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Struggling to afford medicines: a qualitative exploration of the experiences of participants in the FreeMeds study

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ABSTRACT

Introduction. Existing research has established that some people struggle with prescription charges. This paper reports on the experiences of a sub-sample of people who participated in the FreeMeds study (a randomised controlled trial of prescription charges) about their problems paying for medicines. **Aim.** The aim of this study was to explore participants' previous experiences with paying for medicines, and the impact of receiving free medicines through the Free Meds study. **Method.** Semi-structured interviews were carried out with 23 people (21 were available for analysis), purposefully selected from the 1061 participants in the FreeMeds trial. Trial participants had to live in an area of high socio-economic deprivation (NZDep 7–10), either take medicines for diabetes and/or take anti-psychotics and/or have chronic obstructive pulmonary disease. Transcripts were analysed thematically. **Results.** Prior to being enrolled in the study, prescription charges were an important issue for many of the participants, who faced multiple health challenges. Some reported having to go without medicines until they could afford them, and many reported having to make hard choices, such as choosing which of their medicines to pick up, or choosing between medicines and other expenses like food. Echoing the quantitative results from the trial, some participants reported previous hospitalisations because of their inability to pay for and hence take, their medicines. Few participants had discussed the affordability of medicines with their doctor. Participants reported that being exempted (through the FreeMeds trial) had reduced their stress and allowed them to afford medicines they would normally have gone without. **Discussion.** The study supports the government's decision to eliminate prescription charges, to remove one barrier to health and wellbeing for people facing significant disadvantages.

Keywords: Prescription co-payments, qualitative, poverty.

Introduction

Prescription co-payments have been identified as a barrier to medicines access[1–3] which may lead to poorer health[4,5] and increased use of other services.[3,6,7] In New Zealand, in 2020, the standard prescription charge (ie the co-payment for picking up a prescription) was $5 per prescription item. (The $5 prescription charge was removed by the government on 1 July 2023.) Families or individuals were exempt after paying for 20 items within a year. Although these charges were lower than in some other countries, there were no exemptions for people with low income or high health care needs. User charges for general practitioners (GPs) also add to the financial barriers to accessing medicines. According to the New Zealand Health Survey, the number of people who reported being unable to pick up their medicines because of cost had been dropping over time, from 7.3% in 2011/12 to 3.3% in 2021/22.[8] However stark inequities were evident, with Māori, Pacific peoples and people in areas of high deprivation much more likely to report an inability to pick up medicines due to cost.[8] People with disabilities were seven times more likely to report going without medicines because of cost than those without disabilities.[8] It is likely that the prescription charge was one reason for inequities in access to medicines.[9,10]

Internationally there are only a few published qualitative studies that explore the experiences of people who cannot afford their medicines[11–13] and only one in

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WHAT GAP THIS FILLS

What is known about the topic: Even small prescription charges can prevent people from accessing medicines they need, leading to increased use of other health services. The FreeMeds randomised controlled trial found that eliminating $5 prescription charges led to a reduction in hospital use.

What this research adds: This paper provides some of the human stories of participants in the FreeMeds study. Many reported having to make changes to how they took their medicines or making choices between obtaining their medicines or other essentials. Some reported hospitalisations due to inability to afford medicines. Few participants had discussed their inability to afford medicines with their general practitioners.

New Zealand.[14] This paper presents the qualitative component of a randomised controlled trial (RCT) of prescription charges (the FreeMeds study).[15] The aim of this qualitative component was to explore participants' previous experiences with paying for medicines, and the impact of receiving free medicines through the study.

Method

Participants were selected from those in the FreeMeds study. All participants in the FreeMeds study were aged 18 years or older and lived in an area of high deprivation (NZ Dep 7–10). All took prescription medicines. Participants either had diabetes (for which they took medication) and/or took anti-psychotic medicines and/or had chronic obstructive pulmonary disease (COPD). Participants were recruited from a range of cities, towns and rural areas around New Zealand that did not have a pharmacy that provided free prescriptions. Qualitative study participants were drawn from the intervention group, who were exempted from the standard $5 per item prescription charge for 1 year as part of the study (although we accidentally included one control group participant in the qualitative study and included the data in their analysis because the responses were strikingly similar to other participants).

We used maximum variation sampling[16] to ensure that we had a balanced representation of participants: ethnicities, geographical location, age groups, gender and reason for study inclusion (condition/medicines). Selection of participants was partially informed by the notes made by recruiters and interviewers for the quantitative component of the Free Meds study. The notes considered participants who might provide information-rich accounts. In addition to this, we also randomly selected some participants who met criteria needed to ensure variation. Selection of participants was iterative: after doing some interviews, we reflected on what type of participants we were missing and then selected more. If we were unable to contact a participant, we replaced them with someone with similar characteristics.

The interview schedule was drafted based on previous research on medicines affordability[11–14] and discussed among team members. We asked about participants' life circumstances, health problems and treatments. Questions were included about whether they had been able to afford medicines in the past, if anyone had helped with this and whether they had had to make choices between medicines (or between medicines and other items of expenditure) in the past. We also asked if they had discussed medicines affordability with their GP, whether they had ever shared medicines as a way of being able to afford them, whether they knew about the exemption after 20 items and whether the FreeMeds study had made any difference.

Potential participants were initially approached via text message. We intended to do in person interviews, but COVID-19 restrictions prevented this. We used Zoom to call participants' landline or cell phone (so the interviews were audio-only). Interviews ranged from 20 min to an hour. Approximately half were carried out by PN and half by LI. Interviews were carried out between July and November 2020. Due to the then newness of Zoom to phone technology, two of the 23 interviews carried out were not recorded or the recording was lost.

The interviews were recorded in Zoom and transcribed by a professional transcribing service and undergraduate pharmacy students working on the project. Transcripts were checked for accuracy. Thematic analysis was used[17] deductively and inductively. Initial coding was based on the interview guide. We followed Braun and Clarke's six-step process of familiarising ourselves with our data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report.[17] NVivo was used to code the transcripts and coding was discussed repeatedly among the authors (LI, PN and MC) and refined. All coding was checked by a second author, while some codes were amalgamated during the process.

This qualitative part of the Free Meds study received ethics approval from Va'a o Tautai-Centre for Pacific Health under delegated authority from the University of Otago Human Ethics Committee (D20/100). Those contacted were informed that interviews were voluntary and if they chose not to be interviewed, this had no impact on their participation in the FreeMeds study or their access to the free prescription medicines. We obtained both verbal and written consent from participants. Participants were sent a $30 grocery voucher via post as an acknowledgement for their contribution and participation.

Results

Participants

Twenty-one interview transcripts were available for analysis. These interviews were with 11 males and 10 females,

between the ages of 29 and 77 years (mean age = 57 years). Nine identified as Māori, 10 as Pākehā (European) New Zealanders, one as both Māori and Pākehā and one as a Pacific ethnicity. This was roughly similar to the ethnic make-up of FreeMeds participants as a whole. Participants lived in a range of different household situations: seven lived alone, while others lived in multi-generational and large households and one was currently in emergency housing.

In the interviews, participants generally reported having poor health. As well as the condition(s) that made them eligible for the study, they reported a range of other mental and physical health problems,or example, one had had a major organ transplant. Most reported taking multiple medicines, and five had been recently hospitalised. Two participants reported having family members as their full-time caregivers due to the severe impact of their health problems. Two others lived with family members who they supported because of poor health or disability. This highlighted the considerable burden of ill-health and disability participants and their families faced.

Participants' experiences are now described under the themes: struggling to afford medicines, help with paying for medicines, informing GPs about medicines affordability, the exemption after 20 items and the impact of the FreeMeds study.

Struggling to afford medicines

Most participants reported struggling to pay for their medicines in the past. Some participants initially said that they had not struggled with affordability in the past, but then as the interview developed, they recounted times when they had not been able to pay. Only two participants did not seem to struggle with affordability, but they still needed to budget to pay for their medicines. One of these attributed her ability to pay for medicines to not having to pay rent.

Some participants reported going without medicines until they could afford them. This included one participant who reported going without insulin and other medicines for a week and another went without asthma preventers.

Many reported having to make hard choices, such as choosing which of their medicines to pick up or choosing between medicines and other expenses like food.

> Sometimes I just couldn't afford it …. I'll get one [medicine], then not the other or leave that one there for a couple of weeks until I can get that one now …. Or sometimes go without. (Participant 4)

Most participants reported having to manage their household budget, or to give up other essential household expenditures, such as food or petrol, to afford their medicines.

> I make sure that I take all what I'm supposed to take. I never mess around with this. … I'll go without something to make sure that I've got all my medicines that I need. (Participant 16)

Reducing expenditure on food and petrol and not being able to afford rent were commonly discussed. The idea of having to constantly juggle expenditure, make choices and going without was a common theme in the participants' accounts and it was clear that this was stressful for them. One participant reported taking less pain medication than prescribed so that he can pay his mortgage:

> I take pain killers every night. But during the day I just put up with it. (Participant 7)

Two participants reported sharing prescription medicines with others because of cost. Participant 4 borrowed prescription medicines from people he knew until he could afford to get his own.

> Yeah, I had to because I couldn't afford it. And I, I've also borrowed, borrowed off people I know like if I can have some of theirs. I knew what I had to take, and they had some, like metformin, glipizide, aspirin. (Participant 4)

Some participants reported previous hospitalisations because they were unable to afford their medicines. For example, Participant 10 reported that in the past, she had been unable to afford medicines for more than a week and had sometimes been admitted to a psychiatric ward due to her condition deteriorating.

Help with paying for medicines

We asked participants if they had ever received help with paying for their prescriptions. One participant said they would rather go without than ask for help. Some participants got help from family members although one said:

> Yeah, it is awkward and especially at the age that I am … and my parents don't like it, I don't blame them. (Participant 10)

Another participant had received help in the previous year from a DHB (District Health Board) initiative. Some participants reported that they had arrangements with their pharmacy when they could not afford their medicines. For example, participant 13 said:

> The chemist was very good and used to say to me, well pay half now and just come back later. It was really nice to have something like that. (Participant 13)

Others reported having an account at their pharmacy that they paid into every week, so they could easily pick up medicines when needed. Some participants had received

Disability Allowance to help with medicines costs, but they remarked on the considerable paperwork required, and how complicated and frustrating the system was to navigate.

Informing GPs about medicine affordability

Participants described varying relationships with their GPs. As described above, almost all participants had struggled to pay for medicines. Some of these had discussed this with their doctor, but more than half had not, and in two cases we were unsure whether they had or not. Those who had discussed this issue with their GP reported a range of outcomes. In one case a diabetes nurse had helped the participant by supplying items directly, in another a GP had stopped prescribing two different strengths of a drug (because this incurred two charges) and in another the GP had recommended the person enrol in our FreeMeds study. One participant reported frustrating interactions with her GP and psychologist after she said she could not afford her medicines, but they insisted that she had to, or else she would become very unwell.

The lack of discussion about medicines affordability did not necessarily indicate a poor relationship with health professionals. Some of those who had not discussed their inability to afford medicines with their GP also reported that they had good or excellent relationships with the GP. They reported a range of reasons for not discussing the issue, including embarrassment, believing it was inappropriate and the GP not asking. Participant 19 reported an excellent relationship with their GP, but despite this:

> Q: Do you get to tell him, or does he consider what you can afford and what you couldn't? A: No. I felt too embarrassed …. I just keep that to myself. (Participant 19)

Others seemed to feel that discussing this was inappropriate or unnecessary. This includes participant 23, who said:

> No, we've never gone down that track. I've just accepted whatever she has given me; I've just accepted it. I haven't really questioned it. (Participant 23)

One of the consequences of not talking to GPs about their struggles with medicines affordability is that GPs may be completely unaware that their patient is not taking some of their medicines.

> Q: So, did your doctor sometimes prescribe stuff and think that you were taking it but actually you wouldn't pick it up? A: Yeah absolutely. (Participant 3)

Exemption after 20 items

As described in the introduction, after paying the $5 charge for 20 items, people did not have to pay for the rest of the year. The findings suggest that some participants were confused about this. When we asked participants whether they knew about the exemption after 20 items, most said they had never heard of the scheme. However, during the interviews, it became clear that some participants did know about it and had used it regularly. For example, participant 13 noted this in their interview when asked about using the 20-item exemption.

> No, I haven't. [i.e. used the 20 item exemption] The reason would be that when you've reached $100 on prescription charges after that you're exempt … and all the rest of the medications from there on and for the rest of the year are free. (Participant 13)

This participant clearly knew that after $100 (20 item exemption), medicines were provided without charge. There appeared to be a lot of confusion with the participants referring to showing their 'little cards' and 'tickets' to the pharmacists when paying for their medicines, which we think refers to their Prescription Subsidy Card (issued after they pay for 20 items). However, it is also possible that they were referring to their FreeMeds Study ID cards.

The impact of FreeMeds study

Only a couple of the participants reported they did not notice a difference when their prescriptions were paid for by the FreeMeds study. Most of the participants reported being positive about having their prescriptions paid for and experienced less stress by being able to get other health care that they could not previously afford. Participant 15 spoke about being able to afford other medicines because of FreeMeds:

> I'm always up to date with most of my medications, you know like with my medications now. And I'm not skipping them just to save them. It's probably helped me get other health care stuff that I need. Like with having the reflux and that I can get other medicines as well, like indigestion tablets and I've just been able to get some footcare stuff and things like that. (Participant 15)

Another participant said it was great to be able to afford a better and healthier diet being in the FreeMeds study, and Participant 3 related that it was beneficial to have extra pain relief to help after major surgery:

> I'm really stoked my stuff was free you know, otherwise it would have been really difficult. (Participant 3)

Many participants talked about the reduction in stress when they did not have to worry about paying for their medicines. Participant 9 stated that:

> Well its helped me, not having to stress about 20 dollars, 30 dollars and all the rest of it. You know, it's true every penny helps when you are on a benefit. (Participant 9)

Discussion

Almost all of the 21 participants had experienced difficulties in paying for their medicines. They recounted going without essential medicines and sometimes suffering serious consequences as a result. They also recounted pressure on other household expenditure as a result of having to pay for medicines. Although benefits such as the Disability Allowance, DHB or PHO (Primary Health Organisation) programmes exist, these had not ensured that participants had regular access to medicines. The confusion evident in some participants' accounts illustrates some of the difficulties of the existing system of prescription charges, exemptions and assistance (such as the 20 item exemption, DHB and PHO programmes, Disability Allowance and charitable assistance). Few participants had discussed their inability to afford their medicines with their GP. Community pharmacies often helped people to access medicines by setting up accounts, as reported elsewhere.[18]

The government announced its intention to universally remove the $5 prescription charge in July 2023 in the May 2023 budget,[19] informed by the results of the FreeMeds RCT.[15] This qualitative study demonstrates that removal of charges is likely to make a significant difference to the lives of people like our participants: those in areas of high deprivation, with significant health problems. The National/ACT/New Zealand First coalition government elected later in 2023 said they will reintroduce prescription charges except for people with a SuperGold card or a Community Services card (ie those over 65 or earning a very low income).[20]

The qualitative component of the study shows the human stories behind the quantitative results of the FreeMeds study, i.e. that free prescriptions had a significant impact on hospitalisations.[15] This illustrates one of the on-going day-to-day struggles of those who live in poverty. Findings are similar to our earlier paper,[14] suggesting that although the number of people reporting problems affording medicines may have dropped,[8] the reality for some groups has not changed. The study adds to the international literature that suggests that prescription co-payments add to the financial stresses faced by disadvantaged households, and that people use a variety of health-damaging strategies in response to charges (such as reducing doses).[11–14] Sharing of medicines because of cost was mentioned only by a minority of participants, resembling the findings of studies of medicines sharing which found that cost was not a common reason for sharing.[21,22]

Limitations of this study are: the people who heard about and chose to enrol in the FreeMeds study may differ from others who did not enrol. We tried to select a diverse sample from within the FreeMeds intervention group, but our participants may have had different experiences from non-participants. However, their experiences are likely to be broadly similar to other people with low incomes experiencing on-going health problems. Some participants struggled to describe their experience clearly, for example initially reporting that they had not had difficulties affording medicines, but later describing past difficulties. Therefore, we may have under-estimated the difficulties they faced, or misinterpreted some comments.

The implications of this qualitative study add to those of the quantitative part of the FreeMeds study. They reiterate the importance of removing prescription charges for those with low incomes and high health needs. In addition, this qualitative study suggests that if charges are re-introduced for some people, the process of gaining exemptions needs to be simple and clear to avoid patient confusion. We also recommend that GPs ask patients about whether they have any problems paying for their medicines, because people are unlikely to report this voluntarily.

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Data availability. Anonymised data may be available on request from the authors.

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