Navigating the health system during COVID-19: primary care perspectives on delayed patient care

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ABSTRACT

AIM: The primary care response to the coronavirus disease 2019 (COVID-19) pandemic has required significant changes to the delivery of healthcare by general practices. This study explores the experiences of New Zealand general practice teams in their perception of delayed patient care during the early stages of the pandemic.

METHOD: We qualitatively analysed a subtheme of delayed patient care of the General Practice Pandemic Experience New Zealand study, where general practice team members nationwide were invited to participate in five surveys between May and August 2020.

RESULTS: 164 participants initially enrolled in the study, with 78 (48%) completing all surveys. Four delayed-care themes were identified: patient contributors, health system contributors, impacts and opportunities for minimisation. Respondents noted that patients avoided healthcare, downplayed symptoms and feared going out. Non-essential care was put on hold, allied services were reduced and access to secondary care was variable. Certain diseases and screening were commonly impacted. As lockdown lifted a backlog of work resulted. Flexible review periods, outreach care, self-screening, cross-sector collaboration and improved public awareness were strategies for timely healthcare.

CONCLUSION: Reducing barriers to patients seeking care and improving integration and relationships across the health system would minimise future pandemic disruption and delayed patient healthcare.

The coronavirus disease 2019 (COVID-19) pandemic brought about sudden changes in the delivery of healthcare throughout Aotearoa New Zealand. In response to level 4 "lockdown" from 25th March 2020,[1] all areas of the health sector made changes to prepare for a potential influx of unwell COVID-19 patients, as had been seen overseas.

In primary care, non-urgent healthcare (such as screening) was discouraged, telehealth consultations were encouraged[2] and patients were screened and streamed for respiratory illnesses. In secondary (hospital-based) healthcare, the National Hospital Response Framework[3] was implemented, with routine outpatient appointments cancelled or moved to telehealth where possible. Elective surgery was cancelled, and in some districts, non-urgent referrals were declined or discouraged.[4,5]

Some New Zealand research is emerging on the impact of these changes on timely patient care. A New Zealand patient experience study over the early pandemic lockdown period found a majority had delayed seeking healthcare during this time. Many non-urgent problems were dealt with by observation and self-care.[6]

New Zealand Ministry of Health data show a reduction in both planned and unplanned care at primary and secondary levels. Hospital inpatient treatment reduced the most, by 63.8% in April 2020 when compared with April 2019.[7] Research in both Australia and New Zealand suggests that delays in diagnosis and management contributed to this decrease in primary and secondary healthcare activity.[8,9,10] However, conversely, decreases in overall healthcare activity, particularly in primary care, may also result in delayed diagnosis and

management. People living more sedentary lifestyles because of lockdown may have also contributed to the way symptoms were experienced for some heart conditions.[9] In New Zealand, ambulance services reported lower acuity calls and increasing mental health issues, suggesting there was a reduction in access to primary care.[11]

Internationally, there has been growing concern over "collateral consequences" of COVID-19 lockdowns diverting attention away from management of long-term conditions.[12] A UK study in a large, deprived population has retrospectively shown a reduction of 40–50% in first diagnosis of common primary care conditions from March to May 2020, with concern that some of this represents undiagnosed conditions.[13] With reduced screening and non-urgent diagnostic services in the UK's relatively prolonged lockdown, modelling has predicted a large increase in avoidable cancer deaths.[14]

As a patient navigates the health system, multiple factors can contribute to delaying their care. These have been modelled in pre-pandemic settings as patient, provider/system and disease factors.[15]

We present the first qualitative analysis of the experience of large group of New Zealand primary healthcare professionals on their perception of delayed patient care during the early COVID-19 pandemic.

Methods

This paper is part of the previously described General Practice Pandemic Experience New Zealand (GPPENZ) study, which followed the same group of primary care healthcare team members through a series of five online surveys over a 16-week period from 8 May 2020.[16] The participants included general practitioners (GP), nurse practitioners (NP), practice nurses (N) and practice managers (P), with a small number of dual-role practice managers and nurses (PMN). Invitations were distributed widely through national medical and nursing organisations, local and regional networks and social media. Specific platforms for Māori, Pacific and rural members of the health workforce were included.

The five surveys sought basic demographic information and asked open-ended questions allowing for free-text responses to a range of specific prompts. These included changes to the delivery of patient care, challenges and solutions, personal and professional experiences of the pandemic setting and opportunities for the future. Excerpts from survey responses are identified by the discipline of the respondent and an index number (eg, "GP80" is the eightieth general practitioner).

A team of researchers analysed the data using simple descriptive statistics and, for the open-text data, a thematic analysis within a constant comparative approach,[17] also drawing on ideas from the Andersen Model of Total Patient Delay as represented in a Model of Pathways to Treatment by Walter et al 2012.[15] A codebook was developed.[16] For this paper, content on the themes of delayed care, harms and secondary care interface was coded by ZW and GW using Nvivo software[18] (with each author peer-reviewing the other's coding). The primary analysis for this paper consisted of questions related to delayed care, management of conditions not related to COVID-19, harms and support for Māori, Pasifika and high-health-needs groups. Further secondary analysis was performed where delayed care was coded in more general survey questions (eg, from survey one: "What challenges have you experienced over this time?"). A thematic content analysis was conducted drawing from relevant codes, within a framework developed by SB, GW and ZW, and then circulated for review by all authors.

Ethical approval was obtained from The University of Otago Human Ethics Committee (reference number: D10/114).

Results

The threat of COVID-19 infection, combined with patient and health system factors, were raised as elements that contributed to delayed patient care in the early pandemic period covered by the surveys. Further themes emerged on the impact of delayed care and opportunities for the future to avoid delayed care.

Patient contributors to delayed care

There was widespread concern from respondents that their usual patient group was not seeking care in the normal way. Some reported a dramatic decline in

workload, attributed to patients mistakenly believing that medical services were overwhelmed and avoiding adding to the load. Respondents commented that patients appeared to be minimising or tolerating their symptoms, considering them too minor to justify seeking care in this period:

> *"Impression is that patients are likely delaying seeing the GP for health matters as not wanting to bother the doctor or not seeing their needs as important." – GP86*

> *"Rightly (in some situations) or wrongly (in other situations), assumed their questions were insignificant." – N7*

Respondents reported that many patients combined this with a fear of being unsafe if they ventured out, and that patients were reluctant to expose themselves to infection risk, for example in a practice waiting room:

> *"Not coming in for medication as they didn't want to be exposed to others in the waiting room." – N20*

> *"Pacific community scared to leave home and get meds, literally taken lockdown message to heart." – GP41*

It was noted that public messages emphasising the vulnerability of older people and urging them to stay home for their own protection seemed to have had the unintended effect of discouraging some from obtaining healthcare when they needed it. Moreover, some interventions aiming to protect older people may have reinforced the impression that they were not allowed to go out for healthcare:

> *"Elderly particularly had great fear, especially with security guards on the gates of villages, felt it was too dangerous or they weren't allowed to leave the village even for essential health." – PMN2*

High-needs patients, including those with limited English and older people, were also said to find telehealth less suitable. Many had no internet connection, were not confident they could hear well on the phone or believed they would not be assessed properly:

> *"Many patients who were not keen to talk on the phone or were not technology savvy just sat on their medical problems and left chronic conditions untreated." – GP76*

Financial concerns also appeared to play a role in keeping people away, with loss of employment due to the lockdown:

> *"Many patients have been made redundant or pay/hours have been reduced. It is very tricky for patients to pay their bills and no doubt this would make them reluctant to seek healthcare." – GP76*

> *"With high unemployment, patients are expecting a reduction in fees, therefore delaying treatment options if they cannot afford them." – N12*

Fully subsidised COVID-19 consults were noted to have offset this slightly, and one respondent reported that the "mid-severely anxious had more time and tended to ring for more appointments" (GP80).

Health system contributors to delayed care

Health system COVID-19 related arrangements also appeared to contribute to delays in care. Respondents acknowledged that certain areas of care had been put on hold because of the pandemic, with screening and routine follow-ups the most affected:

> *"Things needing immediate attention were dealt with in level 3 and 4 but everything else was put on hold." – N2*

> *"As a practice we had to prioritise the services we offered with all non-essential services being put on hold. This undoubtedly will impact on our chronic disease patients who have routine appointments for things like asthma and diabetes management put off indefinitely." – NP8*

Practices also introduced new procedures required for consultation, such as telehealth and phone triage before being seen in-person by a doctor. Respondents also noted that the triage of minor respiratory infections (which pre-pandemic patients would have self-managed at home) took time away from other patient care:

> *"Lots of time taken up with triaging. Finding the process quite laborious as we are assessing patients who would normally be at home managing themselves, which is just taking up*

Table 1: Participants in General Practice Pandemic Experience New Zealand study.[16]

	Total (%)
Survey 1	164
Survey 2	136 (82.9%)
Survey 3	118 (72%)
Survey 4	112 (68.3%)
Survey 5	91 (55.5%)
Completed all surveys 1–5	78 (48%)
Demographics	
Mean age (years)	50
Female	125 (76.2%)
Ethnicity (total count*)	
European	144 (87.8%)
Māori	9 (5.5%)
Pacific Peoples	5 (3.0%)
Other	14 (8.5%)
Occupation	
General practitioner (GP)	93 (56.7%)
Practice nurse (N)	38 (23.2%)
Nurse practitioner (NP)	11 (6.7%)
Practice manager (P)	18 (11%)
Practice manager and nurse, dual role (PMN)	4 (2.4%)
Type of practice	
Exclusively urban practice	115 (70.1%)

* Total count of ethnicities will be greater than the number of respondents because one person can identify as belonging to multiple ethnicities.

valuable GP time. It is preventing us spending time with the patients and catching up on non-Covid work." – GP58

Delays were not limited to GP appointments but affected other services too, including nursing, community services such as palliative care and diagnostic tests, compounding the effect:

"Our access to laboratory service was reduced to three days per week and still is so it was more difficult to do routine disease management." – GP20

"We have a marae-based clinic that was closed during the pandemic. We used a community-based nurse during lockdown but overall, I think our service to Māori in particular was poorer than it usually is and more reactive with less chronic care." – GP31

Respondents noted that, during the lockdown period, secondary care reduced services in anticipation of potential high rates of unwell COVID-19 patients. However, acute care remained almost as normal, with respondents reporting it was "good" and "well accessible," and that there was "no problem referring acutely." Experience with less-urgent care, which required hospital admission or specialist assessment and intervention, was more variable. Some services and specialties provided consultation or advice remotely, especially for high-risk patients. In some cases, there was improved contact with specialists who were more directly accessible for telephone advice:

"It was easy to get good advice during lockdown from the hospital—they were happy to support us doctors in the community, as we were keeping patients out of hospital." – GP 28

"Patients have had access to secondary care by way of telephone consults with their specialists, and this seems to have worked quite well on the whole." – N7

Moreover, although there were barriers in getting patients admitted to hospital, respondents reported that patients were seen quickly and that their care was well managed once they were admitted:

"One thing that was good was that anyone who did need to be seen during the lockdown was seen and dealt with very quickly by secondary care." – GP74

A number of respondents commented that many referrals to secondary care and procedures for their patients were postponed or cancelled during the early pandemic lockdown period. Some patients on waiting lists were sent back to their primary care practice with a request to re-refer when "normal" services resumed. This was a source of frustration and generated a number of emotional responses to the survey. Apart from the extra work involved, it was felt by respondents that these patients had been referred because they needed specialist services that primary care could not provide. Moreover, there was a perception among respondents that secondary care was not particularly busy. This was a further source of frustration for some, who felt patient care was delayed unnecessarily, which left primary care providers responsible for issues usually managed in secondary care:

"Several patients have been 'returned to primary care' who were previously sitting on a waiting list for some kind of interventions—almost all from surgical disciplines. Frustrating and unnecessary as if they were on a waiting list for an intervention it is clear this cannot be provided in primary care." – GP47

"Felt many patients needs were compromised by keeping hospitals 'ready'. Therefore, patients requiring admission were discharged asap then returning to us to either re-admit or administer delayed treatment that should have occurred in hospital." – PMN2

"Mental health just sent back outpatient referral with decline—'send this again when everything back to normal'!!! I sent it at each lockdown stage to determine what 'normal' (!!!) might be." – GP80

Impact of delayed care

A range of serious conditions were reported to have been affected by the delay in being seen: for example, skin, breast

and colorectal cancers, and a considerable number of cardiovascular events where patients had either presented late or had refused emergency admission to hospital in fear of being exposed to COVID-19:

> *"Multiple people with chest pain, joint problems, skin cancers come to mind." – GP25*

> *"Had a lady present with disseminated malignancy much later than she should due to lockdown as she had nobody to bring her in and language barrier (Tongan)." – GP58*

There were also reports of septic shock, thyrotoxicosis and pancreatitis, and cases where other presentations, for example shortness of breath, were possibly misdiagnosed due to the emphasis on identifying COVID-19:

> *"Covid did distract us from other diagnosis especially in early days." – GP58*

Several respondents noted that remote consultation delayed reaching the correct diagnosis when it would have been obvious in an in-person consultation. There were reports of skin infections and abscesses that deteriorated because patients had waited to seek care. Specialist mental health services were also highlighted by many respondents as having been affected by delay, even after lockdown restrictions were lifted in survey five:

> *"There is a five-month waiting list for suicidal teenagers in the community mental health teen service in Auckland. Teens are really struggling with altered schooling and a very uncertain world… DHBs seem very quick to… get their surgical waiting lists down but don't appear to have even considered it for our very high-risk mental health patients." – GP9*

Specific areas of screening noted by respondents to be affected by delays were cervical screening and bowel screening. Fewer in-person consultations also reduced their usual ability to provide opportunistic screening:

> *"We are also not doing screening, so I am concerned about missing cancers etc [and] late diagnosis." – GP86*

> *"Much of the care we provide is 'opportunistic'. Patients would stop in for a cup of coffee and we would then catch them for the blood test they haven't completed, or the smear they've been putting off. Without patients dropping-in, these opportunities have been missed." – P13*

Of note, in the responses was the presence of healthcare worker distress at what was happening to patients, and their inability to provide healthcare in the usual way. Often noted was a "concern that patients might be getting delayed diagnoses" (GP20) and a "fear about missing serious illness" (GP15).

As the threat of an overwhelming pandemic receded, restrictions eased, and respondents reported that patients felt more comfortable seeking in-person care. Non-urgent work, screening and reviews requiring in-person appointments had built up and workloads rapidly increased to cope with the "backlog of things that need to be seen face-to-face" (GP83):

> *"Workload has increased as people come out of woodwork, and we need to catch back up with routine screening and services that we did not do during lockdown." – GP29*

> *"We have worked so hard to talk about preventative care and reviews. So, we will be going up a hill to try get back to our cervical smears, annual diabetic reviews, cardiovascular, etc. We have a 90% high need population, so we end up doing much more to try get our patients in, statistics for Māori or Pacific supports this." – N8*

Practices became much busier with patients who had "saved up" their concerns:

> *"Patients have stored up their health concerns and are now coming in with long complex lists they are expecting us to deal with in a single consult as they can only afford to pay for a single consult." – GP4*

Opportunities for the future to minimise delayed care

Despite the difficulties that the restrictions from the pandemic had caused, respondents pointed to opportunities for change and renewal. One example was flexibility in routine review periods, with reduced

appointment frequency for stable, long-term conditions:

> *"Apply clinical judgement to reviews rather than blanket policy of needing three-monthly review and six-monthly in-person review." – GP15*

> *"I wondered if long term conditions are being neglected, or did we not really have to see as many of our patients as we used to." – GP6*

Opportunities had also been demonstrated for developing areas of primary care to cope with future disruption, whether pandemic-related or otherwise. Proactive outreach services were highlighted as useful in reducing some of the barriers to vulnerable groups seeking care. Taking services to patients instead of waiting for them to come into a practice was likely to have offset potential harm from the neglect of chronic conditions:

> *"We continued throughout to deploy our 'mobile' nurse who links in with the high-needs groups to make contact with patients who have [for example] diabetes. And we continued to run our practice based diabetic clinic run with the DHB diabetes clinic staff." – GP81*

> *"Much lower workload has allowed our nurses to reach out by phone to our vulnerable patients—many have mental health challenges even in normal times, and many live precariously in boarding houses. These calls have been valued by the patients, and by our team for building relationships." – GP53*

Likewise, new self-administered screening methods were recommended by a respondent to avoid delays from pandemic disruption:

> *"It would be my recommendation to expedite the self-swabbing for cervical screening—in this way the programme could be managed in a similar way to bowel screening." – N12*

Beyond the issues of direct patient care, other reflections from respondents concerned developing more responsive and integrated care across the whole health system during the pandemic. One suggestion was to enable the redeployment of health professionals to where they were most needed:

> *"I believe more thought should be done to reallocating staff who were not needed, like casual nurses in hospitals to primary healthcare at no cost to GP services. We got slammed in our first three weeks and while there was much preparation in the hospitals." – N8*

Others highlighted that some funding models were more conducive to workforce flexibility and allowed for time implementing community initiatives:

> *"We are a kaupapa Māori practice, so it's more that we knew the COVID-19 crisis would impact our patient population more, so were extra invested in mitigating this as we could. Our model of funding (eg, all staff salaried, operated by DHB), meant we were really flexible with our team-roles, and freed up our lead GP to dedicate a lot of time working with the local rūnanga who was implementing a community safe zone. This entailed many hours of huis, but we felt this was vital to supporting the community. We also proactively rang all the patients with complex, chronic conditions to develop tailored plans with them and their whānau and ensure their medical needs were catered for and that there was a plan in place." – GP32*

It was also clear that many respondents believed improved communication at local, regional and national levels was needed. To care for patients effectively, primary care professionals needed to have a voice in the decisions made and ensure that these decisions were communicated directly and clearly through official channels as opposed to mainstream media. A considerable number of comments were received about the confusion caused by communication gaps between different parts of the health system and the need for collaboration and consistency across primary and secondary care:

> *"[Ministry of Health] to improve communication with primary care—properly sourcing primary*

care opinions and advising about upcoming updates to things like case definitions before they happen rather than letting us learn about them through the media. Health… needs to work closely with GP colleagues as we are the ones to are at the frontline and dealing with patients' issues—high anxiety and fear, anxiety around testing and covid illness, reduced presentation to hospital and leading to them becoming unwell." – GP69

Above all, respondents said it was important for clear messages to be widely disseminated in any future COVID-19 lockdowns to assure the public that primary healthcare services remain open and that they should not delay seeking care for issues that concerned them:

"Educate the public more about not delaying seeking medical care regardless of the alert level to reduce harm from delayed diagnoses." – GP9

Discussion

This paper describes aspects of potential causes of delayed healthcare due to pandemic disruption and possible solutions from the perspective of a nationwide sample of New Zealand general practice teams.

Respondents noted that patients displayed different health-seeking behaviours over this time. Patients often minimised symptoms and avoided contact due to fear of being exposed to COVID-19 and a concern that healthcare services were too busy. These findings echoed two New Zealand patient-experience surveys over the same time frame.[6,19] New procedures adopted by practices before in-person consultation, such as telehealth and phone triage and streaming for respiratory illnesses, may have added to the impression that medical practices were too busy to see patients unless they were very ill, or that there were too many barriers to getting an appointment. As had been recommended, at higher alert levels many practices prioritised acute or urgent care, and triage and testing of potential COVID-19 infections, over non-essential services such as screening and chronic disease management.[20] Positively, these clinical priorities were refined and adapted throughout 2020 in order to minimise disruption and delayed care.[20] Importantly, in order to support patients to access care when they need it, we need sustained public health messaging that "GPs remain open for business."[21]

Commendably, initiatives such as outreach care provided by primary care practices were a positive response to the need to alter healthcare during lockdown. Other positive long-term changes that may persist after the pandemic include reconsidering review intervals for chronic disease management (largely determined by three monthly prescription limits) and different ways of using technology in healthcare.

Respondents' experience of the interface between primary and secondary care when referring or seeking advice on patients varied significantly. Some reported a positive experience with improved access to phone advice. Others expressed frustration when patients were declined access to non-urgent care in readiness for keeping hospitals "prepared" for potential COVID-19 patients. From the primary healthcare team member perspective, our results suggest that altering the usual healthcare provided by secondary care (eg, cancelling elective surgery, declining non-urgent referrals, or deferring work back onto primary care) has impacts and flow-on effects to other providers who are not necessarily equipped for this, and ultimately contributes to delayed patient care. Although there was clearly a rationale for the immediate secondary care response when significant COVID-19 community transmission seemed likely, as the threat receded there was little evidence of secondary care being proactive in helping general practices to address potential delayed care issues.

This study highlights the importance of integration and relationships across our healthcare sector and communities in providing timely care for patients. Respondents valued improved interpersonal communication with secondary care colleagues where this occurred. A kaupapa Māori practice worked with local rūnanga with the aim to protect patients from COVID-19. In contrast, communication gaps caused stress in the system, and respondents wanted primary care input into writing case-definitions and guidelines and for messages to come through official

channels rather than media. The importance of primary care involvement in pandemic planning and response, and support for dealing with higher acuity illness in the community, has been highlighted also in a Canadian review article.[22] Improved integration could see redeployment of resources, such as staff moved to the area of greatest need. Rural generalists have been used as an example of flexibility between primary and secondary care roles in response to the pandemic.[23] Also, flexible funding models were demonstrated to be effective in allowing health staff to adapt working practices with the community.

A major strength of our study is the unique real-time surveys that allowed us to capture the experience of healthcare professionals as they occurred during the early pandemic period. We also reported from a large, diverse group of primary care team members from throughout Aotearoa New Zealand. Our responses were limited to free-text responses by survey only. However, as this study commenced during the COVID-19 pandemic lockdown, this was deemed the most feasible means to assess the experience of busy healthcare teams.

Once lockdown restrictions eased, this study, and others internationally,[24] identified a potential backlog of untreated patients' "routine" issues usually diagnosed or managed by primary care. It was evident from respondents that practice teams worked hard to keep going under stressful situations, quickly reinstated business as usual and tried to mitigate effects of delayed care where possible. The concerns raised by our group warrant careful monitoring of disease incidence, morbidity and mortality data. As these become available, the true impact of these delays must be determined, with learning embedded into practice. However, it is critical that remedial work starts now, with primary care targeting those vulnerable to delay and secondary care streamlining the referral process.

Compared to other countries, New Zealand had a relatively short period of lockdown and very low incidence of COVID-19, but nonetheless the provision of healthcare was disrupted, and together with uncertainty, the period was stressful for healthcare workers. It is widely acknowledged that New Zealand's health system has been underfunded for two decades and, even before the COVID-19 pandemic, increasing concerns have been raised about unmet need and delayed care.[25] Had New Zealand been tested more severely with a larger number of unwell COVID-19 patients or a longer period of lockdown, the years of under investment in our health system could have meant that our ability to provide adequate clinical care would have been more severely compromised.

Careful attention to policy choices along with nimble planning and funding changes are needed to reduce the barriers for patients seeking care and improve integration and relationships across the health system. This would minimise future pandemic disruption and delayed patient healthcare.

Competing interests:
Nil.
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