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# Finding Medical Care for Colorectal Cancer Symptoms: Experiences Among Those Facing Financial Barriers

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## Abstract

Financial barriers can substantially delay medical care seeking. Using patient narratives provided by 252 colorectal cancer patients, we explored the experience of financial barriers to care seeking. Of the 252 patients interviewed, 84 identified financial barriers as a significant hurdle to obtaining health care for their colorectal cancer symptoms. Using verbatim transcripts of the narratives collected from patients between 2008 and 2010, three themes were identified: insurance status as a barrier (discussed by $n$ = 84; 100% of subsample), finding medical care (discussed by $n$ = 30; 36% of subsample) and, insurance companies as barriers (discussed by $n$ = 7; 8% of subsample). Our analysis revealed that insurance status is more nuanced than the categories insured/uninsured and differentially affects how patients attempt to secure health care. While barriers to medical care for the uninsured have been well documented, the experiences of those who are underinsured are less well understood. To improve outcomes in these patients it is critical to understand how financial barriers to medical care are manifested. Even with anticipated changes of the Affordable Care Act, it remains important to understand how perceived financial barriers may be influencing patient behaviors, particularly those who have limited health care options due to insufficient health insurance coverage.

## Keywords

barriers to care; care seeking; colorectal cancer; insurance

Colorectal cancer (CRC) remains a leading cause of cancer death in the United States despite the efficacy of early detection. With only 40% of CRC cases diagnosed early, an alarming number of cases are not identified until symptomatic, reducing survival outcomes (Centers for Disease Control and Prevention, 2010; National Cancer Institute, 2011). Timely patient identification and care seeking for CRC symptoms is critical.

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Patient barriers to symptom identification and care seeking include normalizing symptoms (Cockburn, Paul, Tzelepis, McElduff, & Byles, 2003), lack of knowledge, embarrassment (De Nooijer, Lechner, & De Vries, 2001), fear of cancer (Smith, Pope, & Botha, 2005), and beliefs about care seeking (Rogers, 2010). Structural barriers, including insurance status, are also important to consider. In a large study of 7,661 CRC patients the 3-year relative survival proportion was 71% for the privately insured versus 53% for the uninsured (McDavid, Tucker, Sloggett, & Coleman, 2003). Yet having health insurance does not uniformly increase access or use of health care services (Devoe et al., 2007). Underinsurance, defined as excessive out-of-pocket expenses and/or severely limited scope of benefits (Blewett, Ward, & Beebe, 2006; Oswald, Bodurtha, Willis, & Moore, 2007) also leads to differential access and use. Women with Medicare engaged in less cancer screening compared with women with Medicare plus prepaid insurance (Hsia et al., 2000). Screening eligible individuals experiencing an employer mandated switch to a high deductible insurance plan had significantly fewer colonoscopies in the 12 months following the change as compared with individuals continuously enrolled in a traditional HMO plan (Pollack, Mallya, & Polsky, 2008; Wharam et al., 2008). Countries with government sponsored health care programs such as Canada, still struggle with access issues for cancer care (Ahmad, Jandu, Albagli, Angus, & Ginsburg, 2013; Gillan et al., 2012), demonstrating that insurance coverage does not always translate into adequate accessibility.

While differences in access and use of preventive cancer screening services by insurance status has been well documented (Courtney et al., 2013; Matthews, Anderson, & Nattinger, 2005; Robinson & Shavers, 2008), behaviors of symptomatic individuals who face financial barriers are less well understood. Therefore, our aim was to identify CRC patients who experienced financial barriers and explore the actions taken to overcome these barriers to obtain medical care.

## Method

### Participants

Participants were recruited as part of a study of patients interviewed about a recent (>6 months) CRC diagnosis described elsewhere (Siminoff et al., 2011). Participants were recruited from three academic and two community health systems in Virginia and Ohio. One health system in each state maintains an insurance program for uninsured patients and is considered a “safety net” provider. Potentially eligible participants were identified through medical records. Once identified, invitation letters were sent to participants; a telephone call was made 1 week later for a final eligibility screen and to assess interest in participation. Eligible patients were scheduled for an in-person interview. Inclusion criteria for the study were as follows, aged 18+ years, diagnosed with CRC within the previous 6 months, Stage I to IV (TMN staging) and experienced symptoms prior to seeking care. Exclusion criteria included diagnosis because of a preventive screen, too ill or otherwise not cognitively able to complete the interview (assessed by the treating physician). Consenting participants completed a 2-hour semistructured interview. Informed consent and medical record release forms were obtained from all participants. Of the 303 individuals who were eligible, 256 consented (84.5%), 39 refused (12.9%), and 8 could not be recontacted (2.6%). The final sample size was 252 participants; an additional 4 participants were excluded after consenting because they did not complete an interview. This analysis is conducted with a subsample of 84 patients (33%) who reported experiencing any type of financial barrier in seeking or obtaining health care for their CRC symptoms. As the aim of this study was to explore financial barriers to care seeking, insurance status classifications (insured, underinsured, and uninsured) were determined from the coding of interview responses and are described below. All relevant institutional review boards approved this study.

## Measurement

The subsample who experienced financial barriers was identified by examining two data points obtained through chart review and patient self-report: (1) insurance status and type of coverage (if insured) at the time of interview and (2) experiences of financial barriers that influenced their decision to seek or delay care seeking, identified using a series of closed-ended and open-ended questions. Any patient who discussed experiencing financial and/or insurance-related barriers to obtaining health care was included in this analysis.

## Interviews

Interviews were conducted with CRC patients between 2008 and 2010 by trained, graduate-level research assistants. Patients were interviewed an average of 4 months (but not more than 6 months) after diagnosis. Development of the semistructured interview guide was informed by Kleinman’s concept of explanatory models and the model of shared decision making (Kleinman, 1980; Siminoff & Step, 2005). The guide was purposefully constructed to elicit patients’ illness narrative regarding their experience of CRC symptoms from their initial awareness of the symptom to their obtaining medical care. Pilot interviews (completed with 40 CRC patients by a doctorate-level research coordinator) confirmed the usability of the guide as developed. Using open-ended questions and standardized probes, the following major topics were addressed in the interview: (1) symptom recognition and appraisal, (2) influences of family and friends on health care–seeking behaviors, (3) social support, (4) ease of access to health care, and (5) sociodemographics and psychosocial factors. Several established methods were used to aid recollection of events, including the use of anchor points, thinking aloud, and storytelling (Barsky, 2002; Friedenreich, Courneya, & Bryant, 1998; Maunsell, Drolet, Ouhoummane, & Robert, 2005). The interview opened with five anchor point questions; for example, when was your last birthday. Anchor points were used throughout the interview to situate events on a timeline and participants were reminded and encouraged to think aloud throughout the interview. Finally, the semistructured guide was purposefully constructed to encourage a chronological telling of the events. All interviews were audio recorded and transcribed verbatim. Medical chart reviews conducted by trained graduate-level research assistants, were used to verify patient reports of physician visits and symptoms.

## Demographic Variables

Patients were asked to report their age, income, education, gender, race, marital status, and health insurance status at the time of the interview. To calculate total time to diagnosis (TTD) we used a well-accepted definition of TTD as the time period from when the patient first noticed CRC symptoms to when a diagnosis of CRC was made (Macdonald, Macleod, Campbell, Weller, & Mitchell, 2006; Smolderen et al., 2010; Terhaar sive Droste et al., 2010). We calculated TTD as a continuous score in months. Chart reviews provided cancer stage at diagnosis and were used to verify patient-reported dates for visits to a health care provider and date of CRC diagnosis.

### Thematic Analysis

We used a directed content analysis methodology (Hsieh & Shannon, 2005). This methodology stipulates that coding categories, derived from theory or past research, are identified prior to beginning data analysis. The initial coding categories derived from literature were financial barriers and insurance status. In addition, this methodology also allows for the identification of new themes and ideas that move beyond the predetermined coding categories (Hsieh & Shannon, 2005). Hence, interpretation is framed by existing theory/research but is able to inform and further develop what is already known. An initial review of the transcripts was performed to identify all patients who discussed financial barriers to obtaining care for their CRC symptoms. Once the subsample was identified a complete reading of those transcripts was undertaken. Coding commenced using line-by-line coding, iterative analysis, and memo writing to identify primary themes and to explore the relationships between primary themes and subthemes (Corbin & Strauss, 2008). Definitions for all themes and subthemes were developed and refined throughout the coding process. Transcripts were analyzed iteratively until no additional themes emerged. All data analysis was completed by Maria D. Thomson and a trained research assistant using Atlas.ti Version 6.0. Final themes were discussed with the research team.

## Results

### Demographic and Health Care Access Characteristics

Eighty-four patients (33% of the total study sample) were identified as having experienced a financial barrier to care seeking for their CRC symptoms. Table 1 displays detailed sociodemographic information for the subsample and the full study sample. Overall, the subsample of patients who experienced financial barriers were younger, had less income, and were more likely to be unmarried compared with the full study sample. No differences in race/ethnicity or level of attained education were identified between the subsample and the full study sample.

### Themes

In our analysis of patients experiencing economic barriers to care seeking for CRC symptoms, we identified three primary themes: (1) insurance status as a barrier, (2) finding medical care, and (3) barriers attributed to insurance companies. The experience of economic barriers was not restricted to patients who did not have health insurance, demonstrating a more nuanced effect of health insurance status. Table 2 displays the themes, subthemes, and their frequencies and Table 3 displays representative quotes for each theme and subtheme.

**Theme 1: Insurance Status as a Barrier—**All individuals who reported having some sort of financial barrier to care had health insurance barriers. Patients stated that they worried about the financial ramifications for themselves and their families if they had to have expensive testing or were diagnosed with a serious illness. Patients were worried about incurring large medical bills for which family members would be responsible. This was particularly worrisome for patients who were the primary income earner. The subthemes of lack of insurance, lost insurance, waiting for insurance, and insufficient insurance explore how insurance status influenced the experience of barriers to medical care.

## Subthemes of Insurance as a Barrier

***Subtheme 1: Lack of insurance coverage:*** Forty-one (49%) of the subsample patients (16% of the total sample of 252 patients) had no health care insurance either at the time when their symptoms were first observed or at the time of their diagnosis. Uninsured patients eventually received care, for example, through receipt of care from one of two safety net hospitals. However, these patients waited to seek care until they deemed it unavoidable because they lacked insurance. Most were initially unaware that they could apply for subsidized care through the health systems' coordinated care program for uninsured patients. It is interesting to note that among this group of uninsured patients, 10/84 (12%) reported working in jobs that did not offer health care benefits. These patients discussed the particular vulnerability of being uninsured and unable to qualify for Medicaid; they also stated that taking time off to seek medical care was problematic.

***Subtheme 2: Lost insurance coverage:*** Fifteen patients (18%) discussed experiencing interruptions in insurance coverage. The reasons for interruptions in coverage included changing jobs, being laid off or reduction from full- to part-time work, which often resulted in a loss of insurance coverage. Other's reported that they lost their Medicaid insurance coverage because their spouse made too much money, being removed from a parent's insurance policy due to age, or cancellation of insurance because of increasingly high premiums. During these periods of no insurance, neither did patients seek care nor did they follow up on previous recommendations regarding their CRC symptoms. Patients reported patterns of procrastination and even helplessness as a result of losing their health insurance.

***Subtheme 3: Waiting for insurance coverage:*** Some ($n$ = 10, 12%) patients discussed waiting for coverage to begin before seeking care. We found that these patients actively planned how to obtain insurance coverage once they began experiencing symptoms. For example, some patients began looking to switch their employer to one that provided health insurance benefits. A common theme for older individuals was a decision to wait until they turned 65 and qualified for Medicare.

***Subtheme 4: Underinsurance:*** It is often assumed that having health insurance is sufficient in itself. However, 20% of patients ($n$ = 17) who reported having health insurance (either Medicare, Medicaid, or private health insurance), expressed concerns about being able to afford their medical care due to inadequate coverage. These patients were worried about the copayments and deductibles that accompanied physician visits and medical tests and consequently delayed seeking medical care. Insured patients also worried about the ramifications of being diagnosed with a serious illness. For instance, primary household earners experienced worry regarding how a serious diagnosis could affect their ability to work.

**Theme 2: Finding Medical Care—**Despite financial barriers all patients eventually did obtain care. However, the strategies used to overcome their financial barriers differed by insurance status. Patients who were uninsured or intermittently insured (i.e., those who lost or were waiting for coverage) used social networks to find resources that offered care to the uninsured and discussed how these methods often took longer but were necessary to obtain care. None of the underinsured patients discussed using the emergency department (ED) instead of primary care. However, despite having insurance, these patients described experiencing financial barriers as a delay to care seeking.

### Subthemes for Finding Medical Care

***Subtheme 1: Health care providers ameliorating insurance barriers:*** Twelve (14%) patients described how they encountered physicians who advised them to apply for Medicaid prior to scheduling an appointment or were proactive in helping them obtain care. For example, some physicians reportedly offered contacts for patients to find financial assistance (i.e., phone numbers or referrals to obtain locally available indigent care). Other patients discussed seeking out physicians willing to provide pro bono or discounted care. Once patients initiated a conversation about payment difficulties, physicians (or their staff) often offered office visits and exams at discounted costs or altered care plans (e.g., ordering bloodwork or lifestyle alterations prior to ordering colonoscopy). Only one underinsured patient identified this as a method for overcoming financial barriers.

***Subtheme 2: Emergency department use:*** Among patients with no or lapsed insurance, 12 (14%) stated that they used the ED to obtain their care specifically for the CRC symptoms. Many did this because they did not have insurance or access to a primary care provider (PCP) and hoped that their symptoms would be treated without the need for further tests or diagnostic scans. Patients who discussed using the ED did so out of necessity rather than preference and described it as the only option once their pain became intolerable, despite concern about costs. ED experiences were generally described as poor. Patients discussed feeling that they received poor care because they did not have insurance ($n$ = 15; 18%) including physicians not paying attention to them, only providing minimal investigation, or asking too few questions. Patients expressed frustration at being told to follow up with a PCP knowing that they would be unable to do this. For example, physicians in the ED would tell patients they needed to see their primary care physician or obtain a colonoscopy. While many patients discussed using the ED for acute medical emergencies only uninsured or intermittently insured patients discussed using the ED due to lack of insurance.

***Subtheme 3: Deciding to pay:*** Our sample included insured patients who discussed financial barriers to care seeking for their medical symptoms. These patients discussed having to make decisions about whether and when to seek medical care. Although these patients eventually decided to seek care despite the costs, there was often a period of delay. Patients discussed delaying care seeking in an attempt to save the money necessary to obtain care.

**Theme 3: Barriers Attributed to Insurance Companies—**Patients who were considered underinsured, meaning that they had health insurance but discussed experiencing financial barriers to obtaining care for their CRC symptoms discussed ways in which they felt insurance companies were obstructing their ability to obtain proper medical care. Patients who were uninsured or intermittently insured did not discuss barriers related to insurance companies. Underinsured patients identified two ways that insurance companies obstructed their ability to seek and obtain medical care, by dictating tests and procedures that were and were not covered (i.e., diagnostic colonoscopies) and through the threat of penalization.

### Subthemes for Barriers Attributed to Insurance Companies

***Subtheme 1: Dictating care by coverage:*** Underinsured patients (*n* = 4; 5%) were concerned about how insurance companies seemingly dictated their care through determinations about which tests would be covered, rather than allowing doctors to make decisions. This was particularly distressing for patients who had difficulty paying out of pocket for anything not covered by their insurance companies.

***Subtheme 2: Penalizing use:*** Three underinsured patients described waiting to seek care for their CRC symptoms due to fears of being penalized for using their insurance. These patients discussed feeling vulnerable and worried that insurance companies may terminate their coverage if a serious diagnosis was received or would increase deductibles if expensive diagnostic procedures were necessary to obtain a diagnosis.

## Discussion

One third of our sample reported economic barriers to care seeking, which is similar to other estimates (Rasmussen, Collins, Doty, & Garber, 2013). CRC patients experiencing such barriers were not restricted to the uninsured. For example, some patients lacked sufficient insurance coverage (i.e., high deductibles and out-of-pocket costs) while others experienced noncontinuous (i.e., lapsed) insurance coverage. The strategies used to obtain care varied by insurance status but often resulted in delayed care seeking. In our sample, uninsured patients and patients with lapsed insurance sought care through physicians who would provide charity care (discounted or pro bono) or the ED. Provision of charity care may have consequences for care quality. Despite the best intentions, reliance on individual physicians to provide charity care creates an ad hoc approach that is unsustainable to both patients and physicians. For example, the costs of tests, such as colonoscopy, are largely out of the control of physicians and the absence of referral networks for uninsured patients as well as physicians having to absorb costs for discounted or pro bono care make this approach unsustainable. The number of U.S. physicians reporting the provision of charity care is decreasing (Cunningham & Hadley, 2008). This means even greater numbers of uninsured will go without medical care, use indigent care resources such as community health centers or rely on less effective sources (i.e., ED). Greater concentrations of uninsured patients accessing indigent care or the ED also affect quality of care. For example, patients receiving care for coronary artery disease at sites with greater proportions of uninsured patients were less likely to receive guideline concordant care compared with sites with fewer uninsured patients (Smolderen et al., 2013). In our sample, 40% of patients with financial barriers did not have access to a regular PCP, yet these same patients were told to follow up with a PCP on discharge from the ED. This remains a significant loophole through which the uninsured may be forgotten. While it is an inappropriate use of the ED to treat nonemergent medical issues, it is also inappropriate for uninsured patients to be denied follow-up for potentially life-threatening illness such as CRC. While only those who were fully uninsured (with the exception of one underinsured patient) attempted to access charity care to address their CRC symptoms, insured patients often delayed care seeking or testing until money was secured, which also carries quality-of-care implications. Underinsured patients are likely less visible than uninsured, as such future research should examine physician fee policies and eligibility of patients who are inadequately insured, perhaps by examining patients who pay cash for services.

The phenomena of delaying care until qualifying for Medicare at age 65 was unanticipated. As this was not directly asked it may be more widespread than we report. Such delays can have negative and costly health outcomes, particularly for illnesses such as CRC, where early detection and diagnosis are critical for improving survival rates and lowering costs of care. However, the extent to which this occurs is unknown as these patients are considered insured once they qualify for Medicare, thus the time these patients spent uninsured or insufficiently insured remains unreported.

Our results suggest that having insurance (when it is inadequate), can itself be a barrier to obtaining care. Underinsured patients represent a population whose health care needs are going unmet but whose barriers to care seeking remain unacknowledged as they technically do have health insurance. In addition, these patients perceive that the insurance companies dictate access to care through determinations of covered and noncovered costs. While this may work to reduce medical spending, it constrains physician decision making and may lead to care decisions based on what is covered by insurance or affordable for the patient rather than what is medically advisable (Pollack et al., 2008). Finally, some underinsured patients voiced a reluctance to use their insurance due to concerns over increasing deductibles or termination of their policy. This indicates that greater educational efforts are needed to allow patients to understand their coverage and their rights as policy holders.

Our work has some limitations. The experience of economic barriers was not directly asked, however we used lengthy, in-depth interviews to ask specifically about patient-experienced barriers to care seeking and triangulated with medical chart information regarding insurance status. Therefore, we are confident that we captured thorough descriptions of the economic barriers to care seeking experienced by this population of patients. Similarly, while we did not specifically ask all patients whether they inquired about discounted or pro bono care, the absence of these conversations from the insured patient’s narratives, despite the in-depth interviews, suggests that they did not. Future work is needed to better understand whether underinsured patients do not seek such options or if clinicians and their staff do not identify these patients as requiring assistance and do not offer alternative payment arrangements.

## Conclusions and Practice Implications

Patient narratives provide depth and nuance to our understanding of the motivations and circumstances that shape care-seeking behaviors. These nuanced understandings are important to consider when evaluating practice or policy implications. While examination of the informal practice policies of individual clinicians would improve identification and inclusion of underinsured patients in alternative payment arrangements, policy work at the federal and state levels is also important. Initiatives in the Affordable Care Act address several of the problems outlined in this work. Medicaid expansions and subsidies for new private plans may help uninsured and underinsured patients afford more comprehensive and continuous health insurance. Improved access to primary care can have far-reaching effects for both prevention and timely diagnosis of CRC. In addition, improving PCP payments and creating integrated care delivery models (i.e., medical homes and Accountable Care Organizations) could potentially improve access to both preventive and diagnostic care for many chronic illnesses, including CRC. However, it remains unclear to what extent the Affordable Care Act can and will address care seeking among the uninsured and underinsured, particularly among states that opt out of components such as Medicaid expansion. In addition, private insurance is increasingly being subjected to high deductibles and copays as a way to encourage policy holders to opt for less expensive tests, even as it is unclear what policy holders do when experiencing serious symptoms. It is important to understand whether and how these costs are discouraging appropriate use of the health system. As patients typically play a small role in the choice of diagnostic tests and procedures (Klabunde et al., 2005) discouraging individuals to seek out care for symptoms in their earliest stages is an ill-advised policy. While the barriers to care seeking and methods of overcoming these barriers were different depending on insurance status, all patients in our sample described having limited choice in their health care access and diagnostic process. Ongoing research will be needed to evaluate the extent to which access to care for un- and underinsured individuals improves with the Affordable Care Act. In particular, it will be important to assess the effects of Medicaid expansion (or lack thereof) on access and use of cancer screening and diagnostic services, particularly if there is no mechanism for covering diagnostic tests. Such an oversight may affect not only access to critical diagnostic services but it may also affect patient decision making regarding screening participation (Green, Coronado, Devoe, & Allison, 2014).

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## Table 1

Sample Demographics (*n* = 84).

| Characteristic | Current analysis subset (*n* = 84)<br>Mean (*SD*) | Full study sample (*n* = 252)<br>Mean (*SD*) |
|---|---|---|
| Age (years)** | 53 (9.8) | 58 (12.2) |
| Time to diagnosis (months) | 11.7 (14.3) | 9.4 (10.6) |
| Characteristic | *n* (%) | *n* (%) |
| Gender | | |
| Male | 45 (54) | 132 (52) |
| Female | 39 (46) | 120 (48) |
| Race | | |
| Caucasian | 38 (45) | 133 (53) |
| African American | 44 (52) | 111 (44) |
| Other | 2 (2) | 8 (3) |
| Marital status* | | |
| Married | 37 (44) | 132 (52) |
| Divorced | 20 (24) | 50 (20) |
| Single | 22 (26) | 41 (16) |
| Widowed | 5 (6) | 29 (12) |
| Education | | |
| <High school | 17 (20) | 49 (19) |
| High school diploma | 28 (33) | 67 (27) |
| Some college | 27 (32) | 78 (31) |
| Bachelor’s degree | 11 (13) | 47 (19) |
| Employment status | | |
| Employed | 33 (39) | 112 (44) |
| Unemployed | 51 (61) | 140 (56) |
| Income** ($) | | |
| <10,000 | 24 (29) | 42 (17) |
| 10,000–29,000 | 28 (33) | 63 (25) |
| 30,000–49,000 | 17 (20) | 46 (18) |
| 50,000–74,000 | 5 (6) | 26 (10) |
| 75,000–100,000 | 7 (8) | 33 (13) |
| >100,000 | 3 (4) | 30 (12) |
| Declined to answer | | 12 (5) |
| Stage | | |
| 1 | 6 (7) | 21 (8) |
| 2 | 20 (24) | 61 (24) |
| 3 | 29 (35) | 100 (40) |
| 4 | 29 (35) | 64 (25) |
| Unknown | | 6 (2) |

|  | **Current analysis subset (*n* = 84)** | **Full study sample (*n* = 252)** |
|---|---|---|
| **Characteristic** | **Mean (*SD*)** | **Mean (*SD*)** |
| State |  |  |
| Virginia | 58 (69) | 168 (67) |
| Ohio | 26 (31) | 84 (33) |

[*] $p < .05$;

[**] $p < .001$ (indicates significant differences between the subsample and parent sample).

## Table 2

Identified Theme Counts and Frequencies.

| **Theme** | **Frequency *n* (%)** |
|---|---|
| Theme 1: Insurance status as a barrier | 84 (100) |
| Lack of insurance | 41 (49.4) |
| Lost insurance | 15 (18.1) |
| Waiting for insurance | 10 (12.1) |
| Underinsured | 17 (20.4) |
| Theme 2: Finding medical care | 30 (36) |
| Health care provider ameliorating barriers | 12 (14.4) |
| Emergency department use | 12 (14.4) |
| Deciding to pay | 6 (7.2) |
| Theme 3: Barriers attributed to insurance companies | 7 (8) |
| Dictating care by coverage | 4 (4.8) |
| Penalizing use | 3 (3.6) |

## Table 3

Representative Quotes of Identified Themes and Subthemes.

| Theme | Representative quote |
|---|---|
| Theme 1: Insurance status as a barrier | |
| Lack of insurance coverage | “Well initially I didn’t do anything because I did not have insurance and the job I was on didn’t offer insurance. So I just kind of put it to the side. But after I lost my job and I had time to sit down in the emergency room all day I decided to bring a book and sit in the emergency room and get checked out.” Participant 18; time to diagnosis (TTD) = 31 months<br>“So basically I would say you know I lived with it you know for quite a few months, and mainly because I didn’t have health insurance is why I didn’t go sooner, but I should’ve.” Participant 98; TTD = 5 months |
| Lost insurance coverage | “But then when I realized that things were going on and I went to my Primary Care Physician, but I kind of postponed going to him because I didn’t have insurance yet because I lost my insurance going from full-time to part-time.” Participant 110; TTD = 59 months<br>“They cut off my Medicaid because they said my husband makes too much money. I don’t know.” Participant 160; TTD = 54 months |
| Waiting for insurance coverage | “And the idea of a catastrophic disease with no insurance was just, all I could think about was what was going to happen if I really was sick and had no insurance, and my daughter would end up being the one to have to carry the burden. And that was one of the reasons why I didn’t go when I did, because uh, until I turned 65 and got Medicare, I had absolutely no insurance. Everything had to be paid.” Participant 25; TTD = 6 months<br>“But Dr. X really thought I was dying, and she urged me to continue to keep coming. One way or the other we’ll figure out how we can help you with your medical. I said, well, if nothing else, when 65 kicks in I’ll see what they can do.” Participant 555; TTD = 6 months |
| Underinsurance | “The only personal issues there was is me having the money to go to the doctor, even though they said, ‘Well you’ve got insurance.’ You know I have insurance, but the insurance don’t pay 100%, so that always was a driving force to whether I went to the doctor or not, whether I had the money.” Participant 84; TTD = 4 months<br>“We’ve got a high deductible. Keep the co-pay, keep the payment down every month. Because we have to seek out and get our own insurance. We don’t belong to a company’s insurance, or anything like that where they pay for it. We’re paying for that out of pocket.” Participant 583; TTD = 19 months |
| Theme 2: Finding medical care | |
| Health care providers ameliorating insurance barriers | “The critical issues were, when I first called, I asked them for example ‘How much is it? How much is the office visit?’ and things, and they gave me some numbers and I said ‘Wow, I don’t have any health insurance, and gee, is there something you know you can do?’ and she said ‘Well actually, yeah, let me check something,’ and they have, they do a certain amount of pro bono work and they do things, and so then ‘cause that was even jus to go in for the visit or just to have it checked, you know to have it looked at. So it wasn’t that ‘No, you can’t come in;’ it was ‘It’s all fine,’ but the prices were really high, but then she negotiated.” Participant 113; TTD = 13 months<br>“He said, ‘Take some blood and start from there,’ because I said I didn’t have health insurance. So what he did was, instead of jumping and running and having a whole bunch of other tests done, he says ‘Let’s start slowly. Let’s start with blood.’ I can afford. I paid that bill off and then ‘We could go to something else then for a more serious other exam. You know let’s not just jump to a CT scan or something like that. Let’s just do the blood and we’ll start at the bottom and work our way up as far as affordability and everything else.’” Participant 98; TTD = 5 months |
| Emergency department use | “You know every day I wasn’t feeling well. I was in severe pain. And I finally went to the Emergency Room down up this way, but they didn’t do anything for me. They would just give me pain medication and they would refer me to a doctor, but I didn’t have insurance so when I went to the doctors, they wouldn’t do anything for me.” Participant 130; TTD = 6 months<br>“Well I guess about a year before I, you know, you know, . . . I tried anything from enemas to everything I could, you know. Because I just, and I kept going to different Emergency Rooms and they just kept sending me, sending me back with a Band-Aid.” Participant 3; TTD = 7 months |
| Deciding to pay | “However I was hammered financially and am still hammered financially from the bills created during the motorcycle wreck. It was a factor I mean you know, I didn’t need any more medical bills but it didn’t stop me a second. If you’re talking about this event, I was going to the doctor hell or high water.” Participant 8; TTD = 1 month<br>“My life is more important than insurance, so I’m like I don’t care if I never pay that bill. I’m not going to die because something’s wrong with me.” Participant 524; TTD = 15 months |
| Theme 3: Barriers attributed to insurance companies | |
| Dictating care by what is covered | “The insurance companies are dictating what the doctors can and can’t do. I mean, I truly believe if I had had a CAT scan two or three years earlier they probably would have caught it a lot sooner.” Participant 57; TTD = 4 months<br>“And I definitely wanted to make sure it was listed as a screening because your health insurance will pay for a screening, if you have pre-existing then sometimes it’s not coded the same.” Participant 510; TTD = 1 month |

| Theme | Representative quote |
|---|---|
| Penalizing use | “Maybe only from the standpoint of I don’t want another problem because I don’t want it to have any impact on my health insurance. I don’t want to lose my health insurance or something like that, so.” Participant 97; TTD = 3 months<br>“Just if you use the insurance they’re going to jack it up on you.” Participant 583; TTD = 19 months |