Qualitative assessment of organizational barriers to optimal lung cancer care in a community hospital setting in the United States

Satish Kedia, PhD,[a] Kenneth D Ward, PhD,[a] Siri A Digney, MS,[a] Bianca M Jackson, MPH,[b] Andy C Collins, PhD,[a] Fedoria Rugless Stewart, PhD,[b] Nicholas R Faris, MDiv,[b] Kristina S Roark, RN, BSN,[b] and Raymond U Osarogiagbon, MBBS[b]

[a]Division of Social & Behavioral Sciences, School of Public Health, University of Memphis, and [b]Multidisciplinary Thoracic Oncology Program, Baptist Cancer Center, Memphis, Tennessee

Background Lung cancer is a major public health challenge in the United States with a complicated process of care delivery. In addition, it is a challenge for many lung cancer patients and their caregivers to navigate health care systems while coping with the disease.

Objective To explore the organizational barriers to receiving quality health care from the perspective of lung cancer patients and their caregivers.

Methods In a qualitative study involving 10 focus groups of patients and their caregivers, we recorded and transcribed guided discussions for analysis by using Dedoose software to investigate recurrent themes.

Results Analysis of the transcriptions revealed 4 recurring themes related to organizational barriers to quality care: insurance, scheduling, communication, and knowledge. The participants perceived support with navigating the health care system, either through their own social network or from within the health care systems, as beneficial in coping with the lung cancer, seeking information, expediting appointments, connecting patients to physicians, and receiving timely care.

Limitations Institutional and geographic differences in the experience of lung cancer care may limit the generalizability of the results of this study.

Conclusions This study offers insights into the perspectives of lung cancer patients and caregivers on the organizational barriers to receiving quality care. Targeting barriers related to insurance coverage, appointment scheduling, provider-patient communication, and patient or family education about lung cancer and its treatment process will likely improve patient and caregiver experience of care.

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Lung cancer is a major public health challenge in the United States. It is the leading cause of cancer death in the United States, accounting for 27% of all cancer deaths, and it has an aggregate 5-year survival rate of 18%.[1] Advances in diagnostic and treatment options are rapidly increasing the complexity of lung cancer care delivery, which involves multiple specialty providers and often cuts across health care institutions.[2-4] Navigating the process of care while coping with the complexities of the illness can be overwhelming for both the patient and the caregiver.[5] With increasing regulations and cost-cutting measures, the health care system in the United States can pose many challenges, especially for those dealing with catastrophic and life-threatening illnesses. Any barrier to accessing care often increases anxiety in patients, who are already trying to cope with the management of their disease.[6-8]

The concept of barriers to quality care (such as the receipt of timely and appropriate diagnostic and staging work-up and treatment selection according to evidence-based guidelines) is generally used in the context of improving health care management or prevention programs.[9-13] Barriers might include high costs, transportation, distance, underinsurance, limited hours for access to care, patient sharing by physicians, and a lack of access to information about physicians' recommendations.[10,14-16] Such bar-

riers have been categorized as organizational (leadership and workforce), structural (process of care), clinical (provider-patient encounter), and macro (policy and population).[17,18] Organizational barriers are defined as impediments encountered within the medical system and health care organizations when accessing, receiving, and delivering care.[12] Several organizational barriers have been identified in the literature based on characteristics of the targeted population (eg, race, ethnicity, type of illness), key stakeholder views, and aspects of care (eg, screening, preventive practice, care, and treatment).

In a systematic review, Betancourt and colleagues reported provider-patient interactions, processes of care, and language as some of the barriers to receiving quality care.[17] Although cancer screening has been shown to reduce mortality in the adult population for several types of cancer,[19-21] barriers that impede access to services have been identified as emanating not only from the macro level (eg, age of screening, reimbursement problems, screening guidelines) or inter- and intra-individual levels (eg, awareness of screening, various perspectives on life and cancer, comorbidities, social support), but also from the organization (organizational infrastructure that inhibits screening because of limited participation in research trials) and provider levels (impaired communication regarding screening between patient and physician, low commitment to shared decision-making, provider's awareness of screening and screening guidelines).[18] Other organizational barriers, such as difficulty navigating the health care system, poor interaction between patients and medical staff, and language barriers, have been identified in a systematic review of breast cancer screening in immigrant and minority women.[22]

Other barriers to quality cancer care reported by patients include knowledge about the disease and treatment, poor communication with providers, lack of coordination and timeliness of care, and lack of attention to care. Providers have identified other barriers to quality care, which include a lack of access to care, reimbursement problems, poor psychosocial support services, accountability of care, provider workload, and inadequate patient education.[23] Few qualitative studies have been conducted to understand the organizational barriers that lung cancer patients and their caregivers face within the health care system.

Through the use of focus groups, we sought the perspectives of lung cancer patients and their caregivers on the organizational barriers that they experience while navigating the health care system. Identifying and understanding these barriers can help health care professionals work with patients and their caregivers to alleviate these stressors in an already difficult time.[3,24] In addition, a more thorough understanding of patients' and caregivers' perspectives on organizational barriers may help improve health care delivery and, thus, patient satisfaction.

TABLE 1 Number of participants per focus group[a]

Group no.	No. of patients [no. of caregivers] (n = 22 [24])
1	6 [7][a]
2	5 [5]
3	2 [2]
4	5 [5]
5	4 [5][a]

[a]Some patients brought more than 1 caregiver.

Methods

With the approval of the Institutional Review Boards of the University of Memphis and the Baptist Memorial Health Care Corporation, we conducted focus groups with lung cancer patients and their informal caregivers to understand the challenges they encounter while navigating the health care system during their illness. The Baptist Memorial Health Care system is centered in the Mid-South region of the United States, which has some of the highest US lung cancer incidence rates.[25]

Research staff identified potential participants from a roster of patients provided by treatment clinics within the system. Patients eligible for this study had received care for suspected lung cancer within a community-based health care system within 6 months preceding the date of the focus group. Eligible patients were approached by the research staff by cold calling or in-person contact during clinic visits for their consent to participate in the study. From a compiled list of 219 patients, 89 received initial contact to gauge interest. Of those, 42 patients were formally approached and asked to participate; 22 agreed to participate, and 20 did not participate for reasons including illness, previous participation in other forms of patient feedback, lack of interest, failure to show up to focus group sessions, change of mind, lack of transportation, or other commitments. Patients identified their informal caregivers to form patient-caregiver dyads. All patients and caregivers provided written informed consent before participating in the focus groups.

We conducted 10 focus groups during March 2013 through January 2014 – 5 with 22 patients and 5 with 24 caregivers (Table 1). Eight of the focus groups were conducted in Memphis, Tennessee, and to obtain the perspectives of patients from a rural setting, we conducted 2 focus groups in Grenada, Mississippi. All of the focus groups were facilitated by a medical anthropologist (SK) and a clinical psychologist (KDW), neither of whom was affiliated with the health care system. Each facilitator was accompanied by a note-taker. Patient-caregiver dyads came to the designated location together. Two focus groups (one

for patients, the other for caregivers) were then conducted simultaneously in 2 separate rooms. The facilitators used a pilot-tested focus group interview guide during each session. The items in the focus group guide revolved around experience with the health care system in diagnosis and treatment; timeliness with appointments and procedures for diagnosis and subsequent care; physician communication in being informed about the disease, treatment, and getting questions answered; coordination of care; other challenges in receiving quality care; and suggestions for improving the patient and caregiver experience with the health care system.

The focus group sessions lasted 1 to 2 hours and were audio-recorded and transcribed verbatim. The data were analyzed by using Dedoose software version 5.0.11 (Sociocultural Research Consultants, Los Angeles, California). Data collection and analysis were conducted concurrently to achieve theoretical saturation. Creswell's 7-step analysis framework was used as a guide to code and interpret the data.[26] The process involved collecting raw data, preparing and organizing transcripts, reading the transcripts, coding the data with the help of qualitative software, analyzing the data for themes and subthemes, interpreting the themes, and devising the meaning of the themes.[26] Initial codes were categorized and compared to determine recurrent themes. Three members of the research team independently reviewed the transcripts, extensively discussed the content, and developed consensus around the identified themes. Critical and rigorous steps were taken throughout data collection and analysis to ensure the credibility, transferability, dependability, and confirmability of the qualitative data.[27-29] In addition, elements of the Consolidated Criteria for Reporting Qualitative Research checklist were used to strengthen the data collection, analysis, and reporting process.[30]

Results

The 10 focus groups included 46 participants: 22 patients and 24 caregivers (some patients brought multiple caregivers). Of the 22 patients, 12 were women and 7 were black. An equal proportion of patients had at least a high school education as had a college or postgraduate degree. Although all of the patients had had a lung lesion suspicious for lung cancer, 19 eventually had a histologic diagnosis of lung cancer. The remaining 3 patients were all evaluated in a thoracic oncology clinic but were eventually found to have metastatic breast cancer, lymphoma, and a granuloma. Nine patients were either currently in the treatment decision-making process or actively receiving treatment, 11 had completed treatment within the preceding 6 months, and 2 had completed treatment more than 6 months previously. Treatment covered the spectrum from curative intent to palliative care. Of the 24 caregivers, 18 were women and 7 were black; 12 caregivers had at least a college education, of whom 2 had postgraduate degrees (Table 2).

Based on participants' feedback, we identified 4 main levels within the system where barriers to optimal care occurred: policy, institutional, provider, and patient. From our qualitative analyses, we identified a central theme associated with each level, around which the barriers coalesced. The themes were insurance, scheduling, provider communication, and patient knowledge. At the *policy level*, medical insurance was perceived to affect the timeliness of care and to be a deterrent to timely diagnosis and quality treatment. Lack of insurance was a daunting obstacle for indigent patients. However, even those who were insured felt that dealing with insurance companies was a significant barrier to care. At the *institutional level*, appointment scheduling caused problems for both patients and their caregivers. At the health care *provider level*, communication was perceived as a major problem. And finally, at the *patient level*, both patient and caregiver lack of knowledge of lung cancer and the processes inher-

TABLE 2 Patient and caregiver characteristics

Characteristic	Patients (n = 22)	Caregivers (n = 24)
Sex		
Female	12	18
Male	10	6
Race		
Black	7	7
White	15	17
Education		
High school (any)	11	7
College	9	12
Postgraduate	2	5
Histology		
Confirmed lung cancer	19	NA
Suspected lung cancer[a]	3	NA
Stage of lung cancer		
IA-IB	7	NA
IIA-IIB	2	NA
IIIA-IIIB	3	NA
IV	7	NA
Treatment phase		
Treatment planning or treatment ongoing	9	NA
Treatment completed ≤6 mo.	11	NA
Treatment completed >6 mo.	2	NA

[a]Three patients were seen in a lung-cancer-specific clinic for nodules suspected to be lung cancer, which, on histologic diagnosis, were determined to be metastatic breast cancer, lymphoma, and a granuloma.

TABLE 3 Themes common to patient and caregiver perceptions of organizational barriers

Theme (level)	Examples
Insurance (policy)	Lack of insurance and lag time in insurance processing caused delays in treatment and/or diagnosis Insurance caps on tests and office visits presented difficulties in getting second opinions
Scheduling (institutional)	Long wait times before seeing provider during appointment Rescheduling and/or cancellation of appointments Difficulty obtaining appointments with providers
Communication (provider)	Insensitive disclosure of condition to patient Provider not properly preparing patient for procedure and/or outcomes Patient not formerly informed of condition
Knowledge (patient)	Patients/caregivers not knowledgeable about lung cancer, treatment options, or duration of treatment

ent in lung cancer treatment were barriers for optimal diagnosis and treatment (Table 3).

Insurance barriers
At the policy level, health insurance was reported as a significant barrier to accessing health care. Patients and caregivers reported delays in diagnosis and/or treatment because of either lack of insurance or lag time in insurance processing of clinician requests. Insurance restrictions on tests, procedures, and office visits presented difficulties in getting additional opinions from providers regarding diagnosis, prognosis, or treatment plans. Some patients were no longer able to see providers after they had met the test or office visit limit allotted by insurance providers. One patient shared the following experience with office visits leading up to their lung cancer diagnosis:

> **Patient** … with my insurance I just had only 12 office visits … and I had already maxed those out.

In other instances, insurers would not cover hospital or clinic visits if certain logistic protocols were not met. This would sometimes leave patients stranded for a period of time without receiving any care.

> **Caretaker** … went home and went to one of those minor emergency clinics and they sent her to [xx hospital in another city]. There they did nothing. That was then over the weekend, and my son wanted to get her out of there to get her into practice because they weren't doing anything. They said, 'No. Your insurance won't pay for it unless you stay here till we sign the papers to be transferred.' … It was a bandage. Period.

Some insurers would not cover certain health services outside of routine testing protocols for the patients' conditions. This lack of coverage caused patients to pay out of pocket for needed care.

> **Patient** Nothing in the lymph nodes, but if it hadn't been for me going ahead with this [coronary] calcium score, the insurance wasn't gonna pay anything. If it wouldn't been for the 79 bucks or the family situation, I wouldn't be sitting [here] today.

Individuals who had not yet met the age requirement for Medicare reported being without insurance for a period of time, which contributed to delays in accessing care.

> **Caregiver** [xx patient] probably … could've been diagnosed maybe even months ago, but she is in that in-between where she gets Social Security but she's not 65 until November, so she has no insurance.

Scheduling barriers
At the institutional level, patients and caregivers reported problems with appointment scheduling. Logistic problems with adjusting work schedules and arranging for transportation as well as long wait times before evaluation by a provider were recurrent themes expressed by both patients and caregivers. Many had become resigned to the expectation of long wait times during appointments.

> **Patient** I have to call the month before to make the appointment because they don't take appointments so far—'Oh, we're not working on that yet.' I find that very annoying ….

> **Caregiver** The last time I was there I waited four hours.

> **Caregiver** … your appointment at 9:00 and you get called back at 9:30 or 10:00 and you get to see the doctor by 11:00, but that's not any different than anywhere, unfortunately ….

Rescheduled appointments also posed a problem for participants. Constant rescheduling was an inconvenience

for both patients and caregivers. Many were unhappy with rescheduling because both patients and caregivers had prepared mentally and physically for an appointment, only to be told that they would have to reschedule, which caused delays in the care process.

> **Patient** *I think every single visit I had with him gets rescheduled at least twice ….*

> **Caregiver** *Three times this week we've been geared up, ready to have chemo and they keep changing it.*

> **Patient** *Everything was fine with me, but they keep cancelling my appointments ….*

Some participants perceived that the popularity of physicians might explain the difficulty with scheduling. Patients suggested that it is challenging to get appointments with better-known physicians, so they are more accepting of appointments at any time, even if the time is inconvenient for them.

> **Caregiver** *Of course, … if you have a popular doctor, sometimes you don't always get the appointment you want …*

Participants also expressed frustration with the way appointments were rescheduled. They felt as though the physicians were not concerned about their lives outside of office visits.

> **Patient** *… patients actually have lives. Many of them have jobs or families or responsibilities.*

Communication barriers
At the provider level, poor communication between health care providers and patients was perceived as a major impediment to the quality of care patients received. Both patients and caregivers emphasized the importance of open patient-provider interactions and that there was a lack of such open communications in many instances. There was concern regarding the way diagnoses or prognoses were relayed to patients. Many times, physicians were insensitive and disregarded the sentiments of the patients and caregivers when delivering news about the patients' condition, as one caregiver shared,

> **Caregiver** *… the pulmonary man came … in the room and said, 'Oh, don't worry about your lungs. Something else will get you first,' which was a very, very bad thing to say.*

Participants also expressed concerns that they were not properly prepared for treatments by their physicians because vital information was not discussed. They felt as if physicians were not realistic about potential outcomes. This resulted in patients and caregivers being too optimistic and later disappointed when the outcome was not what they had originally expected.

> **Patient** *Until I got to this office, I was totally oversold on everything. I was told surgery … robotic, not invasive. Day one, surgery. Day two, tubes out. Day three, go home. I expected to be home on Sunday night, stir-frying vegetables, and making dinner, feeding my cat. I was in ICU four days … I went home with oxygen. I mean I thought I was just gonna walk outta there…. You take a little thing out and you put a Band-Aid on, and you go home.*

Data also revealed that patients were unsure of their condition, even following treatment. Information was not communicated to patients about the specifics of their disease, either because of miscommunication or minimal patient-provider time spent during office visits. This lack of communication between patients and providers often left patients and caregivers uncertain about exactly what condition they had or what they were being treated for.

> **Patient** *I just can't have the time with Dr. xx, cuz he's so busy...*

> **Patient** *… I didn't understand. Which exactly what type of cancer did I have, cuz I'm—really to tell you the truth—I'm still wondering.*

Knowledge barriers
Patients and caregivers also identified a lack of education and knowledge about lung cancer diagnosis and treatment as a barrier to their care. Patients and caregivers were not always fully knowledgeable about lung cancer, treatment options, or the duration of treatments. They relied on the provider to disclose such information or direct them to credible sources. In many instances, patients were misinformed about the causes of lung cancer. There were misconceptions that lung cancer was only caused by a history of smoking or genetic predisposition. Patients who did not smoke or did not have a family history of lung cancer were often confused and dismayed by the diagnosis.

> **Patient** *I was trying to figure out, why do I have lung cancer. Never smoked a day in my life.*

Patients were often unaware of treatment options or side effects of various treatments. They relied on physicians to relay information and make decisions for them about treatment plans.

Patient *I was told chemo would probably be the best thing for me, and I just had faith that Dr. xx knows more about it than me.*

Patient *I'm doing chemo but it's — what I'm doing is different. Of course, I don't know anything about it actually either. It's what I hear from other people.*

Other patients relied on their own sources for information about their condition, either through the Internet, from family members and/or friends, or from preconceived notions.

Patient *Well — of course in the meantime, I read — because they said it was a small cell, very aggressive, so I felt like everything I read — that's the deal. I think we've become where we can get on the internet and look up so much, that to me, I was gonna be gone.*

Patient *When he said, 'Cancer,' I said, 'Well, I thought cancer was a heredity thing? That you have to have somebody in your family that has it…'*

Discussion

Organizational barriers are an important consideration in the delivery and receipt of high-quality, patient-centered lung cancer care. This qualitative study of patients being treated for lung cancer and their informal caregivers revealed several common perceived organizational barriers to receiving care, including health insurance coverage restrictions, appointment scheduling difficulties, quality of communication with physicians, and failure to properly educate the patient and family about the disease and what to expect of the treatment process.

The provider communication and patient knowledge barriers seem to reinforce each other and could be improved through focused efforts on the quality of communication between patients and their caregivers and clinical care providers. Patients expect, but are often deprived of, open and active dialogue with their providers. Improved communication can be helpful in educating patients and their caregivers about their disease, prognosis, and treatment goals. Although communication ranks highly as a patient and caregiver priority, there is often a disconnect between patients and caregivers and their physicians.[31] Patients and caregivers often want to be more involved in the decision-making process, and effective communication between physicians and patients has been linked to the patient's ability to understand, and also receive high-quality care.[32,33] Failure to communicate effectively and educate patients on key aspects of their condition strips them of their autonomy in decision-making.

The involvement of a navigator for patients being treated for lung cancer could be pivotal in relieving the communi-cation and scheduling barriers. The nurse navigator assists with coordinating effective communication and providing needed information between providers and patients and their caregivers. A navigator also serves as a single point of contact for patients and caregivers to communicate questions outside of physician visits or concerns that may not be urgent enough to warrant immediate physician response.[34] The navigator coordinates patients' appointment schedules and physician referrals and communicates the details of the next steps in the care-delivery process. This helps remove the barriers to care and improve patient outcomes and the quality of health care delivery, especially for patients and caregivers dealing with a life-threatening illness within a complex referral process.[35]

Multidisciplinary care, a much-recommended alternative care-delivery model, should, in theory, promote connectivity of providers and collaboration between providers, patients, and family members. This model could help reduce barriers for patients and caregivers.[3,24,36] A network of connected providers can better coordinate treatment plans, easily share test results, and provide built-in second opinions. Given the increasingly multimodal approach to the diagnosis, staging, and treatment of lung cancer, the multidisciplinary model could allow physicians to consider multiple perspectives and care-delivery options and, ideally, develop consensus around the optimal approach for each individual patient in one setting. This can shorten the length of time before treatment and establish a plan that is tailored to the patient's needs.[24]

The National Academy of Medicine (formerly, Institute of Medicine) proposes that modern health care systems have 6 aims for quality improvement: safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity.[37] It would take changes in the design and implementation of organizational support systems at the policy, institutional, and provider level for those aims to be achieved. Further investigation of the problems identified by patients and caregivers could lead to innovative solutions to improve lung cancer care. Future work should evaluate the most effective communication styles in patient-provider interactions, particularly in regard to to lung cancer diagnosis and treatment, and investigate how multidisciplinary models influence patient-provider communication and patient care.

Limitations

This study has several limitations. Less than half of those approached for the study participated in the study for various reasons, which may have introduced selection bias in terms of not having the perspectives of patients not willing or able to participate in the study. Though focus groups are known to generate rich in-depth views of certain issues, they have been criticized as potentially lacking rigor and generalizability. To address this concern, we used a standardized script for each focus group and involved multiple

members of the research team in data analysis and interpretation. Also, this study enrolled participants from a single health care institution and did not use a comparison group. There might be institutional and geographic differences in the experience of lung cancer care, which might further limit the generalizability of the results of this study.

Conclusions

Despite those limitations, this study offers valuable insight into the barriers that lung cancer patients and caregivers encounter while navigating a community-level health care system. Eliminating or minimizing these barriers will require strategic plans that help mitigate insurance-related,

scheduling, provider-patient communication, and patient/caregiver knowledge acquisition problems and translate them into tactical actions for quality improvement. This is one of the first qualitative studies conducted to understand the organizational barriers that lung cancer patients and their caregivers face within a health care system. Additional research is needed to explore these barriers and develop viable solutions.

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