar experiential patterns were brought together to develop core themes and build the narrative of the analysis.

Trustworthiness is an important aspect in qualitative research, particularly during thematic analysis. Trustworthiness refers to the rigour of the study and the degree of confidence readers can have in the data and interpretations. Lincoln and Guba outlined 4 criteria for trustworthiness that have been widely accepted.¹³ These include credibility, confirmability, dependability and transferability.¹³ Throughout the analysis process, our team kept reflective research journals to document and “bracket” our personal ideas,

experiences and scientific beliefs about COVID-19 to carefully and consciously separate these from our developing understanding of how patients perceived and experienced health care after a positive diagnosis.¹⁴ The research team met regularly to discuss the coherence of our interpretations, and we kept an audit trail of our discussions and analytic decisions. Finally, we constantly returned to the transcripts to ensure our interpretations were grounded in the data until we reached consensus on the validity and applicability of the final analytic framework.

Ethics approval

This study was approved by the North York General Hospital Research Ethics Board (REB no. 20-0027).

Results

Between July and December 2020, we conducted interviews with 26 patients who were followed by the North York General Hospital COVID Follow Up Clinic. Demographic information about the participants is included in Table 1. The interviews were on average 40 minutes in length (range 20–50 min).

In accordance with our phenomenological informed approach, the interviews were semistructured to support participant-led accounts of their experiences. As such, our interview guide included questions to understand the communication and interaction with physicians around participants' COVID-19 symptoms; however, the participants frequently directed the conversation to talk about their experience of receiving the positive diagnosis at home and the subsequent isolation period. Our analysis was grounded in the data, and 3 major themes emerged regarding participants' overall experience from receiving a positive diagnosis after testing to the end of their quarantine period: lack of adequate communication, inconsistency of information from various sources, and the social implications of a COVID-19 diagnosis. Exemplar quotations from the interview data that support each theme are provided in Box 1.

The process of testing and follow-up

Participants had been to the emergency department or COVID-19 assessment centre for either asymptomatic testing after exposure or symptomatic testing owing to mild COVID-19-related symptoms. Almost all found out the results of their tests through an online portal; a few received their results in the first instance via a telephone call from the COVID Follow Up Clinic physician. Many were surprised by their positive test and found the process of waiting at home in isolation and repeatedly checking online until the test results became available after 24–72 hours to be stressful. Once they found out about their positive diagnosis, they were immediately concerned about who they may have exposed before testing.

Communication challenges

As COVID-19 was a new illness with so many unknowns, participants expressed several concerns and feelings of anxiety about their positive diagnosis. Several interviewees emphasized

Table 1: Study participant demographic characteristics

Characteristic	No. (%) of participants <i>n</i> = 26
Gender	
Female	18 (69)
Male	8 (31)
Age range, yr	
20–39	13 (50)
40–59	5 (19)
≥ 60	4 (15)
Information not provided	4 (15)
Marital/partner status	
Married/partnered	9 (35)
Single	11 (42)
Information not provided	6 (23)
Living arrangement	
Lives alone	3 (11)
Lives with someone else	16 (62)
Information not provided	7 (27)
Time between testing/symptom onset and interview, range, wk	
3–4	15 (58)
5–8	11 (42)
Self-reported perceived severity of disease	
Asymptomatic	2 (8)
Mild	11 (42)
Moderate	12 (46)
Information not provided	1 (4)

that while they received multiple telephone calls from different agents of their local public health units, these calls provided neither reassurance nor answers to the questions they had. The participants explained that the timing of these calls was sporadic, the calls were frequently received at the beginning of their illness when the participants were feeling unwell or were otherwise occupied, and the agents generally declined to share (or lacked) medical expertise.

Several participants found that they did not have many questions at the start of their quarantine period, which is when they were contacted by a COVID Follow Up Clinic physician. However, participants often developed questions further into their self-isolation period but had not been provided with any information about where and how to follow up. This was further complicated as the COVID Follow Up Clinic physician often represented the only primary care doctor who proactively contacted them during their quarantine.

Many of the participants also highlighted very similar questions that they did not get answers for, despite the numerous telephone calls they received following their positive diagnosis.

Box 1: Exemplar quotations from the data

The process of testing and follow-up

- “That day [after testing] I came back home and I just kind of waited it out. And then the next day I was like, you know, constantly checking my results. I think it was the next day that I got my results. And once I had my results, then I had to inform all of my relatives that I had come into contact with; my brother, my sister, everyone that I came in contact with, I had to inform them.” [P2]

Communication challenges

- “And it’s a nurse that’s calling me, but there’s a script. There’s a standardized procedure for them to follow Because you’re basically reading off a specific set of questions to an individual to try to find out stuff. And there’s like an FAQ, but for whoever is sick, we’re only going to have so many questions at the time” [P9]
- “What I would have found helpful would have been, and maybe still, a number I could Well, I mean, again, I guess its Telehealth. I could have phoned Telehealth ... but I might have found it helpful if there had been a specific number I could have called to ask more questions.” [P11]
- “No one can give me any answers. I’ve been told I’m not contagious anymore, but will I ever test negative again? I still feel very tired and weak and am scared to death to be around my grandchildren. Should I even tell people I had COVID, like if I have to go for a dentist appointment? Do I need to show them a negative test? No one can give me answers to these questions. I feel like nobody really knows what’s going on with this and I don’t know who else to ask to try to get answers.” [P26]

Inconsistency of information

- “From their first phone — Ontario’s first phone call and then these guys [referring to the hospital physicians] and then the York Region first phone call. They weren’t on the same page ... that never got resolved, so every day I was getting 2 different dates that I would be finished. I kind of explained to — not “kind of” but I fully explained to both of them what was going on. Every time they said either they would talk to their supervisor or review it. Something. Then, after 5, 6 days, they said, ‘Maybe the systems aren’t updated.’” [P15]
- “I got a lot of calls from — I don’t know, from a health agency, I think in the area I live in. They tried to find out who I was in contact with, what I was doing. And I got — one letter was deposited in front of my door about the quarantine, and then I got 2 letters, one that told me my quarantine was over such and such date, and then I got another letter that told me my quarantine was over 2 days later. I got the letters really late. It was kind of confusing.” [P18]
- “I feel like a lot of information are kind of — like the information I give is kind of, I have to repeat myself a lot, I guess, because who handles what is not connected. So, I have to give a lot, like, oh, when did I get exposed? How did I get exposed and what was the situation? I had to repeat that a lot I sort of thought that, like, everything was connected and, yeah. So, I thought like, why do I have to give this information again?” [P1]

Social implications of a COVID-19 diagnosis

- “Some people know that I’ve had COVID, and other people don’t know. I’m careful. I just say I haven’t been feeling well. But most people are pretty good about it. They’ve been kind. I’ve had one incident of, really, elder abuse I had to report to the police, a neighbour. And I had to block their number, and there’s a police record on it. Somebody harassing me and, “Why didn’t you get tested earlier?” This type of thing. That’s what I don’t need.” [P11]
- “The phone call from [the doctor] gave me peace of mind because it’s not like you’ll get sick and just tell everybody, right? It’s like, kind of like a stigma, right? People get scared. So it was, like, peace of mind. Imagine, I didn’t have anyone to talk to about this, but now it sounded like [the doctor] was going to help me.” [P3]
- “I think that’s pretty important for, not so myself, but for other people. If, you know, my symptoms were, for myself, like I said, not too concerning, but I would think that if somebody else was in my position, they might appreciate a follow-up call especially if they didn’t know their symptoms were going to get worse and they did get worse, if that makes sense.” [P16]

The information provided to participants was largely general knowledge about symptom and quarantine management. Study participants discussed that physicians from the COVID Follow Up Clinic and the agents from local public health units were unable to answer more specific questions they had, including why they had contracted SARS-CoV-2 and other close contacts had not, how long the virus would remain in their system and details about their immunity to SARS-CoV-2 postquarantine. The lack of specific information available from the COVID Follow Up Clinic physicians and public health professionals further contributed to participants’ confusion and persistent anxiety about COVID-19, even after recovering from the illness. Participants’ preferred timing of a physician-based follow-up phone call was toward the end of patients’ quarantine period once they have had time to formulate their thoughts and potential questions.

Inconsistency of information

Despite contact with several different public health professionals and also a physician from the COVID Follow Up Clinic following positive diagnosis, a lack of consistent information was highlighted as another frustration by the interview participants. This was exemplified predominantly by patients who received conflicting information regarding the length of their self-isolation period. Often, different ranges of time were provided by the physician from the COVID Follow Up Clinic and the first agents from the local public health unit they spoke with, as well as by different agents within the public health units that they received subsequent calls from. Owing to a lack of consensus around the length of their self-isolation period, patients tended to take it upon themselves to extend their own quarantine “just to be on the safe side,” despite any personal inconvenience or family hardship this caused.

The inconsistency of information was further described by participants as challenges related to sufficient recordkeeping from the local public health units. Many participants shared that they received several calls from their local public health unit during the quarantine period, but each agent lacked prior knowledge of their specific case and previous conversations with other agents. As such, different agents asked many of the same questions during each conversation, seemingly with no context or knowledge of information shared by the patient in previous calls. This made it even more complicated to resolve issues related to the self-isolation period, because the agent who committed to reviewing their case or discussing it with their supervisor would not be the same agent making subsequent follow-up phone calls.

Social implications of a COVID-19 diagnosis

Participants shared concerns about stigma associated with a positive result. This was rarely dealt with explicitly in the follow-up conversations with health care and public health professionals but came up frequently in the interviews. Participants were highly conscious of with whom they shared their positive diagnosis owing to the perception of negative attitudes and behaviours from others.

For this reason, participants appreciated having a physician from the COVID Follow Up Clinic check in on them post-diagnosis to offer advice, resources and a listening ear. Many expressed that this check-in was a beneficial experience, whether in alleviating concerns, improving their state of mind or addressing their sense of isolation.

During the interviews, participants also took steps to distance themselves from the illness owing to its potential social implications. This frequently took the form of minimizing their overall need for support, despite noting how helpful they had found the physician telephone call and describing persistent anxiety, lingering symptoms, remaining unanswered questions and feelings of social isolation related to the positive diagnosis. Participants typically highlighted the need for and value of more physician-led follow-up for “other” COVID-19 patients in similar situations to their own but declined it for themselves. For example, when asked if the number of telephone calls they received from health care professionals was adequate, participants’ answers tended to follow a similar formula of “this many calls were adequate for me, but other patients like me might have wanted more physician check-ins.”

Lastly, a primary concern of many participants was the possibility of having contracted SARS-CoV-2 during their visit to the emergency department or COVID-19 assessment centre for testing. More specifically, participants feared that waiting in line may have caused them to contract SARS-CoV-2 when they may not have actually had the illness before their arrival. This is despite the fact that their visit to the emergency department or COVID-19 assessment centre was prompted by other known exposure or the experience of mild COVID-19-related symptoms. Participants consistently expressed confusion and concern about how they could possibly have contracted SARS-CoV-2 and whether they had spread it to others before and after going for testing.

Interpretation

In this study of patients who tested positive for SARS-CoV-2 infection and were sent home to self-isolate, we found that patients experienced considerable challenges once they were given a positive test result, even when symptoms were relatively mild and patients simply had to self-isolate as required. Participants described persistent anxiety, lingering symptoms, many unanswered questions and feelings of social stigma related to the positive diagnosis, both during the quarantine period and afterward. Their experiences of “going home positive” were characterized by communication challenges related to the timing and focus of telephone calls received from the COVID Follow Up Clinic and other public health professionals, inconsistent information received about their quarantine period and public health policies, and social isolation owing to the perceived stigma of COVID-19. Ensuring that previously collected data are available to public health professionals following up with people would be highly beneficial for ensuring that the guidance provided is as consistent as possible. Participants highlighted the value of physician-based follow-up telephone calls for patients after diagnosis to offer advice, resources and a listening ear, but they would have preferred these calls toward the end of the quarantine period once they had time to gather their thoughts about potential questions. There was also a strong desire among participants for more coordination between the various health authorities so that they did not have to figure out who to follow.

Although communication challenges and ever-changing information is expected during a pandemic, this work brings to light the impact that anxiety and uncertainty have on patients and families. There have been several qualitative studies published on the experience of COVID-19 patients, some in specific populations and most of which have focused on hospitalized patients.^{16–21} Many reports discuss similar findings to those in our study,^{18,19} including touching on the emotional and mental state of patients as they received their diagnosis, the repercussions and their experience of care once diagnosed. However, data have been lacking on patients with COVID-19 in Canada who did not require hospitalization after a self-initiated test. Perceptions, stigma and knowledge about COVID-19 are certainly evolving with time; however, many of the challenging structures and communication gaps discussed in this paper still exist. The impact of stigma regarding a communicable disease should not be readily dismissed, as it can have an important impact on patient’s willingness to report symptoms, seek care or receive vaccinations.²² This seems especially important as other communicable illnesses such as mpox (formerly known as monkeypox) become more prevalent.

This study was conducted in the middle of the second wave of the COVID-19 pandemic, between July and December of 2020. In a pandemic, it is likely that there will always be patients with mild to moderate symptoms; this has been seen in waves related to the Omicron variant (in 2022) and others. The needs of people who test positive, in the

current pandemic and in future pandemics, and have to manage and quarantine at home are likely not different from the needs of our participants. Our clinical experience indicates that, even now, many patients still do not understand the testing or quarantining requirements. This is especially crucial as eligible patients often miss the window for outpatient therapy with remdesivir or nirmatrelvir-ritonavir. Understanding their experience and needs will be crucial to providing equitable and safe care and supportive public health policy. In our jurisdiction, and likely many others, coordination between hospital, city and provincial health units to unify the approach to providing consistent guidelines to patient questions is severely lacking. Although scientific information about COVID-19 continues to evolve, many of the questions our 2020 participants had still exist and the pathways to having them answered have not necessarily improved. Further research into how best to support this group and co-designing interventions to meet those needs are important next steps for this area of research.

Limitations

This study was conducted in a single community health care centre in Ontario, Canada. Nevertheless, we believe we had reasonable variability in the demographic characteristics of the participants and that North York General Hospital represents a fairly typical community hospital setting.

Some volunteer bias is inevitable in this type of qualitative study; those who did not participate may have had a systematically different experience from those who participated in some way. To minimize the impact of this, we employed rigorous qualitative methods, invited all patients who were seen in the COVID Follow-up Clinic to participate and interviewed until we felt thematic saturation had been reached. The follow-up calls conducted by the COVID Follow up Clinic were conducted in English, and we were able to conduct the interviews only in English owing to resource issues, so we cannot account for the experiences of patients who could not communicate in English.

In addition, because potential participants were told about the study by health care workers who spoke to them at the COVID Follow-up Clinic, there is potential for social desirability bias in our sample. Although this may have affected the patient's initial agreement to be contacted about the study, it was made clear that the treating providers would have no idea whether they ended up participating in the study, and therefore, we feel confident that only those who wanted to participate followed through with the interview.

We do not have complete demographic information for all participants. We endeavoured to complete as much of this as possible from the transcript data; however, some variables could not be collected from the participants within the interview (e.g., marital status).

Conclusion

Testing positive and experiencing care during self-isolation at home is becoming more common as the COVID-19 pandemic evolves. In our study of patients sent home from hospital with a

positive COVID-19 diagnosis, participants shared their experiences of the stigma of testing positive and the frustration of poor communication structures and inconsistent information. The needs articulated by this unique population are still relevant today and are applicable to the design of support interventions to ensure access to equitable and patient-centred care during current and future pandemic situations.

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obtained research ethics approval and performed data collection. All of the authors contributed to the analysis and interpretation of the data. Katie Dainty, M. Bianca Seaton, Braden O'Neill and Rohit Mohindra drafted the manuscript, and all authors contributed substantially to its revision, gave final approval of the version to be published and agreed to be accountable for all aspects of the work.

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Data sharing: Because of the confidential nature of qualitative interviews, the data are not available for sharing.

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