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3 **Going Home Positive: A qualitative study of the experiences of care for COVID positive**
4 **patients who are not hospitalized**
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6
7 **ABSTRACT (216 words)**
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9 **Background:** More than 3.0 million Canadians have been diagnosed with COVID-19. Most
10 patients with COVID-19 have had mild symptoms that do not require hospitalization. We sought
11 to understand the patient experience of care while being isolated at home after testing positive
12 for the COVID-19 virus.
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15 **Methods:** We conducted a phenomenologically informed qualitative descriptive study using in-
16 depth semi-structured interviews to identify common themes of experience for patients sent
17 home from hospital with a positive COVID-19 diagnosis. Between July and December 2020, we
18 conducted interviews with 26 patients who were followed by the XXXS COVID Follow-Up Clinic.
19 Patients with mild-moderate symptoms were interviewed 4 weeks after their COVID diagnosis,
20 we conducted the interviews and performed a thematic analysis of the data concurrently, in
21 keeping with the iterative process of qualitative methodology.
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25 **Results:** From our analysis, three themes were developed regarding participants' overall
26 experience: lack of adequate communication, inconsistency of information from various sources,
27 and the social implications of COVID-19 diagnosis. The implications of a positive COVID test are
28 substantial, even when symptoms are non-existent or mild and patients self-isolate as
29 recommended. Participants noted communication challenges and inconsistent information
30 leading to exacerbated stress.
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34 **Interpretation:** Experiencing care during self-isolation at home is an area of increasing
35 importance. These findings can inform improved support, ensuring access to equitable and safe
36 COVID-19 care for these patients.
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Going Home Positive: A qualitative study of the experiences of care for COVID positive patients who are not hospitalized

Introduction

More than 3.0 million Canadians have been diagnosed with COVID-19 since the onset of the pandemic in March 2020 [1]. Most patients with COVID-19 have mild to moderate disease that does not require hospitalization [2] although severe symptoms and death can occur.

In Ontario, patients presenting to the emergency department (ED) 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, manage symptoms, and indications to seek further medical care. Patients with positive polymerase chain reaction (PCR) testing for SARS-CoV-2 are then contacted by local public health units to discuss their symptoms, recent contacts, and develop a quarantine plan. To provide additional support for patients seen in the ED or COVID Assessment Centre who tested positive for SARS-CoV-2, or for whom the clinical team felt there was a need for close follow-up during assessment, XXXX Hospital implemented a primary care physician-led virtual call-back clinic system (known as the COVID Follow Up Clinic).

To date there has been significant focus in the scientific literature on severe illness and long COVID syndrome. However, given that most people do not experience severe illness and the increasing likelihood that COVID will transition to an endemic disease [3], it is important to understand the mild or asymptomatic patient experience of isolating at home after testing positive and the perceived value of virtual follow-up systems. Further waves of the pandemic are inevitable and improvements in the design of follow-up systems to better meet the needs of the full spectrum of patients will be beneficial.

Methods

Study design

We conducted a phenomenologically informed qualitative descriptive study using in-depth semi-structured interviews to identify common themes of experience for patients sent home from hospital with a positive COVID-19 diagnosis. Phenomenological research attempts to understand the lifeworld of people from their perspective as “insiders” who perceive, derive meaning, and form understandings of particular phenomena. [4] This approach seeks to generate in-depth knowledge of what is it like to experience a particular thing or situation by focusing on the aspects that are most salient and significant to those who have lived through/with it. [5] It is a useful approach for health-related quality of life research and supported our goal of understanding relevant experiences and perceptions expressed by patients accessing healthcare in this unique pandemic situation.

Setting and sample

This study was conducted at and approved by the research ethics board of XXXX (REB# 20-0027). We used purposive sampling to recruit adult patients who had come to the ED or COVID assessment centre at the hospital, been sent home and subsequently received a positive diagnosis, and then received a follow up phone call from a family physician with the hospital's

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3 COVID Follow Up Clinic. These participants all also received calls from local public health
4 organizations, whose activities were independent of the COVID Follow Up Clinic. Eligible patients
5 were identified by the primary care physician working at the COVID Follow Up Clinic and provided
6 consent to be contacted by our research team to learn more about the study. Patients who
7 subsequently agreed to participate in this research were given an opportunity to review the letter
8 of information and consent form, ask questions, and provide verbal consent prior to starting the
9 interviews.
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12 13 Data collection

14 Data for this study were collected between July and December of 2020. Interviews were
15 conducted by a PhD trained, female, research coordinator with extensive experience in
16 qualitative methods (MBS). The interviewer had no prior relationship with the study participants.
17 Our team developed an interview guide focused on three domains: recent experiences accessing
18 healthcare for COVID testing and follow up, impact of the condition, and additional
19 questions/knowledge needs (see Appendix A). To facilitate the generation of participant-led
20 accounts, the selection of follow-up probing questions, question order, and phrasing of the
21 questions varied according to each patient's narrative.
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24 The interviews were approximately 40 minutes in length (range 20-50 minutes) and were
25 conducted by telephone, digitally recorded, and transcribed verbatim by an external
26 transcription service. We continued to conduct interviews until our research team determined
27 through discussion, review, and comparison of the transcripts that we had reached the point of
28 thematic saturation and assessed no further insights would be gleaned from interviewing
29 additional patients.[6,7]
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32 33 Data analysis

34 We used an iterative approach, conducting the interviews while concurrently performing
35 a phenomenologically-informed thematic analysis of the data. [8] Team members KND, MBS, and
36 SC reviewed and coded the interview transcripts independently, compared the codes to develop
37 a final coding scheme, and then analyzed the data according to standard thematic analysis
38 techniques. [9] We attached descriptive emergent codes to segments of the text in each
39 transcript, then grouped the codes into broad topic-oriented categories that reflected
40 overarching subthemes, and then all text segments that belonged in the same category were
41 compared. Subthemes that express similar experiential patterns were brought together to
42 develop core themes and build the narrative of the analysis.
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45 Throughout the analysis process, our team kept reflective research journals to document
46 and "bracket" our personal ideas, experiences, and scientific beliefs about COVID-19 to carefully
47 and consciously separate these from our developing understanding of how patients perceived
48 and experienced healthcare after a positive diagnosis [10]. The research team met regularly to
49 discuss the coherence of our interpretations and we kept an audit trail of our discussions and
50 analytic decisions. Finally, we constantly returned to the transcripts to ensure our interpretations
51 were grounded in the data until we reached consensus on the validity and applicability of the
52 final analytic framework.
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Results

Between July and December 2020, we conducted interviews with 26 patients who were followed by the XXXS COVID Follow Up Clinic. The patients were interviewed approximately 4 weeks after their COVID-19 diagnosis, and all had mild to moderate symptoms of the disease. More detailed demographic information about the participants is included in Table 1.

From our analysis, three 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 COVID-19 diagnosis. Exemplar quotes from the interview data that support each theme are provided in Table 2.

The Process of Testing and Follow-up

Participants had been to the ED or COVID assessment centre for either asymptomatic testing after exposure, or symptomatic testing due to mild COVID-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 phone 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 prior to testing.

Communication Challenges

As a new illness with so many unknowns, participants expressed several concerns and feelings of anxiety about their positive COVID-19 diagnosis. Several interviewees emphasized that while they received multiple phone 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, 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. 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 COVID-19 and other close contacts had not, how long the virus would remain in their system, and details about their immunity to COVID post-quarantine. The lack of specific information available from the COVID Follow Up Clinic physicians and public health professionals further contributed to participants'

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3 confusion and persistent anxiety about COVID-19, even after recovering from the illness.
4 Participants' preferred timing of a physician-based follow-up phone call was towards the end of
5 patients' quarantine period once they have had time to formulate their thoughts and potential
6 questions.
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8 9 ***Inconsistency of Information***

10 Despite contact with several different public health professionals and also a physician
11 from the COVID Follow Up Clinic following positive diagnosis, a lack of consistent information was
12 highlighted as another frustration by the interview participants. This was exemplified
13 predominantly by patients who received conflicting information regarding the length of their self-
14 isolation period. Often, different ranges of time were provided by the physician from the COVID
15 Follow Up Clinic and the first agents from the local public health unit that they spoke with, as
16 well as by different agents within the public health units that they received subsequent calls from.
17 Due to a lack of consensus around the length of their self-isolation period, patients tended to
18 take it upon themselves to extend their own quarantine just to be on the safe side, despite any
19 personal inconvenience or family hardship that this caused.
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21 The inconsistency of information was further described by participants as challenges
22 related to sufficient recordkeeping from the local public health units. Many participants shared
23 that they received several calls from their local public health unit during the quarantine period,
24 but each agent lacked prior knowledge of their specific case and previous conversations with
25 other agents. As such, different agents asked many of the same questions during each
26 conversation, seemingly with no context or knowledge of information shared by the patient in
27 previous calls. This made it even more complicated to resolve issues related to the self-isolation
28 period, because the agent who committed to reviewing their case or discussing it with their
29 supervisor would not be the same agent making subsequent follow up phone calls.
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34 35 ***Social implications of COVID-19 diagnosis***

36 Participants shared concerns about stigma associated with a positive result. This was
37 rarely delt with explicitly in the follow-up conversations with healthcare and public health
38 professionals but came up frequently in the interviews. Participants were highly conscious of
39 with whom they shared their positive diagnosis due to the perception of negative attitudes and
40 behaviours from others. In some instances, participants dealt with the stigma directly.
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42 For this reason, participants appreciated having a physician from the COVID Follow Up
43 Clinic check in on them post-diagnosis to offer advice, resources, and a listening ear. Many
44 expressed that this check-in was a beneficial experience, whether in alleviating concerns,
45 improving their state of mind, or addressing their sense of isolation.
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47 During the interviews, participants also took steps to distance themselves from the illness
48 due to its potential social implications. This frequently took the form of minimizing their overall
49 need for support, despite noting how helpful they had found the physician phone call and
50 describing persistent anxiety, lingering symptoms, remaining unanswered questions, and feelings
51 of social isolation related to the positive diagnosis. Participants typically highlighted the need for
52 and value of more physician-led follow up for "other" COVID patients in similar situations to their
53 own, but declined it for themselves. For example, when asked if the number of phone calls they
54 received from healthcare professionals were adequate, participants' answers tended to follow a
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3 similar formula of ‘this many calls were adequate for me, but other patients like me might have
4 wanted more physician check-ins.’
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6 Lastly, a primary concern of many participants was the possibility of having contracted
7 COVID-19 during their visit to the ED or COVID assessment centre for testing. More specifically,
8 participants feared that waiting in line may have caused them to contract COVID-19 when they
9 may not have actually had the illness prior to their arrival. This is despite the fact that their visit
10 to the ED or COVID assessment centre was prompted by other known exposure or the experience
11 of mild COVID-related symptoms. Participants consistently expressed confusion and concern
12 about how they could possibly have contracted COVID and whether they had spread it to others
13 before and after going for testing.
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16 **Interpretation**

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18 Our study of COVID-positive patients who were sent home to self-isolate found
19 substantial implications of a positive COVID test, even when symptoms are non-existent or
20 relatively mild and patients simply had to self-isolate as required. Participants described
21 persistent anxiety, lingering symptoms, remaining unanswered questions, and feelings of social
22 isolation related to the positive diagnosis, both during the quarantine period and afterwards.
23 Their experiences of ‘going home positive’ were characterized by communication challenges
24 related to the timing and focus of phone calls received from the COVID-19 Follow Up Clinic and
25 public health professionals, inconsistent information received about their quarantine period
26 during these calls, and social isolation due to the perceived stigma of COVID-19. Ensuring that
27 already-collected data are available to public health professionals following up with people
28 would be highly beneficial for ensuring that the guidance provided is as consistent as possible.
29 Participants highlighted the value of physician-based follow-up phone calls for patients like
30 themselves post-diagnosis to offer advice, resources, and a listening ear, but they would have
31 preferred these calls towards the end of the quarantine period once they had time to formulate
32 potential questions.
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36 While communication challenges and ever-changing information may be expected during
37 a pandemic, this work brings to light the impact anxiety and uncertainty have on patients and
38 families. There was a strong desire among participants for more coordination between the
39 various health authorities so that they did not have to figure out who to follow. There have been
40 several qualitative studies published on the experience of COVID-19 patients, some in specific
41 populations and most of which have focused on hospitalized patients.[11-15] Many reports
42 discuss similar findings to those in our study (Aliyu, Roberts, etc) including touching on the
43 emotional and mental state of patients as they received their diagnosis and pondered its
44 repercussions and their experience of care once diagnosed. [12,14] However, our study is the
45 first to look at COVID positive patients in Canada who did not require hospitalization after a self-
46 initiated test.
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50 This study was conducted in the middle of the second wave of the COVID-19 pandemic,
51 between July and December of 2020. As the pandemic continues, it is likely that there will be
52 more patients with mild to moderate symptoms; this pattern has been seen in the current wave
53 related to the Omicron variant. [1] Understanding their experience and needs will be crucial to
54 providing equitable and safe care. While scientific information about COVID continues to evolve,
55 many of the questions our participants had still exist and the pathways to having them answered
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3 have not necessarily improved. Further research into how best to support this group and co-
4 designing interventions to meet those needs are important next steps for this area of research.

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6 **Limitations**

7 This study was conducted in a single community health care centre in Ontario, Canada.
8 That said, we do feel that we had reasonable variability in the demographics of the participants
9 and that XXX represents a fairly typical community hospital setting.

10 Some volunteer bias is inevitable in this type of qualitative study; those who did not
11 participate may have had a systematically different experience from those that participated in
12 some way. To minimize the impact of this we employed rigorous qualitative methods, invited all
13 patients who were seen in the COVID Follow-up Clinic to participate and interviewed until we felt
14 thematic saturation had been reached.

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16 Finally, perceptions, stigma, and knowledge about COVID is definitely evolving with time
17 however many of the challenging structures and communication gaps discussed in this paper still
18 exist.
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22 **Conclusion**

23 Testing positive and experiencing care during self-isolation at home is becoming more
24 common as the COVID-19 pandemic evolves. Our participants shared their experiences of the
25 stigma of testing positive and the frustration of poor communication structures and inconsistent
26 information. By understanding the experience of needs of this patient population, we can better
27 design support interventions to ensure access to equitable and patient-centred care for
28 everyone.
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Table 1
Study Participant Demographics

Participant	Gender (M/F)	Age Range (Years)	Marital/Partner Status	Time Since COVID onset	Perceived severity of disease
P1	M	Unknown	Unknown	3 weeks	Mild
P2	F	20-30	Unknown	3 weeks	Mild
P3	F	Unknown	M/P	3 weeks	Moderate
P4	M	70+	M/P	N/A	Asymptomatic
P5	M	20-30	S	4 weeks	Mild
P6	F	20-30	Unknown	N/A	Asymptomatic
P7	F	20-30	S	4 weeks	Mild
P8	M	Unknown	Unknown	3 weeks	Mild
P9	M	30-40	S	3 weeks	Moderate
P10	F	40-50	M/P	6 weeks	Moderate
P11	F	70+	S	3 weeks	Moderate
P12	F	20-30	S	5 weeks	Moderate
P13	F	40-50	Unknown	4 weeks	Mild
P14	F	70+	S	6 weeks	Moderate
P15	M	30-40	M/P	3 weeks	Mild
P16	F	30-40	M/P	5 weeks	Mild
P17	F	40-50	S	5 weeks	Moderate
P18	F	Unknown	Unknown	4 weeks	Moderate
P19	M	30-40	M/P	4 weeks	Mild
P20	F	50-60	M/P	6 weeks	Moderate
P21	F	Unknown	Unknown	Unknown	Unknown
P22	F	Unknown	M/P	8 weeks	Moderate
P23	M	Unknown	Unknown	8 weeks	Moderate
P24	F	Unknown	Unknown	8 weeks	Mild
P25	F	20-30	Unknown	8 weeks	Mild
P26	F	60-70	M/P	4 weeks	Moderate

TABLE 2
Exemplar Quotes from the Data

<p><i>The Process of Testing and Follow-up</i></p>
<p><i>“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]</i></p>
<p><i>Communication Challenges</i></p>
<p><i>“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]</i></p>
<p><i>“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]</i></p>
<p><i>“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]</i></p>
<p><i>Inconsistency of Information</i></p>
<p><i>“From their first phone – Ontario’s first phone call and then these guys [referring to the XXX 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 two 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 five, six days, they said, ‘Maybe the systems aren’t updated.’” [P15]</i></p>
<p><i>“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</i></p>

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letter was deposited in front of my door about the quarantine, and then I got two 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 two 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 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 neighbor. 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]