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Elucidating patient-perceived role in “decision-making” among African Americans receiving lung cancer care through a county safety-net system

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Abstract

Purpose—We explored patient-perceived role in “decision-making” related to active treatment and palliation among African Americans receiving lung cancer care through a county safety-net system.

Methods—Drawing from a cohort of over 100 African Americans treated in a safety-net hospital, we invited a subsample of 13 patient-caregiver dyads to participate in a series of dyadic, ethnographic interviews conducted at the patients’ homes. Over 40 hours of transcripts were analyzed in an iterative process resulting in reported themes.

Results—Findings from ethnographic interviews demonstrated that healthcare communication with physicians is difficult for patients. While caregivers and patients describe a deep engagement in lung cancer care, they expressed a concurrent lack of understanding of their prognosis and outcomes of treatment. Dyads did not discuss their lung cancer experience in terms of decision-making, rather most articulated their role as following physician guidance. Distinct lack of understanding about disease course, severity, and prognosis may constrain patient perception of the need for informed decision-making over the course of care.

Conclusions—Dyadic interviews detailing safety-net patient experiences of lung cancer care raise important questions about how clinicians, as well as researchers, conceptualize processes of informed decision-making in vulnerable populations.

Implications for Cancer Survivors—Safety-net patients may not perceive their role as involving informed decision-making, and further may lack understanding of disease course and

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Conflicts of Interest:

Simon Craddock Lee, Emily G. Marks, Joanne M. Sanders, and Deborah J. Wiebe declare that they have no conflict of interest.

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975 (revised 2000). This study was approved by our medical center’s Institutional Review Board (STU112011-064) and for conduct by the administration of the county hospital. Informed consent was obtained from all research participants to be included in the study.

individual prognosis. Safety-net patient dyads expressed high involvement in care and a desire for clarity; clinicians should be prepared to clearly communicate disease stage and prognosis.

Keywords

decision-making; safety-net; lung cancer; qualitative methods; patient-physician communication

Introduction

Given low overall survival rates, treatment decisions in the weeks following lung cancer diagnosis are critical. The majority of lung cancers (57%) are diagnosed in advanced stages; overall 5-year survival rates for small cell and non-small cell lung cancer are 6% and 18%, respectively [1]. Outcomes are worse for African American patients who are often diagnosed at younger ages, with more advanced disease [2–4]. Such disparities have been well-documented through comparative studies with other populations.

However, research on understanding “decision-making” in the course of lung cancer care has largely developed independent of work theorizing inter-personal processes – dynamics between both patient and caregiver as well as between patient and provider — that may impact patient-physician relationships. Research suggests that involving the primary caregiver, spouse or other family member, can directly impact cancer treatment outcomes [5, 6] but further work is needed to advance understanding of care-giver roles and effects in decision-making with respect to active treatment and palliation, as well as transitions to end-of-life care [7, 8]. Moreover, despite clear evidence of differences in care practices and disparities in outcomes among minority and underserved patients, studies have largely ignored how socioeconomic status or racial/ethnic group status may affect decision-making processes [9, 10]. Studies suggest low socioeconomic status (SES) patients, including many African Americans, are disproportionately less likely to receive guideline-based treatment for their lung cancer [11], raising questions about overall patient-physician communication, as well as the interpersonal processes involved in treatment decision-making itself. Studies of lung resection rates and of end-of-life (EOL) care find marked differences in rates of treatment choice and suggest that factors such as religiosity, physician-patient racial concordance, and information-sharing/communication during provider interactions may be contributing factors [12–14].

In general, most patients with cancer report a desire for full information regarding prognosis [15, 16]. This desire for full information is consistent across patients with varying levels of desire to participate in decision-making, although the match between preferred role and actual participation varies [17]. African American cancer patients report higher information needs than non-Hispanic whites [18] but perceive receiving less information and support from their providers [19] and rate their quality of care less highly than whites [20]; in other studies, black patients with cancer are also less likely to acknowledge having a terminal illness [21].

Type and amount of medical information, as well as how it is transmitted by the provider to the patient, may have a direct effect on treatment decisions. Patients’ beliefs, values, and attitudes create an additional level of interpretation of this medical information, leading

clinical investigators to frame decision making as a “communication process” [9]. Such clear communication has been shown to contribute to receiving care that accords with patient values [9], although caregiver involvement can introduce additional complexity [7, 22, 23]. A patient’s acknowledgement and understanding of his/her illness has been associated with treatment decision-making, particularly in advanced cancer [24]. Ineffective or unsatisfactory communication may directly affect whether patients proceed with provider-recommended procedures. For example, compared with white patients, black patients were more likely to receive life-prolonging care, even after conversations about EOL care have occurred [25], suggesting that key information was either inadequately conveyed or received.

Many patients and their caregivers perceive physician interactive styles differently and report difficulties in understanding what medical information has been provided [26], further constraining their ability to make informed decisions with clinicians. In safety-net settings, such as county hospitals, that disproportionately serve under- and uninsured patients, [27] providers are further challenged by the need to care for patients with lower health literacy and fewer resources [28]. Together, these factors adversely impact patient-physician communication and patient understanding with the potential to decrease informed decision-making [29, 30]. Prior studies have neglected to examine how characteristics of this population may alter the course of patient-provider interactions and decision-making. In this study, we use a qualitative research design to elucidate the relationships between patient-perceived role and decision-making in lung cancer care, drawing from serial interviews on the safety-net lung cancer treatment experience with African American patient-caregiver dyads.

Methods

Given established disparities in treatment and care for lung cancer experienced by African Americans, this hypothesis-generating study explored how social dynamics of patient-caregiver dyads might shape decision-making in the safety-net setting. We sought to apply anthropological methods of dyadic, ethnographic interviewing [31–33] to understand the experience of lung cancer care among African Americans treated at Parkland Health and Hospital System. Parkland is the publicly-funded, integrated health system for all residents of Dallas County and is the sole provider for under- and uninsured patients seeking cancer treatment [34, 35]. This study was approved by the UTSW Institutional Review Board (STU112011-064).

Recruitment and data collection

The study team used electronic medical record (EMR) data abstraction and manual chart review to identify African American lung cancer patients who had completed at least one visit with their oncologist at the ambulatory oncology clinic within this county safety-net hospital system. All patients were approached in the clinic and informed consent was obtained prior to participation in the study. One hundred patients (74%) completed a staff-administered survey, during which time patients were asked to identify a primary caregiver — usually a spouse/partner or family member — and subsequently offered the opportunity

to be contacted for a series of three joint interviews with their primary caregiver at a location of their choice.

Patients who agreed to be contacted (n= 45; 43%) were called by research staff within one week of survey completion. Interviews were scheduled with at least 2–5 months between each session to better understand how lung cancer treatment and progression impacts the patient-caregiver experience. To acknowledge their time, dyads were offered a \$30 honorarium at the end of each session (\$90 total for series completion). The study team developed an interview guide to probe patient and caregiver experiences of support and communication with both family members and medical providers over the course of active treatment and follow-up. A medical anthropologist with expertise in ethnographic methods (SL) conducted all interviews at individual patient homes across Dallas County. Patients and caregivers discussed multiple aspects of the lung cancer experience including initial diagnosis, discussions with their medical team, understanding of treatment success and prognosis, EOL care as relevant, as well as their relationship to each other and extended family (see Appendix: Interview guide, questions for initial session).

Patients and their caregivers were contacted 6–8 weeks after the completion of the prior interview to schedule the next session; sessions were approximately 90 minutes each. Thirteen participants initiated dyadic interviews with a caregiver, nine dyads completed second interviews, and five dyads completed the full three-session series. Reasons for not completing the series included patient death, illness burden (e.g., loss of speech, etc.), and lost to follow-up at second or third contact. Several sessions were delayed due to hospitalization events. Thus, a total of twenty-seven interview sessions were conducted with 13 dyads, resulting in over 40 hours of interview data.

While almost equal numbers of male and female patients participated in interviews (6 women), all but one caregiver were female. Caregivers identified as spouse/partner (n=4), adult children (n=4), and other family members (n=5).

Data analysis

Interviews were captured using a digital audio recorder and transcribed by a professional transcriptionist. Transcripts of each interview were coded in NVivo 9 (QSR International, AU) by a masters-level qualitative analyst using an inductive text-driven approach to thematic content analysis [36, 37]. Data were analyzed based on conversation, i.e. each dyad was treated as its own unit of analysis. After the first four interviews were completed, the research team undertook iterative readings of transcripts to produce an initial list of codes as they emerged. We then applied these broader codes to the first set of interviews. The research team discussed emergent themes and consolidation of codes after more than half of the interviews had been analyzed [38, 39]. We developed additional codes as they emerged during analysis of the second and third interview sessions. By conducting these latter interviews concurrently with transcript analysis, the interviewer was able to explore new ideas during interviews as new themes were identified. Once the second-half of the interviews were analyzed and our coding structure was finalized, the analyst re-analyzed the first set of transcripts, applying the new codes generated by the later interviews.

We assessed for sociodemographic and clinical differences between the interview dyads and the larger group of survey respondents using Fisher's Exact Tests. Statistical analyses were conducted using SAS software, Version 9.3 (SAS Institute Inc., Cary, NC).

Results

Approximately equal numbers of men and women were enrolled in the cohort; most patients ranged from 50 to 70 years of age (72%); 45% were surveyed within 6 months of diagnosis. Over half of patients reported receiving less than a high school education (53%). Based on age, sex, education, marital status, smoking history, and time since diagnosis, the dyadic interview participants (n=13) were representative of the overall study cohort of African American lung cancer patients receiving care through this safety-net hospital system (n=87; all Fisher's Exact Tests were non-significant, see Table 1). Our analysis identified four major themes in the experience of lung cancer care, which we have grouped as: Challenges to effective communication, Caregivers as advocate and facilitator; Lack of understanding of prognosis and outcomes; Clinicians make decisions. Selected additional quotations are included in Table 3 by theme.

Challenges to Effective Communication

Our findings indicated that healthcare communication between patients, caregivers, and clinicians is constrained by use of medical language. However, our interviews revealed that while such challenges commonly frustrate patients and their family, these frustrations were rarely expressed to providers during their clinical visits. Patients and caregivers described these interactions with providers in the following ways (see also Table 3.1– 3.3):

Mhm. 'Cause really I ain't had a chance to sit down and talk with nobody one on one. It's always been a group [of providers]. Not one on one. Then you talk to a group, like you say, this one will say something then this one will say something. Try to get you away from what you really want to know. (Patient, third interview, dyad 113)

...I be asking them why is the, you come here every day it's a different team. You talk to me, you take all my blood. What is going on with me? Why you can't just tell me what's happening? You getting all the blood and you not telling me the results of the blood tests. And they're taking me somewhere way around here about in the inside of me and that ain't what I want to hear. I want to hear what's going on with my blood tests and no one, they wouldn't tell me that. (Patient, first interview, dyad 121)

Patients may have unexpressed concerns or anxieties, but seem to consistently avoid questions and discussions related to prognosis and progression. As in the first case below, the patient seems to express the expectation that the provider would initiate a discussion about disease progression based on the provider's expert knowledge and judgment.

They ain't saying nothing about nothing worsening, you know, getting bad or nothing... I believe if something was bad, they'll tell me. (Patient, second interview dyad 121)

Never even asked [oncologist]... how long do you have?...– I’ve never asked him that. I don’t feel that’s a question that needs to be asked right now. (Girlfriend, first interview, dyad 111)

Caregivers as Advocate and Facilitator

Caregivers discussed the need to be present for medical visits and other interactions in clinic settings to help their patient family member to understand what information was provided by the medical team or to explain procedures as they happen. Caregivers assert that simply “being there”, as well as providing instrumental support, for example, by taking notes during medical appointments, is a core component of the caregiver role, even if the clinical discussion itself is difficult for the caregiver to understand (see also Table 3.4).

Every doctor, every nurse, whatever you were, I was seeing. I’m writing your name and I want to know...what department are you in, and I could tell him, “Okay now this one here, I tell him remember the one with the glasses that wear her little hair up like that, okay they’re from this department and they going to do this. That one over there, he’s going to give you medicine, this one here he’s going to do that,”... he got used to them. (Daughter, first interview, dyad 48)

Patients and their caregivers express engagement in cancer treatment through adherence. By attending treatment appointments, maintaining the recommended diet, and taking medications, even when difficult or painful, patients and caregivers report active adherence to their current treatment regimen (see also Table 3.5–3.7)

Listen to your doctors and do what they tell you to do. (Patient’s mother, first interview, dyad 51)

We are more or less on track – I think everybody’s on the same page... Seems like everything seems to be working just fine for us. Our appointments, we haven’t missed a one, day or night. His medication, we’re up to date on that. (Patient’s girlfriend, first interview, dyad 111)

Lack of Understanding of Prognosis and Outcomes

While patients and their caregivers describe deep engagement in lung cancer care, they expressed a concurrent lack of understanding of prognosis and treatment outcomes in most cases (see also Table 3.8).

Is this ever gonna quit or if it ain’t somebody needs to tell me. If it ain’t gonna quit or if it is gonna quit. ‘Cause I needs to know something. Ain’t no sense keeping me in the dark, and I’m the one that’s got this stuff...we really need to know. (Patient, third interview, dyad 45)

I think it’s real good because... to me is going better, you know...you notice his age difference, that’s all it is. That’s it, but then I know that one of the requirements of his progression, of course by them removing one of the lungs of course he’s short-winded so, but that’s it. (Daughter, third interview, dyad 48)

In this excerpt, an adult daughter attributed her father’s limitations to age and rationalized shortness of breath as a logical consequence of resection. Over the remainder of the

interview, her comments show no indication of understanding the implications of possible disease progression. Many interview participants also express distinct lack of understanding of disease stage:

From what he had told me earlier, it was like a phase 3 and I don't know what that is, you know stage 3... they had done the biopsy and he told me it was like phase 3. But I want to know what that is in laymen's terms, what does that mean? I say when I go this week to the doctor, I'm gonna ask all kinds of questions and stuff. (Patient, second interview, dyad 94)

But, I guess that was how I was looking through the medical record and one sheet, somebody wrote down stage four and so well I said, well where did that come from? I don't know nothing 'bout no stage four... So I said maybe that is just a misunderstanding... So well maybe that's just, you know an error. How far many stages do they go? (Wife, first interview, dyad 45)

While patients expressed positive attitudes regarding treatment options in general, we found that in cases where surgery was offered or discussed, patients expressed notable fears or concerns about "cutting," as other studies have previously reported (see also Table 3.9) [40–43].

I was so worried about being cut though, I did not want to be cut at all, that I was grateful for because I didn't want to be cut...Because it's like every time somebody gets cut, it go like that *snap* and they say like the air hits and it spreads. I don't know if that's true or what but I do know that the majority of people that get cut, especially for lung cancer, they don't make it. (Patient, second interview, dyad 78)

Clinicians make Decisions

In our interview discussions, patients and their caregivers did not frame their treatment experience in terms of "decision-making." Rather, when they spoke about their treatment, patients framed the care they received in terms of decisions their clinicians had made for them (see also Table 3.10–3.11).

They've been really straightforward with me you know. So it's no decision to really make, but the decision to make is well if you got a cure, then I'm willing to try with you, you know to where with you to see if that cure can work with me. And that's basically what I, what I be relying on. (Patient, first interview, dyad 76)

Some patients seemed to struggle with the notion of patients making decisions about their treatment at all, when their doctors were the experts. Indeed, some patients and their caregivers found the notion of having such a conversation about decision-making incongruent with their experience and their expectations.

Interviewer: Did they give you a chance to have the kind of conversation you and I are having now ...

Patient: Nah...

Interviewer: Or is it too difficult to do in the clinic?

Patient: Probably too, you know, I never sit down and talk with nobody like this in the clinic. They always tell me what's going, you know, what they want me to know. I never really got the chance to just express out how I feel or what's going on. (Patient, first interview, dyad 121)

Patients and their caregivers spoke in detail about their experience of care, many in the context of religious beliefs that reveal a more complex dynamic within the treatment milieu than is often conveyed in the simple terms of active or passive patient roles. A patient initially presented with a surgical treatment option explains how he planned to choose chemotherapy instead, only to return to his appointment to learn that surgery was no longer an option:

Hell, it wasn't even a 30-minute surgery.... It sounded good — oh it was coming at me and you know, in my thinking like — wow — but I prayed on it and the next day, I went back for the decision. So my decision was that no — cause I had either surgery or another month of chemo and we can wash it away. So I was going in strong — well, I'll tell you this, I'm taking the chemo point blank. That's the way — we'll let it wash away and I didn't have to say anything 'cause their decision was already made because then the doctor said [surgery] was a waste of time... (Patient, third interview, dyad 126)

In this case, the patient had been reluctant about a surgical route and enthusiastic about chemotherapy, taken with the notion of “washing out cancer.” But the interview did not convey knowledge about the surgical oncologist consult regarding implications of a small lesion, its location and operability. Instead, framed by the patient's appeal to prayer, the decision appeared to have been made. This interaction exemplifies the complexity of patient-provider decision-making processes, where the outcome was not incongruent with the patient's preference; but it was not truly a patient-driven decision.

Now why should I be in here bitter side and well, me- that's why I didn't go that way. I went the way that I know that okay, this is how we going to do it and the doctor's thought I was crazy, but this is the way we gonna do it because I had a God that telled me this is the way I'm gonna do it. (Patient, third interview, dyad 126)

We found that patient accounts did not reflect transparent moments of patient decision-making, rather they reflect nuanced conversations between clinicians and patients who trust them to provide what they need. Indeed, that patient recounts:

So [the doctor] say, “what I gotta do is that I'm gonna have to send you for a PET scan” and I say, “why do I have to take a PET scan?” because, you know, she said I was talking about, you know, you have two options and I said, “what's the options?” She say, “Well, we can have surgery and take it right on out, or you can just do two more treatments, two more months of treatment of chemo” and I say, “Well, I'm really tired of chemo” but, you know, that was just my thinking then....[doctor] sat down and explained it to me first. After she gave me the good news, how it had shrunk and then she, she sat down and she told me. that it was still up to me, what I wanted I want to do because she really had no, “no, don't do, I

don't think you all need to cut him." And it wasn't there yet; it was just throwing it out there that. But I had to still do the PET scan, so we could see it, where it was at. And so she set me up with them right away (Patient, second interview, dyad 126)

Decisions about receipt of cancer care return to issues of adherence that follow from understanding the guidance doctors give. Further, patients are aware of the broader context of county safety-net care in which conversations with clinicians occur.

That's the number one thing is to understand what [doctors are] saying and if you do understand what they're saying, **go about what they tell you to do**. I mean if they – they're not gonna tell you to do anything wrong. And even if they're telling you, it's for the benefit of your health, not for theirs. And just go to all of your appointments. Don't miss any. You can't. There's other people out there that's sick that need that appointment. You've got it, they've set it for you, be there. (Patient, first interview, dyad 111)

Discussion

Our study data suggest that physician-patient communication and decision-making among safety-net patients differ from how such processes play out in mainstream populations among whom prior studies have been conducted. While this cohort of African American patients generally liked and respected their physicians, our interviews reveal that patients and their caregivers are often unsatisfied with clinician interactions and report uncertainty about their limited medical knowledge of the relationship between disease stage and treatments [44]. In this cohort of safety-net patients, however, we found this frustration was rarely communicated to their providers during clinic visits. This is a notable finding among low-income, minority, under- and uninsured patients where the social context of care may increase patient desire to avoid being perceived as "difficult," resulting in more passive patient behaviors [45].

While initial conversations with patients and their caregivers would seem to indicate relative understanding of their illness, our extended interviews suggest a need for greater nuance. In some cases, we found that failure to understand progression and disease course (e.g., metastasis) was associated with misunderstanding the relevance of surgical intervention for resectable versus unresectable disease [12]. Patients or caregivers repeatedly endorsed the idea that "cutting" contributes to disease progression, as prior studies of African American patients have also reported [40, 43]. Thus, when clinicians indicated patients would not receive surgery, patient dyads often expressed relief, apparently, at having avoided an invasive procedure. Only one patient dyad indicated they understood that surgery was not an option because their cancer was inoperable or surgery likely ineffective at this point in their disease course. Our interview data suggest that superficial reports of patient understanding of disease, in truth, only reflect increased familiarity with the treatment regimen that patients were currently receiving and consequent compliance. This finding corresponds to recent studies reporting varied understanding of disease course, treatment, and prognosis [46–49].

Nationally, low rates of overall survival for advanced lung cancer make clear communication all the more urgent, especially among disparities populations that are more

frequently diagnosed at later stages. In populations with lower health literacy, talk of “stage” itself may be misleading. Patients and their families ask, How long until the next stage? How many stages are there? Few understand, and their clinicians may not explain, that stage is an artefact of the diagnostic process, used to identify an appropriate treatment regimen, but do not understand that a patient’s lung cancer does not progress in units of ordered time from one stage to a later stage.

Our findings point to the need for further studies to explore decision-making across different SES populations [50]. Our study raises concerns about how clinicians conceptualize the process of patient “decision-making” among safety-net populations in particular, where understanding of prognosis may be absent or confused [48, 51]. Our cohort of patients strongly agreed with the importance of keeping appointments and complying with physician recommendations. However, our interview findings suggest that patients did not perceive conversations in which clinicians raised types of treatment as discussions of actual “treatment options.” Patients and their families rarely framed any of their experience in terms of patient “choices.” In contrast to some prior studies of African American cancer patients [52], our patient dyads reflected the belief that decisions about treatment rest with their clinical team. Our interview data do not *support* the idea that safety-net patients make clear distinctions between *clinician recommendations* about treatment and *clinician decisions-to-treat*. Thus, in contrast to the premise of many prior decision-making studies, clinician communication styles intended to preserve patient autonomy may not be optimal for underserved patients at every stage of their illness [53, 54].

Our findings have direct implications for decision-making because, absent a clear understanding of stage and relation to prognosis, many patients we spoke to were: unaware of relative likelihood of decompensation; unprepared to understand palliation as opposed to curative treatments; and consequently, had not prepared for family planning about end-of-life preferences such as hospice, etc. End-of-life and palliative care studies have extensively documented how the specter of mortality can inhibit patient-provider conversations about prognosis and treatment options [18, 55–57]. Indeed, our patient dyads themselves struggled with these topics and conversation was awkward, even uncomfortable, for several patients and caregivers, despite iterative, extended interview sessions during which the investigator was otherwise able to establish significant rapport. We acknowledge, however, that we were interviewing patients in active treatment and follow-up as opposed to during explicit hospice or palliative care when patients would be more aware of EOL-related decisions that might result in greater emphasis on patient control [52, 58]. Similarly, religious belief and use of prayer introduced factors that could enrich models of interpersonal decision-making beyond the patient-provider binary. Among patients, such as those seeking care in safety-net settings, who may not think about their care experience in terms of specific choices, clinicians who speak directly with patients about their spiritual beliefs can create new opportunities to clarify patient expectations of the care they are receiving [59].

Limitations of this study include a small sample size and the inability for some dyads to be available for all three interviews due to prior caregiver commitments or patient illness. The resource intensity of conducting ethnographic interviews with economically-disadvantaged and actively ill patients stipulated a relatively small study sample. To address this, we

sought to survey every African American lung cancer patient treated at Parkland using validated measures, both to establish a baseline understanding of psycho-social factors and to demonstrate that the subsample invited to interviews was representative of the overall population of African American lung cancer patients treated at the county hospital. Although we offered gift cards to each dyad, we do not believe additional financial incentive would necessarily decrease attrition. Many people who seek care in safety-net settings, like Parkland, hold hourly employment on unstable schedules, often for multiple employers. Thus, the inability to take time off work rather than compensation for research participation poses a challenge for studies in this population.

Our study is the first, to our knowledge, to explicitly focus on the lung cancer experience of African American patients in a safety-net setting. There is a paucity of studies exploring decision-making issues among lower-SES and minority patients like those we report on here [16, 17, 60]. Although there may be particular racial/ethnic dimensions to patient-clinician communication needs, it is important to note that race construct-specific cultural issues did not emerge from these iterative interviews with our patients and their caregivers, even when prompted. In this context, our study contributes to a very limited literature that has sought to explore whether socioeconomic status (SES, proxies including low educational attainment, low income, urban/teaching hospital) constitutes a stronger challenge than race or ethnicity to fostering robust patient-physician communication [60–63]. Proxies for SES like income and education may mediate the association of race with quality of clinician communication [64]. Thus, while cultural group-specific framing may be important to how future interventions are tailored for delivery, the broad lack of patient knowledge about prognosis and treatment options we found suggest these SES-related factors may be more effective targets than other contributors specifically cast as racial or ethnic cultural attributes [4].

Conclusion

While our participants almost uniformly expressed trust and confidence in their clinicians, our study findings suggest several practical considerations to improve clinician communication and, thereby, facilitate ability of lung cancer patients and their caregivers to make informed decisions concerning their course of care, even if the decision is to allow treating clinicians to determine that course. First, because many safety-net patients defer to their care team, clinicians should *initiate* conversations about diagnostic stage, prognosis and disease progression. To ensure accurate understanding, clinicians should ask patients to repeat back what they know and what they think that means about what comes next for their care. To provide optimal care, clinicians should initiate discussion of palliative symptom management in parallel with curative treatments. Further, asking about spiritual beliefs creates opportunity to clarify patient expectations about treatment, as well as to convey clinician concern about an important dimension of patient life. Clear communication about these issues early in the course of treatment would encourage patients and their caregivers to articulate values and expectations, in advance of confronting the need to make decisions about end-of-life, comfort care and appropriateness of hospice. Lack of understanding and consequent lack of discussion leaves patients and family members unprepared should disease progress, directly impacting quality of care and the overall survivorship experience of lung cancer.

Our results call for future studies to clarify whether the lack of understanding of prognosis we identified reflects failure of clinician communication about prognosis, failure of patient comprehension, patient denial, or some combination of these factors – all of which may be further complicated by how patients perceive their role in decision-making, given the safety-net milieu. Dyadic ethnographic interviews detailing safety-net patient experiences of lung cancer care, thus, raise important questions about how clinicians, as well as researchers, conceptualize processes of informed decision-making in such vulnerable, underserved populations. Patient lack of knowledge of prognosis may impact perception of choice within the safety-net patient-clinician relationship. It follows that efforts to develop interventions seeking, for example, to increase rates of receipt of guideline-based care [65] or to improve clinical trial participation [66, 67], will need to account for these issues as they relate to decision-making in safety-net cancer care.

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Appendix: Interview Guide

Question domains for initial session

- Tell me about the time when you first found out you were sick.
- Tell me about the first time you talked with XXX about your sickness.
- Does s/he go with you to your medical appointments? Tell me more about that.
- It sounds like you have a lot to cope with. How does XXX help you manage?
- When you have gone to see the doctor, do you two talk about things afterwards? During?
- Some people find that coping with illness is made more difficult by family members. Tell me what it's like for you? For the two of you?
- Who else do you talk to about taking care of YYYY?
- Who else do you talk to about your illness?
- Do you think your relationship, how you are coping, is different from how other people/couples might manage? Tell me more about that. How do you think you are different/similar?
- Tell me how you feel about his/her treatment?

- Do you think you understand enough to make decisions/help YYY make decisions?
- How do you two feel about the care you are getting?
- Talk to me about getting to and from appointments?
- Have you talked about what comes next?

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Table 1

Demographics: Interviewees vs. remaining sample

	Overall Cohort N=87 n (%)	Dyad Interview Patient N=13 n (%)	<i>p</i> value*
Age at Survey, years			
46–60	49 (56.3)	8 (61.5)	0.7733
61–86	38 (43.7)	5 (38.5)	
Sex			
Male	41 (47.1)	8 (61.5)	0.3840
Female	46 (52.9)	5 (38.5)	
Education			
11th grade or less	46 (52.9)	7 (53.8)	1.0000
High school graduate/GED or greater	41 (47.1)	6 (46.2)	
Marital Status			
Married/partnered	22 (25.6)	6 (46.2)	0.1835
Divorced/Widowed/Single NM	64 (74.4)	7 (53.8)	
Ever Smoked, Yes	81 (93.1)	13 (100)	1.0000
Time Since Lung Cancer Diagnosis			
6 months	39 (44.8)	7 (53.8)	0.5661
> 6 months	48 (55.2)	6 (46.2)	

GED = General Educational Development; NM = Never Married.

* Fisher's Exact Test *p* value (2-Tail).

No significant differences identified.

Table 3

Selected additional quotes by theme

Challenges to Effective Communication	
1	Well the doctor don't tell me much...I have to bring it out of the doctor. You see how I have to bring it out of the doctor when we be in the room back there. "What's a matter with me?" and "How I'm doing?" and this and that. (<i>Patient, first interview, dyad 45</i>)
2	Look here, when you can't sleep and you can't eat and you can't do nothing what are you going to do? See that's what I'm talking about, see if I could sleep and eat I'd be all right. That's the reason why they need to get me out there at that hospital and find out why I can't, why I cannot eat and I cannot sleep. That's what they need to do. And that's what I've been asking them to do. They won't even tell me. It's my fault cause I can't sleep and eat. If they was to tell me that. I would understand that. (<i>Patient, third interview, Dyad 45</i>)
3	Well, I just want them to tell, keep me up with them. Let me know what's going on. What they know, tell me. I know how to handle it. If it's good or bad, I still got to know...That's all I, that's all I want to know: just, just where I'm at and how I stand. If it's going to take me away in the next few months, tell me so I won't be thinking, you know, oh, I'm doing good and all of a sudden I'm blown. (<i>Patient, first interview, dyad 121</i>)
Caregivers as Advocate and Facilitator	
4	You know how doctors are, they'll kinda talk over your head somewhat and so I'm kinda here to kinda help him and say, "Can you put it like in a laymen's terms so we can understand it in depth?" We got a pretty good understanding of what's going on with him. (<i>Daughter, first interview, dyad 111</i>)
5	I just figure I'd keep on and take my medicine and this and that you know back and forth to my appointments and stuff. I figured that was it. I don't know, do what I needs to do and you know, I might come out of this stuff alright. (Patient) Yeah, he go every week and all the time. (<i>Wife, first interview, dyad 45</i>)
6	...I think the bus start running around 5:00 something so my earliest appointment is at 7:00 yeah. So I'll be able to be on time, that's why I like being on time because you got to find a place...but I'm pretty much know where I got to go now because I done been there so many times. (<i>Patient, first interview, dyad 94</i>)
7	I have to do the part that the doctors don't do and that gives me the motivation that okay, I know how that hurt and I tell her that, "oh, that was a bad one [radiation treatment]," but I don't stop. I'm not gonna stop because then... my taste buds coming back so little by little. (Patient, first interview, dyad 126)
Lack of Understanding of Prognosis and Outcomes	
8	No it's not difficult. At first I mean when it first happened you know yeah it was difficult, hard, but now it don't you know it don't bother me... I mean it don't bother me I just want to know, you know. No it don't bother me. I just want to know. Yeah that was my plan to ask them. (<i>Patient, first interview, dyad 122</i>)
9	Straight up radiation, chemo. No surgery. I'm not too keen on surgery...If you can avoid cutting on that cancer, please by all means. You know. I'm hoping they – they said he has like a 60–70% chance of it being taken care of this first shot. (<i>Patient, first interview, dyad 111</i>)
Clinicians make Decisions	
10	They can just go in there and the hole won't be that big, the surgery won't be that long, but I didn't have to even tell them what I wanted. They told me; it was their decision what we should do. So the doctors probably looked at it and, well, it's too small and it's a risk.... I got a good doctor, though. She's amazing. Dr. X, I put him way up there because then when he makes a decision, he makes some damn good decisions because I didn't know, I was just telling what the decisions because that's just the way I felt and what God was given me. (<i>Patient, second interview, dyad 126</i>)
11	About two days later [the doctor] told me you are going to get the port put in and start the chemo and I was like okay and he said I'm going to save your life and meant it with passion. (<i>Patient, second interview, dyad 78</i>)