

**Title: Cancer pain self-management in the context of a national opioid epidemic:  
Experiences of patients with advanced cancer using opioids**

**Running Head: Cancer pain and the opioid epidemic**

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## AUTHOR CONTRIBUTIONS

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### Lay Summary:

Patients with advanced cancer suffer from significant pain and frequently receive opioids to manage their pain. We interviewed 26 patients with advanced cancer and found that the majority of patients experienced stigma about their opioid use during their cancer pain experience. All patients clarified that the opioid epidemic related to this stigma. Several struggled to use opioids for pain because of this stigma and the logistical complications they experienced with pharmacies and insurance coverage. Many were afraid to share their concerns about opioids with their providers.

### Precis:

This qualitative analysis found that the U.S. opioid epidemic has stigmatized opioid use and undermined pain management in individuals with advanced cancer. Patients reported significant guilt and fear around using opioids, and endorsed restricting or avoiding opioids when managing their advanced cancer pain.

## **Abstract**

**Background:** The U.S. opioid epidemic has prompted dramatic changes in public attitudes and regulations governing opioid prescribing. Little is known about advanced cancer patients' experiences using opioids in the context of the epidemic.

**Methods:** We conducted semi-structured interviews with patients with advanced cancer and evaluated their experiences self-managing chronic pain with opioids. Two authors coded the interview transcripts; the larger team used thematic and framework analytic methods for qualitative analysis.

**Results:** We interviewed 26 patients between May 2019-April 2020. Patients consistently described the negative impact of the opioid epidemic on their ability to self-manage pain. Negative media coverage and personal experiences with the epidemic promoted stigma, fear, and guilt surrounding opioid use. As a result, many patients delayed initiating opioids and often viewed their decision to take opioids as a moral failure, describing this as "caving in." Patients frequently managed this internal conflict through opioid-restricting behaviors (e.g. skipping or taking lower doses). Stigma also impeded patient-clinician communication; patients often avoided discussing opioids, or purposely conveyed underusing them to avoid being labeled a "pill seeker." Patients experienced structural barriers to obtaining opioids such as prior authorizations, delays in refills, or being questioned by pharmacists about their opioid-use. Barriers were stressful, amplified stigma, interfered with pain control, and reinforced ambivalence about opioids.

**Conclusion:** The U.S. opioid epidemic has stigmatized opioid use and undermined pain management in individuals with advanced cancer. Interventions seeking to alleviate cancer pain

should attend to the multiple, negative influences of the opioid crisis on patients' ability to self-manage.

*Keywords:*

*Opioid, cancer, chronic pain, cancer pain, judgment, qualitative research, mass media*

Total number of each:

- 1) Text pages: 22
- 2) Tables: 2
- 3) Figures: 0
- 4) Supporting files: 1

## Introduction

Over two thirds of advanced cancer patients experience significant pain,<sup>1</sup> and opioids are the mainstay of treatment.<sup>2</sup> Unfortunately, an epidemic of opioid abuse has ravaged the U.S. over the past 20 years. Numerous regulations of controlled substances have been implemented to combat this epidemic. Although these regulations have been primarily directed at minimizing opioid use for chronic non-malignant pain,<sup>3</sup> recent evidence demonstrates substantial reductions in opioid access among cancer patients – even those with advanced cancer.<sup>4</sup>

The epidemic has also shifted public perceptions of opioid medications. The media has covered the tragedy of opioid addiction extensively, and little attention has been paid to necessary uses of opioids.<sup>5,6</sup> Opioid medications have become heavily stigmatized with much of the public now viewing them as inherently dangerous and their use immoral.<sup>5-8</sup> One questionnaire study suggested that opioid stigma may dissuade advanced cancer patients from using opioid analgesics;<sup>9</sup> however, little in-depth research has evaluated patients' experiences self-managing pain within the context of the current epidemic.

Known patient-level barriers to opioid use and cancer pain management include knowledge gaps, desire to avoid side effects, fatalism, and fear of addiction.<sup>2</sup> These barriers have been largely identified from studies predating the U.S. opioid epidemic,<sup>2,10</sup> or conducted outside of the U.S.<sup>11-14</sup> Little is known about how these barriers might have evolved, or been compounded by the milieu of the current epidemic. We conducted this qualitative study to investigate advanced cancer patients' expectations and experiences using opioids to manage pain in their home environment.

## **Methods**

### **Study Overview:**

We conducted semi-structured, qualitative interviews with advanced cancer patients, in accordance with COREQ qualitative research guidelines.<sup>15</sup> These interviews were embedded within a larger study aimed at developing a mobile health intervention to support self-management of cancer pain using opioids.

### **Study setting and participants:**

Patients were recruited from outpatient and inpatient oncology and palliative care clinics at the Dana-Farber Cancer Institute (DFCI) located in Boston, MA. Adult patients were eligible if they 1) had metastatic/locally advanced solid malignancy, 2) had pain resulting from their cancer  $\geq 3$  months, and 3) were prescribed short- and long-acting opioids. Participants were excluded if they reported 1) chronic opioid use for non-cancer pain, 2) a history of opioid use disorder, 3) currently taking opioids related to a recent surgical procedure, 4) any condition that would hinder participation in the interview, and 5) non-English speaking. The study was approved by the Dana-Farber/Harvard Cancer Center IRB.

**Study procedures:** Patients were identified by screening clinic and hospitalization lists, and eligibility was confirmed by the patient's treating provider. After obtaining written informed consent, patients completed a brief baseline survey. Participants were then scheduled for a 60 minute, in-person or telephone interview conducted by a female pain psychologist-(DA) or a female research assistant-(DK) trained in qualitative interviewing. Patients received a \$25 gift card in remuneration. Clinical characteristics were abstracted from the electronic medical record.

**Semi-structured interviews:** Interviews followed a semi-structured guide (See Appendix A) developed by a multidisciplinary team of investigators with backgrounds in pain psychology,

nursing, medical oncology, palliative care, primary care, and sociology. Open-ended questions spanned four domains: Experiences and challenges using opioids, patient provider communication, and non-pharm self-management. Participants were not specifically asked about the opioid epidemic. If a patient spontaneously discussed the epidemic, the interviewer explored this topic. Thematic saturation was observed after 20 interviews. At this point, the opioid epidemic was identified as a major theme spanning all interviews; therefore, the interview guide was amended to ask specifically about the epidemic, and an additional six interviews more fully explored this topic and confirmed thematic saturation.

### **Qualitative Analysis**

Interviews were transcribed verbatim and were analyzed line-by-line and summarized by a female pain psychologist (DA) and a male nurse scientist (RK) using thematic qualitative analysis methods.<sup>16,17</sup> An inductive approach was used to combine the Framework analysis<sup>16</sup> and thematic analysis.<sup>17</sup> This analytic approach included both prefigured codes guided by interview questions and codes emerging from the data. Through recurrent meetings with the larger study team, all codes were iteratively revised to develop a final codebook. After finalizing the codebook, two investigators (DA,RK) group coded 5 interviews, then independently coded 5 interviews and met to reconcile differences. Once the Kappa statistic indicated a high inter-rater reliability for 10 coded interviews ( $>0.85$ ),<sup>18</sup> DA&RK coded the remaining interviews individually. NVivo qualitative analytic software, version 12.0 (QSR International) was used. After indexing every patient's unique data across all five interview guide domains in a Framework matrix, the larger study team reviewed all coded and indexed data to identify emergent themes. Subsequently, coded data pertinent to themes were transferred to a separate analytic matrix and the authors drew comparisons both within and across interviews to identify

pertinent themes. Participant data is presented using pseudonyms.

## **Results**

### **Study cohort and participant characteristics**

Study recruitment and interviews occurred from May 2019-March 2020. Of the 51 patients approached for participation, 35 consented and 16 declined for reasons including being too ill/fatigued or being uncomfortable discussing their opioid use. After consenting, nine patients withdrew from the study because of clinical deterioration, leaving 26 participants in the analytic cohort.

The majority of patients were female (69%), white (85%), married (85%), had a college degree or higher (69%), and were a mean age of 60 years old ( $sd=10$ ). The most common type of cancer was breast, followed by gastrointestinal and genitourinary (Table 1).

### **Primary theme: The opioid epidemic, stigma, guilt and influences on pain self-management**

The influence of the opioid epidemic on patients' pain self-management processes was identified as a major theme within every interview. The opioid epidemic was observed to underpin patients' beliefs about opioids, to shape their use of opioids and pain self-management behaviors, to influence their interactions with providers, and their access to opioids. We identified three primary subthemes related to the opioid epidemic: 1) The influence of stigma on opioid use and pain self-management behaviors, 2) Patient-clinician communication challenges, and 3) Logistical barriers to opioid access. See Table 2 for complete list of subthemes, topics, and quotes.

#### ***Subtheme 1: The influence of stigma on opioid use and pain self-management behaviors***

Nearly all participants had overwhelmingly negative perceptions of opioids that they connected to personal/family experiences of substance use disorders, or to negative media



coverage and public attitudes concerning the epidemic.

*“I was quite fearful of becoming addicted... because of the media hype.”* (Alan, 67, prostate cancer).

The media coverage influenced participants’ beliefs about opioids, often resulting in fear, inner conflict, and guilt.

*“I was nervous about them [opioids], certainly because of all I’ve read about them, you read so much about addiction these days, I don’t want any part of these things.”* (Otto, 72, prostate cancer).

For some, family caregivers’ negative perceptions of opioids appeared to amplify their own inner conflict.

Many patients compared opioid use to other forms of substance use. For these patients, opioid use was framed as a moral issue and using opioids therefore threatened their ethical self-image and resulted in inner conflict.

*“I’m not a needle person, I don’t have an addictive personality...I don’t need to take this [opioid] now, I thought I was being a hero, I can wait...”* (Kaitlin, 55, rectal cancer).

Patients seemed to resolve this inner conflict by drawing a sharp distinction between opioid use for cancer pain and its use for reasons perceived to be less legitimate.

*“I don’t take them [opioids] for fun, obviously...I take them because I have cancer.... I have pancreatic cancer, it’s painful, versus people who take it for pleasure”* (Edna, 64, pancreatic cancer).

Stigma and fear of addiction served as powerful deterrents to initiating opioids. Many patients described actively avoiding opioids until their pain was very severe or led to

hospitalization for a pain crisis. Patients viewed long-acting opioids as particularly dangerous, and many specifically avoided these seeking to reduce their risk of “addiction.”

*“I was reluctant to try the extended-release medications because of addiction, so I was on the immediate release medication and it was not being managed, it was my fault.”*  
*(Tamera, 48, uterine cancer)*

In hindsight, many recognized that they may have benefitted from earlier opioid use. Even still, they perceived their decision to use opioids as a defeat or moral failure, with a few referring to this as “*caving in*.” Very few patients were unconcerned about addiction. Most participants described other forms of opioid-restricting behaviors, and chose to take them only as a “*last resort*.”

*“So, it was kind of a scary thing once I started, because of all the controversy about using and abusing and becoming addicted to them...I don’t like the idea of taking opioids... but I’ve succumbed to taking that every single day.”* (Oliver, 61, prostate cancer).

Several patients acknowledged and agreed with providers’ advice to use opioids more proactively, yet still deviated from these recommendations and restricted their opioid use in an effort to resolve their own internal conflict. Participants described intentionally deviating from prescription schedules or taking lower doses than prescribed, often without informing their care teams, and sometimes in dangerous ways. For example:

*“because of the negative connotation about addiction and then abuse of OxyContin, especially... I was trying so hard to bite it or chew it or cut it with a knife ... I wanted to manage it with the lowest dose I possibly could...”* (Grace, 52, breast cancer).

Opioid-minimizing behaviors seemed to reassure patients, provide a sense of control over their

addiction fears, and helped to resolve moral conflict associated with their opioid use.

### **Subtheme 2: Communication challenges with clinicians**

Stigma surrounding opioids also operated as a barrier to patient-provider communication about pain management. Many patients hesitated to ask their care team for guidance about using opioids to manage pain, or they consciously conveyed underusing their opioids because they were afraid of being judged or viewed as a “*pill seeker*.”

*“It was during the time when everybody wanted to take opioids away, and I was afraid whether I was doing it right...So it was like okay, I’ll just stay under the radar and this is helping some.”* (Lilly, 59, ovarian cancer).

*“So I don’t like taking pills, and I was very much like I didn’t want to be seen as a pill seeker, as someone who just wants drugs.”* (Mary, 51, Ovarian cancer).

Patients reported getting relatively little teaching about pain management – and when they did, it primarily centered around proactive use of opioids. Many patients described difficulty understanding basic principles such as how to interpret their prescriptions, even after being on opioids for extended periods of time.

Although nearly all patients worried about addiction, most were uncomfortable raising these concerns with care teams. Several patients described waiting several appointments to ask about their addiction concerns, with many never overtly discussing addiction fears. Although several patients described receiving education about when to take their opioids, many described receiving overly simplified responses regarding addiction concerns – that “*cancer patients don’t get addicted*,” (Phoebe, breast cancer, 53) or exhortations to “*not worry*” about addiction. Many patients accepted these explanations at face value, yet they also described ongoing addiction

worries and opioid restricting behaviors.

A few patients perceived that providers might purposely hesitate to prescribe opioids or answer questions about its addictive potential because of a lack of knowledge or liability fears.

For example, one patient stated,

*“Some [physicians] may be fearful of answering questions in which they may not be giving correct information or whatever...I have questions, I’ll ask them. So a lot of hesitancy on responding.”* (Asma, 65, breast)

### **Subtheme 3: Logistical Barriers to Opioid Use**

Many patients described significant difficulty in obtaining opioids due to logistical or health systems barriers. Patients often bemoaned insurance regulations including unexpected changes in prescription coverage and seemingly arbitrary rules about the types or amounts of medications that could be filled.

*“Insurance company got jitters because of all the attention with oxycontin.”* (Asma, 65, breast) [explaining having to change her opioid due to insurance restrictions]

They also described pharmacy obstacles such as requirements for hand-written prescriptions, or extra paperwork to corroborate the legitimacy of their prescriptions. These barriers frequently resulted in patients receiving less medication than prescribed or experiencing delays in refills. As a direct consequence, patients described rationing their opioids or running out of them altogether – resulting in poor pain management and even opioid withdrawal. In a few cases, these logistical barriers were so disruptive that patients requested that their doctor change their prescriptions to different formulations.

Several patients also described receiving “push back” from pharmacy staff, in the form of questions to corroborate the legitimacy of their opioid requirements, or requests to speak directly

to the prescriber. These lines of questioning were uniformly perceived as judgmental and publicly humiliating. This extra scrutiny and the additional logistical barriers served to reinforce participants' moral distress, concerns about addiction, and anger toward people who abused opioids.

*“Trying to partner with the pharmacy to ease their concern, because they make you feel like you’ve done something wrong...because of the opioids.”* (Hannah, 68, breast)

## **Discussion**

Through qualitative interviews, we found that the opioid epidemic has negatively impacted advanced cancer patients' ability to self-manage pain through multiple, interrelated, and mutually reinforcing mechanisms. The epidemic has markedly stigmatized opioid analgesics, amplifying cancer patients' fear and guilt around opioid use. These factors contributed to opioid-restricting and sometimes dangerous behaviors, hesitancy to ask care teams for pain management support, and suboptimal pain control. Insurance- and pharmacy-related opioid barriers further reinforced stigma, and made patients more fearful and ashamed regarding their opioid needs. Many patients continued to express fear and internal conflict related to their opioid use, which they appeared to mitigate by minimizing opioid use and by externalizing blame toward others who misuse opioids.

Addiction fears have long been identified as a barrier to cancer pain management; yet, most knowledge of this subject predates the opioid epidemic.<sup>2,13</sup> Our findings suggest that the epidemic has amplified these fears, and caused shame that permeates numerous aspects of patients' pain management efforts. For example, shame inhibited patients from using opioids and from discussing their opioids with providers. Patients who eventually communicated concerns with their physicians noted receiving simplistic answers downplaying the risks of “addiction” in

cancer contexts.<sup>3</sup> Although the risk of de novo opioid misuse disorder is likely low in the context of advanced cancer,<sup>19</sup> patients' addiction worries operate as substantial barriers to pain control and therefore deserve thorough conversations that acknowledge the current climate around opioid use.

Interestingly, nearly every patient in our study referenced media coverage of the opioid epidemic – typically using highly charged words such as “addict,” “oxy,” “pill-seeker,” “junkies,” and “narcotics.” Sensationalized stories and stigmatizing language are a hallmark of the media's coverage of the epidemic,<sup>5–8</sup> which appears to be directly influencing the way in which advanced cancer patients' view their own analgesic medications. This is supported by studies in the chronic non-cancer pain literature also showing heightened stigma related to the epidemic.<sup>20</sup> Although opioid misuse disorder is a serious public health crisis, more balanced media coverage that also acknowledges safe and appropriate uses of opioids might benefit cancer patients.

Participants cited frequent insurance and pharmacy-related barriers that delayed or limited the amount and types of opioids they received. These barriers were stressful, and often led to periods of poorly controlled pain or even opioid withdrawal. Since the 2016-Centers for Disease Control guidelines on opioid therapy for chronic non-cancer pain, numerous new insurance, pharmacy, and state-based regulations have been created to limit opioid prescribing.<sup>21,22</sup> This includes limiting first-time opioid prescriptions to 7-14 day-supplies,<sup>23</sup> insurance formulary restrictions,<sup>22</sup> and Medicaid policies requiring pharmacists to review and verify opioid prescriptions that exceed certain doses/quantities or those that are prescribed concurrent with benzodiazepines, antipsychotics or other high-risk medications.<sup>24</sup> While a cancer diagnosis is often sufficient to exclude patients from these regulations, patients are often forced

to wait without medication while extra paperwork is processed. Our findings suggest that heightened regulations not only have a direct negative impact on cancer patients' pain control, but they were also perceived as being punitive, amplifying stigma, and reinforcing patients' reluctance to use opioids.

Strengths of this study include its rigorous qualitative methodology and the timeliness of its findings. Limitations include a lack of racial/ethnic diversity – which is important because racial/ethnic minorities are known to face greater barriers to opioid access and are likely affected more acutely by opioid stigma. and the fact that recruitment was limited to a single center in Massachusetts, a state with the 7<sup>th</sup> highest per capita opioid mortality rate.<sup>25</sup> Whether our findings are generalizable to other settings or patient populations is uncertain.

## **Conclusion**

This qualitative study found the opioid epidemic and related stigma to be a major barrier to controlling advanced cancer pain, negatively impacting patients' self-management experiences at multiple levels. Future research with larger, more diverse populations is needed to determine the extent to which opioid stigma influences cancer pain outcomes, and to identify modifiable targets for intervention. Awareness and proactive communication regarding the opioid stigma may be an important strategy to better supporting patients coping with advanced cancer pain.

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**Table 1. Characteristics of participants with advanced cancer (n=26)**

<b>Characteristic</b>	<b>n(%)</b>
Age, years, [m(sd), range]	60(10) 31-76
Female	18(69.2)
Race	
White	22(84.6)
Black/other	4(15.3)
Education	
> College degree or higher	18(69.2)
Cancer Type	
Breast	6(23.1)
Gastrointestinal	7(26.9)
Genitourinary	5(19.2)
Lung/Unknown origin	3(11.5)
Short-Acting Opioid	
Oxycodone	14(53.8)
Hydromorphone	11(42.3)
Morphine Sulfate IR	1(3.8)
Long-Acting Opioid	
Oxycodone	10(38.5)
Morphine	8(30.8)
Transdermal Fentanyl	7(26.9)
Methadone	1(3.8)
Interview location	
In-person	13(50)
Telephone	13(50)
Interview length, time, m, range	40, 19-67
Average Pain (0-5)	2.92(.12), 2-4
Worst Pain (0-5)	3.96(1.8), 2-5
Pain Interference, m(sd), range	26(1.8), 9-40
≥ 22*	17(64)

Note: From the NIH- Patient Reported Outcome Measurement Information System (PROMIS), participants completed items from the PROMIS-Pain intensity 3a (average and worst pain score: higher scores representing more severe pain); PROMIS Pain Interference 8a (higher scores represent higher interference, \*scores $\geq$ 22=significant pain interference)

**Table 2. Primary Themes and Exemplary Quotes**


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**Major Theme: The opioid epidemic, stigma, guilt, and influences on processes of pain self-management**


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**Subtheme 1: The influence of stigma on opioid use and pain self-management behaviors**


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***1a. The negative media coverage and personal experiences of the opioid epidemic***

- “I did have the word oxy in my brain from news reports, so when OxyContin came into my life, I was a little like, aah [referring to feeling afraid]– you know?” (Grace, 52, breast cancer)
- “Just what I read and hear, addiction is not a lot of fun. Yeah...and coming off addiction probably can be even less fun. So obviously in the back of my mind I’m concerned about that down the road.” (Joe, 76, pancreas cancer)
- “I read the paper and I watch the news, so I certainly knew that there was a crisis and that there were many deaths from inappropriate use. I was alarmed by it as everybody has been. I was shocked at what we learned about the pharmaceutical company and how they had promoted it inappropriately and doctors that had been giving out prescriptions indiscriminately.” (Hannah, 68, breast cancer)
- “Well, it killed my brother so – I don’t like them.” (Ellie, 31, gastrointestinal cancer)

***1b. Fear, guilt, and shame related to opioid use***

- “Cause you know, I do feel guilty... I don’t even smoke, I never smoked, I was not a drinker, so for me taking the pills, it’s like wow” (Frances, 65, ovarian cancer)
- “The fear of addiction...I just watch too much television where it’s always like someone gets in an accident and it starts off as oxys, and then when the oxys run out, they run to other drugs to make up for – they just need the drug – they go to crack... I’m not a needle person. I don’t really have an addictive personality.” (Kaitlin, 55, gastrointestinal cancer)
- “Not knowing if my body would become addicted. I had no idea because, again, it was my first experience ever with anything like this. And so, I had no experience and all I had was nervousness about potential...I could become addicted.” (Rose, 73, pancreas cancer)

***1c. Opioids restricting behaviors***

- “I probably could have benefited from it a lot sooner if I wasn’t so afraid” (Lilly, 59, ovarian cancer)
- “I’m sort of paranoid about that [addiction]...that’s perhaps why I’m not as eager to take multiple amounts of them [short-acting dose].” (Esther, 67, breast cancer)
- “Even now I’m trying to gear more towards Advil so I can get rid of the opioids... I don’t want to get hooked.” (Dylan, 69, lung cancer)

**Table 2. continued*****1d. Rationalizing opioid use and externalizing blame***

- “I don’t take them for fun, obviously...I take them because I have cancer...I have pancreatic cancer, it’s painful, versus people who take it for pleasure.” (Edna, 64, pancreas cancer)
- “I believe it is a different situation. I believe...you have these junkies, sorry to call, it the way it is. They let themselves get hooked on it, you know?” (George, 51, lung cancer).

**Subtheme 2: Communication challenges stemming from opioid stigma*****2a. Avoiding conversations about opioids***

- “I didn’t want my doctor to think I was looking for pills, either” (Grace, 52, breast cancer).
- "I have never done that [ask provider questions about opioids] because I’m afraid of being judged." (Tamera, 48, uterus cancer)

***2b. Provider reassurances regarding opioids***

- “I have to take it, because I’m sick and I have pain. And so, what he [physician] explained to me was I’m not the typical candidate that they’re talking about on TV. I’m taking it because I have pancreatic cancer, it’s painful, versus people who take it for pleasure,” (Edna, 64, pancreas cancer)
- “They had to re-assure me 2-3 times, listen you have cancer, you have a legitimate reason, no one is going to be judging you, this is something you need,” (Mary, 51, ovary cancer)

**Subtheme 3: Logistical barriers to filling opioid prescriptions: reinforcing stigma, and impeding pain control**

- "I feel really bad for people that really need it because they’re a lot of people out there... abusing it, and it makes... it hard for them, for us, to get our medications...it’s ridiculous how hard it is to get the medications now. " (Frances, 65, ovary cancer).
- “Instead of the long-acting, I keep – I have some – a smaller dose for short-acting, and so a couple of times I’ve had to kind of piece it together until I can get it delivered.” (Asma, 65, breast cancer)

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**Table 2. Continued**

- “This pharmacy had asked if I could get a letter from my doctor just stating that I was her patient and cancer, stage four, and that I would be prescribed these medications. So I got that letter ...So just talking with them and trying to make a partner with them so that they weren't concerned about why I was getting them on such a routine basis, or why I was getting as many as I was... My doctor wasn't happy and she said it's none of their business. But she wrote the letter. But she thought it was inappropriate. They didn't by regulation need it. They just - I don't know... - they are so punishing. You just feel like you've done something wrong. It was just really hard...And I didn't want them looking scant at me when I walked in... because they are so misused and we've got this horrible epidemic, just there's a certain initial stigma in taking these drugs, and I didn't want to feel that.” (Hannah, 68, breast cancer)