

ORIGINAL RESEARCH ARTICLE



## Patient perceptions of copay card utilization and policies

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### ABSTRACT

**Background:** Copay cards are intended to mitigate patient out-of-pocket (OOP) expenses. This qualitative, exploratory focus group study aimed to capture patient perceptions of copay cards and copay adjustment programs (CAPs; insurers' accumulator and maximizer policies), which redirect the copay card utilization benefits intended for patients' OOP expenses.

**Methods:** Patients with chronic conditions were recruited through Janssen's Patient Engagement Research Council program. They completed a survey and attended a live virtual session to provide feedback on copay cards.

**Results:** Among 33 participants (median age, 49 years [range, 24–78]), the most frequent conditions were cardiovascular-metabolic disease and inflammatory bowel disease. Patients associated copay cards with lessening financial burden, improving general and mental health, and enabling medication adherence. An impact on medication adherence was identified by 10 (63%) White and nine (100%) Black respondents. Some patients were unaware of CAPs despite having encountered them; they recommended greater copay card education and transparency about CAPs.

**Conclusion:** Patients relied on copay cards to help afford their prescribed medication OOP expenses and maintain medication adherence. Use of CAPs may increase patient OOP expenses. Patients would benefit from awareness programs and industry – healthcare provider partnerships that facilitate and ensure access to copay cards.

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## Introduction

Patient out-of-pocket (OOP) costs for prescription drugs are rising and can represent a substantial financial burden, especially for patients with chronic disease requiring regular medication [1–5]. These rising costs can put patients at risk for financial difficulty and may impact health outcomes if treatment is suboptimal as a result of reduced medication adherence due to OOP costs [6,7]. Pharmaceutical manufacturers have established financial assistance programs to support patients' access to healthcare provider-prescribed medication. One type of program is a copay card, where patients receive a coupon to cover their prescription OOP costs at the pharmacy up to a set maximum amount, which is determined by manufacturers on an individual basis for each medication [8,9]. These programs, sometimes referred to as copay assistance programs or copay coupons (Table 1 [4]), are only available to patients with private insurance [10,11].

The prevalence of copay card utilization is on the rise, primarily due to the fact that patients in the United States have faced approximately 25% higher cost

sharing for prescription medication during the last five years, mostly driven by changes in plan design [12]. In immunology, for example, the proportion of prescriptions filled using copay cards in the United States ranged from 18% in Alaska to 62% in Nevada during 2019–2021 [5]. It has been suggested that copay cards may steer patients to more expensive brand-name options versus lower-cost generic versions, by providing a financial incentive to their use [10,13–15]. It has also been acknowledged that where there are no generic or less expensive appropriate alternatives, copay cards can provide financial benefits to enable patient access to medicines that provide therapeutic benefits for patients [10,16]. However, copay programs may allow patients to circumvent benefit plan designs, so a number of payers have now instituted policies to mitigate any distortion of benefit plan design by copay coupons. Referred to as copay adjustment programs (CAPs) or, alternatively, as accumulator and maximizer programs, these policies prohibit the copay amounts covered by copay cards from counting toward a patient's maximum OOP expenditure [17,18]; therefore, patients bear

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a greater cost burden [11,19]. In the United States, current insurance design trends and individuals with no insurance or underinsurance leave many exposed to high OOP healthcare costs, including medications: 32% of covered workers face an annual deductible of over \$2,000 [20] and 23% of working-age people are considered underinsured [21]. From 2018 to 2021, the prevalence of insurance plans with CAPs in place has increased, with accumulators rising from 44% to 80% and maximizers from 14% to 61%. It has been estimated that 43% and 45% of insured patients are subject to implemented accumulator and maximizer programs, respectively [22].

With an accumulator, once the copay card value is exhausted, the patient remains responsible for the full or any remaining deductible or OOP maximum [4,23]. The result has been referred to as a copay 'cliff', where patients may see unexpected, very large increases in their copay from one month to the next at some point in the benefit year [9]. Maximizers equalize copay card value and patient copay amounts throughout the year; however, these copay card amounts do not count toward the patient's deductible or OOP maximum [9]. Use of CAPs also means that patients remain responsible for any other OOP costs, such as physician visits or hospitalizations or costs for concurrent illnesses, for as long as they do not meet their annual deductible or OOP maximum.

Increased cost burden and inability to afford medication OOP expenses can potentially impact health outcomes, and have been associated with depression [24] and decreased medication adherence [18,25] with an increase in mortality [26]. Conversely, lower OOP costs have been identified as an independent predictor of patient

adherence to, and persistence on, medication [7,19,27]. Furthermore, medication adherence is associated with improved clinical outcomes in patients with chronic illnesses such as cardiovascular and metabolic diseases [28–30]. Copay cards can save patients substantial amounts (hundreds to thousands of US dollars) on their OOP costs for each prescription [27,31–36]. Current research indicates that patients view copay cards favorably; however, many patients are unaware of these programs [6,32,37].

This qualitative, exploratory focus group study was designed to examine patients' experiences with discovering, applying for, and using copay cards. The study aimed to identify the barriers and challenges that patients experience when using copay cards, and to understand patient perspectives on copay accumulators and maximizers and the impact that these programs may have on their access to treatment and medication. Patients were also asked to discuss a hypothetical future scenario in which copay cards were limited or not available.

## Materials and methods

### Patients

Eligible patients were those with chronic disease, residing in the United States and participating in Janssen's Patient Engagement Research Council (PERC) program, which has been previously described [38,39]. Patients participating in PERC were recruited via patient advocacy groups, online advertising, social media, and physician referrals. Socioeconomic diversity of patients was enabled through subjective sampling. A survey of patients participating in PERC was conducted in

**Table 1.** Definition of key terms.

Term	Alternative term(s)	Definition
Copay	Co-payment	A flat fee paid by a patient in order to access health care services
Copay Accumulator	Accumulator	A feature or program within an insurance plan whereby a manufacturer's payments do not count toward the patient's deductible and OOP maximum. The manufacturer copay card/coupon funds prescriptions until the maximum value on the coupon/card is reached. After that, the patient's OOP costs begin counting toward their annual deductible and OOP maximum
Copay adjustment program (CAP)	Accumulator or maximizer	Can be either a Copay Accumulator or Copay Maximizer
Copay Coupon	Copay assistance program Copay card	Financial assistance that helps patients with insurance afford prescription medications by covering part or all of a member's deductible and copay
Copay Maximizer Program	Maximizer	A feature or program within an insurance plan whereby a manufacturer's payments do not count toward the patient's deductible and OOP maximum. The maximum value of the manufacturer's coupon/card is applied evenly throughout the benefit year
Cost Sharing		The share of costs covered by insurance that a patient pays out of their own pocket. This term generally includes deductibles, coinsurance, and copayments, or similar charges, but it does not include premiums, balance billing amounts for non-network providers, or the cost of non-covered services
Deductible		A deductible is an amount an insured party pays OOP before an insurance company pays a claim
Out-of-pocket (OOP) costs		Expenses for medical care that are not reimbursed by insurance, including deductibles, coinsurance, and copay for covered services plus all costs for services that aren't covered

Adapted from ASCO policy brief: Copay accumulators and copay maximizers [4].  
OOP, out-of-pocket.

April 2022 to identify respondents with recent experience using copay cards. Of 103 respondents, 39 (38%) met study inclusion criteria, i.e., reported using a copay card in the prior 12 months. Overall, 33 (85%) of the 39 eligible patients completed a pre-work survey and 29 (74%) agreed to participate in a 2-hour focus group. Patients with Medicaid or Medicare as their only form of insurance were excluded from participation due to their ineligibility for copay cards. Patients signed a consent and release form and were compensated for their time. Review/approval by an ethics committee was not required as all patient data were de-identified. The study was conducted in accordance with the Helsinki Declaration of 1964 and its later amendments.

### Procedures

The study comprised two parts: a written pre-work survey followed by a live virtual group session. Each patient completed a 15-minute pre-work survey (see Supplementary Material) to assess their baseline knowledge and experience with copay cards. The survey results were compiled by the research specialist.

Patients subsequently attended a 2-hour, live, virtual focus group session to discuss their understanding of copay cards and describe the impact of these programs on their prescription use, affordability, and overall health. Each session was attended by five or six patients and at least one relevant Janssen medical/scientific team member. Sessions were conducted by a research specialist using a discussion guide, developed by an expert in research methods for patients (as has been described previously [38]). Information was provided to patients in the form of definitions and examples of accumulator and maximizer programs. Audio recordings were made of the live sessions and these recordings were transcribed by a transcription firm with experience in medical market research. The live sessions were organized into four areas for patient feedback regarding copay cards: first impressions, everyday impact, barriers, and a hypothetical future scenario where copay cards were limited or unavailable.

Key themes corresponding to the study objectives were distilled from analysis of the transcripts and direct observations by a research specialist. Recommendations were developed based on discussions with the patients during the sessions.

### Data analysis

Conversational (narrative) analysis was used to identify concepts in the data. A research specialist, experienced in narrative analysis and drawing insights from interactions with diverse populations, directly observed the

data (during data collection and through transcript analysis) and identified concepts. Analytic insights were evaluated against new observations using an iterative process; concepts were refined as they continued to emerge from the data. This process continued until all data were analyzed and the frequency of each concept had been examined to understand its importance. Formal thematic coding of the qualitative data was performed using MAXQDA (VERBI Software, Berlin, Germany). Two researchers conducted coding to mitigate bias. Patient demographics and survey results were analyzed with descriptive statistics.

## Results

A total of 33 patients completed the pre-work survey and 29 of these patients participated in one of five focus group sessions held in May 2022. Among the overall group of 33 patients, median age was 49 years (range, 24–78), 64% were women, 48% were White, 33% were Black, and 85% had some college or postgraduate education (Table 2). The most frequently represented PERC disease categories were cardiovascular-metabolic disease (21%) and inflammatory bowel disease (IBD; 18%).

### Patient feedback: first impressions

#### Copay card awareness

When patients were asked how they learned about copay cards, most patients stated that they learned of them through their physician's office or pharmacy. Often, patients were unaware of copay cards until they expressed concern regarding their OOP liability for their medication.

'When I was first put on a biologic, one of the concerns I had was cost. My doctor has a junior doctor who shadows him. She just sat with me in the room and was like, "Even though it costs hundreds of thousands of dollars a year, most of my clients paid \$5." It was hard for me to believe that. She told me, "Go online, sign up for the program, and get the ball rolling before they start sending you the medication."' — patient with IBD

'I wouldn't have even known to look at commercials or whatever for assistance.' – patient with multiple sclerosis

When patients were asked what they think of when they hear 'copay card/coupon', they did not necessarily refer to copay cards as 'copay assistance'; though the terms 'assistance' and 'discount' resonated the most with patients. Patients' understanding of the term 'copay' versus 'cost of medication' varied, and

**Table 2.** Patient characteristics.

Characteristic	Pre-work survey respondents (N = 33)	Focus group participants (n = 29) <sup>a</sup>
Median age, years (range)	49 (24–78)	49 (24–78)
Age group		
18–29 years	2 (6)	2 (7)
30–49 years	14 (42)	13 (45)
50–69 years	15 (45)	13 (45)
≥70 years	2 (6)	1 (3)
Female	21 (64)	17 (59)
Race or ethnicity		
White	16 (48)	15 (52)
Black	11 (33)	8 (28)
Asian American/Pacific Islander	2 (6)	2 (7)
Multiracial	2 (6)	2 (7)
American Indian or Alaska Native	1 (3)	1 (3)
Hispanic	1 (3)	1 (3)
Education (highest level)		
Post-graduate	9 (27)	8 (28)
Bachelor's degree	13 (39)	13 (45)
Some college	4 (12)	3 (10)
Associate degree	2 (6)	2 (7)
Technical or trade school	3 (9)	2 (7)
High school diploma or GED	3 (9)	2 (7)
PERC disease category		
Cardiovascular-metabolic disease	7 (21)	6 (21)
Inflammatory bowel disease	6 (18)	6 (21)
Ankylosing spondylitis	5 (15)	5 (17)
Multiple sclerosis	5 (15)	4 (14)
Pulmonary arterial hypertension	4 (12)	4 (14)
Psoriatic arthritis	3 (9)	2 (7)
Multiple myeloma	3 (9)	2 (7)

data are n (%) unless otherwise specified.

GED, General Educational Development; PERC, Patient Engagement Research Council.

<sup>a</sup>Focus group participants were a subset of the pre-work survey respondents.

interchangeable language, such as ‘copay’, ‘cost’, or ‘copay assistance’, can add to patients’ confusion and stress. Patients also demonstrated confusion with respect to terms such as ‘copay’, ‘medication cost’, and ‘deductible’, and how to differentiate among the terms.

### Application process

Patients reported that applying for a copay card was generally ‘quick and easy’. During the first use of a copay card, the application process varied; some patients found it had already been completed for them and others required assistance from their physician or pharmacist. Fourteen (48%) of the 29 patients found their pharmacy or drug manufacturer kept their information up to date and on file, eliminating the need for a physical card/coupon. This method was preferred by most patients as it required minimal upkeep.

‘One of my meds was pretty expensive, and the pharmacy tech actually commented, “I think there’s a discount card.” They filled out all the paperwork; came back about five minutes later with a much cheaper price. Whenever we have any issues like that, I just go talk to the pharmacy tech; they take care of all the paperwork for us, and we get the discounted price. I’m happy.’ – patient with cardiovascular-metabolic disease

‘It was pretty quick, an hour. And then I emailed it back, and it was approved right away. When the year was up, we refill out the paperwork and do it all over again to get reapproved for the next year.’ – patient with pulmonary arterial hypertension

However, some patients found that while the initial application was easy, they were required to continually update their information and stay on top of changes. Many reported only being aware of changes or updates to their copay card when they received a bill. Often, this process was stressful and time-consuming for patients, requiring triangulation between multiple parties to resolve issues.

Two patients reported that the manufacturer had many different programs (income based, financial assistance, or copay assistance) in place, and that it was difficult for them to find help for their specific situation.

Ultimately, patients agreed that while applying for and maintaining copay cards/coupons could be burdensome, the extra time and effort was worth it because of the outcome.

‘It doesn’t always go smoothly, but I think there’s a level of understanding that goes along with it. I mean, this is a huge benefit, and a little bit of inconvenience is OK.’ – patient with multiple myeloma

‘To me, my health was worth my time to do the investigating, to find the end result. But is that desirable? No. Is it something that they make easy? No. They don’t make it easy, but it has improved from the manufacturer’s standpoint down to the doctor to the pharmacy – the whole process.’ – patient with ankylosing spondylitis

### Patient feedback: everyday impact

In general, patients agreed that copay cards were necessary to afford medications as prescribed because they mitigated OOP expenses.

‘There’s no way I would have been able to afford that medicine, and I honestly would have been like, you know what, thanks for the diagnosis. I think I’ll just have to deal with what I have.’ – patient with multiple sclerosis

Patients associated copay cards with reducing financial burden and improving general health. In the pre-work survey, patients were asked to review a list of factors and identify which, if any, had been impacted by copay card utilization in terms of value gained. Patients reported that copay cards had a high value when it came to the amount of money saved each month, mental health, the amount of money spent on medication OOP costs each month, physical health, the ability to afford medication, and medication adherence (Figure 1). Overall, 93% of patients reported that copay cards had a moderate or high value regarding how much they saved each month. In this metric, no meaningful difference was observed based on race or ethnicity.

Patients reported that copay cards gave them the ability to afford medications and take them as prescribed because of reduced OOP expenses; patients viewed medication adherence as crucial to maintaining health. Patients noted that a generic version may not be available for those taking newly approved medication and that copay card utilization was the only perceived option for affording these products.

*'The most important one for me was being able to take my medication as prescribed because the big thing with pulmonary hypertension meds is you need to be adherent to them because if you're on the right therapies, the medications can slow down disease progression. That's really important to me.'* – patient with pulmonary arterial hypertension

Patients also reported that their mental health was improved because copay cards reduced the stress and worry about being able to afford medication OOP expenses. Many patients noted that stress can aggravate their disease symptoms and considered financial concerns a primary cause of anxiety.

*'MS and stress do not go well together as I'm sure many of your diseases also have the same thing. The mental weight of having that medication paid for is huge.'* – patient with multiple sclerosis

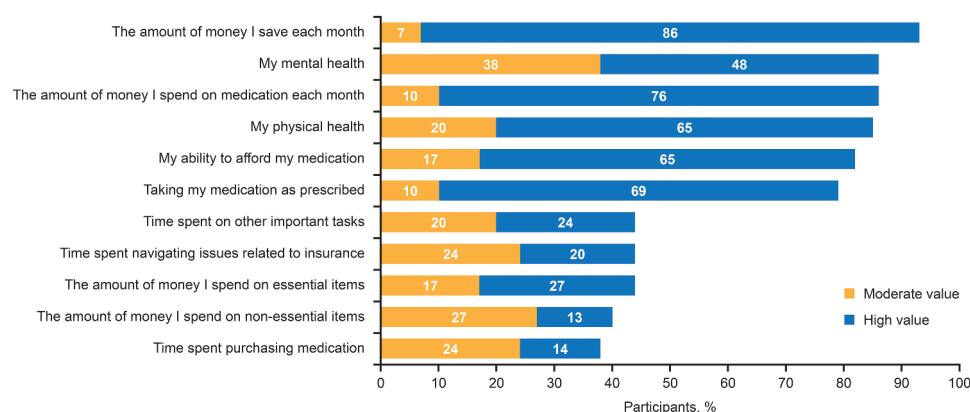
*'... If I didn't have assistance, ... I'd always be stressed which would probably then cause other health issues and probably anxiety, lack of sleeping; my mental health would probably deteriorate always being worried or in pain ...'* – patient with cardiovascular-metabolic disease

### Patient feedback: awareness of accumulators and maximizers

Six patients suspected that their insurance plan had accumulators in place, even if they were not aware of the term prior to the focus group. While these patients did not believe their copay card value went towards their deductible, they were generally unaware of accumulator programs or when they were put in place. Three patients were aware that their insurer implemented accumulators. These patients mentioned that increased OOP costs were not limited to prescriptions but also impacted overall medical costs, such as in-office visit copays.

*'I found out about their accumulators and quickly realized that I would have to be paying out-of-pocket in copays. So, that means you're paying specialty copays for every appointment. So, it impacted the amount of time I spent with my specialist because ... instead of a regular copay of \$30–35 to see a doctor, I'm paying \$90–150 to see a specialist. If the accumulator wasn't still in place, that wouldn't be a concern, but it is.'* – patient with IBD

Exposure to OOP costs varied among patients and determined the level of awareness about insurance benefit design. Awareness increased when patients were exposed to high OOP costs. Those with low OOP cost (e.g., USD 5/month) were less aware of how their copay card was being applied to their yearly deductible.



**Figure 1.** Pre-work survey responses of moderate value or high value regarding how copay card utilization affects several factors (N=33). On a scale of 1–4, where 1 is “none” and 4 is “high”, patients reviewed a list of factors and rated the value copay card utilization has on each of them. Other important tasks listed in the survey question were work-related and family-related; examples of essential items listed in the survey were mortgage, rent, groceries and gasoline.



## Patient feedback: views toward accumulators and maximizers

### Accumulators

Patients had mixed reactions when informed about accumulator programs and the potential for their insurers to utilize them. Five members felt insurance ‘double-dipping’ (i.e., not accepting manufacturer payments toward deductible/OOP limit) was unfair to patients. Four other members could understand the insurance company perspective because they perceived that OOP costs should not be fulfilled by a third party (i.e., the drug manufacturer). However, these individuals generally suspected that the insurance companies’ motivations were financial and ‘all about their bottom line’.

‘I think I would be angry, and it makes a big difference in the end because I have so many medical expenses. I feel like I would be getting robbed by an insurance company.’ – patient with ankylosing spondylitis

Patients suspected that addition of accumulators to their insurance plan would raise OOP costs considerably.

‘I reach my deductible limit in maybe June, July, every year because my medications are so [much more] expensive than my other medications. So [addition of accumulators] would be hard for us. It would be hundreds of extra dollars per month.’ – patient with multiple sclerosis

### Maximizers

Patient perceptions were less negative about maximizer versus accumulator programs. Although maximizers also prohibit copay assistance from applying to OOP maximums, many felt a maximizer program would help them to avoid running out of copay assistance mid-year, as it spreads the copay assistance across the year.

‘I would think the maximizers may be more beneficial, where you know you’re getting coverage, you can budget saying, OK, this medication’s been covered every month at this dollar, and this is what I’m going to have to put in [of] my own money.’ – patient with IBD

‘Everyone has a different type of deductible, but I know some people have really high deductible plans, so [maximizers] may not be beneficial to all patients.’ – patient with IBD

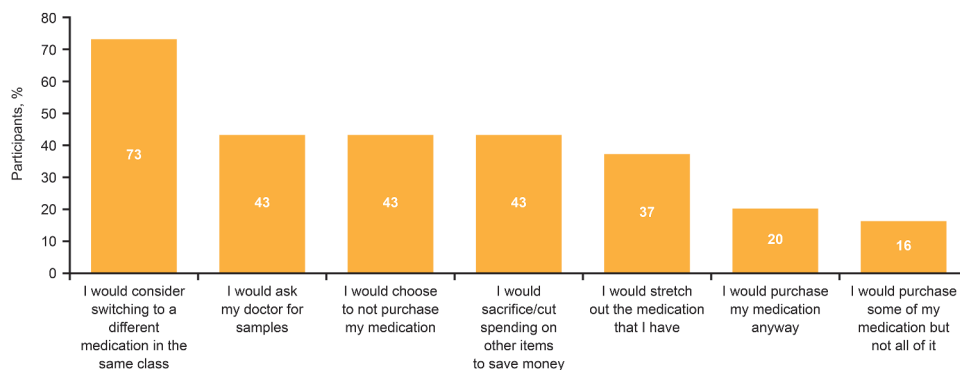
### Patient feedback: future scenario

Patients struggled to foresee practical solutions should copay cards become limited or non-existent. During the pre-work survey they were asked, ‘If you lost access to your copay card/coupon, what actions would you consider taking?’ A majority (73%) chose ‘I would consider switching to a different medication in the same drug class’. However, patients were able to choose multiple scenarios and approximately 40% said they would not purchase their medication, or they would stretch out the medication that they have (Figure 2). In this metric, no meaningful difference was observed based on race or ethnicity.

During the discussion, several patients suggested that stopping medication entirely would be their only option, which would risk disease progression while also negatively impacting quality of life.

‘With my particular disease, if I tried to stretch my medications, I probably would die or get really, really worse fairly quickly. I would probably work a crazy amount of shifts just to purchase this medication anyways because I know that the reason why I’m doing so well today is because of my medications at the doses they’re on.’ – patient with pulmonary arterial hypertension

Patients expressed concern that lack of copay cards could force them to decide between stopping



**Figure 2.** Pre-work survey responses to a question regarding loss of, or limits to, copay cards (N=33). The question asked was: “If you lost access to your copay card/coupon, what actions would you consider taking? Select all that apply.”

medication or risking severe financial difficulties due to high OOP costs. While switching to a different medication in the same class was the most frequently selected option for those who had a viable option (73%), five patients (17%) struggled to envision another option or expressed concern about the disruption and risk that switching medication posed to their health. Patients with IBD emphasized that they would elect to have invasive surgery rather than switching to another medication.

'With the IBD, I probably would give up on medications altogether and have a drastic surgery. I would honestly put myself through the surgeries that they offer. ... I've been on so many medications through my 12 years of IBD, taking on side effects, going through the hassle. It is a mental mind game, and I think I would just be done.' – patient with IBD

Patients who wished to remain on their medication struggled to find sustainable long-term solutions. Common solutions include asking for samples, forfeiting spending on other items, or stretching medication already purchased.

'I would probably ask my doctor for those samples that they always seem to have. They usually can give you a shot in the doctor's office.' – patient with ankylosing spondylitis

Copay cards were generally deemed essential for patients to afford their prescribed medications. When asked about the impact of losing copay cards on various factors, the majority of patients (72%) said this loss would have a high impact on their ability to afford their OOP liability for their medications and on how much money they save each month (Figure 3a). The greatest overall impact (medium and high) was noted by 87% of patients in relation to their physical health. In this metric, a meaningful difference was observed between White and Black patients in response to 'taking my medication as prescribed'. If copay cards were not available, an impact on medication adherence was identified by 63% of White and 100% of Black respondents (Figure 3b).

In the discussion, many patients stated that even when medications were not critical to survival, they improved quality of life, which was very important to them.

'Technically, I could live without it. Would my quality of life be the same level without this medication? Absolutely not. So really kind of getting the insurance companies to realize there's a difference between "I need this drug for survival" and "I need this drug for quality of life." They're very much intertwined.' – patient with multiple sclerosis

Patients felt strongly that medication changes also impacted their mental health: stress from the fear of switching medications could, in turn, impair their physical health.

When asked whether copay card utilization might encourage overuse of medication or use of medication that is not completely necessary, patients said they believed that this was not the case; instead, they stressed that copay cards allow patients to take medication as prescribed without sacrificing financial health or general wellbeing.

'I find it incredibly insulting [to suggest that copay cards encourage overuse]. If we're being prescribed something by our doctor, it's likely it's something we need.' – patient with IBD

### Future directions

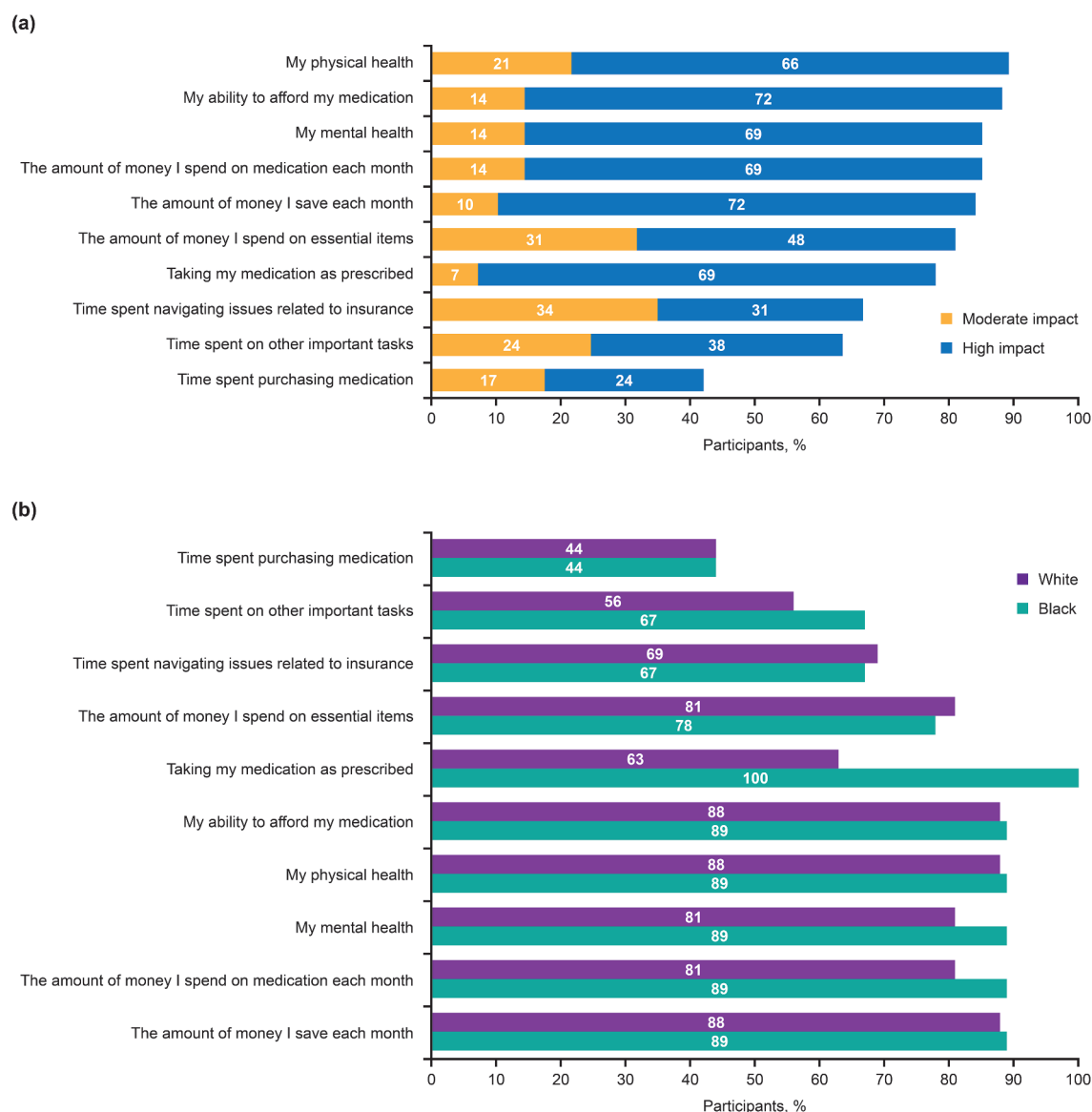
Patients indicated that they would benefit from awareness programs and industry – healthcare provider partnerships that ensure patient access to copay cards. They made specific suggestions for additional communication and education regarding how to access copay cards and how to understand insurance policies and their application (Table 3).

### Discussion

In this qualitative, exploratory focus group study representing patients with a broad range of disease states, patients viewed copay cards as essential to their ability to take their medications as prescribed. Copay card utilization had a positive impact on patients' general health, mental health, and medication adherence, as well as on how much money they could save each month. Patients did not believe copay card utilization encouraged overuse or misuse.

Our findings of patients' favorable view of copay cards are consistent with other patient surveys [32,40]. One study found that copay cards were viewed positively by 70% of patients, with only 4% having a negative view of these programs [32]. These studies demonstrate that overall, patients view copay cards as important tools for removing financial barriers to medication adherence.

Patients were often not aware of copay cards until they expressed concern about their OOP costs to their physician or pharmacist. Our findings are consistent with other research showing that women with breast cancer were unaware of financial assistance options available to them [6]. It has been reported that a small proportion (15–25%) of conversations about



**Figure 3.** Focus group participant responses of medium impact or high impact to a question regarding loss of, or limits to, copay cards from (a) all focus group participants (N=29) according to medium or high impact responses; and (b) the subgroup of participants who were Black (n=8) or White (n=15), including combined responses of both medium and high impact for each subgroup. The question asked was: "If copay assistance were limited/not available, how would it impact these factors?" Patients selected whether copay card utilization had no, low, medium, or high impact on each factor. Focus group participant responses of medium impact or high impact to the question: "If copay assistance were limited/not available, how would it impact these factors?" Patients selected whether copay assistance had no, low, medium, or high impact on each factor. (a) All patients (N=29) according to medium or high impact responses; (b) subgroup of patients who were Black (n=8) or White (n=15), including combined responses of both medium and high impact for each subgroup. Other important tasks listed in the survey question were work-related and family-related; examples of essential items listed in the survey were mortgage, rent, groceries and gasoline.

**Table 3.** Patients' suggestions for communication and education regarding copay cards.

Patient suggestions
<i>How to access copay cards</i>
<ul style="list-style-type: none"> <li>• Make accessible information available to patients at physicians' offices and pharmacies to raise awareness of copay cards</li> <li>• Ensure that doctors' offices are equipped to share information about copay cards during pivotal times (e.g., onset of treatment regimen) and help patients during the copay card application process</li> <li>• Strengthen the network for patients seeking support with issues regarding copay cards</li> </ul>
<i>How to understand insurance policies and their application</i>
<ul style="list-style-type: none"> <li>• Educate patients on insurance policies to facilitate understanding of the impact of OOP costs and raise awareness about specific insurance policies (accumulators, maximizers) that may impact a patient's OOP costs</li> <li>• Encourage patients to reach out to their insurance companies and ask whether these programs are applied to their policy</li> </ul>

OOP, out-of-pocket.



drug-related OOP costs during clinic visits are related to copay card utilization [41,42]. Patients in our study recommended providing accessible information to patients at physicians' offices and pharmacies to raise awareness of copay cards, and partnering with healthcare providers and pharmacies to promote copay cards. A number of pharmacies and health systems have proactively developed systems to investigate and provide prescription drug cost assistance to their patients and these systems have resulted in reduced OOP costs to patients [13,31,33,34,36,43–47]. Sadigh et al found that comprehensive financial programs, including those providing advice to patients about how to secure copay cards, are associated with decreased financial toxicity (less financial worry) to patients, as measured using the Comprehensive Score for Financial Toxicity survey [48].

The patients in our study generally found the initial application for copay cards to be quick and easy. While the effort required to maintain the benefit was reported to be somewhat burdensome and confusing, it was nevertheless viewed as worthwhile. These findings are echoed in the literature from healthcare providers who work on behalf of patients. One study found a median 19-hour turnaround time for copay card approval, which was faster than the time taken for patient assistance program approval (median 154 hours) [34]. Some studies have found that patients who used copay cards started their medication more quickly than patients who did not receive assistance [27], while others reported a modest delay in, or similar, time to treatment start [33,35,49]. In one study, copay card utilization led to faster medication start time than patient assistance programs [35].

Concerns have been raised among some healthcare stakeholders that indiscriminate use of copay cards may lead to increased patient demand for costly drugs [14]. However, the analysis by Brouwer et al indicated that copay cards provided to patients in a large health system did not affect demand for specific medications [13]. Furthermore, Van Nuys et al found that only a minority (21%) of 90 drugs for which copay cards were used in their sample had a generic alternative available; the remainder either had no generic alternative or therapeutic substitution, or had a therapeutic substitution that may not have been the best option for the patient [16]. Feedback from patients in our survey supports this finding with many explaining that a generic version of their medication was not always available. Our patients agreed that copay card utilization did not encourage overuse or misuse of medications, and they expressed their surprise that following

their personalized care plan developed in alignment with their medical team would be questioned.

In our study, not all patients were aware of accumulator and maximizer programs. Different payers use different names for these programs (including Out-of-Pocket Protection [Express Scripts], True Accumulation [Caremark], and Coupon Adjustment: Benefit Plan Protection [UnitedHealthcare]) [23], and insurance companies are not required to disclose their use [17]; these barriers potentially lead to lack of transparency and confusion for patients. However, many patients recognized the impact of these programs on their overall deductibles. Patients expressed concern that these programs could raise their OOP costs considerably. If copay cards were not available, many of the patients in our study envisioned having to switch medications, not filling their prescription, or stretching the medication they have. For these reasons and in the interest of patient wellbeing, the American Society of Clinical Oncology released a position statement calling for legislation to prohibit use of accumulator and maximizer programs and recommending immediate discontinuation of their use, with increased transparency around program design as a minimum [9].

Accumulator programs have been associated with reductions in medication prescription fills and higher risk of treatment discontinuation [18]. This study suggested a racial disparity with respect to medication adherence. When patients were asked to imagine a scenario where a copay card was not available to them, an impact on medication adherence was identified by all Black patients (100%) versus around two-thirds of White patients. This disparity is concerning, particularly when viewed in the context of data by Ingham et al demonstrating that non-White patients were no more likely to use copay cards than White patients but were approximately 30% more likely to be exposed to an accumulator or maximizer program [5]. Concerns about the impact of such programs have also led to policy changes in the United States at state level, and proposals for federal action. As of November 2022, 15 states require payers and pharmacy benefit managers to count copay assistance toward patient cost-sharing limits [50]. Proposed House Resolution 830, if enacted, would require insurers and pharmacy benefit managers to count the value of copay assistance that patients receive toward their cost-sharing requirements, and prevent insurers and pharmacy benefit managers from classifying certain medications as non-essential to avoid patients reaching their OOP maximum [51].

The limitations of this study include the small sample size and the inability to control for confounding factors that might affect patients' perceptions of copay cards (e.g., limited knowledge about the programs or different experiences depending on their disease/treatment duration). While patients in this study were socio-demographically diverse and had a variety of chronic conditions, by nature of their involvement in a PERC program, they were likely to be relatively more health-engaged or actively aware of their disease than the broader patient population, therefore the findings may not be generalizable to all patients with chronic diseases. Despite this potential for bias, awareness of CAPs and how they work was low amongst the participants in our study, suggesting there may be additional challenges and educational needs in the general population. The focus group approach allowed for discussion where patients could build on each other's ideas [52]; however, there is a risk that socially acceptable opinions and 'groupthink' bias may develop in group situations [38]. An additional limitation was the exploratory nature of the study, and there is inherent limited ability to quantify responses with a qualitative research design. Finally, the decision to publish the findings was made after the study was completed.

In conclusion, this exploratory focus group study shows that patients rely on copay cards to help reduce financial exposure to OOP costs and continue to take their medication as prescribed. Lack of familiarity and understanding of CAPs amongst our study participants is a likely indicator of poor payer-provider communication. Patients would benefit from awareness programs regarding copay cards and insurance benefit design. Industry – healthcare provider partnerships would help ensure patient access to copay cards.

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## Data availability statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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