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Original Research

Impact of prescription charges on people living in poverty: A qualitative study

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Abstract

Background: Prescription charges or copayments have been shown to reduce consumption of medicines. For people living in poverty, prescription charges can prevent them from getting the medicines they need, and this can result in poorer health status. Prescription charges are low in New Zealand compared to many other countries, but those living in poverty are not exempt from fees.
Objectives: The aim of this study was to explore the lived experience of people who struggle to pay prescription charges and to propose a model for how being unable to afford prescription charges might affect health.
Methods: Participants were recruited through organizations that provide services entirely or predominantly to low income persons. Semi-structured interviews were carried out with 29 people who had been identified as having problems paying for prescriptions. Approximately half of the sample population was Māori (indigenous New Zealanders). Ethical approval was obtained from the University of Otago.
Results: Participants reported having to make difficult decisions when picking up their prescription medicines. These included choosing some medicines and leaving others, such as choosing medicines for mental health rather than physical health; cutting food consumption or eating less healthy food so as to pay for medicines; or picking up medicines for children while leaving those for adults. Participants also reported strategies like reducing doses to make prescriptions last longer; and delaying picking up medicines. These led to sub-optimal dosing or interrupted treatment.
Conclusions: Even low financial barriers can have a significant impact on low income people's access to medicines and reduce the effectiveness of treatment. Not being able to afford prescription medicines may impact negatively on people's health directly by preventing access to medicines, through reducing expenditure on other items need for health, and by potentiating stigma.

Keywords: Prescription charges; Prescription copayments; Patient experiences; Poverty

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Introduction

Expenditure on pharmaceuticals has risen dramatically in many countries, putting pressure on health budgets.[1] The question of how much patients should contribute toward their medicines costs is controversial in many countries,[2–4] because studies have shown that for people on low incomes, prescription charges can prevent them from getting the medicines they need,[5–8] and this can result in poorer health status.[9–11] However, when facing fiscal difficulties governments sometimes raise prescription charges in order to reduce pressure on their health budgets.

In New Zealand, 29.7% of expenditure on pharmaceuticals is paid for out of pocket, slightly below the average for OECD countries (32.8%).[1] Almost all prescriptions written by GPs are subsidized by the government. Most are fully subsidized, and the patient pays a standard charge per prescription item.[12] There are other charges for prescriptions (such as those for unsubsidized medicines, for blister packing, for delivery to patients' homes and so forth), but this study examines only the standard prescription charge. Until the early 2000s, those on lower incomes were able to apply for a Community Services Card which entitled them to cheaper prescriptions.[13] In the Primary Health Reforms of the early 2000s, charges were dropped considerably and a new flat rate of $3 per prescription item was gradually introduced. In January 2013 this rose from NZ$3 to NZ$5.[14] This has been controversial.[15–17] The charge applies to everyone over the age of 6, no matter what their income or health status. From 2015 children under 13 will also receive free prescriptions.[18] The charge applies for the first 20 prescriptions for an individual or family per year (starting 1 Feb each year). However, there is evidence that many people continue to pay after they have already reached the payment ceiling.[19]

Although prescription charges are relatively low in New Zealand compared with some other countries, the lack of exemptions combined with New Zealand's relatively high and increasing level of income inequality mean that prescription charges can be a significant problem for people with low incomes. Income inequality rose sharply in the late 1980s and early 1990s[20] and the Gini coefficient is now 32.9.[21] New Zealand has no official poverty line, but using the fixed line measure (60% of median income) adjusted for housing costs, suggests that 15% of the total population lived in poverty in 2010.[22]

Health care has become an increasingly important driver of health status and life expectancy,[23] and lack of access to medicines may contribute to poor health status for some groups in New Zealand. There is evidence that Māori and Pacific peoples have reduced access to medicines. Metcalfe et al[24] found that when adjusted for level of need, Māori had considerably lower than expected levels of use of prescription medicines. Jatrana et al[25] found that Māori and Pacific people were more likely to report not being able to pick up a prescription because of cost. 13.6% of Maori and 15.4% of Pacific reported this, compared with 6.4% of the total population. Lower than expected rates of use of specific medicines by Māori have also been reported in a region of New Zealand.[26,27] The results for elderly people are conflicting. A pilot study suggests that some New Zealanders 65 years and older might have difficulties paying for prescription medicines and related costs.[28] However, poverty is less common amongst elderly people,[29] and Jatrana et al found that people over 65 were less likely to report cost-related deferral.[25] People with mental health problems often also have poor physical health status[30] and Jatrana et al found very high rates of deferral (32.2%) amongst people scoring very highly (30+) on the Kessler 10 scale of psychological distress.

While the impact of prescription charges on people's health and use of health care has been assessed quantitatively, there is less qualitative work on prescription charges within the broader context of the lives of those in poverty. Little is known about how charges are understood and seen by them, and how attempting to pay these charges affects other aspects of their lives, their social identity, and their ability to sustain or recover their health.[31,32] Therefore, this study aimed to explore the experiences of people who struggled to pay for their prescriptions, using a phenomenological approach, in which we tried to understand participant's experiences and life-worlds. It aimed further to propose a model of how being unable to afford prescription medicines might adversely affect health.

Methods

Semi-structured interviews were held with 29 people who were currently or who had in the past experienced problems paying for their prescriptions. Participants were recruited through organizations

that provided services to persons with low incomes or with high health needs. All organizations were located in Dunedin, and all participants lived in or near Dunedin (a provincial city in the South Island of New Zealand). One of the researchers (BM) is Māori with genealogical or Whakapapa connection to the local area. This ensured correct customary practice and local protocol (tikanga and kawa) were adhered to. All Māori participants in the second part of the project were interviewed by BM.

Ethical approval for the study was granted by the School of Pharmacy, University of Otago under delegated authority from the University of Otago Human Ethics Committee.

Interviews were held over two summers: between December 2012 – January 2013, around the time that prescription charges were raised (1 January 2013) and between December 2013 – January 2014. An interview schedule was developed to ask about participants' health problems and the medicines they used, and to explore their experiences of prescription charges, whether they had received any assistance for their health care expenses, choices they made between medicines, and choices between medicines and other items of expenditure (Appendix).

Most interviews were carried out at the health service providers' premises while some were in people's homes. They tended to be short, especially when they were carried out at the health service providers' premises. The interviewers introduced themselves and the study first, and then started recording the interview. The recorded interviews were 3–64 min long, with a mean of 13 min. Participants were given a $40 grocery voucher to thank them for their participation.

A thematic approach was taken to analysis. Most themes were developed a priori, based on prior reading and the study's research questions. Some themes arose inductively from the data: either in the process of carrying out the interview, listening to tapes, or reading and re-reading transcripts. Themes were discussed between three authors before coding commenced. Transcripts were coded using NVivo, and assignment of codes was discussed between two authors. Any disagreements were resolved through discussion.

Results

Twenty-nine participants were interviewed. Twenty-one were female, and eight were male. Participants' ages ranged from 19 to 72, with an average age of 45 years. Approximately half of the participants were New Zealand European (13 people) and half were Māori (14 people). Most participants' income came from some form of government support: two were on age-based pensions, 17 on other benefits (mostly because of physical or mental illness and inability to work). Some did voluntary work to keep up their work fitness and get experience to help with eventually getting a job. Three had a mixture of benefits and work, two were in full-time work, two in part-time work, and three reliant on partner's income from paid work.

Most participants reported having multiple health problems for which they took medicines, including mental and physical, chronic, and acute problems. The number of medicines taken ranged from 1 to more than 10, but most participants were at the higher rather than lower end of this range.

Living in poverty

The main reasons why participants found themselves in poverty seemed to be health problems (either mental and/or physical), or loss of a job and inability to find another. Their accounts of their lives were full of references to "going without" and "making sacrifices." Participants commented that other people, including politicians, do not understand what it is like to be poor. They had a sense that the reality of their lives was invisible to others:

> *They can't possibly imagine the difference a hundred dollars makes. They just can't imagine what it does. Cause I used to be like that. I used to have no understanding of what it was like to be poor. But I do now. It's horrible … Really horrible (interview 17)*

Difficult personal relationships appeared to be impairing some people's ability to get income support they were entitled to. One participant was supposed to have access to money inherited from his parents but another family member controlled this and did not always agree to let him have it. Therefore his only regular income was a fraction of a benefit (the benefit level took into account payments he should have received from the inheritance). He lived in a boarding house and reported frequently going without food for long periods of time. One woman's children lived with her part of the week, so government income support agency said she should get food

money from her ex-partner for them, but he refused to pay it.

> *It's frustrating because I keep going into WINZ [Work and Income New Zealand] and I keep saying, look you keep telling me to get help from my ex, but he just won't, and I still have to feed the kids you know. I can't feed them on fresh air (interview 12)*

Paying for health care

Some of the participants used a free health care service staffed part-time by voluntary GPs and other staff. The rest reported poor access to primary health care because of GP charges. Participants reported doctors' charges to be around $30–$46 per visit, $15 for a faxed prescription, and $20 for a prescription in response to a phone call. One participant had been asked not to go back to his/her doctor because of problems paying bills. Some put up with painful and/or serious conditions because they could not afford to see a doctor:

> *I've torn a cruciate ligament, and I can't go to the doctor to get it looked at because it's $46, and I don't have $46 (interview 17)*

Costs of medicines

When talking about prescription charges, although the standard charge is $5 per item, participants understandably tended to multiply these by the number of prescription items they or their families got. For them the 2013 increase was not just from $3 to $5. Participants spoke of regular costs of around $35 to around $75, which were completely beyond their ability to pay. One woman had been working with a budget advisor who said she could afford $5 a week for medicines. She faced a regular cost of $50 when she picked up her 10 items. For some there were additional costs for medicines not fully subsidized.

For those receiving income support from the government, extra money for prescription medicines is available through a Disability Allowance. Some participants received very small amounts of money for this. However, this was paid weekly throughout the year whereas the prescription charges system meant that people's expenditure for medicines was concentrated in the first part of the year (until they reached the 20 item payment ceiling).

Approximately one-third of participants did not know that they should be exempted from the prescription charge after 20 items. Some did not know about it at all, and some knew about it but did not realize that it applied to a family rather than an individual. Many reported going to more than one pharmacy (so the pharmacy staff are likely to have been unaware when they were entitled to the exemption), and some claimed that they did not get the exemption even though they went regularly to one pharmacy. Some of these may have been receiving unsubsidized or partially subsidized medicines (which they still have to pay for) but others appeared to still be paying the standard charge, from which they should be exempt. One participant pointed out how difficult it can be for people with mental health problems and for people on a lot of medicines to keep track of receipts and take them to one pharmacy to get an exemption card, and then to keep this for future prescriptions. Those who got the exemption were grateful to be told by pharmacists about it, and once they got the card, felt the system worked well. Others mentioned that the problem was being able to afford 20 items so as to reach the limit.

Strategies for paying for medicines

Selecting amongst medicines on a prescription

Some participants managed to afford to pick up all their medicines at least most of the time. However, for those who couldn't, one of the major strategies used was to prioritize their medicines and collect only those they could afford. Several participants reported prioritizing medicines for mental health (usually anti-psychotics or anti-depressants) over those for physical health. These participants felt that staying mentally well was more crucial for their well-being than being physically well.

The participant with cancer gave up his cancer treatment on one occasion, but his doctor scolded him and said he should go without his anti-depressants instead. However the anti-depressants were much cheaper (so did not solve the financial problem), and also he felt he really needed them.

> *Like I know I could do without the anti-depressants. … I can, but I can't. It's the quetiapine, my anxiety is the worst. And I know I need that, and I can't give up (interview 11)*

Another participant went without anti-epileptics in favor of anti-depressants and put up with resulting seizures.

I usually, if I'm at home, I usually get warning signals, from, you know with enough time to get home and just let it happen and get myself up and go to bed and sleep (interview 12)

Another reported having gone without pain relief, migraine preventative, and aspirin (in spite of having "a couple of heart turns") to be able to afford anti-depressants. Another also reported going without pain relief after an accident because of the need to prioritize anti-depressants. A participant with severe asthma reported that she always picked up her steroids but had gone without Seretide (fluticasone) in the past because she could not afford it, and also levothyroxine for a month. Participants reported prioritizing medicine for children first if there were prescriptions for adults and children

Kids first. Like if I have to wait for my script, I will wait for next week or next fortnight or whatever, so long as the kids have you know, what they need (interview 21)

Sometimes when people prioritized they later went back to get the other medicines (with or without a break) but sometimes they did not:

Some prescriptions, depending on what they are, can be up to 40, $50 so we only get like a couple of things at a time, and then go back when we've got the money, but most often … we don't go back for the rest (interview 24)

This participant said she would choose asthma inhalers over antibiotics if she had a chest infection. One participant said they could no longer afford any medicines and when they got a prescription they would "biff it in the bin" (interview 27).

Other strategies

The other commonly reported strategy was staggering picking up; i.e. picking up one medicine at a time to avoid all the charges at once (two participants managed to do this at least for medicines they considered essential before the medicines were actually needed).

Very few people talked about saving up for doctors and prescriptions: most had no money for this. One had a cookie jar for change and all change went into this for medicines. Another strategy reported by a couple of participants was to reduce the frequency of medicines taking.

I couldn't pay another $35 prescription charge. It's just a wee bit too high for me. So I've had to sort of cut back on stuff, like maybe take some medications every second day instead of every day, yep (interview 4)

Sacrifices in order to afford medicines

Food was the most common item participants reported going without in order to get their medicines. They reported going without food, cutting down on food and switching to cheaper food: such as noodles, baked beans, chips, and "real basic food" (such as bread, milk, margarine):

I just don't eat. I'll just go and buy a cheap thing. And I'll just, I'll just measure out, ok, I really need these pills, so I say: right, I can eat this for a week, and it may be bread, for a week … .. I'll choose not to eat or I'll choose to go to someone else's place to eat (interview 26)

Some pointed out the adverse effects of this sort of diet on their health. Those with children frequently reported prioritizing food for children over food for adults:

There's days that I don't eat 'cos my son comes first (interview 11)

One participant calculated that $25 for 5 prescription items would feed her family of five for their main meal for two or three nights. Some Māori participants said they lived a subsistence lifestyle:

We get kai (food) from our cousins, who have got fishing boats down there on the wharf, and we grow our own vegetables, and so we live, you know, really a subsistence existence, really (interview 17)

Not all Māori participants mentioned these, but there was a marked difference between the Māori and the other participants, only one of whom mentioned gardens or fishing or gathering food. Most of the non-Māori participants seemed to live in rental accommodation without access to gardens and did not report knowing people who caught or gathered food. The one who mentioned gardening struggled to do this because of a steep garden and health problems.

Other sacrifices participants made in order to pay for their medicines included cutting down on electricity use, delaying paying power bills (which sometimes led to disconnection), buying fewer nappies for children, delaying mortgage repayments (and incurring fees because of this), delaying paying rent, and wearing clothes longer to cut down on laundry detergent and electricity.

Some participants were aware that they were in a catch-22 situation where the consequences of either choice were bad.

> *I don't like to relent on my power, because I need heat and my power bills are horrific because of my illness … I cannot freeze. Because I will get sick. And if I get sick, I need pills, and if I need pills, I have to pay a bill (interview 26)*

Assistance from others

Community pharmacies often helped participants by allowing delayed payment. Some participants mentioned specific pharmacists who would provide medicines whether or not people could afford them. They occasionally reported being in significant debt to these pharmacies but still receiving medicines. They spoke very highly of these pharmacists, but felt uncomfortable with being in debt, particularly because their low incomes made paying back the debt very difficult:

> *Interviewer: So they just, they just kept, the pharmacy just kept giving you the medicines even though …*
>
> *Participant: Yeah, Mr. [name]'s like that, but he'll do anything for you (interview 1)*

Other participants reported less accommodating pharmacists:

> *They kinda like the money right then and there (interview 12)*

One participant reported that their pharmacy would dispense one and a half months supply for half the price, and then s/he would go back and pay the rest and get the other half of the 3 month supply.

Although not explored in depth, there seemed to be little awareness amongst prescribers about the problems people had paying for their medicines.

Participants received assistance from the organizations that referred the investigators to them. Budget managers had been appointed for two participants who had had financial problems in the past. Under this system their benefit payments went to the budget manager, who arranged for the payment of essential bills, leaving only a small amount for the participants. This removed the need to pay for prescriptions at the point of dispensing and ensured that a regular supply of medicines was possible. For example, for one woman, the budget manager had arranged with the pharmacy that they would regularly be paid $7 per week for all her prescription items. The budget manager had looked after her finances for two years and at the time of the interview she owed the pharmacy $30.

Many participants received occasional or regular help from family and friends. One woman reported that her mother had brought her meat this week, and her friends took her into town to save her bus fare. She also went round to friends' for dinner and often got lunch at the health center. Talking about her friends, she said

> *It's just like, you know it's just amazing people like that, that is the only reason I can survive really (interview 12)*

Another woman's grown up children sent money when possible and paid for her to study for a qualification so that she could work to increase her income. Family members such as an ex-partner, sisters, mothers and fathers were reported to have helped pay for medicines, especially for children. One participant said a public health nurse had paid for her children to go to the doctor. It is unclear whether this was part of her formal role or if it was done informally. If it was the latter, it is one of several examples of people in formal positions who went out of their way to informally assist people who could not afford health care. Other examples included pharmacists and staff at the free health center who also brought food in to work and helped participants in other ways.

Pride and shame

Mana, dignity, pride and shame were seldom explicitly discussed in interviews but were a subtext to many discussions. Participants seemed to value self-reliance and those who managed to pay for their medicines were proud of the strategies they used to manage to do this. One participant reported refusing the pharmacy's offer to give him his medicines without charge:

> *Mum brought us up not to just take (interview 2)*

The result of this was that he went without an anti-psychotic for some weeks. Another participant said she does not tell her doctor that she can't afford her medicines:

> *I tell my doctor what he needs to know about my illness, I do not tell my doctor how I pay my bills at all. 'Cause number 1, it's none of his business. And number 2 I still have pride … (interview 26)*

Living in poverty was a source of shame, in private and particularly when it was revealed in public.

> *I've just been to the supermarket and I had to borrow $2 out of my son's wallet and now I just feel like crying 'cos I'm thinking, I had to you know, I had to use $2 of my son's money … (interview 12)*

One participant who was too physically unwell to work was uncomfortable with his partner working while he recuperated:

> *'Cause I don't even want to leave the lady to bring in the money to pay for the bills, and things like that, you know, I want to help as well (interview 29)*

Another said she was "so ashamed" when she had to go to Work and Income New Zealand (WINZ) for help, after running out of money while studying. Prescription charges sometimes exposed participant's poverty to pharmacy staff and other customers in the pharmacy. One participant described this eloquently:

> *I remember I went to the chemist, and I had $3 and I thought it was $3 and they said $6 and I stood there, and then the sweat starts, and there's other people, and you think oh, you feel like a, scum, low life, you haven't even got 6 bucks, you know? … With anxiety, it's bad enough as it is, going to get them, you know? And when you don't have the right, or you think you've got the right amount of money, and you don't, and there's people in the shop, and you think oh, they'll think "what is this idiot? He's just trying to get his, you know? He can't even afford six dollars, you know?" (interview 2)*

This participant, and some others, found it difficult to go to the pharmacy to pick up their medicines regularly, and the stress of potentially not being able to afford them, and being exposed in this way, added to their difficulties.

Prescription charge increases

One group of participants was interviewed just before prescription charges rose from $3 to $5 per item. They predicted that the increase in charges would lead to more intense versions of the strategies they had already developed: such as not picking up medicines, delaying picking them up, prioritizing the "more important" medicines, reducing food expenditure etc. They expressed concern, frustration and resignation. The other group were interviewed a year later and they were asked what difference the change had made. They reported that they had had to intensify previous strategies, and some participants who had not previous had problems reported that they now did:

> *I've never had to wait to get medicine before, but now that there's that extra charge, oh I'll just get mine next week, or in a couple of days or whatever. Whereas I never used to have to do that (interview 21)*

Discussion

Unaffordable prescription charges seemed to negatively affect participants' health in several ways. Firstly and most directly charges sometimes stopped participants from receiving medicines they needed. For some people with mental health problems who already struggled with adherence, they formed another barrier to adherence Secondly, they forced participants to make health-damaging choices such as switching to less healthy, cheaper, food in order to afford their medicines. Thirdly, they undermined people's sense of pride and self-respect. These are represented in Fig. 1, where poverty causes ill-health

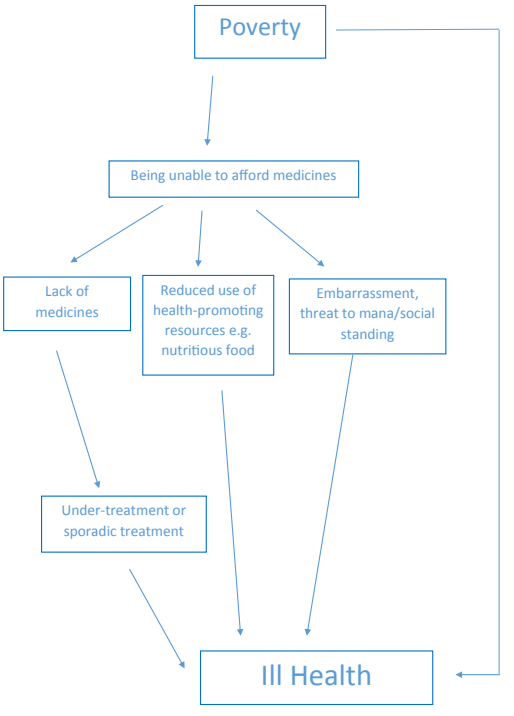

Fig. 1. Impact of being unable to afford prescription medicines.

both directly, and through being unable to afford prescription medicines.

There seemed to be several ways in which some participants were not getting the assistance they were entitled to, or the system for providing assistance was not well designed. These were entitlements to income support (which at least two participants were not receiving because of difficult personal relationships), to extra funding for medicines (through the Disability Allowance), and to free medicines (i.e. exemption from the standard prescription charge) after 20 items. Participants received help from family, friends, from pharmacists and from other health care workers acting unofficially alongside their official capacity. Participants who received this help were very grateful, but this does raise the question of how people without such relationships and networks, or whose mental illness has led to alienation from them, manage.

The study relied on organizations to identify potential participants, and on participants' self-report of their situation. Organizations may have chosen people who they knew had severe financial difficulties. However the study does not purport to be a representative sample of low income people. We deliberately selected people who have experienced difficulties paying for prescriptions. There is no reason to think that the stories participants presented were inaccurate. Other researchers have described the characteristics of patients from one of the clinics who assisted us and found widespread hardship and low health status.[33,34] Participants did not have any incentive to exaggerate their difficulties, and they may in fact have down-played these in order to protect their self-image. In retrospect, the investigators could have asked participants more about whether their GPs knew of their problems paying for medicines. This is important, because if GPs are not aware of this, they cannot adapt their prescribing or advise patients to get the best outcomes, and may not see the need to lobby for reduced prescription charges for people on low incomes. This should be explored in future research.

Few other studies have looked at how people afford their medicines and none have developed a model of how being unable to afford medicines might affect health. Atella et al. also found that people in Italy and the UK reported delaying picking up prescriptions, prioritizing some medicines over others, reducing doses[35] Schafheutle et al, based on UK data, also reported that patients sometimes asked GPs to prescribe for longer periods, or asked advice about cheaper products to buy if they could not afford a prescription.[32] It was difficult to find other qualitative studies on this topic. Schafheutle interviewed people in the UK with asthma and found that participants used some of the same strategies our participants did to manage prescription charges.[31] In the UK many of the people in our study would have been exempted from prescription charges.

In New Zealand, Barnett[36,37] looked at how people dealt with user charges for primary care, and found that delaying or avoiding picking up prescription medicines was common, as were other strategies we found, such as going without other necessities such as food. Many of the participants in this study reported going without food, or changing to less nutritious, cheaper food in order to afford their medicines. Food security has been defined as "the assured ability to acquire nutritionally adequate and safe food that meets cultural needs, and has been acquired in a socially acceptable way." Carter et al reported that 15% of the New Zealand population experienced food insecurity.[38] Previous studies have linked lack of food security to a range of negative health outcomes.[38] Other participants talked about reducing electricity use, or getting into debt. All of these strategies are likely to increase stress and threaten health status.

The current study identified an important but sometimes overlooked aspect of charges for health care, i.e. the impact on people's Mana (pride/social esteem), and the stigma associated with not being able to pay for essential items. This is particularly an issue in community pharmacies, which are relatively public places. In Canada, Wilton argued that poverty amongst people with serious mental health problems living in residential care facilities acted as a barrier to social integration, lowering self-esteem and preventing participation in society.[39]

According to New Zealand Treasury estimates, exempting low income people (those with Community Services Cards) from prescription charges would cost about $22–$27 million a year.[40] However, the financial impact of people going without important medicines, or having to make health-threatening changes to other aspects of their lives in order to afford their medicines has not been estimated.

Many people do not take their medicines regularly and continuously, irrespective of prescription charges. For people with mental health problems there can be extra problems because of

problematic side effects, social anxiety making it difficult to go to GPs and pharmacies, and concerns about their medicines. Prescription charges erect another unnecessary barrier to continuous medicines taking.

Conclusion

Even low financial barriers can have a significant impact on low income people's access to medicines and reduce the effectiveness of treatment. They may also reduce health status through their effects on reducing consumption of other health-promoting resources and through potentiating stigma.

Acknowledgment

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Supplementary data

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