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# Sociomaterialities of health, risk and care during COVID-19: Experiences of Australians living with a medical condition

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## ABSTRACT

People living with pre-existing illnesses were identified as one of the groups most at risk when COVID-19 erupted. In this article, using the method of case studies developed from interviews, we explore how Australians in this category considered their risk and responded to it as they were learning about COVID-19 and living with restrictions and lockdown conditions in the early months of the pandemic. Building on the literature on assemblages of health and illness, therapeutic landscapes and the materialities of care, our analysis considers sociomaterialities of health, risk and care described in six featured case studies. Each person recounted a unique narrative that described the coming together of several different human and nonhuman agents in their experiences. Yet a number of overarching and intersecting themes can also be traced across the participants' narratives: the vital contributions of lay care and self-care as part of the materialities of care, health and wellbeing; the role played by social networks, both online and in-person, for people in learning about and coping with COVID-19 and its potential risks; previous embodied and affective experiences of illness, vulnerability and care; and the role played by place and space in generating either therapeutic or distressing affective atmospheres. These findings have implications for better understandings of the situated sociomaterial contexts of how embodied experience, affective forces and encounters and relationships with other people and with things, place and space come together in crises such as COVID-19.

## 1. Introduction

Since early on in the emergence of the COVID-19 crisis and its rapid spread around the world, news media coverage and public health warnings and websites have repeatedly emphasised that people who are immunocompromised, as well as those with some pre-existing medical conditions (such as active cancer, diabetes, cardiovascular and respiratory diseases, autoimmune conditions, chronic kidney disease, HIV/AIDS, chronic pain and some mental health conditions), are at higher risk of developing severe COVID. Many national and global health agencies have therefore warned that people with these conditions require greater protection from infection with the novel coronavirus SARS-CoV-2: particularly if they are in older age groups. People with existing health conditions are also at risk from reduced access to medical expertise and treatment during periods of stay-at-home restrictions and stresses on the healthcare system imposed by dealing with high numbers of serious COVID cases, as well as loss of support from informal caregivers and social networks (Jordan et al., 2020).

In this article, we report on findings from a qualitative interview-based study which elicited adult Australian participants' accounts of their experiences of the COVID crisis as it was emerging in the first half of 2020. Unlike many other countries with far higher rates of disease and deaths, statistics gathered in 2020 showed that COVID did not cause excess deaths in Australia in that year. However, people with pre-existing conditions were among the most likely to have died from COVID: almost three-quarters of COVID deaths in Australia in 2020 were among such individuals (who were also much more likely to be aged 70 years and over) (AIHW, 2021). In what follows, we present six case studies selected to focus on the experiences of those in the participant group who reported that they were already living with one or more pre-existing medical conditions when the outbreak and associated restrictions began to affect Australia in March 2020.

This article offers original findings in a number of ways. First, this is one of the first studies that uses qualitative methods to provide details of what life was like for this vulnerable group during a time of great social turmoil and fear about how the pandemic would manifest in their

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locality. Second, the study provides insights from Australian-based research of everyday experiences of COVID during the early months of the pandemic. We were interested in how people with existing conditions felt about COVID-related risk during this time, how they experienced the restrictions introduced by the Australian government and what forms of help and support they found that contributed to their coping and wellbeing during the first six months of the crisis. Third, our approach adopts a sociomaterial perspective: more specifically, building on the literatures on assemblages of health and illness, therapeutic landscapes and the materialities of care and showing how this previous work can be extended into analyses of COVID experience. Finally, our findings are presented in narrative-style case studies drawing on detailed indepth interviews, which helps us present rich biographical and sociomaterial details of our participants' experiences.

## 2. Conceptual background

Focusing on the lived experiences of health and illness is a longstanding strength of social research in health and medicine. A narrative approach to people's experiences of health and illness is well-known in health sociology. Anthropologist Arthur Kleinman's (1988) pivotal work on illness narratives drew attention to the dynamic and situated nature of the meanings and feelings of embodiment expressed in people's accounts of their illnesses. More recently, sociomaterialism perspectives that recognise the role of nonhuman agents have begun to gain ground in health-related research. These approaches draw largely on science and technology studies' interest in how diverse agents beyond humans come together (McDougall et al., 2018), or alternatively on new materialism perspectives that build on Deleuzian assemblage theory (Duff, 2016).

Writings on the assemblages of health, illness and recovery highlight that these embodied experiences are always part of more-than-human gatherings (assemblages) that are continually coming together and coming apart as people move through their everyday worlds (Andrews and Duff, 2019; Lupton, 2019; Wiltshire et al., 2020). The concept of therapeutic landscapes, as espoused in cultural geographies, relates to how people's locations in place and space, both built environments and natural landscapes, evoke multisensory and affective states that can contribute to health, wellbeing and care (Thompson, 2021; Wright, 2019). Similarly, an emergent body of literature in health sociology acknowledges the materialities of care in the context of health and illness (Brownlie and Spandler, 2018; McDougall et al., 2018). While contributors to these related but separate literatures are spread across fields or disciplines and do not always refer to each other, they all offer important insights to understanding the sociomaterial dimensions of health, illness, healthcare and recovery. They all emphasise that nonhuman agents are entangled with humans in the provision and experience of health care in both expert and informal contexts, including self-care and the use of digital technologies such as online forums and mobile apps. Together, these more-than-human assemblages generate affective forces of wellbeing, distress, safety, threat or recovery (Wiltshire et al., 2020; Wright, 2019) that can lead to opening or closing capacities for action (Lupton, 2019).

In response to the COVID crisis, some initial qualitative research has been published that focuses on the materialities and affective dimensions of people's experiences in high-income countries such as Australia during conditions such as restrictions and lockdowns across diverse sociocultural contexts. For example, one study using remote home visits facilitated by video-calling software explored how Australian adults across a range of age groups dealt with feelings of isolation, boredom and loneliness by connecting with others using digital technologies such as video and messaging apps (Watson et al., 2021). Two British studies – an analysis of English people experiencing 'long COVID' by Rushforth and colleagues (2021) and an interview study of people living with dementia and their family carers (Tuijt et al., 2021) – highlighted the importance of the online support that people

experienced. Another project employed autoethnography to identify the role played by digital health technologies together with home-based objects and spaces in the author's therapeutic landscapes and mobilities as she lived through lockdown conditions in the UK (Thompson, 2021). A study involving young adult Italians' experiences during lockdown adopted a narrative interview technique facilitated by Skype to focus on how 'new normalities' of domestic and work habits were configured while they were confined predominantly to the home (Moretti and Maturo, 2021). The roles played by people's relationships with their home gardens (Giraud et al., 2021) and domestic animals (Young et al., 2020) in contributing to their feelings of wellbeing, safety and comfort during COVID have further been identified in qualitative studies.

While this emerging literature has begun to identify sociomaterialities and assemblages of health, wellbeing and care in the context of the COVID pandemic, little detailed social research as yet has specifically investigated what it was like for people with pre-existing medical conditions to live through the early months. In our study, we were interested in identifying not only how our participants engaged with other humans, but also with nonhuman agents in the context of place and space as they sought care, grappled with feelings of risk and vulnerability and dealt with the physically isolating conditions of COVID-19 restrictions. The value of a case study approach drawing on people's narratives of their experiences is that it allows for a detailed focus on the sociomaterial and biographical conditions of lived experience. Similar to the narrative interview study by Moretto and Mauro (2021) on Italians' experiences of lockdown, our approach adopts a version of narrative inquiry which is not only about illness experiences but also seeks to surface conceptualisations of risk, stay-at-home restrictions and vulnerability. Indeed, given that our focus was people's experiences of the COVID crisis, their narratives could also be characterised as 'outbreak' or 'pandemic' narratives (Davis and Lohm, 2020; Wald, 2008) as well as illness narratives. Further, our approach recognises the importance of identifying the sociomaterial dimensions of people's stories (Duff, 2016; McDougall et al., 2018).

## 3. Details of the study

The period to which our study refers included a national lockdown from mid-March to mid-May 2020 (Lupton, 2021). These early months of the pandemic were characterised by great uncertainty about how well COVID would be contained in Australia. However, by the end of 2020, it was clear that compared with many comparable countries in the Global North, these strong restrictions had meant that Australia managed to successfully contain the spread of the novel coronavirus during the first year of the pandemic, with fewer COVID cases and deaths compared to similar countries (O'Sullivan et al., 2020). Most Australians endured only approximately ten weeks of strict stay-at-home conditions during the initial national lockdown, although more local lockdowns in some regions were to follow later that year (Lupton, 2021).

Forty indepth, semi-structured interviews were conducted with adults living in Australia by the second author between late May and late July 2020. The study was approved by the UNSW Sydney human research ethics committee. All participants provided informed consent prior to their interview. We offered a gift card to thank and compensate participants for their time. We chose to use voice calls by telephone to conduct the interviews: both because face-to-face interviews could not take place during this period of physical distancing restrictions and because we could easily involve people living across Australia and therefore promote diversity in our participant group. While telephone interviews do not allow for observations of interviewees' bodily demeanours and other visual cues, they can still generate rich and detailed accounts. Indeed, sometimes the more anonymous nature of the interview encounter can encourage a more expansive discussion, particularly of sensitive topics (Trier-Bieniek, 2012).

We did not seek a representative sample when recruiting

participants, but instead focused on heterogeneity. To achieve this, we set sub-quotas to achieve an even spread of participants across gender, age group, and place of residence (metropolitan, regional and rural/remote areas). Interested potential participants responded to an advertisement about the study on Facebook. Using this approach meant that we were able to reach a large number of Australians across the continent. At the time this study was carried out, figures on Australian Facebook use show that 60 percent of all Australians (including those aged under 18) were regular Facebook users, with 50 percent of the Australian population logging on at least once a day (Social Media News, 2020). This method of recruitment proved to be fast and effective, and we easily met our sub-quotas. The interviewee group comprised 18 males, 19 females, and 3 transgender or gender non-conforming people, aged between 18 and 75, who were living in a mix of metropolitan (17), regional (13), and rural or remote (10) areas. We did not actively recruit for or set a sub-quota for people living with pre-existing medical conditions, but we did ask participants if they had such conditions when gathering their sociodemographic details. It turned out that over half (23 out of the 40 participants) reported one or more pre-existing medical conditions: a proportion which is consistent with national statistics (Australian Government Department of Health, 2020).

We used a semi-structured interview schedule which allowed participants to elaborate on their answers. Participants were asked to talk about how they had first heard about COVID-19 what was the most helpful or useful source of information for them to learn about the coronavirus, how their everyday lives had changed during lockdown, what had been the most difficult or challenging aspects, how they had coped with these difficulties, what services they had used and their view on how well the Australian federal and state governments had dealt with the crisis. The final questions invited the participants to imagine what life would be like once the crisis had passed. All interviews were audio-recorded and professionally transcribed. To maintain confidentiality, participants were assigned a pseudonym and all contextual identifiers were removed from the transcripts.

The second author, who conducted all the interviews, wrote detailed fieldnotes for each participant soon after each interview was conducted. Both authors then used the transcripts to augment these notes, inserting illustrative quotations to configure a detailed narrative case study for each interviewee. In this way, our approach is akin to understanding the in-depth interview as a form of storytelling, in which participants recount narratives in response to our questions and we formulate their accounts into our own narratives (Rodríguez-Dorans and Jacobs, 2020). Writing the case studies was part of our analysis, therefore. We focused on the contextual details in how the interviewees recounted their experiences of the early phase of the COVID crisis. Our approach to the interviews positioned them as narratives: a way for our participants to engage in a form of storytelling in response to our prompts. We incorporated a mode of social inquiry which recognises that interviewees' accounts are co-produced with the interviewer: shaped with and through the prompts they are given, the responses of the interviewer to their accounts throughout the interview, their biographical experiences and the broader temporal and sociocultural understandings, discourses and other contexts in which the interview takes place (Denzin, 2019; Fox and Alldred, 2017). As such, the interviewees' accounts offer the opportunity to identify meanings, practices, relationships and sociocultural dimensions in people's accounts of their experiences.

For the present analysis, we focused on the narratives of the 23 participants who reported living with a pre-existing health condition at the time of interview. As noted earlier, we had not deliberately recruited for such people, but as we were conducting the interviews and constructing the case studies for each participant we noted that their experiences offered important insights on what life was like for people with such conditions during the initial phase of the pandemic. Once we had decided to focus on the narratives of people with pre-existing conditions, we selected six case studies from these participants. In making this choice, we sought heterogeneity, including diversity of health

condition(s), age, gender and geographical location so as to identify the entanglements of embodiment and affect with other people, things, place and space. The case studies include three men, two women and one transgender person, living in rural and metropolitan areas and ranging in age from their mid-20s to their late 60s. All reported living with mostly chronic pre-existing medical conditions and all but one listed multiple conditions: including HIV, post-traumatic stress disorder, depression, panic disorder, chronic pain, chronic fatigue, diffuse idiopathic skeletal hyperostosis, osteoarthritis, chronic back pain, borderline personality disorder, type 2 diabetes, high blood pressure, bipolar disorder, emphysema and prostate cancer.

Building on and extending the scholarship reviewed earlier, we focus on the entanglements between affective states, practices, nonhuman things and place and space in the narratives provided by our Australian participants who reported such conditions. The case studies and interview transcripts were analysed with the purpose of identifying the sociomaterial dimensions of participants' experiences during the first six months of COVID and how human agents came together with nonhuman agents in their narratives. We also closely examined the role played by people's existing health status and care arrangements in their accounts of how they experienced the COVID crisis. Further, we looked at how space and place were talked about in participants' accounts, and how these spaces evoked different feelings and embodied experiences. This approach to social inquiry is directed at 'making the mundane, taken-for-granted, everyday world visible' through interpretative and narrative practices (Denzin, 2019, p. 723).

## 4. Case studies

### 4.1. Max

Max, aged in his early fifties, lives alone in the inner suburbs of a large city and describes himself as having a European ethnic background. He had been supported by a disability pension for some time prior to the COVID outbreak as he is living with multiple chronic health conditions, including HIV, post-traumatic stress disorder, depression, panic disorder and chronic pain.

Initially Max did not feel personally at risk, but he gradually realised that the pandemic was going to be a major problem in Australia. An important site for social connectedness for Max was a public hospital he attended weekly for appointments and medications. He described his feelings of discomfort when he first attended the hospital after the onset of the COVID pandemic and the feeling of an impending crisis for which the hospital was preparing. When he noticed that thermal cameras had been installed to check people's temperatures as they walked in the hospital, for Max, the 'feel' of the hospital changed from 'friendly' to a space of surveillance:

It was a bit confronting to see the thermal cameras. It is quite a friendly sort of a hospital, and to see it go into a sort of a, for want of a better word, a more marshalled system, that was a bit confronting.

Max's feelings about other public spaces were ambivalent: they generated feelings of discomfort, anxiety and risk but he also hankered for safe forms of in-person encounters to alleviate feelings of loneliness. One of the most significant impacts for Max was on his social relationships, as he noted the loss of socialising in public spaces such as bars or restaurants (previously valued and safe spaces of belonging for Max) and the loss of physical contact with other people. In contrast, Max's home was described mostly as generating an affective atmosphere of safety and control, albeit under conditions of emotional and physical isolation. Max did find it confining at times to be always in his apartment but found it difficult to find opportunities and safe spaces to move around outside. When he had noticed people not engaging in appropriate hygiene measures in public, he felt frustrated and vulnerable:

I really should have been getting out doing more active things, like finding alternative ways to go for walks. Then when I'd see the crowds down at the beach or down at the park, that would be worse. Sometimes I would be out with a friend going for a walk and the joggers would be coming towards us puffing and panting. Well that's just not really social distancing, and I don't really want their puffing and panting in my face either.

Max had spent extensive time reading news reports and doing his own online research to learn more about the coronavirus and particularly how he could minimise his risk of infection through social distancing and hand washing. Neighbours and friends who lived close by, and a community organisation supporting people living with HIV, were important to help Max in maintaining social integration and participation during the crisis. Volunteers from community organisation rang regularly to check on his welfare, as would a close friend, who would ring and make a time to meet up for a coffee or a walk each day. He also described himself as an 'educator' for his friends, some of whom, he said were over-reacting to the crisis, or reacting in ways that were unhelpful and potentially harmful.

Connecting with others online was another important way that Max managed some of the difficult or challenging aspects of life during the early months of the crisis, including ameliorating feelings of loneliness and isolation. Max said that Facebook has been an essential source of social connection and support as well as information about health issues like COVID. He spoke of the relief he felt knowing that his elderly mother, who has diabetes, was being very careful and vigilant in self-isolating during the crisis. They had maintained their social interactions via digital and social media platforms, including exchanging approximately ten Facebook messages a day.

Max's narrative, therefore, surfaces the entanglements of physical and digitised relational connections in generating affective atmospheres of wellbeing and safety. Max's feelings of discomfort and frustration were deeply entwined with notions of risk and trust in others. Max was particularly sensitised to the risk of being infected from his experience living with HIV long-term, and the related knowledge he had gained through researching virulent viruses and their spread. Staying hopeful and informed and gaining as much knowledge and information that he could about the virus were helpful for Max in managing the uncertainty and fear he experienced.

#### 4.2. Tilda

Tilda, aged in her mid-fifties, describes herself as 'white' and lives with her husband in a remote area 'off the grid'. Tilda lives with a number of chronic health conditions, including chronic fatigue, diffuse idiopathic skeletal hyperostosis (a form of arthritis) and osteoarthritis. She also has a history of pneumonia.

Tilda said that she was highly worried about the risk of COVID from the very beginning. She remembered hearing about the coronavirus outbreak in China in early 2020 through online news media. She said that she felt concerned from this point, because living with chronic illnesses has made her more aware of health-related issues and her own personal risk. Tilda began to feel especially worried when she found out that the novel coronavirus could attack the lungs, given her history of pneumonia. She realised that she would have to be particularly careful and cautious.

I've had so many health issues that I pretty much, my antennae go up when there's some sort of health scare. So yeah, I probably would have been, 'Uh-oh, this doesn't sound good. This could be really bad'.

Tilda went on to describe the considerable lengths to prepare and protect herself from the threat of coronavirus, even ordering an HIV anti-viral medication from South-East Asia that she had been told by a friend could be protective against COVID-19, at a time when the number of active cases in Australia was rapidly increasing. She constituted this

drug as an object affording potential future protection and as a way of feeling better, knowing that she has engaged in contingency planning for the unknown future.

Tilda experienced considerable frustration when her husband expressed a completely different view of the risk she faced from the novel coronavirus. She said that her husband thought that COVID was just another flu/cold, based on his Facebook interactions:

I nearly hit the roof. I just wanted to hit him. Because he still was saying a lot of the things, like on Facebook, where people are like, 'Oh, the numbers are way overinflated. Everybody's just over-reacting. It's really not that bad'. And it's like, 'Do not tell me that'.

Tilda also commented that although she lives in a very remote area, and has been self-isolating since early 2020, she still felt unsafe due to her husband's behaviour. Tilda recounted discovering that her husband was going out shopping without her knowledge, even though they had agreed to stay home and self-isolate, and the feelings of discomfort and betrayal this evoked.

For Tilda, these kinds of responses are a sign that those close to her are not acknowledging her fears and feeling of vulnerability: a vulnerability that is based on her lived experience of both chronic and acute illnesses. Her husband's actions contributed to an affective atmosphere of heightened risk in her own home. In contrast, Tilda viewed her actions as a rational, reasonable and responsible response to circumstances of high uncertainty and precarity, at a time at which where there was very limited information or evidence available for people living with the types of medical conditions with which she was dealing. Tilda's narrative also demonstrates how medications, including experimental ones, can evoke feelings of hope, alleviating fears and giving people a sense of control over what seems to be a highly uncertain situation.

#### 4.3. Theo

Theo, a transgender person in their mid-twenties, lives with their partner, a friend, and numerous pets in a metropolitan area in the island state of Tasmania. They are unemployed, though they have a part-time volunteer position in community radio. They live with chronic back pain caused by a serious back injury as well as borderline personality disorder. Theo identified their ethnicity as Australian born with a Middle Eastern background.

For Theo, affective atmospheres of safety were at first configured with and through news reports of COVID-19 as a problem confined to China and then reinforced by their geographical location in a remote part of Australia. Theo first heard about the novel coronavirus on Facebook and described feeling curious but unconcerned about this new viral outbreak occurring overseas. Theo has continued to feel relatively unworried about the personal risk posed by COVID due to the low number of virus cases and deaths in their state, and the feeling of safety and security of living in a small island community.

Well, being in this area, my thoughts and feelings haven't changed too much ... We live on a tiny little island where as soon as it became an issue, we shut the borders to the rest of you guys on the mainland and we haven't really had a problem since. I am currently sitting in the CBD ... on my phone drinking a coffee and there are people going about their days everywhere here as if nothing was wrong.

Interestingly, Theo's thoughts on this apparent 'normality' of life in their city contrast with what they go on to recount later in the interview. In the early stage of the pandemic, Theo's friend became seriously ill with what the friend believed to be COVID-19, but she was turned away from hospital without a COVID test. For Theo, the most challenging aspect of the coronavirus crisis has been taking care of their sick friend while not receiving any assistance from the government or healthcare. As Theo's excerpt illustrates, they felt that their experience (and that of their friend) was invalidated, and that the system let them down.

[The hospital] didn't believe that she could possibly have it. They gave her a course of antibiotics, told her that she had pneumonia and told her to go home, where she was then sick for another 12 days and I took care of her ... What's really crazy now and really frustrating now is that if you have a scratchy feeling in the back of your throat they will test you [now], but she was so severely ill and they just refused, flat out refused to test her.

From Theo's perspective, the government response and refusal to test community-related 'cases' was politically motivated. This lack of action, bordering on negligence, as Theo sees it, provoked a range of emotions: including fear, uncertainty and anger around not knowing if they would become infected, not knowing how to protect themselves, and how sick their friend might become. Like Tilda, this experience also brought the threat of coronavirus into the previously safe space of their private home. Theo talked about the importance of digital spaces such as their Instagram and Facebook accounts, both for mobilising community support, and collective feelings of anger and frustration, for their friend's experience, as well as for connection with others: 'I don't feel lonely [because] even when I'm alone, somebody is with me.' These platforms, therefore, help to configure affective atmospheres of relational connections and support in an otherwise isolating/isolated space and place.

#### 4.4. Craig

Craig, a retired Anglo-Australian managed in his late sixties, lives in a regional city with his partner. He reported numerous chronic health conditions, including type 2 diabetes, high blood pressure, major depression and bipolar disorder.

Craig remembered first hearing about the outbreak in early 2020 in television and radio news reports. He said that he understood early on from these reports that he was at high risk of becoming seriously ill if infected, because his health problems placed him in the vulnerable group. However, he wasn't worried about the virus at the time in terms of his own personal risk of becoming infected (describing himself as 'fatalistic'). Instead, his main worry was the possibility that he might pass it to others. Craig also talked about the importance he placed on staying home during the lockdown and providing care for his wife, who lives chronic fatigue syndrome and was very unwell.

One of the ways in which Craig's daily life was affected was the obstacles placed in safely accessing health professionals, both himself for his mental health, and his wife. Craig's narrative outlined an affective atmosphere similar to a 'fortress' configured with and through the health care spaces he has been accessing. While this can be confronting in terms of highlighting the risk posed by the coronavirus to people such as himself and his wife, Craig also reported feeling protected by these measures:

I've seen my psychiatrist face-to-face. That was like getting into fortress. There were people testing my temperature at the door and making me wash my hands. Again, that was no problem because I agree totally with that procedure. But you sure know there's a pandemic going on.

Though Craig described valuing solitude, he also talked about the loss of connection he felt in the absence of his local Men's Shed (a community-based hub for support and information exchange for Australian men living in regional and rural localities). For Craig, and the other men in his local community, the Shed was an important site for connectedness and belonging. He recounted missing the practical activities, jokes and 'scuttlebutt' that occurred at the Men's Shed. Craig also talked about staying in regular contact with one of the other men from the Shed who lived alone and was having treatment for cancer during COVID, giving Craig a sense of purpose in giving support to another person living with a serious illness.

In many other respects, however, Craig said that life during the

COVID crisis had been experienced and felt in positive ways. In particular, it had allowing him the time, 'quiet', space, and freedom to focus on individual pursuits, including posting on social media, writing poetry, phoning and visiting friends, household cleaning and taking care of animals. In fact, he reflected that compared to some people, his life had hardly been affected by the lockdown.

I'm an old-aged pensioner now and it just hasn't been different. We don't go out much and the sun is still shining. Holy heck at the beginning of the pandemic, there were so many butterflies in the air you couldn't believe it, particularly in [his city]. It was insanely beautiful weather, the sky was wonderful and really, I thought, 'Gee, if this is isolation, if this is a pandemic, I want some more of it!'

For Craig, his home was unambiguously a place that generated feelings of serenity, safety and contentment. The contrast between his own lived experience of lockdown restrictions and how he imagined the pandemic was negatively impacting on others in many ways allowed him the space and time to feel a sense of gratitude, and ability to focus on things that mattered to him, including human relationships, taking care of animals on his property, and appreciating the natural environment.

#### 4.5. Neville

Neville describes himself as 'white Australian' and is aged in his mid-sixties. He lives in a small rural town with his ex-partner, supported financially by a government pension. He has not worked for many years because of ill health. Neville reported that he had been living with emphysema and depression for a long time. He was also recently diagnosed with prostate cancer, for which he receives hormone and radiation therapy at a major city hospital several hours drive away from his home.

Like other participants living in rural areas, Neville described feeling a sense of security when he first heard about the COVID outbreak coming to Australia. Remoteness and the small number of people who lived in his local community, he felt, offered protection from the virus, and he therefore did not feel at risk.

I thought, well it won't come here ... [I was feeling] pretty smug really that I was living in this little country town, but a little bit on edge because of my age and my emphysema.

Despite these feelings, Neville observed that living in a 'virus-free' locality was accompanied by a greater sense of self-responsibility to 'keep the virus' out of the community, and a heightened sensitivity to the risk of leaving town. Neville described the anxiety and stress he felt when he had to make the long car journey to a major city hospital for his essential cancer treatment.

I had to go to [major city] a few times and that was always a worry. I was more concerned that I would be the one that brought it back to our little town and [infect] my partner. I didn't want to bring it back here. But I had to go.

As a way of dealing with these feelings of uncertainty and threat, Neville said that he had adopted a meticulous approach to avoid 'bringing the virus home'. He makes no stops on the 4.5-h drive and thoroughly cleans his car interior and all his possessions after every visit.

Neville's feelings were complicated by the loss of connection and loneliness associated with not being able to see the few people he had relationships with in his local community face-to-face. In this way, his locality was experienced both as a space of safety and protection but also estrangement and social disconnectedness. Neville did not enjoy remote modes of communication and saw them as offering no option for connection during lockdown.

I have a very small social life here. I've got one friend, but he's locked down in a hospital so that's made a difference there. He lives in an

aged care unit ... He rings me every day but I suppose I don't like phone calls. I like someone to ring up and say that they want something, or they rang for a reason, but not ring to chat. I don't like that sort of chat. You know, I like face-to-face chats.

For Neville, risk seems to be primarily related to the stigma and shame of introducing the coronavirus into the community. The city and its hospital, as well as the entire route along which he drives to reach these places, are sites of potential infection, generating an affective atmosphere of fear and caution. Keeping within his car and engaging in cleaning practices help him feel safer. While his home and locality were considered safe places, Neville was struggling with feelings of loneliness and isolation that he had not found satisfying ways of alleviating.

#### 4.6. Jane

At the time of her interview, Jane, self-identified as white Australian and in her late thirties, was living alone in a major city. She has been living with chronic fatigue syndrome for four years, which she described as posing a significant disruption to her ability to participate in everyday life. This included limiting her engagement in paid work, social activities and physical exercise prior to the COVID outbreak and consequent stay-at-home orders.

Jane recounted in her narrative that these limitations had meant that she has not experienced the pandemic and related restrictions as disruptive in her daily life. Instead, she described a continuation of her pre-COVID life during lockdown. Jane, who described herself as 'a disabled person' due to her chronic illness, viewed the pandemic as an equalising force as it had changed the plans and life expectations of everybody. She observed that lockdown restrictions confining people to their homes meant that everyone's ability to move in the world was now limited in ways that people living with chronic illnesses or disabilities had faced throughout their lives.

Well for me because my life was disrupted four years ago ... So I'm just adapted to a much quieter, slower life than I had before – I already have gone through the emotions of dealing with that being taken away from me.

Jane noted that her state of mind was currently focused on the present – 'a day-to-day approach to life' as she put it, rather than worrying about the future. She said that this approach helped her to cope with the uncertainties thrown up by the pandemic. Her experiences of living with a chronic illness had helped her develop this philosophical approach.

There were other ways that living in pandemic times for Jane was an improvement in her everyday living conditions and feelings of well-being. Lockdown restrictions had given her an opportunity for respite – 'a break from it all' – as she was no longer attending the many medical investigations and appointments that she had prior to the outbreak. Like many of our participants, Jane positioned her home as a space that generated feelings of safety and comfort, shielding her from the threat posed by public spaces, where she felt very vulnerable to infection: 'As a disabled person, to stay at a reasonable level of health I need this safe place'. This was a new affective atmosphere for Jane, however. Until recently, she had lived with housemates in an environment she describes as 'high conflict' and 'chaotic' due to differing views about the importance of risk-minimising practices such as handwashing in limiting risk of exposure to the virus. This created an atmosphere of high stress and worry for Jane. She thus experienced the transition to living alone very positively, explaining that this had provided her with a sense of calm, peacefulness, and ease. In contrast with people such as Neville, her solitude has not been associated with loneliness.

I thought I might be a bit more lonely than I have been, but I haven't. It's just easy ... I love going to parks and being outdoors ... I'm socialising less than I was but not much less because I already had a pretty quiet life and need to rest a lot.

Jane's narrative, therefore, highlights the beneficial dimensions of lockdown conditions for some people with pre-existing medical conditions. Jane was already accustomed to constraints on her ability to leave her home and she was content to spend time alone. Like many of the participants, she also talked about the therapeutic value of spending time in green spaces as a mode of self-care.

## 5. Discussion

Our findings contribute to existing scholarship on assemblages of health, risk, care and wellbeing in the context of the embodied and affective experiences of living with pre-existing medical conditions during the early months of the COVID-19 crisis in Australia. In compiling and presenting our case studies, we are able to provide a detailed analysis of the assemblages of human and nonhuman agents described in the participants' accounts and their role in providing support and care to combat feelings of vulnerability or isolation. Our focus has been on surfacing the complexities of each individual's narrative of their experiences, demonstrating how personal biography and embodiment (including lived experience of chronic or acute illnesses) assemble with other people and things in specific places and spaces. Our six case studies vividly highlight the complexities and dynamics of the ways that humans and nonhuman agents come together to generate feelings of health, wellbeing, safety or security, or alternatively anxiety, anger, vulnerability or discomfort. Each person recounted a unique narrative that described the coming together of several different aspects in their experiences. Yet a number of overarching and intersecting themes can also be traced across the participants' narratives: the vital contributions of lay care and self-care as part of the materialities of care, health and wellbeing; the role played by social networks, both online and in-person, for people in learning about and coping with COVID and its potential risks; previous embodied and affective experiences of illness, vulnerability and care; and the role played by place and space in generating either therapeutic or distressing affective atmospheres.

While news reporting about the pandemic and social media content were important to people's growing understanding and their assessment of how seriously they should take the risk, noticing how other people were behaving in public spaces and conversations with others in already existing social networks, such as friends, family members and neighbours were also influential. Across the case studies, participants drew on place-based stories to articulate their experiences of both safety and exclusion, each talking about how meaningful spaces in their daily lives were transformed in complex ways – with both positive and negative affects. For most people, although feelings of loneliness and social isolation sometimes crept in, the home was a therapeutic space offering safety and comfort, while by contrast, public spaces were viewed as threatening because of other people's unpredictable/risky behaviour and the invisible but palpable threat of infection that lurked therein.

It was evident from the narratives provided by Jane, Neville and Tilda that they felt much safer staying at home, although they did miss their regular social interactions. Max's pre-existing social anxiety and panic disorder improved during lockdown as he was less frequently in public spaces. Similarly, Jane, who had already experienced biographical disruption prior to COVID due to severe chronic illness, described the self-care benefits of a slower and quieter life during COVID. Craig noted that as a retired person, he already had a quiet life and control over how many people he spent time with. In many ways, his life had improved during the COVID lockdown. Theo's place of residence was the small island state of Tasmania, which eventually had been effectively secured against the entry of coronavirus infection through border controls restricting entry from people from mainland Australia. This feeling of remoteness and protection meant that Theo was able to observe other people in their city out and about and living normally, eventually giving them a sense of security and safety once the initial crisis with caring for his friend had passed. The seclusion and protection of remoteness was also experienced by Neville but was complicated by

the need to travel for cancer treatment. For Tilda, however, noticing her husband's lack of care in continuing to go into public spaces to purchase groceries brought the threat of COVID back into her home.

The spatiality of medical facilities emerged as important in the accounts of affective atmospheres for Craig, Max and Neville. Craig noticed that the spaces of health care had become far more 'serious' about the coronavirus risk. These materialities generated an affective atmosphere that made him feel safe and protected from harm in what for him was a therapeutic landscape. For Max, noticing that thermal cameras had been installed at a familiar hospital made him realise the reality of the threat, but also transformed the previously 'friendly' and emotionally comforting space to an unfamiliar and sterile one. In Neville's narrative, he noted that he experienced his trips to hospital as anxiety-producing due to his fear of becoming infected and introducing the virus into his small rural town. The landscapes through which he travelled while attending his appointments were suffused with anxiety. Jane described feelings of respite from the medicalisation of her previous life by no longer needing to attend medical appointments, so that her home and its surrounds were therapeutic landscapes in which she could engage in self-care.

We noted some parallels with pre-COVID research on the socio-materialities of health, risk, care and wellbeing as well as those focusing on life during the pandemic. McDougall and colleagues' (2018) analysis of heart failure self-care and the study on mundane acts of care by Brownlie and Spandler (2018) both found a prevailing focus on self-responsibility for protecting one's own health in neoliberal societies such as Canada and the UK. These dimensions were also evident in our Australian participants' narratives of the relational and social dimensions of living through the COVID lockdown. Participants made frequent reference to taking responsibility for protecting their own health.

Moreover, our case studies showed lived experiences of illness and vulnerability as well as expert and lay advice from others were crucial to some people's recognition and assessment of the risk posed to them by COVID as well as how they experienced being in public and private spaces. This was particularly evident for Max, whose long experience of living with HIV and supporting others helped him not only to identify and assess relevant information about the coronavirus but also act as a peer educator. For Tilda as well, a lived experience of several chronic health conditions as well as pneumonia made her particularly alert to the risks of the COVID outbreak when it first began to receive attention in the news media. While he acknowledged that he was at high risk from death if he became ill from COVID, Craig put forward a fatalistic view, in which he had simply decided to accept whatever would happen and focus on supporting his wife. In Theo's case, it was their personal relationship very early in the pandemic with someone they knew well who became ill with what was suspected COVID that led them to feel anxious. Theo was highly disappointed and frustrated by what they saw as the health system's neglect of their friend.

In-person support was also highlighted by several of our participants featured in the case studies. In Tuijt and colleagues' study (Tuijt et al., 2021), family carers took on even more responsibility for ensuring the health and wellbeing of their relatives with dementia during COVID stay-at-home restrictions. We also found that relational connections involving mundane acts of care were particularly notable as important in our participants' accounts. Friends and neighbours who lived close by as well as those who connected by phone or online became a vital source of connection, support and help during physical distancing or periods of self-isolation or anxiety. Other lay people and community health organisations were integral in supporting people's wellbeing by providing care or social connection: reminiscent of what Brownlie and Spandler (2020) describe as emotional support 'round the edges'.

Our participants also emphasised the integral role that online resources and connections with others played in educating them about the COVID risks that they faced in relation to their pre-existing condition. For them, as for the British participants with long COVID (Rushforth

et al., 2021) and people living with dementia and their family carers (Tuijt et al., 2021), online resources constituted an important therapeutic space. Several participants noted that they provided care and support to other people in their lives, such as their elderly parent, partner and friends, using both in-person and online connections. For these participants, phone calls and digital platforms like Facebook and messaging apps were ways of finding and offering information and support as well as friendship during periods of isolation during lockdown. These digital technologies therefore played a role in generating affects of health and wellbeing (see also Thompson, 2021). In some cases, however, content on social media or the views of close personal contacts were experienced as unhelpful by invalidating participants' feelings of vulnerability and anxiety. The loss of safe public spaces meant virtual spaces and private domain of the home became critical therapeutic landscapes for connection and emotional support, particularly for those struggling with loneliness and isolation during lockdown. Tilda's story brought to the fore how a household member's apparent lack of care can generate affective atmospheres of risk or a non-therapeutic landscape. Others, like Craig and Jane, experienced feelings of comfort, tranquillity and pleasure from home-based leisure pursuits, meeting up with neighbours or companionship with animals. Newly appreciating the attributes of the natural landscape in which they lived also helped to elicit better health and wellbeing: and this was particularly so for people who lived in rural environments (cf. Giraud et al., 2021; Young et al., 2020).

## 6. Concluding comments

Taken together, the six case studies we have featured demonstrate that while news or social media reporting of the emergence of the COVID pandemic played an important role in initially informing people about this new infectious disease, there were other agents involved at key points at which the participants realised that they were personally at risk from COVID. These points included observations of the features of the built and natural environment and the behaviours of other people in space and place as well as conversations with friends, family members or health practitioners. People described feeling unsafe in public places such as supermarkets or medical clinics, because of the threat of contracting COVID, but also how previously comforting spaces were transformed into spaces of estrangement, creating affective atmospheres of risk, anxiety and exclusion. This observation illustrates how the reconfiguration of a once 'safe' and familiar social space that were once experienced as comforting, inclusive and promoting a sense of belonging, can be transformed or reconfigured, evoking a different set of feelings such as fear, distress and discomfort (cf. Brownlie and Spandler, 2018; Moretti and Maturo, 2021).

We have shown how important materialities of mundane as well as medical care were for these people, including opportunities to provide care and support to others and discussions with friends or family about risk. Spatiality and observations of other people's behaviour in place and space were also integral to affective atmospheres of safety, comfort, threat or vulnerability, including in the home, the neighbourhood, the natural environment and the clinic. They highlight the sociomaterial contexts contributing to the ways that these people began to realise that they may be at risk from the coronavirus. It is in these gatherings that agencies and capacities are opened that contribute to human flourishing: including coping with COVID restrictions and maintaining health and wellbeing while also dealing with pre-existing health problems. These findings have implications for better understandings of the situated contexts of how embodied experience, affective forces and encounters and relationships with other people and with things, place and space come together in crises such as the COVID-19 pandemic.

## Author statement

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