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Coping with an Advanced Stage Lung Cancer Diagnosis: Patient, Caregiver, and Provider Perspectives on the Role of the Health Care System

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Abstract Although lung cancer is the leading cause of cancer death in the USA, there have been few studies on patient-centered advanced lung cancer treatment practices. As part of a larger research study on how to use a patient-inclusive approach in late-stage lung cancer treatment, this present study describes patient, caregiver, and provider perspectives on the role of the health care system in helping patients cope with an advanced stage lung cancer diagnosis. Four focus group sessions were conducted with six to eleven participants per group for a total of 36 participants. Two focus groups were held with patients and family members/caregivers and two with physicians and nurses. A major theme that emerged concerned coping with an advanced lung cancer diagnosis, which is the subject of this paper. The patients, caregivers, and

providers spoke passionately about interactions with the health care system and volunteered examples of supportive and non-supportive relationships between patients and clinicians. They advocated for better patient-provider communication practices as well as the expanded use of patient navigation and new patient orientation programs. This study contributes additional knowledge by including the perspectives of caregivers and providers who live and work closely with patients with advanced lung cancer. The findings can inform the development of comprehensive patient-centered care plans for patients living with an advanced lung cancer diagnosis.

Keywords Patient-centered care · Advanced stage lung cancer · Stage IV lung cancer · Coping with cancer · Caregivers · Providers

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Background

Lung cancer is the leading cause of cancer-related deaths in the USA [1]. Lung cancer accounts for a major proportion of health care costs [1, 2]. Over 50 % of stage IV lung cancer patients die within 1 year of diagnosis [3]. The brevity of patient life following diagnosis, cost of care, poor quality of life, and burden of symptoms take a significant toll of patients [4]. In addition, the complexity of care needed makes it difficult for patients and caregivers to deal with the already treacherous terrain.

The argument has been made for involving the patient in the management process to help with the burden of the disease. A study by Choy and colleagues examined patient involvement in treatment decision and care planning and concluded that patients derived a short-term benefit by being engaged in their care which may, in turn, lead to better long-term health outcomes [5]. Current evidence suggests that patient involvement in treatment planning improves patient

satisfaction, quality of life, and adherence to treatment and leads to better outcomes [6]. Additionally, ethical and social justice principles call for providing opportunities for self-determination, especially in cases, such as advanced stage NSCLC, where all treatment choices have approximately the same morbidity and mortality outcomes.

However, there is a paucity of research using a patient-centered, qualitative approach to explore patient and provider relationships and perspectives on cancer treatment, despite the widely established value of patient engagement in care and shared decision-making in improving health outcomes. Notably absent in our literature review was research on the inclusion of patient treatment preferences in treatment planning at the critical time of being newly diagnosed with or having progressed to stage IV lung cancer. Therefore, we conducted a larger qualitative study to address these gaps and to inform future patient-centered outcomes research. Specifically, we wanted to gain insight into patient, caregiver, and provider perspectives on advanced lung cancer treatment success and preferences and how to use patient-centered approaches in both research about and treatment of lung cancer. The present study reports on emerging discussions, during the focus groups, on how the health care system can help patients cope with their advanced stage lung cancer diagnosis.

Methods

Four focus groups were conducted with six to eleven participants per group for a total of 36 participants. The participants were from Nebraska and South Dakota and were receiving care in four Midwest cancer centers (two urban and two rural facilities). The study nurse coordinators from the participating cancer centers recruited the patients using medical records. The nurse coordinators also recruited physicians and nurses utilizing the clinic's personnel list, personal knowledge, experiences, and familiarity of the cancer center. Family members of the lung cancer patients were recruited by calling current lung cancer patients of the clinic.

Patients and family members/caregivers attended the two patients' perspective sessions. In two other focus groups, we obtained the clinicians' perspective from physicians and nurses. Each focus group lasted approximately 90 min and was facilitated by a trained focus group moderator. The use of a trained moderator was essential to create an open environment and to ensure that all the participants had an opportunity to share their perceptions and comment on other's perceptions. The moderator also used probing phrases and questions to help facilitate the discussion and encourage the participants to expand on their views, whenever necessary. There were 13 males and 23 females that participated in this study, including 7 lung cancer patients, 6 family members, 3 patient advocates, 10 physicians, and 10 nurses.

Data Analysis

Focus groups were audio-recorded and transcribed verbatim, transcripts analyzed using a NVivo10 qualitative data analysis software package. A thematic analysis was conducted through an inductive process. Three analysts independently read the transcripts and generated initial codes based on semantic content. Emerging themes and sub-themes were then derived from these codes. The analysts resolved any disagreements or ambiguity by discussion. Following this, the themes were refined accordingly. The primary analyst then recoded all the transcripts using the refined coding scheme. Representative quotes are presented to summarize the key findings.

Results

A broader theme that flowed naturally out of the focus groups concerned coping with an advanced lung diagnosis. The participants extensively discussed how health care providers and the health care system, in general, could help patients cope with an advanced lung cancer diagnosis. This paper presents the perspectives of patients, caregivers/advocates, and providers on the role of the health care system in helping advanced lung cancer patients cope with their diagnosis. The patients, caregivers, and providers spoke passionately about interactions with the health care system, volunteered examples of supportive and non-supportive relationships between patients and clinicians, and discussed how health care providers could help them cope with an advanced lung cancer diagnosis. The following results are organized thematically with illustrative quotes. For simplicity's sake, our thematic headings reflect the patient voice because even the non-patient participants helped flesh out the meaning of the patient's experience (Table 1).

We Depend on You

Patient and caregiver participants viewed their providers and the medical community as advocates and relied on them extensively for guidance throughout their care and treatment. Many had no experience dealing with cancer and were at a loss on what they had to do, what treatment options were available, and what resources to turn to.

I think we came into the whole situation shocked of course but trusting the medical community to do what they felt was best for [him] and you know, we just kind of played it by ear after that. We relied on [our provider] for a lot of insight. Until you start going through it, you aren't going to realize the side effects and the questions you're going to have (caregiver participant).

Table 1 Description of thematic headings

Theme	Description
We depend on you	Summarizes participants' discussion on their dependence on the medical system for emotional and instrumental support. These discussions centered on the role of health care providers as "agents" for their patients.
Be candid but compassionate	Summarizes participants' discussion on the essence of empathetic, yet honest communication between providers and lung cancer patients.
Help us get through it	Summarizes participants' discussion on how the medical system can help patients cope with a lung cancer diagnosis by providing informational support.
Engage us in our care	Summarizes participants' discussion on the desire for shared decision-making and personalized care.

Be Candid but Compassionate

Given the dependency of patients on providers for clinical guidance, one of the themes that naturally emerged was communication. The participants discussed communication between patients, their families, and providers and noted the need to train clinicians in provider-to-patient communication. They advised that the training should emphasize the need for empathy, especially when initially disclosing a cancer diagnosis—news that should be delivered with utmost sensitivity. There was a unanimous agreement that the initial disclosure of a diagnosis of cancer should be “in-person” and preferably in the presence of supportive persons of the patient’s choosing. The following quote summarizes these discussions:

How many doctors call their patients on the phone and say ‘you got cancer’. [He/She] doesn’t care who is at home with them, if they are home by themselves. I just can’t believe a doctor would call a patient. I would think they would say ‘I would like you to come in’. If you can do anything, I wish you could change that...I had a friend who was home by herself when she was told she had cancer’ (caregiver participant).

Participants were also sensitive to how prognosis was communicated. Most felt uncomfortable with the concept of quantifying the amount of time they had left to live. “I was told [5 years ago] that I had 4 to 6 months to live. I don’t think anybody has the right to say that.” Clinician participants noted that discussions with patients about survival time differed among their ranks:

[I am] bringing in some experience from a colleague that I worked with on a study where there was a question about overall survival on the survey. There was a huge variation [on] what providers had discussed with the patients to the point where some patients were angry with [some of] the questions posed about overall survival. [For example, one] study question said, ‘Refer to the old multiple myeloma median survival of five years.’

Some patients were just floored [and asked], ‘You mean I’m only going to live five years?’ (provider participant)

Participants added that they desired honesty from their providers but cautioned that honesty should be moderated with empathy:

I always think it’s prudent of the doctor, if things are going south to say ‘get your ducks in a row’ (patient participant).

[We want] honesty, not harsh words (patient participant).

Help Us Get Through It

The patients and caregiver participants in this study noted that a diagnosis of cancer was overwhelming and that patients required a lot of guidance in order to cope with their diagnosis. They highlighted the importance of medical programs such as orientation classes for newly diagnosed patients and patient navigation programs in helping patients manage their diagnosis. They expressed desire for such valuable programs to be implemented in cancer treatment centers or continued in treatment centers that already have them in place.

[This center] used to have when you were diagnosed [a] new patient class. I think ours was the last one. But it was nice, because as a new patient, you are looking for information. You want someone to tell you, ‘Okay this is what you are going to do. This is what you expect.’ I thought it was helpful (patient participant).

There’s a lot of fear with unknowns because you don’t know how to deal with [a diagnosis of lung cancer]. To me, it was very difficult to learn about the disease and search and find credible information...so I feel really blessed with patient navigators because that has been a tremendous improvement in the cancer community to help bridge that gap and help people navigate through

the system and help answer their questions. But I think we can build on that and make that better (patient participant).

One participant noted that orientation classes, in particular, could serve as a platform for sharing simple but useful tips with other patients, such as keeping a documented account of physician appointments:

When [he] was first diagnosed, the first thing I did was I went and got this little notebook. He was diagnosed in 2011. I have every doctor appointment in here, who we saw, what his blood pressure was. Because people ask ‘when’s the last time you had a CT scan’ and you are going ‘uh, uh, uh’. If anything you would just tell a caregiver [to get] or give them a notebook and a pen and [say] ‘take this with you everywhere you go for any appointment’ (caregiver participant).

In addition to the new patient orientation, another participant suggested the distribution of easy to read educational items for patients to read at a later date. He/she noted that many times new patients were too overwhelmed by the news of a cancer diagnosis to be able to comprehend and retain all that their physicians discussed with them during their initial visit.

I would suggest a brochure or something that’s not a lot of information but just basic and so when that person is told they have cancer and when they can go home [they can] say, ‘Okay, what was that paperwork? I can read that paperwork on my own, in my own time.’ Sometimes you hear things and you don’t comprehend, but if you have something you can go home and read later [it helps] (patient participant).

They also requested that providers continually repeat information to them. Such repetition, according to the participants aided comprehension, especially given their emotional state:

The repetition of information is important. You have to hear it more than once to understand it (patient participant).

Engage Us in Our Care

Patients wanted to be told about, in easily understood terms, and be engaged in, their care and treatment, including treatment planning. They wanted to feel like they were receiving personalized care and appreciated clinicians who took the time to sit down and discuss their individualized treatment plans with them:

I wonder[ed] like what’s the goal of chemo in my situation? It might be different in hers versus mine (patient participant).

The pharmacist came to us and explained every drug, what it was for and what was going to happen (caregiver participant).

Particularly, the clinicians discussed the importance of faith, complementary alternative medicine, and mainstream medicine in coping. Some shared stories about patients who had opted to decline treatments based on their faith or used alternative/holistic approaches in addition to treatment at the cancer centers. The consensus seemed to be that these ways of coping were to be encouraged. “*One patient mentioned doing sweat lodge ceremonies and native healing ceremonies; I told her ‘go for it!’*” (provider).

Discussion

The findings from this study highlight the significant role health care providers play in helping patients cope with a lung cancer diagnosis. Poor communication between patients and providers has been cited as one of the key barriers in achieving patient-inclusive care planning in real-life situations [7]. In the present study, effective communication between patients and providers was overwhelmingly identified as vital in helping lung cancer patients cope with their diagnosis. This study is not alone in identifying health care professionals, specifically oncologists, as an important source of cancer-relevant information, treatment care, and guidance for patients [8], highlighting the important role clinicians could play in advancing more patient-inclusive approaches to care. Similar to the results of this study, a phenomenological study exploring the experience of breast cancer patient with patient-physician communication indicated that patients valued a positive relationship with physicians and wanted it to be characterized by respect, honesty, attentiveness, and expressions of genuine concern for the patient [9].

Furthermore, this present study corroborates with other studies that have shown that cancer patients trust their physicians and look to them for guidance, instruction, and support [9, 10]. In one previously reported study, a participant described this dependence as “handing themselves over to the expert” [10]. Given such dependence, health care providers providing cancer care are tasked with serving in the capacity of a support system for their patients, in addition to providing medical care. Also of concern to our participants was how cancer diagnosis and prognosis were communicated to patients. Patients requested that bad news, such as a cancer diagnosis, be given in-person and in the presence of a support person, should the patient wish to have them present. Indeed,

the American Board of Medical Specialties has listed *Interpersonal and Communication Skills* as one of six core competencies every physician must master. The findings from this study and several others demonstrate that there is room for improvement.

The participants also advocated for the use of patient navigation programs and new patient orientation classes to guide both new and existing patients as they dealt with a lung cancer diagnosis. Patient navigation programs have indeed been proven to be effective in other types of cancers [11, 12]. Although there is a dearth of literature on the effectiveness of orientation classes for newly diagnosed cancer patients, not only may these classes be an effective means of providing information and guidance to newly diagnosed patients but they could also serve as a peer support group for newly diagnosed patients.

Collectively, the findings from this study have implication for oncology practice, specifically with respect to patient-physician communication and relationship building as well as care planning for lung cancer patients. Research indicates that effective communication, information sharing, and relationship building could facilitate a partnership between providers and patients and allow patients to retain a much-desired sense of control [13]. The hallmark of patient-centered care is the treatment of the whole person and not just the disease. Therefore, it is important that medical school and continuing education curricular for health care providers emphasize the importance of and teach skills in provider-patient communication, cultural competency, and relationship building. In addition, continued patient-centered outcomes research is needed to better address ways of coping with the diagnosis, care, and treatment of a serious disease.

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