Trials

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Exploring patient perspectives on the impact of resuming cost sharing: a qualitative analysis

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Abstract

Introduction The ACCESS trial showed that those who received a copayment elimination benefit had a modest improvement in their adherence to medications, but no improvement in clinical outcomes. This is consistent with other studies that have demonstrated that time-limited copayment elimination was welcomed by participants. However, the removal of such benefits can be problematic, as participants may have become accustomed to receiving the benefit, and made changes to their spending that would need to be reconsidered. We aimed to explore participants' experience with resuming cost sharing for their medications at the end of the ACCESS trial and if this experience influenced their willingness to participate in future trials like ACCESS.

Methods We conducted semi-structured interviews with 21 former participants of the ACCESS trial who were receiving the copayment elimination intervention, with discussions focused on the loss of the copayment elimination. The interviews were recorded, transcribed, and analyzed in duplicate using thematic analysis.

Results Four primary themes emerged from the analysis, including emotionality regarding loss of benefits; notification of benefit termination, describing tangible losses from coverage ending, but resistance to acknowledging negative impacts; and acceptability of receiving a temporary financial benefit. Many participants described negative emotions around the loss of coverage and concern about affording care for their chronic diseases. Despite negative emotions about the end of their study benefit, participants generally had a positive view of the study and would participate again in a future study of this nature.

Conclusion The positive tangible and emotional benefits of the copayment elimination over 3 years outweighed the negative emotions and impacts associated with having to become reaccustomed to life without it.

Patient and public contribution Within the ACCESS trial, participants were involved in the design, modification, and implementation of the program using multiple focus groups. The current study aimed to engage patients to provide input on their experience and engagement with the copayment elimination program.

Keywords Chronic disease, Cardiovascular prevention, Copayment elimination, Qualitative research

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Background

Many experimental studies trial different interventions to optimize individual and population health. An important, and often forgotten, factor of interventional research is what occurs when a study comes to an end. At times, this includes study interventions such as financial or other incentives for new medications or programs designed to improve health. When data has been collected and a study intervention has come to an end, researchers move on to subsequent projects, and participants are expected to move on as well. However, if an intervention is well-received by participants, the removal of the intervention may cause distress; this may occur especially in the case of unique studies which evaluate financial interventions, which could potentially lead participants to budget differently during the study period. This raises the concern that when the financial benefit is lost, lower-income participants may experience financial or emotional hardship that may make participants less inclined to participate in future studies. However, studies involving financial interventions can be informative in guiding necessary changes to health and social policies.

Currently, older adults (65 +) in Alberta, Canada, pay a copayment of 30% up to $25 for each prescription drug listed on the Alberta Drug Benefit List [1]. In Canada, approximately 80% of people diagnosed with cardiovascular-related conditions reported spending at least 5% of their household income on prescription medication and pharmaceutical products [2, 3]. Critically, a 2012 survey found that those reporting a financial barrier to medications are three times more likely to stop using prescribed medications [3]. This phenomenon is often referred to as cost-related non-adherence. Previous studies have shown that access to more comprehensive drug insurance can increase the use of preventative medications in individuals diagnosed with cardiovascular conditions, resulting in improved clinical outcomes [4–6].

The *A*ssessing outcomes of enhanced *C*hronic disease *C*are through patient *E*ducation and a value-ba*S*ed formulary *S*tudy (ACCESS) (Clinicaltrials.gov #: NCT02579655) [7] was a randomized controlled trial in Alberta, Canada, which tested the impact of eliminating patient-borne copayments for high-value medications that treat and prevent the progression of cardiovascular conditions. These include but are not limited to, antihypertensive, antihyperglycemic, antiplatelet, and cholesterol-lowering medications (Appendix 1). The study benefit was provided for the duration of the study (36 months). Eligible participants were older adults (65 +), with an annual household income < $50 000, and at high risk of cardiovascular events (diagnosis of any one of chronic kidney disease, coronary artery disease, heart failure, or stroke or at least two of diabetes, high cholesterol, high blood pressure or smoking) who were recruited in the community [8, 9].

Upon completion of the trial, participants' medication coverage reverted to the default in Alberta for those aged 65 +, a premium-free government-sponsored insurance that requires a 30% copayment on medication costs. The results showed that the rate of cardiovascular-related hospitalizations and deaths did not differ between those who received the additional coverage and those who did not over the course of the trial, in spite of modestly improved adherence (ranging from 3 to 5% in the proportion of days covered) across several classes of indicated cardioprotective medications [10]. The fact that adherence increased suggests it may be the case that those who lost the study benefit and returned to regular insurance at the end of the study may have been adversely affected. Even if participants were not harmed from a health outcomes perspective, they certainly lost a financial benefit that was seemingly providing value.

Our objectives were to explore the impact, tangible and emotional, of the medication benefit loss on the participants, whether the drawbacks of losing the benefit outweighed the positives of taking part in the study in the first place, and if the experience impacted their view on participating in research overall.

Methods

Study design

A qualitative descriptive approach was chosen for this study to allow for rich data to be conveyed in participants' own words, particularly because we were investigating a sensitive and personal topic, like the emotional impact of losing the study benefit [11].

Data collection

Semi-structured interviews were used to explore participants' experience with losing the copayment elimination benefit at the end of the ACCESS study and if this experience would influence their willingness to participate in future trials. Only participants who received exclusively the copayment elimination benefit were eligible to participate in this study (i.e., not those who solely received the self-management support intervention, nor those who received both interventions). Within this group, we further used purposive sampling to ensure that we collected data from a broad range of study participants. Specifically, the sampling criteria included speaking with those who identified as men and women, those with varying levels of income at baseline (< $15,000 CAD, $15–30,000 CAD, and > $30,000 CAD), those with and without stated financial barriers at baseline, and the number of prescribed medications at baseline (0, 1–3, 4–6, 6 +)—as a marker of likely level of benefit from the intervention. A

question guide was used to ensure similar material was covered during each interview (Appendix 2). Interviews were conducted over the phone by author ST, a female doctoral student. The interviewer was introduced as a researcher at the University of Calgary working under the supervision of author DJTC. Participants were informed of the purpose of the interviews, the proceedings were recorded, and a professional transcriptionist transcribed each recording. The duration of each interview ranged from 45 to 60 min.

Data analysis

Interview transcripts were imported into NVivo 12 software. Analysis was undertaken by three independent reviewers (ST, BM, JF). The first three interviews were independently coded by all three reviewers. Thereafter, two of the three reviewers independently coded each interview transcript, and all coders met to discuss each transcript. During the meeting, the coders would discuss any discrepancies in coding and whether or not nodes needed to be created, recoded, or reorganized. A fourth reviewer would join the discussion when discrepancies were significant (DJTC). Inductive thematic analysis approaches were used to code the transcripts. A preliminary coding template based on the interview guides was initially used. Codes were inductively added until saturation (55 items). That is, while 15 interviews were initially conducted, more participants were interviewed until no new themes or codes emerged from the data, indicating that no new information or relationships were emerging. During focused coding, reviewers (JF, ST) re-examined all 55 items to further collapse codes based on semantic similarity (e.g., a similar meaning was captured by another node). The reviewers iteratively collapsed nodes until all items were agreed to be reasonably distinct from one another. All codes were eventually amalgamated into four broad themes (25 items).

Results

We conducted interviews with 21 participants out of 39 contacted, all of whom had received the ACCESS copayment elimination intervention, completing the 3-year intervention period between 7 and 9 months before the interview. There was roughly an even split of men and women, those who described perceiving financial barriers to chronic disease care at baseline, and those who did not. A diversity of income levels, within the range for inclusion in ACCESS, was reported by study participants (Table 1). Other characteristics, which were not specifically and purposively sampled, were less balanced.

Our inductive thematic analysis yielded four primary themes: (1) emotionality regarding loss of benefits, (2) notification of benefit termination, (3) describing

Table 1 Participant demographics

Age	65–70 years	10
	71–80 years	8
	> 80 years	3
Gender	Woman	11
	Man	10
Ethnicity	First Nations/Inuit/Metis	2
	Caucasian/White	18
	Visible Minority	1
Born in Canada	Yes	20
	No	1
Household income	Less than $15,00	6
	$15,000–$29,000	8
	$30,000–$50,000	7
First language	English	19
	Other	2
Highest level of education	Less than high school	3
	High school	4
	Some post-secondary	9
	Post-secondary or higher	5
Health literacy[a]	Adequate	16
	Inadequate	5
Number living in household	1	5
	2	12
	3 +	4
Living environment	Rural	17
	Urban	4
Marital status	Married/common-law	12
	Divorced/separated	4
	Widowed	5
Financial barriers	Yes	10
	No	11
Barriers to accessing providers	Yes	3
	No	18
Number of medications at baseline	0	1
	1–3	6
	4–6	6
	6 +	8
Chronic conditions	Coronary heart disease	8
	Diabetes	11
	Chronic kidney disease	4
	Stroke	4
	Heart failure	8
	High blood pressure	18
	High cholesterol	16
	Current smoker	5

[a] Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. *Fam Med*. 2004;36(8):588–594

tangible losses from coverage ending, but resistance to acknowledging negative impacts, and (4) acceptability of receiving a temporary financial benefit.

Theme 1: emotionality regarding loss of benefits

When asked about the end of their copayment elimination benefit, more than half of the participants expressed a range of negative emotions (disappointed, stressed, shocked, etc.). While there were negative emotions associated with the loss of coverage, there was also a sense of resignation among many participants. When asked about the loss of their copayment elimination benefit, many participants also reported that they "…took it with a grain of salt and just paid the bill, that's it" (Participant 1, 73-year-old woman). Essentially, these participants appreciated the coverage while it lasted and resignedly understood that there was no alternative to resuming out-of-pocket payment for their copayments. As Participant 2 (68-year-old woman) states "No, I really appreciated the time I had. Like I said, I was sorry it ended, but everything's got to end sometime I guess."

Most participants' primary concern was how they were going to manage the resumption of copayments, with many upset about the loss of the copayment coverage. As Participant 3 (72-year-old woman) describes "I don't know, I just felt, poof, like I just wanted to leave the drugstore and forget about ever taking pills again." Many participants described how they had become dependent upon the additional coverage and were concerned about how they would continue to pay for their medications and other related health expenses now that they had resumed covering their copayments. Participant 4 (66-year-old woman) stated: "So far, we are still ok. I still flinch a little when I have to go and fill prescriptions now because I know, I go in usually with all of them at once and I know there's going to be a 100 and some dollars out of my pocket." Given that many participants espoused the belief that medication adherence should be prioritized above all else, being faced with resuming copayments seems to have fostered a sense of helplessness in some participants. As Participant 5 (75-year-old man) describes "I can't do anything you know…We are paralyzed here." Unsurprisingly, most participants reported uncertainty when planning for their financial future. Participants expressed a general concern about their inability to afford medications in the future or that a financial or health-related setback would lead them to financial ruin. One Participant stated "[It makes me feel] bad in a sense, frustrated, you can't do anything about it. You just can't do anything about it, right. We only buy necessities, right, you've got to buy necessities. We don't save any money really." (Participant 6, 70-year-old woman).

Theme 2: notification of benefit termination

A letter indicating the end of their copayment benefit was sent to participants a month before its end date. Unfortunately, nearly half of the participants reported not receiving the letter (or at least that they had no recollection of receiving this letter). Of those who remembered receiving the letter, several participants still reported that they would benefit from more frequent or earlier reminders of the benefit's termination. Almost all the participants that received the notice reported uncertainties when planning for their financial future. In addition, more than half reported negative emotions, such as shock or being upset over the loss of their benefit. The notice of the coverage ending seemed to have elicited similar feelings to its actual termination. As Participant 7 (76-year-old man) explains "Well, I guess there was a certain amount of disappointment, but like I say, I have mentally prepared myself for it that it was going to come, but at the same time a person always says, boy it would have been nice if it would have gone a little bit longer and that's just the way things were, I knew was going to end, so."

Unsurprisingly, half of those that did not receive or did not remember receiving the letter wanted alternatives to the letter such as a phone call to ensure that participants were adequately notified. When queried, participants also suggested earlier or more frequent reminders. A majority of those that were not notified also reported having feelings of uncertainty regarding planning for the end of the coverage. In comparison to the group that was notified about the termination of the benefit, a greater number of uncertainties about planning for the future were reported by participants that were not notified. Further, a greater proportion of the participants who did not receive the letter also reported being surprised by the loss of coverage. As Participant 6 (70-year-old woman) describes "We were wondering why it went up so much in sort of short space of time, but yeah the drugstore didn't tell us that. Yes, and then we just said, we have to suck it up because there's nothing we can do. Your medication take priority over everything else. Yeah, we had to buy less consumables you know. Plus, only because we didn't know why the insurance, why the medication went up so quickly, you know."

Theme 3: describing tangible losses from coverage ending, but resistance to acknowledging negative impacts

In addition to the emotional impact described in Theme 1, many participants also recounted tangible losses associated with the end of their copayment elimination benefit. Participants recounted that they had noticed improvements in their health awareness, ability to adhere to medication regimens, and overall health while

receiving the benefit. Subsequently, after the cessation of the benefit, participants had to cut from other areas to compensate: "You know, so it just, yeah, sometimes it's good and then when you go in and they say, it's this and I go, oh, ok, yeah I shouldn't have gone grocery shopping first, I should have just got my medications" (Participant 8, 71-year-old woman). When asked about changes participants have had to make to their lifestyle since their benefit had ended, approximately half of the participants reported a need to make changes to their discretionary lifestyle spending and a need to reduce their spending on food and groceries after the end of the program. As Participant 9 (69-year-old man) explains "You've got to decide where you are going to spend it. Do I want to buy groceries and fresh fruit and do I want to exercise where I can get to the pool because really for me there are not a lot of other options. I can't go hiking or climbing mountains. I can't walk even a half a block without having to sit down, but if in the pool I can exercise hard and I can get my blood moving and that really helps with diabetes."

When asked whether circumstances changed for them during the ACCESS trial, many participants noticed an increase in costs after their copayment elimination benefit ended, compared to what they were paying prior to the copayment. Many of those who noted such increases had also experienced health-related changes during their time in the program resulting in increased medication expenditures from their pre-intervention baseline: "I know I'm not going to get to a point where I can't afford my medications and for instance when I had my heart attack when I was in the hospital, they changed my diabetic medication to one that seems to be working much better and it is also helpful for my heart condition, but boy it's expensive, it's a newer drug. And I can see talking to my doctor about finding an alternative to that, although I don't want to because it works so well" (Participant 4, 66-year-old woman).

Participants expressed that current and future financial concerns were exacerbated by other extrinsic factors such as having a fixed income, inflation, and lack of access to health-related resources in their region. For example, many participants expressed concerns over the increasing cost of living and health-related expenses, such as the ability to purchase fresh food, access to exercise facilities, and travel to regular appointments. Participants also expressed apprehension regarding added costs associated with disabilities (e.g., pressure off-loading cushion, walker, wheelchair, etc.), as well as limited access to health services in rural areas: "Like I said there's no doctors here, there's not dentists here. There's no public transportation here. You can pay 15 dollars and once a week there's a bus that takes you into [town], but then you've got a limited time to be there and then you've got to be on that same bus back […]" (Participant 9, 69-year-old man).

Interestingly, despite describing specific tangible losses after losing the copayment elimination benefit, many participants reported not being profoundly impacted by its loss, particularly in their ability to purchase and take their medications. The majority expressed having perceived no impact from the loss of the benefit. Participant 10 (74-year-old man) stated "Not really noticeable, no. I mean there probably was, but I mean not in so many dollars and cents, like you say, I never kept track of it. It was just, I never really ran short, so I figured that was ok too." While this appears contradictory to reports of having to cut back in other areas of their life after losing the additional coverage, many expressed prioritizing their medication above all else. Nearly all participants described redirecting their spending to more discretionary causes (savings, vitamins, gym pass, etc.) while enrolled in the ACCESS Trial. Therefore, when faced with the prospect of returning to the prior state, participants were prepared to do so, not having become overcommitted to other less negotiable costs (i.e., mortgage, vehicles, other commitments). Additionally, participants described having to prioritize medication costs as a matter-of-fact, even when describing having to cut back on other expenses to obtain medications: "That's right, we must have the medication. You know, if you have to cutback on everything else, our medication takes priority, we never cutback on our medication" (Participant 6, 70-year-old woman).

Theme 4: acceptability of receiving a temporary financial benefit

While many participants had negative feelings about the loss of the copayment elimination benefit, participants unanimously reported positive sentiments when asked to reflect upon their participation in the study. Participant 9 (69-year-old man) describes lifestyle benefits "Well because it gave me a few more years of better health. That's something that's really important. You can't, there's so many things you can't do as it is as you get older, but the less help you get the harder it is just to stay healthy." Participant 11 (81-year-old woman) noted: "being much more aware of the little bit of extra money that I had coming in, so it was all very positive for me." In addition, Participant 12 (72-year-old woman) notes "yeah it did, it just offered me comfort and a little piece of mind and I enjoyed having it covered".

Many were very appreciative of the benefit and cognizant from the beginning that it was time-limited. Participant 3 (72-year-old woman) states "Oh, that was the most wonderful thing I took part in for many, many years. That was awesome. It was really awesome to go through that. It kind of helped with my health,

the study, not just because it was paid for, well partly because it was paid for, but it made me see how good I felt for the time I was on it compared to before when I was taking my pills trying to save some every couple days or whatever. That study was wonderful. Most wonderful thing I've done for a long time." Numerous participants also stated that they would participate in the program again if there was the opportunity to do so, with more than half of the participants expressing a wish that the program could have continued. Many participants even mentioned that copayments should be permanently eliminated. As Participant 13 describes (84-year-old man) "… we were grateful for receiving it. We were sad that it was through and we were sort of feeling that perhaps that's one of the steps where seniors can have help is in having help in the cost of drugs because a lot of the drugs nowadays are really, really expensive."

While the primary aim of the intervention was to provide financial relief for medication copays, it appears that being part of the program may have had other benefits simply from participating in completing the study data collection surveys. Participant 14 (13-year-old woman) explains "I felt very good. I enjoyed filling out those, the questionnaires that we would get. It made me concentrate or think about, you know, how we are living, how healthy we are living or how unhealthy we are living and you know, the food that we are eating. It sort of brought it to the surface and saying, ok well I am doing things right. I thought it was beneficial." Nearly half of the participants revealed that they found it rewarding to contribute to research—independent of benefits they received personally—and hoped that the information they provided would benefit others in similar circumstances. In summary, participants' perceptions of their participation were bittersweet—sad that it was over, but grateful to have received the benefit while it lasted, and happy to have been a part of something bigger. As Participant 15 (82-year-old man) describes "I was happy to participate. In fact, I would be happy to participate in any kind of trial. First of all, because of my age, I'm 86, but I'm still in good shape. Financially we are not well off, but we are not destitute either. We are below the, living below the poverty level, but we are able to cope very nicely, but participating in any study if it helps somebody else I will be glad to do it.". A majority of participants also reflected that other individuals, especially those in similar or worse financial situations, would benefit from a permanent copayment elimination program. Participant 9 (69-year-old man) states "Absolutely, I think it's hugely beneficial […] I would say if you really want to help seniors, you really want them to stay and be able to live in their homes and not end up in long term care facilities, assisted living or independent living it's a great way to assist."

Discussion

The current study explored patients' perspectives of losing a copayment elimination benefit and the resulting impacts on their quality of life and health behaviors. Participants experienced a range of negative emotions and stress stemming from the resumption of their copayments and resulting financial uncertainty. This is concerning as feelings of financial uncertainty and stress have been associated with reduced medication adherence and refusal of recommended treatments [12]. Alongside feelings of disappointment, participants also felt that they had to immediately concern themselves with managing future payments for their prescription medication. As many participants conveyed that medication adherence was their utmost priority, funds were often reallocated from what was previously allotted for exercise, groceries, commuting, and other health-related expenses (e.g., medical devices, testing equipment, supplements, etc.) during the time that they were receiving the benefit. This is in spite of the fact that reducing healthy food intake [13] and exercise participation [14] can contribute to adverse health outcomes for people with these conditions. While there is a known association between the financial burden of medication cost and adverse health outcomes [15–19], our study provides further insights into the potential mechanisms for this finding via emotional and other tangible impacts of increased medication costs.

In contrast, participants reported relatively little impact of losing the benefit on their medication adherence and overall health. One explanation for this finding is that the average cost-sharing savings were determined to be $35/month for each participant [10], so for many people, this financial burden may have been manageable at baseline and not have represented a particularly significant financial benefit during the study. Given that the copayment elimination was distributed over 3 years, and the interviews were conducted a few months after its cessation, it is plausible that they had accumulated enough savings and had been able to redirect enough funds to buffer any immediate significant financial impact. It may also be the case that participants were focused primarily on their ability to fill their prescription medication when answering this prompt, but were not able to focus on other related losses. When prompted about more specific financial losses, participants did endorse the need to redirect funds from other health-related activities. Many participants described prioritizing medications above other costs, which resulted in being able to afford their medications at the expense of limiting other spending.

The nuanced responses illustrate the benefit of using a qualitative approach and the importance of considering other indirect health-related impacts beyond medication adherence.

When examining the burden of medication costs, patients' adherence is a primary endpoint often considered, and less attention has been afforded to other factors that indirectly impact one's health and quality of life. This is particularly concerning as emotional impacts, like increased stress [12, 20–22], are also associated with adverse health outcomes. On a related note, value-based copayment coverage has been shown to offer other indirect health-related benefits that are associated with reduced adverse health outcomes. For example, in a prior qualitative descriptive study including ACCESS participants, copayment elimination allowed participants to afford other health-related goods and improved their relationship with healthcare personnel [23]. The observations from the current study are also consistent with the notion that reduced medication costs may have "side benefits". Furthermore, we have previously demonstrated that coupling an educational intervention with copayment elimination increased the likelihood that participants found the intervention helpful and reported a change in their perspectives on health [24]. When one does not have to worry about the cost of copayments, a person may be enabled to focus and spend more on other aspects of health management [24]. Conversely, the reverse was also shown in the current study, whereby participants reported reducing the amount that they were previously spending on other aspects of health promotion (e.g., gym memberships, healthy foods, and travel to see healthcare professionals) once the copayment coverage ended. In summary, these other health-related impacts are an indirect means by which the financial burden of copayments can result in further adverse health outcomes.

Given the difficulty of becoming accustomed to receiving a benefit and then having to revert to how circumstances were before, some have raised ethical concerns about the provision of a time-limited copayment elimination benefit. Though the program was limited to 3 years, participants seem to have still appreciated the additional financial aid, even if it was temporary. Many were thankful for the benefit and aware that it was designed to be time-limited from the outset. Unsurprisingly, many participants wanted the program to be extended. We found it particularly encouraging that despite the loss of coverage in the end, many participants still enjoyed being part of something bigger and contributing to research that could have a future impact on "others like them". This is particularly meaningful as patient and public involvement in research have been proposed to facilitate equitable patient-centered care [25–27] and patient-relevant research [28], especially for groups that may otherwise be underrepresented. The knowledge that participants were still enthusiastic about their participation in a study and viewed it to be "bitter-sweet" is promising for similar future work.

Finally, several participants expressed a general need for more consistent communication which is important to consider when conducting this type of interventional research. In particular, participants generally wanted more regular updates on their progress throughout the study, in addition to earlier notice regarding the end of the study benefit period. More constant communication with the patients involved in the study might have aided participants to be "mentally prepared" and alleviated some of the negative emotions and uncertainties associated with the termination of the copayment elimination benefit.

Limitations

A notable limitation of the current study was possible social desirability effects. As the association between increasing copayment costs and reduced adherence is a robust and reliable finding within the literature [12], the lack of such reports in the current study was somewhat unexpected. Social desirability distortions, a concern for all interview-based study designs, could have contributed to this result. That is, if participants' medication adherence were impacted, they may be uncomfortable admitting this in the context of an interview for a health-related research study. However, the use of interviews is still advantageous as it facilitates more thorough answers [29].

Another potential limitation concerns the generalizability of our findings. First, the participants in this study were primarily Caucasian/White, from rural areas, Canadian-born, and adequately health literate. We had aimed to evenly recruit participants based on (1) financial barriers, (2) number of medications, (3) gender, and (4) age. Given the number of demographic factors we had prioritized balancing, there was a less proportionate representation across other sociodemographic factors. Our results may, therefore, not be entirely representative of the perspectives from individuals who identify as visible minorities, non-Canadian-born residents, and those who have lower levels of health literacy. Secondly, given that the current study was conducted in Alberta, Canada, the current findings would mainly translate to implementations of copayment elimination programs in other publicly funded healthcare systems [30]. That is, a similar population in a context with more or less copayment or cost-sharing at baseline may have greatly differing experiences and opinions to the ones expressed in the current

study. Nonetheless, the themes yielded from the current inductive thematic analysis of participants' experience with the cessation of a time-limited benefit would likely translate across different healthcare contexts and even different interventions that include a financial benefit of one kind or another.

Conclusions

In the current study, we found that the loss of a time-limited copayment benefit was associated with a wide range of negative emotions. The return to paying standard copayments after 3 years of copayment elimination was reported to have resulted in the reduction of other health-related spending to enable and prioritize medication adherence. Despite a lack of reported impact on adherence, the consequences of redirecting their funds resulted in health behavior changes that have also been associated with adverse health outcomes and impacts on quality of life. This showcases the indirect consequences of medication costs that have been relatively unexplored. Despite these changes, participants generally felt very positive towards the study, even after having lost their study benefit, and would recommend that others participate in the study.

Appendix 1

Medication list	
Antiarrhythmics	**Anti-diabetes medications**
Disopyramide *(Rythmodan)*	Metformin *(Glucophage)*
Procainamide *(Procan)*	Glipizide (Glucotrol)
Mexilentine *(Mexilentine)*	Gliclazide *(Diamicron)*
Flecainide (Tambocor)	Glyburide *(Diabeta)*
Propafenone *(Propafenone/Rythmol)*	Glibenclamide (Euglucon)
Amiodarone *(Amiodarone/Cordarone)*	Acarbose *(Glucobay)*
Digoxin *(Toloxin)*	Repaglinide *(Gluconorm)*
Nitrates and nitrites	Linagliptin *(Trajenta/Jentadueto)*[a]
Isosorbide Dinitrate *(Cedocard-SR)*	Saxagliptin *(Onglyza)*[a]
Isosorbide-5-Mononitrate *(Imdur)*	Sitagliptin *(Januvia/Janumet)*[a]
Nitroglycerin *(Nitrostat/Nitro/Nitrolingual/Nitro-dur/Trinipatch/Minitran/Nitrol)*	Pioglitazone *(Actos)*
Statins	Rosiglitazone *(Avandia/Avandamet)*
Atorvastatin *(Lipitor)*	Dapagliflozin *(Forxiga)*[a]
Rosuvastatin *(Crestor)*	Empagliflozin *(Jardiance)*[a]
Simvastatin *(Zocor)*	Canagliflozin *(Invokana)*[a]
Pravastatin *(Pravachol)*	Linagliptin/Metformin HCL *(Jentadueto)*[a]
Fluvastatin *(Lescol)*	Sitagliptin / Metformin HCL *(Janumet)*[a]

Medication list	
Lovastatin *(Mevacor)*	
Non-statin cholesterol-lowering drugs	
Cholestyramine *(Olestyr)*	**Other blood pressure medications**
Colesevelam *(Lodalis)*	Clonidone *(Catapres/Clonidine)*
Colestipol *(Colestid)*	Methyldopa (Aldomet)
Bezafibrate *(Bezalip)*	Hydralazine (*Apresoline*)
Fenofibrate *(Feno-micro/Feno-Super/Lipidil Supra)*	Minoxidil *(Loniten)*
Gemfibrozil (Lopid)	Doxazosin *(Cardura)*
Ezetimibe *(Ezetrol)*	Prazosin *(Prazo)*
Evolulocumab (*Repatha*)	Terazosin *(Hytrin)*
Beta blockers	**Anticoagulants**
Acebutalol *(Sectral)*	Warfarin *(Coumadin)*
Quinapril *(Accupril/Accuretic)*	Rivaroxaban *(Xarelto)*[a]
Atenolthalidone)	Dabigatran *(Pradaxa)*[a]
Bisoprolol (Zebeta)	Apixaban *(Eliquis)*[a]
Carvedilol (*Coreg, Coreg CR*)	Dalteparin *(Fragmin)*
Labetalol *(Trandate)*	Tinzaparin *(Innohep)*
Metoprolol *(Lopresor)*	Enoxaparin *(Lovenox)*
Propranolol (Inderal)	Heparin *(Heparin Leo)*
Sotalol (*Betapace*)	Nadroparin *(Fraxiparine)*
Nadolol *(Nadol)*	Fondaparinux *(Arixtra)*
ACE-inhibitors	Danaparoid *(Orgaran)*
Benazepril *(Lotensin)*	**Insulin**
Cilazepril *(Inhibace/Inhibace Plus)*	Insulin Aspart (Novorapid)
Enalapril *(Vasotec/ Vaseretic)*	Insulin Detemir (*Levemir*)
Perindopril *(Coversyl/Coversyl Plus)*	Insulin Glargine *(Lantus)*
Captopril *(Capoten)*	Insulin Glulisine *(Apidra)*
Fosinopril *(Monopril)*	Insulin R *(Novolin/Humulin)*
Lisinopril *(Zestril/Prinivil/Zestoretic)*	Insulin Lispro *(Humalog)*
Ramipril *(Altace)*	
Trandolapril *(Mavik)*	Insulin Humulin 30/70
Angiotensin receptor blockers	Insulin Humulin N
Candesartan *(Atacand/Atacand Plus)*	Insulin Humulin R
Eprosartan *(Teveten/Teveten Plus)*	Insulin Novolin NPH
Irbesartan *(Avapro / Avalide)*	Insulin Novolin Toronto
Losartan *(Cozaar / Hyzaar)*	Insulin Novolin Mix (30/70, 40/60, 50/50)
Telmisartan *(Micardis/Twynsta/Micardis Plus)*	**Smoking cessation aids**
Valsartan *(Diovan)*	Varenicline *(Champix)*
Olmesartan *(Olmetec/Olmetec Plus)* Entresto (*Sacubitril/Valsartan*)	
Calcium channel blockers	
Nifedipine *(Adalat XL)*	
Amlodipine *(Norvasc)*	
Felodipine *(Plendil)*	
Diltiazem *(Diltiaz/Cardizem / Tiazac)*	
Verapamil *(Verap/Isoptin SR)*	

Medication list
Diuretics
Hydrochlorothiazide *(Hydrazide/ Hydro)*
Furosemide *(Lasix)*
Spironolactone *(Aldactone / Aldactazide)*
Indapamide *(Lozide)*
Metolazone *(Zaroxolyn)*
Chlorthalidone (*Thalitone*)
Amiloride *(Midamor/ Novamilor / Amilizide)*
Triamterene *(Triazide*)
Anti-platelet agents
Clopidogrel *(Plavix)*
ASA-Dipyridamole *(Aggrenox)*
Ticagrelor *(Brilinta)*

Appendix 2

Interview guide—copayment elimination

Objectives

1. Learning about whether or not the participants' lives and health outcomes will change after they complete the intervention and no longer enjoy the benefits of copayment elimination.
2. To explore the patients' perspectives of losing the copayment elimination benefit on their quality of life and health behaviors.
3. To describe participants' experience with losing (financial) benefits provided through a study.

1. How did your experience of paying for medications change once you enrolled in the ACCESS trial and started receiving the study benefit?

- Did the ACCESS benefit affect your ability to fill your prescriptions/take your medications? If so… how?
- Not all medications were covered, did receiving this benefit have any impact on your other medications and/or health supplies?
- Tell me about other necessities (for instance, health-related expenses, healthy foods, other?) you could spend more money on while receiving this benefit.
- Were there any changes to your lifestyle/spending habits as a result of the benefit.

2. It has now been a few months since you stopped receiving the ACCESS trial benefit, describe what has changed for you now that you are paying copayments for all of your medications again.

- Tell me about any changes you have had to make to your lifestyle/spending habits since finishing the ACCESS trial.
- Did you make similar changes to how things were before the ACCESS study? Or have circumstances changed for you during the time you were receiving the ACCESS benefit?
- Tell me about any other spending you have had to cut back on as a result of paying for your medications again.
- How does having to pay for your medications again impact your spending on other necessities and expenses?

i. Food.
ii. Shelter.
iii. Other health products (testing supplies, etc.…).

3. Has there been any impact on your ability to purchase your prescriptions/take your medications now that you are paying a portion of the medication costs again?

- If yes, describe:

i. Have you had to:

1. Only take some medication
2. Only take medications on certain days
3. Only refill prescriptions when you could afford it, rather than when you ran out of medication

- If no, why not? Do you anticipate that this will become a problem in the future?

4. Did you know that the ACCESS trial medication benefit was ending?

- How important was it for you to be notified in advance? What did you do/change with that information?
- Did you have enough notice? Should this have been done in another way?

5. It can be inconvenient to get used to things being a certain way and then having them change back to how they were before. Looking back, how do you feel about having participated in the trial?

- Was it worth it?
- Would you participate in the trial again, if you could go back?
- What should researchers know/do to make the experience better for study participants in future studies like ACCESS?

Authors' contributions
DJTC and BJM conceived of this study. Data collection was completed by ST. ST, BM, and JF conducted the analysis of this data under the direction of DJTC. ST and JF wrote the first draft of the manuscript, which was critically edited and approved by all authors.

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Data availability
De-identified participant data available upon request.

Declarations

Ethics approval and consent to participate
Ethics approval was received from the Conjoint Health Research Ethics Board (CHREB) at the University of Calgary (REB#13–1241) and the University of Alberta Health Research Ethics Board (Pro00062473). Individual participants consented to participate in this research via written informed consent.

Competing interests
The authors have no conflict of interest to report.

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