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Lived experience of affordability as a barrier to prescription medicines: A longitudinal qualitative study

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ABSTRACT

Background: Lack of affordability is a major barrier to medicines access in many countries. It can result in ethnic and other inequities in medicines use and these have been documented in New Zealand. We aimed to understand the lived experience of barriers to accessing medicines faced by groups that are likely to encounter them, and to explore how they played out over time. This paper presents results related to affordability.

Methods: We carried out a longitudinal qualitative study, repeatedly interviewing 21 households about their lives and access to medicines, over a year. Participants were Māori, Pacific, former refugee, or Pākehā (New Zealand Europeans) with limited incomes.

Results: Many participants faced social disadvantage and many had physical and mental health problems. Often, they had busy and stressful lives, and this formed the backdrop to issues with medicines. Charges for GPs and medicines could directly prevent access, but also eroded relationships with healthcare providers, reducing acceptability of services. There could be confusion about charges, and when they were perceived as unreasonable participants felt aggrieved. At the time of the study, most (but not all) pharmacies had prescription charges, and limited financial resources drove some participants' choice of pharmacy. Some felt forced to choose between cost and physical accessibility or quality of care. Lack of affordability also interacted with other barriers to access, such as lack of transport, to prevent access to needed medications. Lack of affordability also made participants more vulnerable to the impact of small mistakes in prescribing and dispensing.

Discussion: Exploring lived experience provides insights into the multiple ways that lack of affordability prevents access to medicines: directly, through interaction with other barriers to access including transport, by damaging trust and reducing acceptability of services, and by making participants less able to deal with mistakes made by health professionals.

1. Introduction

Access to medicines is a human right¹ yet in many countries medicines are unaffordable to many people^{2,3} Affordability is one of the five dimensions of access in Levesque's model of access to healthcare⁴ and in New Zealand was identified as one of the five primary drivers of access to medicines.⁵ In high income countries, receiving a prescription medicine is at the end of a long chain of processes: people have to identify their symptoms as being amenable to medical treatment, they have to access primary care, be prescribed a medicine, take the prescription to a pharmacy, and pick up the medicine from the pharmacy and pay any associated costs.⁶ The New Zealand health system is largely publicly funded through taxation, but there are significant user charges for primary care. This is provided by (mostly) private GP practices. Patient costs vary.^{7,8} Afterhours GP visits are significantly more expensive.⁹ GP referral is needed to access specialists and hospital treatment (apart from emergencies).¹⁰ Medicines that require a doctor's prescription are usually supplied for up to three months¹¹ by a community pharmacy. At the

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time of the study, almost all incurred a \$5 (\in 2.7) charge per item for everyone 14 years of age and over. After receiving 20 items in one year, an individual or a family were supposed to be exempt from this charge (although this exemption may not have been accessed by all those entitled to it).

Affordability is only one of the potential barriers to accessing medicines. Others might include limited transport options and geographical access to care, ^{12–14} acceptability of services and lower quality interactions with healthcare providers¹² and misunderstandings and miscommunication between healthcare providers and patients. ¹⁵ People from ethnic minorities might experience racism, ^{12,16} hold beliefs about health and illness that differ from Western biomedicine, ^{12,17,18} be skeptical about the benefits of Western medicines and have concerns about side effects. ¹⁹

Lack of affordability of medicines can result in lower rates of medicines use amongst some population groups. In New Zealand, inequities in medicines use have been documented in quantitative studies²⁰⁻²³ Maori receive significantly fewer medicines than European New Zealanders²²²³ and this is also likely to be the case for Pacific peoples.²³ Patterns of use of specific medicines, such as allopurinol for gout and asthma reliever inhalers also suggest inequities.²⁴ There is no published research on refugees' medicines use in New Zealand.²⁵ However, in many countries refugees also experience significant barriers to accessing and using health services (particularly primary care)^{26,27} often due to language and communication challenges, financial hardships, difficulties in navigating health systems, transportation problems and acculturation challenges.^{25,28} Similarly, little research has been done in New Zealand on patterns of medicine use by people in poverty and how this compares with those with more material resources, although existing work suggests inequities in access.^{21,29} We have recently argued that inequities in medicines use in New Zealand are likely to be worse than reported in existing research because of problems with data.³

Although many studies have looked at affordability of medicines, few use qualitative methods.^{31–33} The aim of the study reported here was to understand the lived experience of barriers to accessing medicines faced by people in groups that are likely to encounter them, and to explore how these barriers played out over time. This paper reports on findings related to affordability.

2. Methods

We carried out a longitudinal qualitative study, following participating households over twelve months.³⁴ Households were eligible if they belonged to one of four population groups likely to experience problems accessing medicines: Pacific, Māori, refugee and Pākehā (New Zealanders of European descent) living in poverty; and someone in the household took medicines regularly.

Methods were piloted with two households struggling financially. For the full study, we recruited 6 Pacific households (of whom one dropped out of the study), 5 Māori households, 5 former refugee households, and 6 Pakēha households who were struggling financially. Participants were recruited through community organisations and networks, and healthcare providers. There was no connection between the participants, except one household included the daughter of another participant. Participants gave informed consent to participate in the study.

Our aim was to follow households for 12 months with regular face to face interviews. In reality, some households were included in the study for a slightly longer or shorter period. As well as face to face interviews, we had phone conversations and phone interviews, Zoom interviews, and used WhatsApp, text message and voice messages (where necessary with language interpreter), and WhatsApp emojis (for one participant who was not literate). We also wrote fieldnotes about our participants, their circumstances, and our interactions. The frequency of interactions varied between participants, and over time. Covid-19 and related restrictions significantly impacted the nature of our interactions. During lockdowns we kept in touch with participants using whatever means suited them best.

Each of those doing the fieldwork (the first 4 authors) were responsible for one population group (Pacific, Māori, refugee or Pākehā living in poverty) and all interaction with participant households. During interviews and interactions, we asked about people's lives and how things were going. We focussed on healthcare and medicines, but we also learnt a lot about people's lives. We sometimes assisted participants in small ways: it felt impossible to stand by when things went wrong, but we always documented this in our fieldnotes, and on many occasions we learnt more about barriers by trying to help. While our approach was not truly ethnographic (we were not usually participant observers) our long-term involvement with participants generated considerable insight into their lives.³⁵ Our small attempts to assist were consistent with a concern for reciprocity and care for participants in indigenous research ethics.³⁶

Interviews and fieldnotes were audio-recorded and transcribed, and transcripts were checked for accuracy. It was challenging to deal with the vast amount of material generated. We attempted to deal with complexity by initially writing vignettes of each of our households (analogous to Sheard and Marsh's idea of pen-portraits³⁷). These summarised our participants' histories, context and what their lives were currently like. These provided a more holistic view of our household and give rich contextual understanding to the quotes and fragments produced by more conventional analysis.

In addition, each of those doing fieldwork went through our own transcripts and, using nVivo, identified material relating to access to medicines and vaccines. This resulted in 180 pages of excerpts from our transcripts and fieldnotes on the topic of access to medicines (more than 67,000 words) and we examined this material as a group (with four of us physically present for several days). In an inductive process, we collectively searched our data for themes relating to medicines access and coded material to these themes.

In this paper we present participants' views and stories, focussing on affordability as a barrier to accessing medicines. This focus on barriers necessarily gives a very negative account of the New Zealand health system, which does not necessarily reflect the overall perceptions of participants, except perhaps the refugee participants. Names used are pseudonyms.

3. Results

3.1. Participants

Our participants' ethnicities were more complex than our inclusion criteria suggest. For example, one of the Māori households also had Tongan (Pacific) members. For the Pākehā participants facing poverty, we did not apply any criteria for defining poverty, but sought participants through services for people on low incomes (such as food banks). All but two of these households were completely dependent on government benefits for their income, and the two households with working members were also struggling financially (in part because of high healthcare costs).

At the time of joining the study our participants were 5 single person households, 2 couples living without children, 8 couples living with children, 2 households of a single adult with children, and 6 multigenerational households. Household size varied from 1 to 20 people. Most of the participants lived in small or medium sized cities (population approx. 35,000–500,000). Two households lived in a rural area, and one was in a semi-rural area.

Most of our participants had stressful lives, frequently experiencing struggles with income, housing, food, physical and mental health problems, accessing and carrying out treatments for these problems, and dealing with bureaucracy. Some also had interactions with child protection and/or the justice system, either as victims or offenders. For those living in big households, often in inadequate accommodation, every aspect of everyday life, such as meal preparation, getting children ready for school, and adults ready for work, was challenging. One household of 20 people lived in a 3-bedroom house). Lack of financial resources reduced participants' choices and reduced their ability to respond to adversity. The researchers were struck by the sheer number of challenges and hurdles the participating households dealt with in their daily lives. This sense of too much going on in people's lives formed the backdrop to problems accessing medicines.

3.2. Affordability and getting prescriptions

The cost of seeing a GP varied considerably for participants. Some participants in rural and urban areas did not have to pay. Some visited a free urban clinic staffed by volunteer GPs (two households were recruited *via* that clinic, and another happened to go there). Although they all liked the clinic and valued the service (which included free prescriptions) there was a long wait time for GP visits, especially if patients wanted to see the same GP. Another participant had left a different free GP service because of the waiting time for appointments and seeing a different GP each time. The most any participant paid to see a GP was NZ\$54 (€30). She was in paid employment, and in spite of very high healthcare costs for her and other family members, she did not qualify for any reductions in the cost of GP visits. Her son turned 14 during the study, so she then also had to start paying for GP visits and prescription charges for him. His multiple health problems added substantially to the family's health-related costs.

Cost directly drove participants' choice of doctor. One young man said:

I did used to be with another GP practice who was my family doctor from birth basically. I did like them and ... but they were very expensive, especially for me when I was a student. I'm partly employed now ... It's like \$35 for a consultation, which is just a bit too much for me to pay (Victor).

He now used the free clinic described above.

In New Zealand medicines for chronic conditions are usually prescribed for 3 months, after which time the patient needs to either see their GP or request another prescription from the GP. This is usually done by phone or, increasingly, through an online portal. Many participants complained about the cost of requesting another prescription, and this seemed to vary considerably between practices (NZ\$12 to NZ\$25 (ϵ 7–14)). Annoyance with this charge was widespread amongst participants:

But if I ring up for prescription to start up again, blimming doctor will charge me (Tipene).

Costs added an element of potential argument and conflict between patients and their GP practices. Kate had booked a doctor's appointment to get another prescription. The doctor was unwell, so the appointment was postponed and she was given a prescription in the meantime. She argued that she shouldn't have to pay the \$25(€14) fee for requesting a prescription because she had intended to get this at the appointment (which she had booked) and she didn't think she should have to pay for both the prescription and the appointment (which she still needed). When the practice asked her to pay \$25 for the prescription, she said "I blew them up. I said, no. I said I had an appointment, you know. So, she said they would wipe it. I bet you they don't." Another participant reported that previously she had paid a \$20 fee (€11) for a 3-month prescription, but now she had to request a new one every month, tripling the cost to her (Elsa). Some level of irritation about money and what would be an appropriate charge was a common theme in people's interactions with GP practices.

3.3. Affordability and getting medicines

At the time of the study, the standard prescription co-payment for almost all medicines was \$5 (\notin 2.7) per item. After an individual or

family paid for 20 items in a year, they were exempt from this copayment. Patients had to pay for any blister packing of medicines (although one refugee family reported that they got funding for this from the government agency that pays benefits), and some medicines attracted extra costs because they were not subsidised or not fully subsidised by the government.

Medicines were provided without charge to refugees when they first arrived in New Zealand. Children also got free medicines until they reached 14 years old. In both cases the transition was difficult for some participants.

Some participants received a disability allowance from the government to contribute to healthcare costs. However, this was not adequate to cover cost of healthcare, medicines and transport.

Disability Allowance is supposed to cover for medical costs and healthrelated issues. ... whether it's transport to the supermarket and back, transport to get the medications, the medications themselves, the doctor's visits, all of my costs, it works out roughly about \$80 a week. They give me \$56 a week to cover that (Stuart).

3.4. Paying for medicines at the pharmacy

The standard \$5(€2.7) charge per item was a significant cost to many, especially those taking many medicines and those who also had to pay to see their GP (most participants). Charges were concentrated at the beginning of the year (until the 20-item ceiling was reached), making them difficult to manage on a low income. One solution was to have an account with the pharmacy and pay a small amount regularly throughout the year. For example, one participant paid the pharmacy \$5 per week all year round. However, these accounts could create confusion and tension between customers and pharmacy staff. One Maori participant was in credit by a significant amount at his pharmacy, but was confused about how much. The pharmacist had asked him to stop making payments. In the past, Julie had had an account with her pharmacy but had been unable to keep up payments. She had been charged interest on the debt she owed the pharmacy, and then the pharmacist referred her to a debt collection agency who threatened to take her possessions away.

The co-payment led to tension between patients and pharmacy staff in other ways too. One participant reported paying \$40 (€22) for their eight medicines but having to return them to the pharmacy when they needed to be blister packed. The pharmacy then charged her another \$50 (€27) for a new batch of medicines plus the blister pack. Other participants reported being charged for medicines they did not want. For example, one refugee participant said.

She is for example saying to the pharmacist, "I don't need the paracetamol. I don't want to pay for this paracetamol because I don't use it." The reply of the pharmacist is, "No. I need to give you the paracetamol because it's on the prescription." Isabella says, "I have so many paracetamols that I can sell to you the paracetamol." (Isabella, through an interpreter).

For some participants, paying for medicines left little money for food and other expenses. One participant scheduled her doctor's visit and prescription pickup so that enough money would be available in her account. Others reported having little to live on after paying regular copayments. The situation was even worse for people who required unsubsidised medicines. For example, one refugee participant did not feel that her pain was taken seriously and was adequately treated by her GP and specialist. She was then prescribed an unsubsidised pain medication that was extremely expensive for her and meant that her family had to significantly reduce their food consumption and try to seek assistance from a food bank.

That was the money for groceries for the household because they had to pay for other expenses as well, electricity and water, and had to take that money away from the food to buy the medication.... it's really stressful and worrying for her, and it upsets her because it's difficult for her to give her children food to take to school. She gets really sad.. but then her children say, "It's better if you use the money for the medication" (Noor, through an interpreter).

Epi-pens (adrenaline in an auto-injector for severe allergic reactions) were also expensive and one refugee participant and one Pacific participant went without them because theirs had expired, and they were unable to afford a new one.

3.5. Co-payments affecting choice of pharmacy

At the time of the study some pharmacies had chosen, for business reasons, not to charge the standard \$5 (\notin 2.7) co-payment. Some participants lived in cities with a small number of these. In one city both free pharmacies were in the central city, and some participants expressed annoyance that they were not easily accessible to many people with low incomes.

it means the poor people suffer yet again, and the rich people can just go shop or whatever, and pick it up for free. I know we've got two places in [city] you can get it free ... There's nothing in [low income area] (Elsa).

Two participants liked the service and convenience of the free pharmacy they used. However, others preferred their local pharmacies and faced a choice between cost and service. One Pacific participant spoke very highly of the service at her local pharmacy and chose to go there even though it wasn't free. One Pākehā participant (Kate) thought she would reluctantly have to start going to a free pharmacy even though her current pharmacy was very handy for her, being next to the doctors.

Detailing one participant's experience further illustrates the limitations of "free pharmacies" within our participants' complex lives. Stuart strongly preferred his local pharmacy, who would deliver his medicines to him with no additional fee. However, the co-payment for his regular five medicines was about \$25 (€14), and when he needed a few additional medicines for an acute condition, this became unaffordable, so he tried to use a 'free' pharmacy in the neighbouring city. There was a bus, but social anxiety prevented him from using this, and a taxi would be prohibitively expensive. A neighbour collected his medicines for him but had had to make multiple trips because the medicines were not ready when expected. The pharmacy also had stock problems that meant medicines were not provided. He was very frustrated with the 'free' pharmacy and went back to using his local pharmacy, which provided much better service. However, paying co-payments left very little money for food. A refugee family also made a similar choice:

She said they used to go to [pharmacy brand] but then they are very rude there and when they tried to ask questions they are impatient and they withhold information (Isabella, through an interpreter).

Isabella reported that this pharmacy also refused to blister pack her medication. Since then, she had found a new pharmacy where she had to pay, but the staff were kind and approachable and blister packed her medication for her.

The ability of the prescription co-payment to drive pharmacy choice and the complexities of individual lives was starkly illustrated by the experience of Julie (a Pākehā participant). She had foot surgery and when discharged from hospital she was given a prescription including for an anti-coagulant, to reduce the risk of post-operative stroke. She did not realise that she had been given the prescription rather than the actual medicines until she got home. Because she could not afford the copayment her only choice was a 'free' pharmacy, which would require two visits (one to drop off and one to pick up the medicines). Unlike her regular pharmacy, they were unable to dispense the prescription while the customer waited. Her friend who had picked her up from the hospital was unable to drop off and pick up the prescription because of lack of money for petrol. In order to ensure she got the anti-coagulant the researcher picked up the prescription, took it to the pharmacy, and then picked up her medicines in the evening and delivered them to her. A similar situation arose some months later when the participant's husband was discharged from hospital, they dropped off the prescription at the 'free' pharmacy and the researcher picked it up and delivered it to them in the evening. Some months later after, another hospital discharge the same situation arose. In this case, it was further complicated by her recent suicide attempt and the need to control her access to medicines within her home. Her regular pharmacy was aware of this situation but the 'free' pharmacy, which concentrated on dispensing high volumes of prescriptions, was not.

3.6. Affordability and mistakes

Participants frequently recounted mistakes made in the process of obtaining medicines, either in the prescribing process, dispensing, or delivery. In most cases the onus was on participants themselves to fix these mistakes, so they could get the medicines they needed. For example, on a Friday, Gwen rang her medical centre and ordered a prescription. She carefully listed the medications needed to a nurse. The prescription was sent to the pharmacy close to her work (15 km from her home). Gwen drove 30 km to pick up her blister packed medicines, and when she got home, she realised that one medicine had been forgotten. She rang the medical centre, who said they would fax a prescription for the missing item to a pharmacy near her home, which stayed open late. Gwen rang that pharmacy, and they said they did not have the prescription. Gwen then rang her pharmacy, and they said they had the prescription but were closing in 10 min. They agreed to leave the medicine at the medical centre because it stayed open later. Gwen again drove 30 km to pick up the missing medicine, but the staff member implied that she had to pay a large bill that she owed them before she could get her medicine. After two 30-min round trips, having to unexpectedly pay a large bill and considerable stress, she had almost all her medicines, but still didn't have the anti-nausea pills she wanted. So, the following week she had to ring the practice about this.

Even though Gwen was relatively privileged compared to many participants (she had a job and a car) it still took considerable time and energy to obtain her medicines.

I guess what happened was I had to do the job that the doctor should have done. He should have checked to make sure that all the medication was in the blister pack and then I discovered that there was something else that I hadn't got so I had to ring back again.

She did not complain to anyone because she said:

I just think, my life is so busy with work and stuff, I don't have the time to go in. If I was retired I'd go in and I'd have them on and I'd have a big thing about it [i.e. tell them off and have an argument], but I don't have the time or the energy to actually do it so I pay or go backwards and forwards.

4. Discussion

Affordability was a significant barrier our participants experienced in accessing prescription medicines. Even small healthcare costs led to a sense of grievance and arguments that could be destructive to relationships. Affordability interacted and compounded with other barriers in the lived experience of our participants. For example, transport and affordability interacted in complex ways: lack of transport made it difficult to access 'free' pharmacies especially since this often required multiple visits. Affordability also magnified the impact of small dispensing mistakes. Lack of affordability drove people to less desirable care (eg pharmacies that cannot dispense while people wait), and reduced continuity of care, thereby exacerbating inequities.

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Although affordability has clearly been identified as a key driver of medicines access in New Zealand⁵ and affordability is one of the five dimensions of access to healthcare in the Levesque model,⁴ our study is novel in being able to capture how affordability interacts with and compounds other barriers to medicines access.

Previous studies have also identified difficulties with medicines on discharge from hospital, such as unexpected or unexplained changes to medicines leading to confusion and reducing adherence.^{38–41} Few studies mention difficulties in actually obtaining medicines after discharge.⁴¹ Leaving hospital is stressful and patients often feel unprepared for managing their care at home^{42,43} and the need to obtain and pay for medicines immediately from a community pharmacy adds to this stress.

Getting the right medicines to people requires complex inter-related systems. Both community pharmacies and (almost all) GP practices are privately owned and run in New Zealand. Both operate within complex legal requirements, and receive at least some funding from government, meaning that they must also fulfil funding rules and requirements. Patients' needs and situations differ dramatically. Therefore, minor mistakes seem to happen reasonably frequently. In our participants' experience they bore the responsibility and costs of fixing these mistakes, and they spoke of having limited capacity to do this, because of limits on their time and/or money and/or transport and/or emotional energy. Existing literature on errors focusses on harm to patient health, rather than broader concerns like this.^{44,45}

Lack of affordability of medicines clearly increases inequities. In New Zealand, the standard \$5 (€2.7) co-payment has been shown to increase hospitalisations for people with ongoing health problems living in deprived areas.⁴⁶ This study shows how the seemingly low co-payment interacts with other barriers, such as distance, to reduce access, but also how it and other charges damage relationships with healthcare providers. People with sufficient resources to simply pay for all charges as they arise do not have to have accounts with pharmacies, or arguments about who owes what; they might feel that a charge for re-ordering a prescription from a doctor is annoying or expensive, but they do not have to take this money out of the family's food budget. The study also shows that the complexity of the system and the frequency of mistakes mean that a high level of literacy and advocacy are required, further advantaging those with more resources. People with few resources often relied on family members, friends, and neighbours but often they were also struggling and had few resources.

4.1. Limitations

Although we attempted to get a diverse sample, only a small number of households were included from each population group (Pacific, Māori, refugee and Pākehā living in poverty). This does not represent all household types, or all the problems people face in accessing medicines. Although we worked with very skilled interpreters, language differences are likely to have affected refugee participants' ability to tell us their stories. It is possible that participants did not tell us some things in order to present a good account of themselves, but after repeated and sustained contact we became close to many of our participants and they shared things that they would not have otherwise. In describing interactions with healthcare providers, we only have one side of the story, we do not know the providers' experiences or perceptions, or whether treatment was appropriate. However, the stories of people like our participants are not often told in healthcare or in research; it was our aim to prioritize them.

5. Conclusion/recommendations

Affordability was a significant barrier to medicines in our study. This suggests that attempts to improve access to medicines should involve reducing financial barriers, even if they seem to be small. In New Zealand, prescription co-payments were eliminated in 2023 47 after the

fieldwork for this study was completed, but partially re-instated in mid-2024.⁴⁸ At least in theory, people with very low incomes (the equivalent of approximately 18,500€ for a single person living with others⁴⁹) no longer have to pay co-payments. Many, although not all, of the households in our study would have met this criteria. Establishing eligibility for co-payment exemption is likely to increase bureaucracy, which may further disadvantage people with few resources. There is also no exemption for people with high family health needs. We recommend that prescription co-payments be completely eliminated in New Zealand, as they have been in some other countries.⁵⁰

Lack of affordability directly reduced people's ability to afford medicines, but importantly it also eroded relationships with healthcare providers, and increased participant's vulnerability to small mistakes in prescribing and dispensing. Although small mistakes may be inevitable, we recommend that convenience for patients and families should be a priority in designing systems, to ensure good outcomes for people with limited resources (money, time etc). Ideally, people with lived experience of health inequities should be involved in co-designing userfriendly systems.

Longitudinal qualitative research allowed us to explore lived experience of barriers to accessing medicines and, in particular, the ways in which these barriers interacted. This is a useful method that could be used in other countries and with different population groups.

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CRediT authorship contribution statement

Pauline Norris: Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. Shirley Keown: Writing – review & editing, Writing – original draft, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization. Molly George: Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis. Vanda Symon: Writing – review & editing, Writing – original draft, Methodology, Investigation, Funding acquisition, Formal analysis. Rose Richards: Writing – review & editing, Methodology, Funding acquisition. Sandy Bhawan: Writing – review & editing, Methodology, Funding acquisition, Conceptualization. Lauralie Richard: Writing – review & editing, Methodology, Funding acquisition.

Declaration of competing interest

The authors have nothing to declare.

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Data availability

Ethics approval for the study was granted on the basis that the transcripts would not be available to anyone except the research team.

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