

Beyond the case numbers: Social determinants and contextual factors in patient narratives of recovery from COVID-19

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Abstract

Objective: This study aimed to describe and contextualise COVID-19 recovery from the perspective of patient-lived experience, to inform the evolving public health response to the pandemic.

Methods: Narrative interviews were completed with 37 adult Australians between six and 10 months following their COVID-19 diagnosis. Verbatim transcripts were analysed thematically and trustworthiness was supported by multiple strategies to ensure rigour.

Results: Three themes were identified: 1) trajectories of recovery, 2) back to 'some sort of normal' and 3) the importance of work. Resumed participation in activities of daily life, the influence of social determinants of health and the impact of contextual factors were prominent features in the recovery narratives.

Conclusions: The COVID-19 pandemic presents both challenges and opportunities for public health systems to formulate appropriate responses and make improvements. Behind the case numbers, patient narratives described the uncertainty, diversity and multiple pathways to recovery that need to inform public health policy.

Implications for public health: Looking beyond the case numbers reveals a complex landscape characterised by uncertainty, diversity and multiple pathways to recovery. The pandemic presents challenges and opportunities for public health in Australia and New Zealand, lived experience expertise is crucial to the formulation of an effective response.

Key words: COVID-19, lived experience, recovery, social determinants, long Covid, post-acute COVID-19 syndrome

Background

As COVID-19 case numbers rise across Australia and New Zealand due to the Omicron variant, public health responses have abandoned the 'COVID zero' approach pursued by many jurisdictions in the first 18 months of the pandemic. This pivot has been accompanied by calls to 'look beyond the case numbers', as the two countries begin to 'live with COVID'.¹ This study describes and contextualises recovery from COVID-19 from the perspective of patient-lived experience.

Most people with symptomatic COVID-19 make a full and rapid recovery, with symptoms resolving within a few weeks.² However,

emerging evidence indicates approximately 30% of people infected with SARS-CoV-2 experience sustained biopsychosocial problems for months after infection.³ The multisystem sequelae of COVID-19 infection is recognised by the World Health Organization (WHO) as Post-Acute COVID-19 Condition (PACC).⁴ However, the term 'Long COVID' is more commonly used and arose from the initial identification of this syndrome by patients.⁵

The current case description of Long COVID describes this syndrome as occurring in "individuals with a history of probable or confirmed SARS CoV-2 infection, usually three months from the onset of COVID-19 with symptoms and that last for at least two months and cannot be explained by an alternative diagnosis".⁴ The symptoms of Long

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COVID may be sustained from the acute phase, emerge following an initial recovery and/or follow a relapsing and remitting course.⁴ The most common features of Long COVID include cough, shortness of breath, headache, fatigue, chest pain, joint pain, depression and insomnia, although a recent systematic review identified 55 symptoms and long-term effects experienced after infection.⁶

The influence of social determinants of health and contextual factors on COVID-19 recovery have recently become more pertinent. **Figure 1** integrates the findings of an international scoping review⁷ and rapid review completed by the authors⁸ to illustrate social determinants and risk factors already linked to COVID-19 incidence and outcomes.

Australia and New Zealand's public health system responses to the COVID-19 pandemic continue to focus on vaccination, hospital admissions and resourcing to address acute infections.^{9,10} Key aims include reducing case numbers, minimising mortality and hospitalisation, managing acute health system demand and increasing vaccine availability. However, an urgent need to address longer-term health outcomes for people with COVID-19 has been identified alongside these control strategies.¹¹ Driving these calls are the projected rise in morbidity from COVID-19, despite mortality decreasing with widespread vaccination.¹²

A recent policy review asserted Australia's response to Long COVID must put patients at the centre of the health system.¹¹ Lived experience research about COVID recovery is emerging, but many existing studies have focused exclusively on healthcare workers,¹³ acute illness¹⁴ or specific experiences such as healthcare service contact.¹⁵ The aim of this study was therefore to describe and contextualise COVID-19 recovery from the perspective of patient-lived experience, to inform the evolving public health perspective on this topic.

Methods

Ethics approval was sought and received from a metropolitan public health service (HREC/2020/WH/70312). The Consolidated criteria for Reporting Qualitative research (COREQ)¹⁶ has guided the reporting of this study.

Research team and reflexivity

The positionality of the two lead researchers (DH, ED) was a key topic of reflection throughout data analysis. DH (who conducted the majority of narrative interviews) is an occupational therapist and experienced health researcher, with more than 20 years' experience in public health services and expertise in qualitative methods and knowledge translation. ED was a Master of Public Health student with particular interests in epidemiology and public health policy. She received training and mentorship from DH throughout the analysis process, with both researchers meeting regularly to discuss and reflect on the findings as they emerged. The remainder of the research team are members of the Western Health COVID-19 Recovery Collaboration (WHCOVRE), a multidisciplinary group of clinician researchers from medical, nursing and allied health and public health backgrounds. Their perspectives are also informed by their work as clinicians in public healthcare, and in some cases direct care of people with COVID-19.

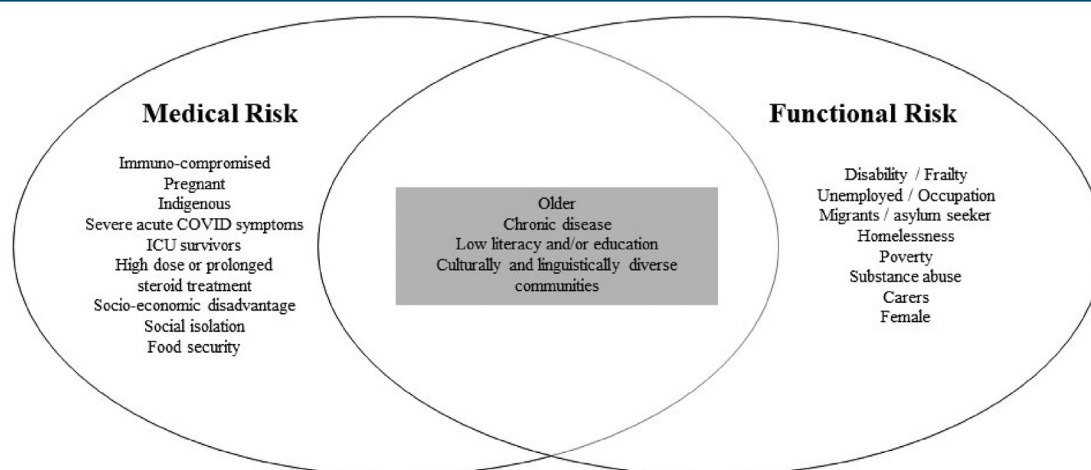
Methodological orientation

This study adopted a narrative qualitative approach to learn about the lived experience of people with COVID-19, complemented by interpretative phenomenological analysis (IPA). Narrative qualitative research analyses 'illness stories', which provide a rich source of contextually embedded data.¹⁷ There is no universal approach to narrative analysis and IPA was applied to preserve the individual narrative characteristic via an idiographic focus.¹⁸ IPA seeks to explore how people make sense of their 'lived experience' as they constantly interpret and make meaning from life events.¹⁸

Study context

This study occurred in a large Victorian public health service, which serves a population of 880,000 people across multiple campuses. Many local communities experience socioeconomic disadvantage, cultural and rapid population growth.¹⁹ The local area has experienced a COVID-19 prevalence rate approximately double that recorded in Victoria.²⁰

Figure 1: Population groups at higher risk of poor outcomes following COVID-19 infection.^{7,8}



Participant selection

Purposive sampling was used to recruit participants with experience of recovering from COVID-19 infection. This sampling method is appropriate to both narrative approaches and IPA analysis, as it ensures the phenomenon of interest is targeted.¹⁸ Recruitment occurred within a longitudinal case control study, sampling all patients diagnosed with COVID-19 at the health service since February 2020. Potential participants were invited to a single interview via text message, which included the reasons for conducting the study and its intended application to practice.

All participants had contracted COVID-19 during 2020, either within Australia or overseas. Vaccination or antivirals were not available at this time, and all had experienced only one COVID-19 infection. Services for people with sustained symptoms or Long COVID were also in their infancy and all interviews were completed within the first half of 2021.

The inclusion criteria for participation were 1) over 18 years of age, 2) COVID-19 diagnosis via positive polymerase chain reaction test, 3) more than six months post COVID-19 diagnosis, and 4) able to participate without interpreter support. Participants did not have to meet the WHO case description of Long COVID to take part in this study. The exclusion criteria were 1) intensive care unit (ICU) admission and 2) aged care residents. ICU patients and aged care residents were excluded due to the extensive research already occurring with these cohorts, high risk of death and/or multiple medical issues which may preclude informed consent.

Participants who expressed interest received a detailed plain language statement and explicit written consent was obtained from all participants. Each interviewer introduced themselves at interview commencement and reiterated the rationale for the study. Participants were also provided a transcript copy to member check, which several returned with minor alterations (typographical amendments or minor deletions or additions).

Sample size

Sample size planning was informed by the model of information power²¹ and feasibility considerations. The concept of information power asserts that samples which hold higher levels of information relevant to the study aim require fewer participants to achieve an adequate and appropriate sample size.²¹ In contrast to the commonly cited standard of 'saturation', this model provides guidance for samples that meet the study aim without making claims of including all aspects of the phenomenon of interest. Variability in lived experiences was anticipated, but rigorous methodological orientation and highly skilled interviewers reduced the participants required for sufficient information power. Analysis began immediately after member checking, which provided a mechanism for recognising the achievement of adequate information power. The research team collaboratively agreed this had occurred after analysis of 37 narratives. While no one withdrew, we acknowledge the sample represents only a cross section of local people with COVID-19.

Data collection

A narrative interview schedule was developed, enabling participants to tell their recovery story in a personalised form and language. Interviews began with a single overarching prompt: "Please tell me the story of your experience with COVID-19 in the past few months".

At the conclusion of the interview, the researcher posed minimal prompts to clarify or elaborate on points within the narrative. Given its brevity, no piloting of the interview schedule was undertaken. Only participants and interviewers were present, and the interviewer took field notes to record their interpretations at that time. All interviews occurred by phone or Zoom at a mutually convenient time and were digitally recorded for verbatim transcription. Interviews took 15 to 60 minutes to complete, depending on the detail provided by participants.

Data analysis

Each transcript was analysed independently by DH and ED using the Dedoose software platform.²² Each researcher produced codes for their interpreted meaning of passages, to make "sense of the participant to make sense of their personal and social world".¹⁸ Broader themes were collaboratively identified by reflecting on individual findings, followed by cross-case analysis between narratives.¹⁸ The code co-occurrence feature in Dedoose was also utilised to understand relationships between identified codes and descriptors were applied to identify response patterns related to demographic characteristics. The coding tree and code co-occurrence chart is available on request.

Other researchers (KH, ML, EG, BR) also familiar with the data peer reviewed the themes and confirmed their validity. Each theme was summarised to describe common narrative features, supported by anonymised quotes to indicate the credibility of the analysis. The researchers ensure selected quotes originated from a range of participants, which are de-identified by narrative number (N2), gender (F=female, M=male), age group and healthcare worker status (HCW). Trustworthiness strategies embedded in this study including multiple coding, peer review, collaborative theme identification, prolonged data engagement and regularly scheduled reflexivity discussions.²³ Participants also received a summary of the findings in a newsletter and no responses or feedback was received.

Results

Narrative transcripts from 37 people with experience of COVID-19 recovery provided data for the IPA analysis. Most participants were female (n=21, 57%), with a significant minority (n=15, 40%) healthcare workers. Most were aged over 50 years (n=20, 54%), but the proportion of participants from culturally and linguistically diverse backgrounds (n=7, 19%) was noticeably smaller than in the local community. Only six (16%) of the participants were admitted to hospital because of their initial COVID-19 infection, indicating the majority of the sample had what would be considered mild symptoms initially.

Three themes were identified: 1) Trajectories of recovery, 2) Back to 'some sort of normal', and 3) The importance of work.

Trajectories of recovery

Symptoms were a key feature of recovery narratives and largely determined which healthcare services participants accessed. Three distinct trajectories of recovery were described: 1) complete recovery, 2) gradual improvement and 3) cyclic/relapsing.

Fourteen participants described their recovery as complete, with symptoms resolving during their acute illness. This trajectory was predominantly described by younger participants, some of whom

recovered before receiving their diagnosis; “I got a phone call on the Wednesday saying that I tested positive, and I was actually completely fine at the time ... it was like a bit of a cold for one or two days and then just left” (N24, F, 18-29).

Most participants (n=26) recounted new or persisting symptoms that improved gradually and had progressively less impact on daily life; “It was a real slow process of feeling better. I went out for some exercise probably [a] week after that and I could walk maybe 200 metres and then that was it” (N30, F, 30-49). The speed of improvement varied between participants, and between specific symptoms; “So the palpitations, are less prominent now, but I still get palpitations most days. And that's the main feature of my day” (N6, F, 30-49, HCW). This trajectory also impacted upon pre-existing conditions for some participants, which were exacerbated by COVID-19 and took many months to return to baseline; “After COVID for the first two or three months my sugar was everywhere. But, but my sugar has improved a lot, we had got that back on track” (N38, M, 50+).

Eighteen participants described a third trajectory of cycles of alternating relapse and remission. Some participants experienced a period of feeling better or ‘normal’ before symptoms returned or new problems emerged; “five weeks, six weeks ... I felt like nothing ever happened, did resume as normal activity as I could during lockdown, but then afterwards it kinda came back and that's when I thought, Oh God have I got it again, because (it felt like) what I've had in May” (N5, M, 30-49). Relapses also occurred on a background of gradual improvement, with periods of remission generally became longer over time. However, participant experiences of this trajectory differed from sustained gradual improvement, as their journey felt ‘bumpier’; “So it's sort of like a two spike sort of attack. It gets really hard, then you get better and then it comes back and hits you a second time” (N2, M, 50+).

Getting back to ‘some sort of normal’

For most participants, the endpoint of complete COVID-19 recovery was getting ‘back to normal’. Variations of this phrase were present in thirty (81%) narratives; “I think I'm pretty well getting back to normal now” (N20, F, 50+). This was conceptualised as their ‘normal’ rather than an externally defined standard and therefore recovery looked different for each participant. Despite this subjectivity, participants could evaluate their personal recovery to a high degree of specificity; “I'm like 90% back to not having the impacts of it” (N46, M, 30-49, HCW).

Some participants described their recovery in the context of their symptoms, particularly participants who experienced complete recovery; “[The health department] cleared me on the 18th, and that was purely according to my symptoms.” (N6, F, 30-49, HCW). This perspective of COVID-19 recovery was also reflected in narratives of post-acute investigations, where test results or professional opinions often conflicted with the lived experience of recovery. “I got an email from the [health department] just telling me I'm well enough to go back to work. It was 10, 11 [days] or something. So, I rang them and I said, no, no, no, you obviously haven't communicated between you all. I'm still really not well enough” (N40, F, 50+, HCW). The inability of healthcare representatives to explain why they didn't feel better when test results were indicating full recovery was particularly frustrating and disconcerting for many participants “the resounding response from everybody is we don't know ... It's okay, your lungs are okay. Uh, yes, we can see that [you're] not right. (N6, F, 30-49, HCW)

In most narratives, being ‘back to normal’ involved more than just the resolution of symptoms. Most participants described how their participation in daily life changed as their recovery progressed; “I was feeling quite reckless, getting from our bedroom which was on the first floor, down to the kitchen and back again. So I struggled with that for a couple of weeks, but now, all sort of well and recovered” (N13, F, 50+). COVID-19 had an impact on all areas of their daily life, including personal and domestic activities, hobbies, exercise, and social or community activities; “I'm back, walking, playing golf, doing all the things that I do” (N3, M, 50+).

Participants who were recovering (rather than recovered) described dissatisfaction with their current ability to partially participate in life roles and daily activities; “I can't carry out my daily activities as well, pre-COVID diagnosis. So, they're the main things that I'm dealing with at the moment” (N12, F, 30-49). Some had initiated a process of adaptation in response to their residual symptoms and functional issues to maintain some form of connection with these activities, albeit using a modified format or process; “So, it's stuff that I'm adapting to, to make sure that I am still managing it well, but it is just something that I've had to adjust to.” (N7, F, 18-29, HCW). Therefore, recovery entailed adjusting to a ‘new normal’ rather than a return to baseline.

Uncertainty about what sort of ‘normal’ could be expected post COVID-19 was also a prevalent theme. ‘Normal’ for people with pre-existing conditions already included persistent symptoms and functional impairments, which made it difficult to determine what experiences were directly attributable to COVID-19; “I've got mesothelioma, which is a lung cancer, shortness of breath is a daily life thing for me.” (N9, M, 50+). Many participants also wondered if their current health resulted from COVID-19 infection, normal ageing, or both; “You will be talking and then, but again, I'm 62 ... (is) this is a sign of something else? What was that word? Or what was that?” (N40, F, 50+, HCW).

Participants recognized that everyone's life has been altered by the pandemic. ‘Their normal’ was perceived within the context of the ‘new normal’ including public health measures such as community lockdowns and density limits, to which everyone has needed to adjust. The challenges imposed by such measures were experienced by the entire community but were a compounding factor that delayed or impeded recovery for some people with COVID-19; “I think the biggest trauma's been to be honest in my opinion, the lockdowns and the emotional stress of that side of it” (N39, M, 50+). The impact of these measures on usual levels of physical activity was also described in several narratives as particularly detrimental to cardiovascular, respiratory, and musculoskeletal recovery; “I don't know whether I'm just going to put it down to the fact that I couldn't get over the lack of fitness in my legs after four weeks of doing not much around home, like you couldn't even go for a walk around the block” (N29, M, 50+).

The importance of work

Many participants took time off work while acutely unwell, so returning to work was perceived as a sign that things were getting ‘back to normal’. Employment was a particularly important feature of recovery for the 40% of participants who were healthcare workers, who in many cases knew or assumed they had contracted COVID-19 in their workplaces; “I returned back to work and when I walked in, I was like, oh, God, it hit me like a tonne of bricks seeing all the PPE

gear there and just, yeah, it was just very overwhelming” (N36, F, 50+, HCW). For many of these participants, continued workplace exposure to COVID-19 placed additional strain on their mental health, which was damaging to their overall recovery. “You know, COVID is everywhere and everything is COVID, COVID, COVID, and after a traumatic incident, like having COVID, it's very triggering to come back into that environment and continually face that over and over again” (N30, F, 30-49, HCW).

Regardless of occupation, return to work processes were often described as onerous and contributed to keeping COVID-19 at the forefront of the participants minds; “you are dealing with a few different agencies, you are sort of dealing with your own line management, you are dealing with the [health department] and then in my case I was dealing with [organisation name] as well ... and anyone else who wants to know if you are alright. So, you end up dealing with a lot, talking about COVID a lot.” (N41, M, 30-49, HCW). These constant references to their infection and fears of potential reinfection made it hard for participants to move towards an endpoint of recovery.

While some narratives returned to their previous positions and roles, the first days and weeks back at work were often difficult; “I found the fatigue really knocked me for six. I was tired every night, by 8, 9 o'clock. I was really struggling to get back in mode” (N29, M, 50+). Other participants could not resume their previous role immediately and required a managed approach; “When I did get back, it was a graded return. So, I had a few weeks where I was just working part time or just less hours than regular.” (N30, F, 30-49, HCW). Others moved to new positions that better matched their current level of function; “I'm working as a PPE spotter. That's all I can do [...] for the foreseeable future ... because I'm still not ready to look after a patient. I don't have the brain concentration. I don't have the energy.” (N6, F, 30-49, HCW). While some felt supported by these modifications, other narratives reflected deep feelings of frustrations and despair at not being able to ‘get back to normal’; “We're in the middle of the biggest pandemic we've seen in so long and I feel perfectly useless ... for God's sake, how long until I can actually get back and support and help” (N6, F, 30-49, HCW).

Discussion

The narratives of lived experience in this study clearly demonstrate the complex and deeply embedded role of social determinants and context in the process of COVID-19 recovery, whether or not the person meets the three-month threshold for Long COVID. A diverse range of trajectories of individual recovery, definitions of recovery and work or community experiences were recounted, which emphasises that the meaning and impact of COVID-19 recovery is best understood from an individual, idiographic perspective. Given that public health focuses on issues and outcomes at the community or population level, the inherent heterogeneity of lived experience presents global healthcare with an array of challenges and opportunities.

The description of COVID-19 recovery in this study as getting back to ‘some sort of normal’ emphasised the inter-relationship between symptoms and participation in daily life activities. However, the natural history and endpoint of COVID-19 recovery remain uncertain and so benchmarks for ‘expected’ recovery are not available to manage expectations.²⁴ Without formal diagnostic criteria for Long

COVID or an established evidence base, public health services are also unable to offer certainty about the relationship between test results and lived experience to people affected, as reflective in several of the participant narratives. Agreed definitions of recovery are also important to determining access and discharge criteria for health services; broad definitions run the risk to overwhelming referrals while narrow definitions could compound the access barriers experienced by some participants in this study. Disparities between public health definitions of COVID-19 recovery (primarily the absence of symptoms) and lived experience could unintentionally exclude people from receiving the rehabilitation and support they need to optimize their recovery.

The three trajectories described by the participants suggests that multiple referral, assessment and care pathways are required by people with COVID-19, across all areas of public health. A recent rapid living systematic review²⁵ summarised available models of care for people with Long COVID, with triage to determine the most appropriate level of care identified as a common feature. COVID Positive Care Pathways have been formulated in several Australian jurisdictions,²⁶ but only provide support during the acute phase, aiming to reduce strain on the acute healthcare system. As described in the narratives, care pathways to support the triage of people with post-acute symptoms remain either under-developed or absent. As models of care for people with Long COVID develop across Australia and New Zealand, primary health is potentially the most suitable sector to lead these developments because of its well-equipped skills and structure for undertaking the community engagement required.²⁷ However, these models and pathways face significant obstacles from existing structural barriers in healthcare systems and at the interface with other sectors (such as workplace safety authorities).

Organisational environments in healthcare are often arranged around single diseases or organ systems, however, the primary care services required to meet the complex presentation of Long COVID may be available from multiple independent services.^{28,29} Service systems are also often organised around discrete occasions of care, which do not address the needs of the cyclical recovery trajectories described by our participants. International consensus exists around the need for care coordination and multidisciplinary care to support COVID-19 recovery³⁰ and recognises the failure of public health systems to reorient towards person-centred and integrated care.³¹ The projected number of people requiring sustained support following COVID-19 could stimulate the transformation of healthcare services and systems towards more flexible and tailored approaches, which may also be beneficial to people with other multi-morbidities, chronic diseases and complex care needs. While significant changes would be required to make population health approaches for Long COVID ‘fit for purpose’, the projected cost of this syndrome to the Australia economy³² underscores the urgent need for such change.

In the public health service context, emerging research highlights the multi-morbid nature of COVID-19 and the need for comprehensive rehabilitation. Participants in this study received very little (if any) rehabilitation during their COVID recovery and there remains little research available about effective assessments or intervention strategies to support COVID-19 recovery. The Australian National COVID-19 Living Clinical Guidelines³³ recommend a biopsychosocial approach but acknowledges there is insufficient evidence to endorse any specific intervention. Within these guidelines, individual context is acknowledged in the goals of care, and some social determinants (i.e.

rurality/remoteness, employment) are identified as part of management. However, they are mentioned in passing and so this study is the first to focus on their influence on effective care as antecedents and/or outcomes.

The lack of research available about managing Long COVID contributed to the experiences of uncertainty described by some participants in this study, as clinicians were not able to provide consistent and confident advice. However, there are some precedents which provide potential exemplars for service transformation. Patient definitions of recovery from other areas of practice^{34,35} emphasise the personal meaning of individual recovery and how resuming participation in daily life is often the patient-defined endpoint of illness. As stated in the narratives, recovery from COVID-19 meant getting back to their personal normal. Patient rated outcome measures enable patient-defined recovery, particularly measures of quality of life and/or personal goal attainment.³⁶ The broad similarities between Long COVID and other post viral fatigue syndromes³⁷ also suggest that existing clinical guidelines for conditions like myalgic encephalomyelitis may also be relevant to these patients. Therefore, public health service may not need to start from the 'ground up' when working towards person centred and integrated care for people with COVID-19.

Returning to work was an important recovery milestone for participants in this study. People with Long COVID may require specialist vocational rehabilitation to successfully achieve this aim³⁸ due to the infinite permutations in workplace contexts, job requirements and trajectories of COVID-19. Many of our sample were healthcare workers and their return to work also presents a higher risk of re-exposure to COVID-19. Age, pre-existing conditions and inpatient admission influence the amount of sick leave required following COVID-19,³⁹ although not all workers have access to this benefit.⁴⁰ However, no association with socioeconomic factors has been identified, which emphasises that barriers to employment could arise for anyone recovering from COVID-19. Employment is an important social determinant of ongoing health, as unemployment, under employment and job instability are all associated with poor physical and mental health.⁴¹ As demonstrated by narratives in our study from parents and retired people, it is also important to remember that not everyone is in the workforce. Employment is just one of many activities of daily living and life roles that can be impacted upon by the length and trajectory of COVID recovery.

Strengths & limitations

This study is the first to meaningfully engage with the experience of Australians, providing an analysis from the local context. The voice of patients experiencing Long COVID-19 infection are largely absent from the current evidence base, and this study provides a basis for enabling patient-centred and integrated care. People with lived experience are also the best source for understanding how social determinants impact on COVID-19 recovery, given the unique context of each individual lives. People with mild initial COVID-19 symptoms who go on to develop sustained problems are also an under-represented population in the current evidence base, but formed the majority of the sample in this study.

The findings are limited to a single health service and do not reflect regional, rural, remote or Indigenous perspectives. Purposive sampling from this bounded population therefore provides a limited and inadequate perspective on social determinants. It also reflects the

context and circumstances of the earlier phases of the pandemic and recruitment to this study remains open to explore whether recovery narratives have changed over time. The exclusion of some groups (including aged care residents and non-English speakers) reduces transferability and the potential contribution of this study to understanding the impact of health inequity. While adequate information power was achieved, the heterogeneity of lived experience suggests some aspects of COVID-19 recovery might not have been captured in detail. Furthermore, most participants were infected between March and August 2020 and their experiences therefore reflect the original and early COVID-19 variants. This study collected rich and extensive data, not all of which could be presented in this single article.

Conclusion

This study described and contextualised recovery from COVID-19 from the perspective of patient-lived experience. Three themes were identified: trajectories of recovery, back to 'some sort of normal', and the importance of work. This emphasised how deeply embedded social determinants and contextual factors are within lived experiences of COVID-19 recovery, as both contributors and modifiers of outcomes. Looking beyond the case numbers reveals a complex landscape characterised by uncertainty and diverse pathways to recovery. The COVID-19 pandemic presents both challenges and opportunities for public health in Australia and New Zealand, and the inclusion of lived experience expertise is crucial to the formulation of responsive and effective services.

As we transition towards 'living with COVID-19', there is an urgent need for a longer-range perspective on the impact of the virus on individual health and wellbeing, and the transformation of public health services to adapt to the post COVID world. Given the complex interaction between social determinants, contextual factors and lived experience, studies to explore their impact (both individually and collectively) using qualitative and mixed methods are also recommended to better define recovery processes and outcomes. People with COVID-19 remain the experts in this phenomenon and their inclusion in all phases of research, service design and policy development must be supported to meet the challenges of Long COVID.

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Ethics

Ethics approval was sought and received from a metropolitan public health service (HREC/2020/WH/70312).

Conflict of interest

None.

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Appendix A Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.anzjph.2022.100002>.