

Original Research**Exploring the Impact of Financial Toxicity in COPD: A Qualitative Study**

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Abbreviations: COPD = chronic obstructive pulmonary disease; SES = socioeconomic status; MARC = Medication Adherence Research in COPD; HIPAA = Health Insurance Portability and Accountability Act; COST-FACIT = Comprehensive Score for financial Toxicity - Functional Assessment of Chronic Illness Therapy; COREQ = Consolidated criteria for Reporting Qualitative research

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Pre-proof

ABSTRACT

Background: Individuals with chronic obstructive pulmonary disease (COPD) often face direct and indirect medical costs from unplanned ED visits and hospitalizations for acute exacerbations, out-of-pocket expenses for inhaled bronchodilators, and income loss from disability. Yet financial toxicity, which describes the objective burden and subjective distress resulting from medical costs, has not been studied in COPD. Individual experiences of financial toxicity in COPD offer insight into challenges that may be unique to this population.

Methods: We conducted semi-structured interviews with 30 purposively sampled individuals with physician-diagnosed COPD. Transcripts were analyzed using inductive coding by 2 independent coders, and codes and were categorized through thematic analysis.

Results: Thirty participants completed semi-structured interviews, of whom 56% were women, 43% non-Hispanic White, and 43% non-Hispanic Black. The mean age was 69.5 years, and 24 (70%) had public health insurance only. Several themes emerged including: (1) the sources of material burden in COPD; (2) adjustments to disease management, such as medication nonadherence or foregoing treatments; (3) adjustments to financial planning, including both changes to day-to-day spending and disruptions in major financial plans; (4) emotional impact; and (5) communication with healthcare providers.

Conclusion: Our findings are the first, to our knowledge, to describe the impact of financial toxicity in individuals with COPD. Financial toxicity in COPD is common and may adversely impact disease self-management, financial self-management, and psychological wellbeing. Additional research is needed to examine its impact on patient-reported outcomes and to develop interventions to reduce its burden.

INTRODUCTION

Individuals with chronic obstructive pulmonary disease (COPD), a leading cause of disability in the United States, face unique material burdens.^{1,2} Inhaled bronchodilators, the mainstay treatment for COPD, remain costly in the U.S. due to limited generic options and are estimated to contribute to almost two-thirds of out-of-pocket COPD-specific expenses across all payors.³⁻⁵ Acute exacerbations of COPD can lead to unexpected emergency department visits and hospitalizations.⁶ Comorbid conditions in COPD are common and can impact clinical outcomes and healthcare utilization.⁷ In addition, prevalence of COPD is disproportionately higher in individuals of lower socioeconomic status (SES), attributed to higher rates of tobacco use as well as increased exposure to environmental and occupational risks.⁸⁻¹⁰ While individuals with COPD may face high material burden, it is unknown how they manage the increased cost and its impact on their wellbeing.

Financial toxicity, which describes the objective material burden and subjective distress resulting from both direct and indirect costs of illness, has largely been studied in oncology, where cancer-related treatment has been associated with delaying or foregoing care, medication nonadherence, and reduced health-related quality of life.¹¹⁻¹³ Compared with cancer-related treatment, which often involves high costs with initial diagnosis and active treatment phases, COPD care generally involves lower per-treatment costs but sustained expenditures, often accumulating later in life when individuals have a fixed income due to disability or retirement. Research on financial toxicity in COPD is limited but suggests it is common, with one study demonstrating that over half of privately insured individuals with self-reported COPD worried about medical costs.¹⁴ We previously demonstrated that difficulty affording medications was associated with worse respiratory morbidity, psychological wellbeing, and objectively-measured

medication adherence.¹⁵ What remains unknown is the impact of financial toxicity on quality of life in COPD.

The goal of this qualitative study is to describe experiences of COPD-related financial toxicity. Specifically, we sought to characterize the sources of material burden for people with COPD, the perceived impact of this burden on self-management and wellbeing, and individual strategies to manage these burdens that may guide future interventions addressing financial toxicity in this population.

STUDY DESIGN AND METHODS

Participants

A subsample of individuals enrolled in the Medication Adherence Research in COPD (MARC) study who gave permission to be contacted for future research were contacted to participate in semi-structured interviews. The MARC study was a prospective multicenter cohort study between Johns Hopkins Medicine (Baltimore and Hagerstown, Maryland) and Christiana Care (Wilmington and Newark, Delaware) from 2017 through 2023. Inclusion criteria in the current study were the same as in the MARC study (age ≥ 40 years old, physician-diagnosed COPD of at least moderate severity based upon prescription of a long-term controller medication). Participants who gave permission to be contacted for future research were purposively selected for diversity in race, income, education, insurance status, and a previous survey response to a question about delaying medication refills due to cost. Interested individuals were scheduled for an interview.

All study procedures, including the need for verbal consent and consent script, were approved by the Johns Hopkins Medicine Institutional Review Board (IRB00424551). Verbal

consent was obtained prior to initiation of study procedures, including audio recording of interviews. Participants were reimbursed \$25 for their time.

Interviews

All interviews were conducted between August 2024 and March 2025 using a semi-structured interview guide, detailed in e-Appendix 1. Following a literature review, the interview guide was drafted by SGM and discussed and revised with the help of experts in behavior and qualitative research (MNE, KAR). Interviews were intended to explore sources of COPD-related material burden, mechanisms of financial distress, behavioral changes to financial or disease self-management, and interactions with healthcare providers.¹⁶ The guide included optional follow-up questions based on individual responses. Ongoing review of interview transcripts allowed iterative modification of questions for subsequent interviews to explore themes as they emerged.

Interviews were conducted by a female pulmonary and critical care medicine fellow (SGM) via telephone calls that were audio recorded. Recordings were transcribed by a Health Insurance Portability and Accountability Act (HIPAA) compliant transcription service.

Following the interview, participants completed a demographic questionnaire and the COmprehensive Score for financial Toxicity - Functional Assessment of Chronic Illness Therapy (COST-FACIT), an 11-item measure assessing financial toxicity in the prior 7 days. Respondents ranked each statement on a five-point Likert scale. The scale has a possible range of scores from 0 to 44, with lower scores corresponding to greater financial toxicity.¹⁷ Based upon the COST-FACIT developer's grading system, a score of ≤ 25 corresponds to at least mild financial toxicity.¹⁸

Analysis

Transcripts were analyzed using thematic analysis to provide a descriptive understanding of the impact of financial toxicity on participants.^{19,20} Following the completion of 10 interviews, transcripts were examined by SGM and MNE for identification of themes used to develop a codebook that was then reviewed by all co-authors. Emerging themes from subsequent interviews were iteratively added to the codebook as needed. Transcripts were coded with NVivo 13 (QSR International Pty Ltd, Doncaster, Australia) by two independent coders (SGM and KH). Discrepancies were addressed by the senior qualitative investigator (MNE). Coding comparison between SGM and KH was calculated using percentage agreement and Cohen's kappa coefficient. During analysis, thematic saturation was defined as no new themes emerging for at least three interviews.²¹ A summary of findings and transcripts were presented to our patient advisory board as a form of member checking. Study reporting follows the consolidated criteria for reporting qualitative research (COREQ).²²

RESULTS

Of the 189 MARC participants who provided consent to be contacted, 63 were sent a letter describing the study before attempted contact by telephone. Of the 63, 8 had passed away, 21 were not reached despite multiple attempts, and 4 declined to participate. Thirty individuals completed interviews. Demographic characteristics of participants are described in Table 1. Fifty-three percent were female, 43% were non-Hispanic White, 40% were non-Hispanic Black, and 10% were multi-racial, with a mean age of 69.5 years. Twenty-seven percent had a college degree or higher. The majority of participants (70%) were on public insurance only, with 37% overall on Medicare only, 20% on dual Medicare and Medicaid, and 10% on Medicaid only. Most participants were either retired (43%) or on disability (43%). The median COST-FACIT

score was 22.5 (interquartile range, 18-29; mean \pm SD, 24.43 \pm 8.05) with 63% meeting criteria for at least mild financial toxicity (total score \leq 25).¹⁸

Interrater reliability of assigned interview codes was high (Cohen's kappa = 0.84; percent agreement 98.7%). Participants expressed a range of experiences and challenges related to the costs of medical care for COPD. Key themes that emerged were (1) the material burden of COPD, (2) adjustments to disease management, (3) adjustments to financial planning, (4) the emotional impact, and (5) communication with healthcare providers (Tables 2-5). A conceptual model of key themes is illustrated in Figure 1.

Sources of Material Burden

Participants described direct and indirect costs related to COPD (Table 2). Many described substantial out-of-pocket costs for inhalers, particularly those with Medicare Part D who surpassed the annual prescription drug coverage limit and entered the next coverage phase, often referred to as the “donut hole,” where the beneficiary is responsible for a greater percentage of total prescription costs. Notably, the provision of the Inflation Reduction Act capping out-of-pocket expenses at \$2000 for Medicare Part D beneficiaries went into effect in January 2025.²³ Some beneficiaries interviewed in 2025 who had not previously entered the “donut hole” experienced unexpected increases in out-of-pocket costs compared to the previous year due to increased cost-sharing and higher upfront deductibles. Other contributors to direct costs were medical bills from hospitalizations and increasing health insurance premiums also contributed to direct costs.

“Well, I put out a fair amount of money for medications, even with Medicare Part D. The Trelegy that I take, when I end up in the ‘donut hole’ it becomes pretty significant... I'm probably out-of-pocket, probably put \$3,000 into various medications.” (White, man, 77)

“Up until the first of this year, [my COPD] was fairly well controlled with medication that I had been on for quite some time. My out-of-pocket cost [had been] about \$90 for a three-month

supply. When I went to buy it, I found that it was \$894... I never reached the 'donut hole' before. My medications were covered. Apparently they moved the 'donut hole' from the center to the beginning so that I would have to make the deductible before the medication would be paid for... So I simply stopped taking it because I couldn't afford it." (White, man, 66)

"It was this monstrous bill. I took the bill and I gave it to the VA, and the VA could only pay as much as they were authorized. And there was a remainder of about \$2,000. I really stressed over that for a few months." (Black, man, 73)

Indirect costs incurred by participants included loss of employment or early retirement resulting in lost income. Others mentioned expenses related to receiving medical care, such as transportation to and from appointments. Some individuals also described downstream effects of illness on financial wellbeing, such as a decline in credit score resulting from defaulting on bill payments or accumulating credit card debt.

"I live in a rural area, and my doctors are 20, 30 miles away. When I was on Medicaid, I could use the transportation from the health department, but they do not do that for Medicare... So I have to pay people to take me to the doctor, to sit there and wait on me, and bring me back." (Black, man, 66)

"It caused me to basically get bad credit, have a lot of bills go into default." (Black, woman, 52)

Notably, material burden varied by insurance type. Many individuals enrolled only in Medicare described higher out-of-pocket costs, particularly for inhalers, and entering the "donut hole" before the end of the coverage year. In contrast, those who had Medicaid, both Medicare and Medicaid, coverage through Veterans Affairs, or private supplemental insurance generally reported minimal out-of-pocket costs.

"I lost my [Medicaid] last year. So I'm on Medicare only, and I have to pay monthly for my health insurance. Before, I didn't have to. So for the last year, I've been paying for my health insurance. And my co-pays have increased, and my prescription costs have increased." (Black, woman, 68)

Behavioral Response: Changes in Medical Care

Participants described specific ways that costs incurred from COPD treatment impacted self-management of their disease including medication non-adherence or misuse and foregoing doctor's visits or treatments (Table 3). Some worked with their providers to find less expensive alternatives.

"Last year when we went into the 'donut hole,' I stopped taking Breo [Ellipta] until we were out of the 'donut hole.'" (White, woman, 70)

"A month ago, we found a less expensive alternative. I sold some personal assets so that I can start treating it again. The product isn't quite as effective... but it's better than nothing." (White, man, 66)

Behavioral Response: Changes in Financial Self-Management

They also described how the material burden impacted their financial planning. Some participants decreased day-to-day spending on necessities. As one woman (White, 78) stated simply, "When you get old, you've got a choice between medicine and food." Others decreased participation in leisure activities. One woman (Black, 62) expressed, "I used to be able to do my mani-pedi twice a month. I used to be able to get my hair done every two weeks. I would go to the movies once or twice a month. I would go out to eat at least twice a month. All of that has changed."

Participants sold assets, dipped into retirement funds, or moved residences to pay medical bills. Many expressed that their hopes and expectations for retirement were disrupted by the burden of medical bills. Participants also reported obtaining Medigap or changing Medicare Part D plans to reduce costs. One participant (White, man, 67) included "between \$30,000 and \$40,000 worth of medical bills" in his bankruptcy filing.

"I sold my house. It's hard. I've been here 20 years. I don't want to move. I thought I'd die in this house. But my health is more important than anything, right?" (Multiracial, man, 64).

“I knew that the day was going to come that I was going to retire... I had gotten everything together so that I could travel. And then this happened... I didn't plan on having to put all my money [into] medicines. And these COPD medications are horribly expensive.” (Black, woman, 75).

“I retired not too long ago, and just a few years prior to that, I bought a boat that I had been dreaming about my whole life. I had to sell it because I had to buy medicine. There was no way I could afford the medication and keep the boat. I've been boating since I was 16 years old. A lot of people go, "It's just a boat." Well, to me, it was the dream of a lifetime and the only nice thing that me and my wife had, so. Now I feel like I've gone from living to just hanging around waiting to die.” (White, man, 66)

Participants identified several resources to directly address pharmaceutical expenses such as GoodRx and alternatives to traditional pharmacies, such as Cost Plus Drugs. Some were able to lower pharmaceutical costs through drug manufacturer assistance, while others found their income or insurance made them ineligible. Two participants obtained inhalers from Canada to reduce costs.

“AstraZeneca has a program for Medicare people. When you hit \$600 out of pocket, you get it free for the rest of the year. So I don't have to worry about that \$115 the rest of the year. But everything else took [my remaining budget]. Insurance took it. House payment took it. So thank God I got that free because I could have never afforded it. And that's one thing I cannot do without.” (White, woman, 78)

Navigating assistance programs presented its own challenges and administrative burdens. Many participants found the application and renewal processes onerous. Others expressed mixed feelings about the constraints of the services themselves.

“I basically lost everything trying to continue to be covered to get treatment for COPD. It took me two and a half years.... They just have you running back and forth, running back and forth... In the process of me trying to get disability, I lost my home because I wasn't getting any income at the time to be able to pay my mortgage.” (Black, woman, 65)

A handful of participants were able to access other resources due to comorbid conditions or treatment in subspecialty clinics with dedicated staff. A man with HIV (67) stated, “At the clinic that I go to, I have wraparound services. I have a social worker. I have an insurance specialist.”

Emotional Impact

Many participants expressed worries about possible future financial problems due to material burden, such as medical bills if their COPD were to worsen, prescription costs, changes in health insurance, and ability to support family members or pass on generational wealth (Table 4). One participant reported being started on antidepressants as a direct result of the worry he experienced from inhaler costs.

“It kind of keeps me on edge. I mean, I have trouble sleeping because at night, when I turn the light out, I'm just a slave to my mind, “Maybe if I did this-- maybe if I did this-- maybe if I hadn't done that.” So it definitely impacts my well-being and my mental state.” (White, man, 81)

Several participants referenced increased worry in the setting of uncertainty surrounding current and potential government policy changes.

“Cut my Social Security check, won't be able to survive. They're talking about taking Social Security away. And if they take away Medicaid, then I won't be able to get medical help. And even going down to what you're doing with the research, if we deal with the research, then we won't progress as far as medically. So yeah, I'm real concerned about that.” (Black, woman, 72)

Participants credited their faith, support systems, and individual qualities such as resourcefulness with helping them endure the emotional impact. *“I just trust in the Lord, and I believe he'll get me through it.” (White, woman, 79)*

Communicating with Healthcare Providers

Participants noted differing comfort levels discussing the material burden of care with providers (Table 5). While some initiated conversations about costs with providers, others expressed the perception that helping in navigating costs was outside of their provider's scope or

interest. Many of those who were connected to allied health professionals, such as social workers or clinic nurses, described ways in which they were able to help the participant navigate assistance programs and administrative burdens. Some who did discuss costs with their providers found their attempts to address costs were inadequate or inapplicable.

“One of the first things that I ask when a doctor prescribes a medicine is, how much is that going to cost? Or in the case of the Dupixent, “I’m sure this is a very expensive drug.” But he helped me with writing some letters and navigating the insurance. So that was very helpful.” (White, man, 67)

“I’ve almost stopped [the Advair] because I just cannot afford it anymore... I’ve told the doctors about it, and he said, “Well, here’s a program you can try to go through.” But I never get any satisfaction from them...” (White, man, 81)

DISCUSSION

In this qualitative study of 30 individuals with COPD, we found that financial toxicity impacts many domains of quality of life. Individuals described many contributors to material burden resulting from COPD including high out-of-pocket medical costs, income loss from disability, as well as detractors from long-term financial and credit health such as incurring credit card debt, defaulting on bills, and even filing for bankruptcy. In response to COPD-related material burden, individuals adjusted both their disease and financial self-management. Participants frequently experienced financial worries that impacted their mental health and overall quality of life.

Consistent with prior literature in COPD, the primary driver of direct medical costs in this sample was out-of-pocket costs for inhalers.^{5,24} Those with Medicare Part D as their sole prescription coverage tended to describe higher out-of-pocket costs, particularly if they had previously entered the Part D “donut hole,” while those covered by Medicaid, Veterans Affairs,

or private insurance generally expressed less concern about high co-pays. In spite of the Inflation Reduction Act's \$2000 cap on out-of-pocket expenses for Medicare Part D beneficiaries starting in January 2025, some beneficiaries interviewed after this provision went into effect who had not previously entered the "donut hole" experienced unexpected increased costs due to higher cost-sharing and deductibles, highlighting the varied impact of this policy.^{25,26} Insufficient insurance coverage of medication costs frequently led to medication misuse, forgone care, or change in participant regimens. Individual strategies to reduce pharmaceutical costs included seeking pharmaceutical manufacturer assistance, comparing pharmacies for the cheapest prices, and even obtaining inhalers from abroad. Participants described meeting direct medical costs by using savings, selling assets, and incurring debt as well as decreasing spending on both day-to-day necessities and leisure pursuits. Some connected decreases in everyday and leisure spending to increased social isolation and worse quality of life.

To our knowledge, this is the first study exploring experiences of financial toxicity in COPD. Our results indicate that individuals with COPD report similar levels of financial toxicity on the COST-FACIT as seen in cancer.²⁷⁻²⁹ Many of the themes emerging from our study are consistent with those demonstrated in the oncology literature or after acute critical illness.³⁰⁻³³ COPD is distinct from these illnesses in that it is a chronic, slowly progressive disease rather than a disease with a sudden, unexpected onset often requiring upfront intensive diagnostic workup and treatment. Many oncology populations may include younger, working-age individuals who have employer-sponsored health insurance.³⁴⁻³⁷ Importantly, similar to nationally representative studies of COPD, more than half of our sample were Medicare-eligible adults, reflecting the older average age of people with COPD.³⁸ Lifelong management with chronic inhaled therapies, frequent medication changes, and recurrent exacerbations that may

result in emergency department visits or hospitalizations lead to cumulative out-of-pocket costs through premiums, deductibles, copayments, and coverage gaps that persist over many years and often coincide with fixed or limited income in retirement.^{5,24} As mentioned previously, COPD disproportionately affects people of low SES and is a leading cause of disability, and many individuals may experience work limitation or early exit from the workforce, all of which may result in reduced lifetime earnings and savings.^{2,39,40} These disease-specific features shape how financial toxicity is experienced and managed by people with COPD.

Considering the interaction between age and chronic disease trajectory, disability, and cumulative costs, participants' perceived financial toxicity also appeared to be impacted by individual expectations. Many described the discrepancy between their previous post-retirement plans and their lived reality, which could be disrupted by progression of disease and the financial impact of changes in insurance coverage, from employer-sponsored to Medicare, at a time in their life when they had limited ability to change their financial situation. More work is needed to understand whether these results generalize to other chronic disease populations.

Our findings have important implications for COPD management. While some individuals described the stress of navigating healthcare expenses, others who were well-connected to social support systems or eligible for federal or state assistance described minimal financial distress, suggesting that the experience of financial toxicity is not linearly related to income level. These results echo the need for continued federal assistance programs including Medicaid to help individuals manage increased healthcare costs and access care.^{41,42} Prior research has shown that patient-centered financial navigation may decrease the burden of cancer-related financial toxicity.^{43,44} Future research could investigate the impact of financial navigation on individuals with COPD. More immediately, integrating screening for financial toxicity into

COPD disease management may help identify individuals who might benefit from additional services.⁴ Further quantitative research is needed to evaluate the impact of financial toxicity on clinical outcomes such as health-related quality of life, mental health, and healthcare utilization.

Qualitative semi-structured interviews allow for nuanced exploration of participant experiences that may not be adequately reflected by quantitative measures. Nevertheless our work has several limitations. Although we used purposive sampling to include diverse perspectives, our findings may not generalize to all individuals with COPD since the majority of participants were from one geographic region. Some participants described multiple comorbidities, and in some cases it was challenging to disentangle whether material burden arose from their COPD or comorbidities. Finally, all interviews were conducted by phone, precluding observation of non-verbal cues.

CONCLUSION

In this qualitative study of individuals with COPD, we found that the material burden of COPD care negatively impacts disease self-management, financial self-management, and psychological wellbeing. The interaction between older age and chronic disease trajectory, disability, and cumulative costs provides a unique context for experiences of financial toxicity in this population. Future research should focus on the impact of financial toxicity on patient-reported clinical outcomes, such as health-related quality of life, as well as interventions to mitigate financial toxicity.

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Pre-proof

Table 1. Participant characteristics (N=30)

| Characteristic | Value |
|--------------------------------|--------------|
| Age, Median (IQR) | 69.5 (64-77) |
| Female, N (%) | 16 (53) |
| Race, N (%) | |
| White | 13 (43) |
| Black | 12 (40) |
| Multiple races | 3 (10) |
| Prefer not to say | 2 (7) |
| Ethnicity, not Hispanic, N (%) | 30 (100) |
| Educational Attainment, N (%) | |
| College or more | 8 (27) |
| Some college | 8 (27) |
| High school or less | 14 (47) |
| Insurance Status, N (%) | |
| Medicare only | 11 (37) |
| Medicaid only | 3 (10) |
| Medicare and Medicaid | 6 (20) |
| Unknown public | 1 (3) |
| VA Health Care | 2 (6) |
| Some private | 7 (23) |
| Retirement Status, N (%) | |
| Work full time | 2 (6) |
| Work part time | 2 (6) |
| Retired | 13 (43) |
| On disability | 13 (43) |
| COST Score, Median (IQR) | 22.5 (18-29) |

Data are presented as No. (%) or median (interquartile range)

IQR = interquartile range; VA =

Veterans Affairs; COST =

Comprehensive Score for financial

Toxicity

Table 2. Sources of Material Burden

| Theme | Definition | Exemplary Quotes |
|---------------------------|--|--|
| Direct costs | Direct costs related to medical treatment, such as out-of-pocket costs for medications, medical bills for inpatient or emergency services, medical bills for family members | <p><i>"My health insurance went up from 308 to 348. The - what did I say? - Trelegy, Cigna changed it this year. It used to cost me \$42 a month. It's been costing me 115. And I can't do without it. I've tried to use it every other day to make it last, but my breathing gets too bad... Why do they allow pharmacies to go from \$42 a month to 115? It's what keeps people alive. I keep saying, 'Why does our government allow it?'"</i> (White woman, 78 years)</p> <p><i>"Most of my problem is the COPD. If I put it in a big ball, COPD is going to be like 60% or more of my expenditures."</i> (White man, 81 years)</p> |
| Indirect costs | Indirect costs related to illness, such as costs related to need for care (transportation, home services), loss of income from reduced capacity to work/disability, and behaviors having real or potential impact on financial wellbeing, e.g. incurring credit card debt, defaulting on bills. | <p><i>"I've always put a priority on [medical care]. If I couldn't afford to pay for it outright, I just put it on a credit card. So I ended up running up credit card debt on top of everything else."</i> (White man, 67 years)</p> <p><i>"Well, because I go to the doctor so many times, it's always extra driving, extra parking, extra, extra, extra."</i> (White man, 81 years)</p> <p><i>"My income's cut in half as to when I was working. So that was quite different to get used to."</i> (White woman, 64 years)</p> |
| Effects of insurance type | The impact of insurance type or changes in insurance coverage contributing to (or mitigating) material burden, e.g. high/increasing premiums, loss of Medicaid eligibility, changes in insurance type after retirement, changing providers due to insurance changes, Medicare donut hole, supplemental | <p><i>"I have Medicare and Medicaid. So Medicare pays 80%, and Medicaid pays the other 20. So there, I'm very fortunate. And I know a lot of people that only have Medicare. And yeah, I mean, they have tons and tons of bills."</i> (Black woman, 60 years)</p> <p><i>"When I first started [retirement], [the FSA] covered about everything. Now it covers about half of the health insurance premiums and the out-of-pocket expenses for drugs and the like."</i> (White man, 78 years)</p> |

| | | |
|--|---|--|
| | insurance, Medicaid, deductible, FSA/HSA. | <p><i>“For the last 25 years of my working career, I had excellent health insurance. And to go from that to this is one hell of a wake-up call. Maybe it makes it hurt a little bit worse because I know how good it could be. And it’s kind of funny. Actually, in the background the Trelegy commercial is on right now about how wonderful it can be if you can take this. I can’t take it.”</i></p> <p>(White man, 66 years)</p> |
|--|---|--|

Pre-proof

Table 3. Behavioral Response

| Theme | Definition | Exemplary Quotes |
|--------------------------------------|--|--|
| Changes in Medical Care | | |
| Foregoing treatments | Changes in self-management to reduce costs, such as medication non-adherence/misuse, delaying refills, foregoing treatments or appointments. | <p><i>"Well, with the one inhaler, it's very expensive to me because, like I said, I'm on social security. That's a fixed amount. And I can't always get it when I want to or when I need to. You're supposed to take twice a day. But to keep it from running out as quick, I only take it once a day."</i> (White woman, 77 years)</p> <p><i>"When I lost my medical assistance last October, I did not go to any doctors in November and December. So I didn't go into any doctors, and I was unable to get medications for November and December of last year."</i> (Black woman, 68 years)</p> <p><i>"And right now, I wasn't seeing the doctor that much because I couldn't afford it. And now, once I went-- I know once I went, it's going to be, "You've got to go here. You've got to go here. You've got to go here," because of all my health issues."</i> (Multiracial man, 64 years)</p> |
| Changing prescribing to manage costs | Actions taken by providers directly impacting prescribing and OOP medication costs. | <p><i>"Yeah. I know my COPD doctors have been trying to find stuff that's cheaper, but I don't know. It's just not working."</i> (White woman, 79 years)</p> <p><i>"He asked me did I need any prescriptions. I said, "Yes, but don't write it because I can't get it." And that's how that came up. And they got very angry because being a senior and we can't afford things, and yet they keep charging us an arm and a leg. And then we came up with Wixela. You don't know my doctor. He's just such a sweetheart and very understanding and all that."</i> (White woman, 77 years)</p> |
| Changes in Financial Self-Management | | |

| | | |
|--|--|---|
| <p>Adjusting day-to-day spending</p> | <p>Response to material burden involving changes in day-to-day spending.</p> | <p><i>"Before I spend a whole lot of money on doing something I'd much rather do, I have to say, 'No, nope, you got this coming up. You got this doctor and a co-pay there and a co-pay there.' I mean, these co-pays are eating me alive. And so I always got to consider what I got coming up in the next week or two or the rest of the month... I'll just try to hang on to the money so that I can keep my medical bills going."</i> (White man, 81 years)</p> <p><i>"I don't go out anymore. I can't afford it. I used to go-- I don't drink, but I used to go to the bar and shoot pool. I used to play in a pool league, and I like going to the movies, and I like to bowl. I had to stop. Don't do anything. Can't afford it... And it kills me because I'm in the house all the time. You start going nuts, really, sitting there by yourself all the time."</i> (Multiracial man, 64 years)</p> <p><i>"When I have to get the medicines, then that makes me-- I had to do without a food thing or laundry detergent or I'll have to pay a bill on my next check."</i> (Black woman, 75 years)</p> <p><i>"Do you pay for healthcare, or do you pay for something that you don't necessarily need but want? Some of my daughters' expenses with some of their hobbies and things of that sort, we've kind of had to cut back on a lot of that."</i> (White man, 67 years)</p> |
| <p>Disruption in major financial plans</p> | <p>Behavioral responses or changes in financial planning, adapting major life plans, and/or changes in support-seeking or support-giving to mitigate financial strain.</p> | <p><i>"I have dipped into my 401(k) a couple of times to help manage bills and such. And I have a 401(k) loan right now."</i> (White man, 67 years)</p> <p><i>"It was one of the factors of the [marital] separation was that I still have health insurance. I don't need money. I don't need anything from the house. I just need health insurance. And it's been a long time, a long time."</i> (White woman, 64 years)</p> <p><i>"I live over top of my stepfather's. He's got like this apartment upstairs from his house. And I pay him to live here, but I don't pay a lot. I couldn't swing the mortgage and repairs of the house. That's why I wanted to get rid of it."</i> (White woman, 70 years)</p> |

| | | |
|---|---|--|
| <p>Addressing high pharmaceutical costs</p> | <p>Pharmacy strategies to address financial strain from high out-of-pocket costs.</p> | <p><i>"I bought my Spiriva through a Canadian pharmacy because it was just so much cheaper. Instead of \$300-and-something, it was \$80 for three months."</i> (White woman, 78 years)</p> <p><i>"Most of these manufacturers do have some sort of support system programs but they're pretty minimal. But they are there. And like I said, I have not qualified. I was able to qualify for the sildenafil because it was so outrageously expensive. But the Eliquis, I don't. They require an income less than what I make."</i> (Man, 77 years)</p> |
| <p>Financial self-management</p> | <p>Financial and insurance strategies used to mitigate costs.</p> | <p><i>"I ended up bankrupting on my house, and I also put between \$30,000 and \$40,000 worth of medical bills on top of it. It was my medical bills, my wife's medical bills, and some of my kids' medical bills as well."</i> (White man, 67 years)</p> <p><i>"When my wife and I first got on Social Security, we went to the senior center here. And they held classes and seminars and talked about the different kinds of Part D insurance and Medigap insurance and all of that back in the day."</i> (Man, 77 years)</p> |
| <p>Navigating assistance programs</p> | <p>Addressing financial strain by applying for government assistance programs or healthcare system-based strategies to address financial strain. Enduring administrative burdens.</p> | <p><i>"I've put in applications to get extra help for prescription cost. I had put in applications just in case for medical assistance. And I'm planning on going to see someone soon to see if I can get my cost for my insurance lowered."</i> (Black woman, 68 years)</p> <p><i>"What I've been doing with the hospital-- right now, I owe \$1,500, and it's going to be ongoing because I've got like six appointments from now till November. And I usually get the bills, and I wait. I've got to do it before they go into collections, and I'll call up and ask for some financial help. And once they review it, they'll take and they'll squash the bills that I owe that I show them, and they would give me a free year of service."</i> (Multiracial man, 64 years)</p> <p><i>"There used to be a lady that would come out every year around the time for this when you have your [Medicare] renewal. She would come and explain everything to me and tell me what she thought was a good plan, what wasn't, and stuff like that. Well, don't have that anymore. Companies cut costs by getting rid of people. So we don't get any-- so we don't get the help we should get."</i> (White woman, 79 years)</p> |

Table 4. Emotional Impact

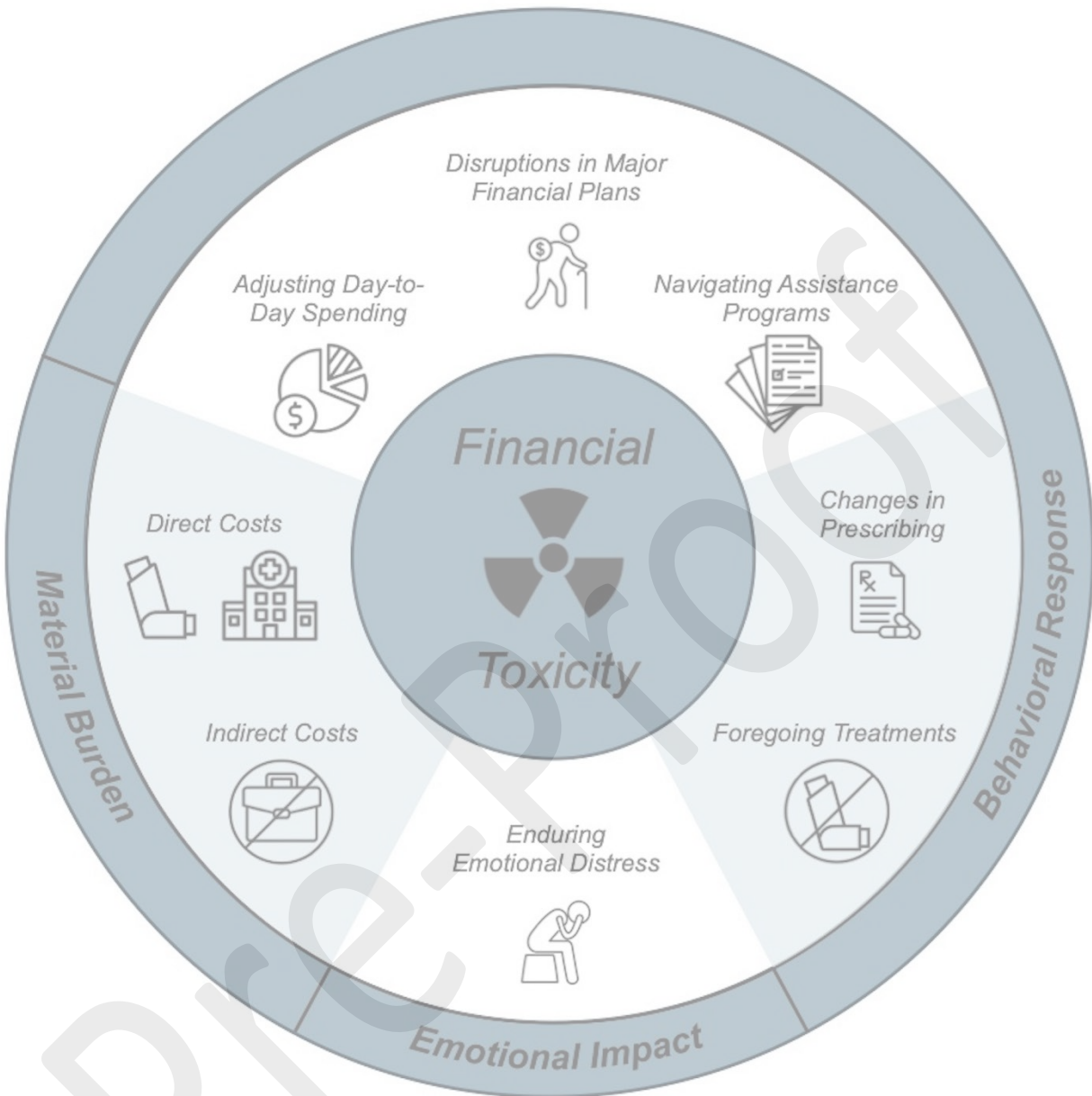
| Theme | Definition | Exemplary Quotes |
|---------------------------|---|--|
| Current financial worries | Worries about current and future financial status. | <p><i>"But the big concern is more of a forward-looking thing of how long will these savings last, will I have anything to pass along to my grandchildren, and those kind of issues."</i> (White man, 78 years)</p> <p><i>"I'm afraid that if I get really sick and have to go in the hospital, that the bills would really pile up."</i> (Black woman, 68 years)</p> <p><i>"I think at this point, I'm more worried about the retirement years, what the picture will actually look like. My spouse is really almost at that retirement age. So not having that extra piece of health insurance is a factor into thinking about when that time comes, what the whole health picture will look like."</i> (Black woman, 52 years)</p> |
| Emotional distress | Emotional and psychological manifestations of financial distress. | <p><i>"I thought I'd have a decent retirement. Of course, things change in this world, and I understand that. What you plan for doesn't always happen that way. But it just seemed like it just-- "How did this all happen to me?" is what I keep saying to myself. One day, I wake up, and I'm just falling apart. I'm just falling apart."</i> (White man, 81 years)</p> <p><i>"I know you understand that it's hard for a little peon like me to be trying to fight the pharmaceutical industry... You going to run me around until I die, and you still ain't going to give it to me. So it's like whatever y'all want to do, go ahead and do it because I don't have the energy to be fighting you people."</i> (Black woman, 65 years)</p> <p><i>"Up until the first of this year, it never affected me mentally or emotionally. I've gone through some very dark times since then. The darkest was three weeks ago when I pulled the trigger on selling my boat. Actually, my doctor prescribed me an antidepressant over this ordeal back when I was still trying to figure out what I was going to do. And I've never done that in my life, but it was the point where I couldn't sleep for worry. And obviously, I mean, I couldn't"</i></p> |

| | | |
|------------------------------------|--|---|
| | | <p><i>get the [COPD] medication that I needed, but the antidepressant didn't cost me anything."</i> (White man, 66 years)</p> |
| <p>Enduring emotional distress</p> | <p>Strategies used to mitigate financial distress.</p> | <p><i>"I pray. I have faith in God. So my situation to me, for me, changes because of him. So that's how I cope through stuff. I still, from time to time, get depressed, but I don't get depressed to a point where I'm like falling in a hole or black hole. I just sit sometimes. I have a conversation with God. Sometimes I have a conversation with God with tears running down my eyes, but it works for me. Yeah, it works for me."</i> (Black woman, 65 years)</p> |

Table 5. Communicating with Healthcare Providers

| Theme | Definition | Exemplary Quotes |
|---|---|--|
| Communicating with providers | Communication with providers about financial strain. | <p><i>"I didn't feel like saying it to the doctors would do anything... I just felt like it was out of their scope."</i> (Black woman, 52 years)</p> <p><i>"I was a little embarrassed, and I was in shock because I didn't know what had happened, why it was that way. I put [the embarrassment] aside because I needed the medication... My doctor, God bless her, spent a lot of time trying to find alternatives that would work."</i> (White man, 66 years)</p> |
| Link to resources or working with other allied health providers | Link to resources or allied health professionals helping in financial strain. | <p><i>"They were really useless. They were more generic things about, 'Oh, this provider can help you with the cost of the drug.' Well, yes, but if you have insurance, they won't do that."</i> (White man, 78 years)</p> <p><i>"Appointments, I guess, I canceled... And I got to the point where a doctor called me... I told him, 'I can't afford all this stuff right now.' He connected me to a social worker... Not long afterwards I started getting my benefits from the VA."</i> (Black man, 67 years)</p> |

Figure 1



Online Supplement

e-Appendix 1. Semi-Structured Phone Interview Guide

I am now pressing play on the recorder and I will be recording the rest of our discussion. Please stop me if you have questions or if you wish to stop recording for any reason. As we discussed during the informed consent, I will be asking some sensitive questions about costs related to having COPD, for example how the cost of COPD has affected you and your family. I want to reiterate that everything we discuss is confidential, and you are welcome to take a break from the interview whenever you want. It is very common for people with COPD to struggle with cost, and these questions will help us understand the burden to people with COPD better and hopefully help make these things easier in the future. There are no right or wrong answers.

1. How have you been managing your COPD in the past couple years? (**Probe if necessary:** comorbidities, medications, exacerbations, pulmonary rehabilitation) (Can you tell me about your COPD symptoms in the past couple of years?) Do you have any other chronic illnesses?

Domain: Material hardship

COPD can be an expensive illness for some people, not only because treatments and hospitalizations can be expensive, but also because it can also greatly affect some people's ability to work and make a living. People who struggle with finances related to treatment can actually have worse outcomes with their illness. So our goal here is to try to get a better understanding of how people with COPD manage these costs.

2. In general, how are you managing your day-to-day expenses and daily necessities? (Probe if necessary income, employment savings and expenses).
 - a. If you had a financial emergency come up how would you handle that?
 - b. How prepared do you think you are for your future financial needs?
 - c. What worries or concerns do you have about your financial preparations?
3. How, if at all, has COPD or other chronic illnesses affected your financial picture? (**Probe if necessary:** out-of-pocket costs, income and expenses, budgeting, retirement planning, savings, quality of life expenses. Have your retirement plans changed? Have you had to change residences?)
4. How has your COPD affected your ability to work and fulfill your other responsibilities? (**Probe if necessary:** FMLA, disability, or other leaves of absence or missed work due to illness)
 - a. (If on disability, how, if at all, has that affected your ability to make ends meet? How, if at all, has that changed how you budget?)
5. What types of things have you had to pay for out-of-pocket that were not related specifically to your medical care (e.g. co-pays, co-insurance) but were still due to your need to get care (e.g. transportation, additional home services)? Can you give me examples?

Domain: Coping behaviors

6. Can you tell me about how you balance or manage the cost of your treatment with other household expenses? Have you had to go without certain things because of your treatment?

(Probe if necessary: lifestyle changes or tradeoffs, expenses prioritized or cut when having difficulty making ends meet)

7. Have you ever been unable to pay for medical care or medicines at the pharmacy? If yes, can you tell me more about that?

(Probe if necessary: How do you prioritize paying for medications for COPD with paying for medications for other medical conditions? How do you choose which medications to skip? What steps, if any, do you take to reduce costs of medications? Have you worked with pharmacists? Have you changed Medicare part D plans? Have you worked with your doctor?)

8. If you were having difficulty navigating your benefits, how would you approach handling that/who has helped you with that?
9. Have you ever worked with a financial planner or anyone who has helped you reduce your costs or set a budget? (to help with budgeting, saving?)
10. Have you ever had to forego other things to pay for your medications or other medical procedures? If yes, can you tell me more about that?

Domain: Emotional response

Another thing that some people deal with as a result of COPD is issues with their mood or mental health. I am now going to ask some questions about this.

11. How has your mood been in dealing with your COPD
12. How, if at all, have the out of pocket costs of your COPD treatment impacted your stress and mood?

(Probe if necessary: What have you done to manage the stress?) Who do you talk to about this? How do these conversations go?

13. What worries about future financial problems do you have as a result of your COPD?

Domain: Reliance on others

Sometimes these issues can affect not only the people with the illness, but also their families or other people in their lives.

14. Have others helped you financially or in some other way? If yes, tell me about that.
15. How, if at all, have the financial costs of your COPD impacted other family members?

(Probe if necessary: Extra caregiving responsibilities, work absences, loss of income)

Domain: Education, resources utilized, and needs

This last set of questions is to get a better sense of what has helped or what has not helped in dealing with these issues, and to understand specifically if there are things medical providers can do to help people who are struggling financially with their illness.

16. Have you discussed the financial aspects of your treatment with your healthcare provider?
 - a. If yes, did you or your provider initiate that conversation?
 - b. If no, have you ever considered bringing it up with your provider? Why or why not?
17. What kind of information, resources, or education did your medical providers give you about the financial aspects of your treatment? What help did your providers offer?

(Probe if necessary: What did you find helpful or useful? What do you wish they had done differently? Has anyone referred you to social work/financial planning/etc.? Are there any other resources that you've found [from providers or elsewhere] that have been helpful?)
18. If you had trouble getting help covering the cost of your COPD treatment, what were the biggest challenges? If you did not have trouble getting help, what made things easy for you?
19. Now I would like you to imagine you are meeting someone who was just diagnosed with COPD. Tell me what financial advice you would give to someone who was just diagnosed with COPD?

(Probe if necessary: what, if anything, do you wish you had known?)

This is the end of our interview. Thank you so much for your time and participation. If applicable: You have expressed some areas where you are struggling. Would you like us to send you a resource guide that we have put together?