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Patient Comprehension and Attitudes toward Maintenance Chemotherapy for Lung Cancer

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Abstract

Objective—Maintenance chemotherapy is a recently approved approach to the treatment of advanced non-small cell lung cancer (NSCLC). We sought to gain insight into patients' perceptions of maintenance chemotherapy using qualitative methods.

Methods—We conducted thematic content analysis of focus groups at a freestanding cancer center and at an associated safety-net county hospital. Patients with advanced NSCLC who had started but not yet completed first-line platinum doublet chemotherapy were provided visual and written explanations of maintenance chemotherapy before being guided in group discussion.

Results—Key themes to emerge for consideration of maintenance chemotherapy included (1) survival benefits, disease control, and “buying time”; (2) the importance of “doing something”; (3) quality of life concerns; (4) the role of provider opinion/preference; and (5) the importance of logistics.

Conclusions—Patients undergoing first-line chemotherapy for advanced NSCLC were able to understand the concept of maintenance chemotherapy, distinguish it from traditional treatment paradigms, identify pros and cons of this approach, and convey reasons for considering it.

Practice Implications—Advances in oncology care that alter therapy modalities and delivery may significantly impact patient perceptions and treatment experiences. Clinical team members may wish to elicit treatment preferences of first-line patients through clinical discussions that anticipate these considerations.

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Keywords

Non-small cell lung cancer; Maintenance chemotherapy; Patient perceptions; Thematic analysis; Dallas; TX

1. Introduction

The advent of maintenance chemotherapy may change the way that patients seek to treat their advanced non-small cell lung cancer (NSCLC). While this new treatment approach has been increasingly well-received by clinicians, there has been little to no effort to understand how patients themselves may perceive this change in treatment delivery. Traditionally, patients with responsive or stable disease after four to six cycles of first-line chemotherapy have been monitored off therapy, with second-line chemotherapy initiated at the time of disease progression. With maintenance chemotherapy, treatment is continued immediately after completion for first-line therapy, either with a new agent (i.e., “switch maintenance”) such as pemetrexed or erlotinib, or with one of the first-line agents (i.e., “continuation maintenance”) such as bevacizumab. Phase 3 clinical trials of switch maintenance with pemetrexed and erlotinib have demonstrated improvements in progression-free and overall survival, resulting in Food & Drug Administration (FDA) approval [1, 2].

However, the role of maintenance chemotherapy for advanced NSCLC remains debated among physicians although several aspects of maintenance chemotherapy for advanced NSCLC have been evaluated, including efficacy, cost, and effect on quality of life [1–3]. Overall survival benefits with this approach have been modest and not consistently seen across studies [1, 2, 4–6]. In some cases the survival benefit appears limited to those patients who do not receive second-line therapy at the time of disease progression [4], which appears to be a relatively limited population when close clinical and radiographic surveillance are implemented [7, 8]. The costs of maintenance chemotherapy are substantial [3]. Similar issues have been raised about maintenance therapy for other cancers [9, 10].

Expert reviews and commentaries on maintenance therapy highlight the importance of optimal study endpoints, restriction of maintenance chemotherapy to regimens associated with an overall survival benefit, and implications for the design and interpretation of clinical trials [11, 12]. However, few researchers have sought to understand patient perceptions of this new treatment paradigm. Patient perceptions merit consideration because this treatment approach may substantially change the treatment experience. Specifically, maintenance chemotherapy eliminates the treatment-free interval in advanced lung cancer clinical care. While this period off therapy until disease progression is less than 4 months on average, it lasts over 6 months in 10–20% of individuals [1, 4, 13].

Focus groups provide opportunities to solicit patient opinions of treatment-related issues [14, 15]. They have the added value of a group dynamic that enables patients to react to one another’s comments and further develop discussion beyond what the investigator may anticipate. Importantly, focus groups may provide clinicians insight into patient opinions and concerns less commonly discussed in medical encounters [16].

Given the lack of insight into patient considerations and continued debate among physicians we sought insight into patient perceptions of maintenance chemotherapy for advanced NSCLC, information that could enhance clinicians’ understanding of patient treatment preferences.

The study sample was conducted through clinical facilities associated with the University of Texas Southwestern Medical Center (UT Southwestern), including Parkland Health and

Hospital System (Parkland) and University Hospital (which includes the freestanding Harold C. Simmons Cancer Center). University Hospital (415 beds) is the principal medical and surgical referral hospital for UT Southwestern. Parkland consists of a 968-bed public hospital and 11 adult clinics that provide health care to predominantly indigent and uninsured residents of Dallas County. Dallas County is the ninth most populous county in the United States, with an estimated 2.4 million residents, of whom 39% are Hispanic, 35% are white, and 21% are African American.[17] At UT Southwestern facilities, approximately half of patients with advanced NSCLC receive first-line chemotherapy, more than twice the rate reported in some prior studies.[18] Among treated patients without disease progression — those for whom maintenance therapy might be a consideration — two-thirds go on to receive second-line chemotherapy.[8]

1. Methods

Focus group methodology has been applied extensively in healthcare and medical research, particularly to assess the illness experience and patient understanding [19]. In lung cancer care, investigators have explored beliefs about surgical resection for early-stage disease and preferences for chemotherapy for advanced-stage disease [20, 21]. To capture subjects who were both familiar with treatment considerations and potentially eligible for maintenance therapy, we limited participation to patients who had already initiated but not yet completed first-line chemotherapy.

We conducted two focus groups at the university cancer center oncology clinic and a third focus group in the oncology clinic at our county hospital partner. Participants had advanced NSCLC and were currently receiving platinum doublet chemotherapy. Patients were identified through treating physicians and recruited by trained research and clinical staff. We excluded patients who did not speak English, or had a speech or treatment-derived cognitive impairment that rendered them incapable of informed consent to participate in a focus group. We recognize this as a potential study limitation. However, although Dallas County is 39% Hispanic, only about 5% of lung cancer patients seen by our facilities are Hispanic. [22] As a result, language exclusion did not have a significant impact on sample selection. Potential subjects were approached either by telephone or in person to participate in a patient group discussion (est. 90 minutes). Interested patients gave verbal assent and were scheduled for a focus group. Participants were compensated with a gift card (\$20) for their time and effort. The study was approved by the UT Southwestern Institutional Review Board.

Clinical data gathered from the electronic medical record included patient age, sex, race, treatment plan, number of treatment cycles at time of consent, treatment response, clinical trial participation, and future treatment plans. Based on eligibility criteria, we identified an initial eligible study population of 47 patients. Of these, ultimately 13 (27%) participated in a focus group (4, 4, 5 participants, respectively), of whom seven (54%) were men and ten (77%) were white (Table 1). All participants were currently undergoing first-line treatment; only those who felt well enough chose to attend scheduled sessions.

To explore implications of a maintenance therapy paradigm, the investigator team generated a discussion guide covering a range of issues related to the patient treatment experience (Table 2). Focus groups were moderated by a qualitative investigator with a second behavioral investigator present to monitor group dynamics and assist with facilitation. Immediately prior to each focus group, investigators explained the purpose of the study, solicited written informed consent, and explained the use of audio recording for the purpose of transcription. Using a two-slide presentation, a physician investigator then presented a brief overview of the traditional model of first- and second-line treatment for advanced

NSCLC and introduced the concept of maintenance therapy (Figure 1). The physician investigator turned the session over to the moderator and left the room. The moderator used the discussion guide to invite conversation about the possibility of maintenance therapy, first posing a question to the group then eliciting comments from participants in turn, allowing unstructured time for participants to compare and contrast their experiences and opinions with each other. As the moderator exhausted the discussion guide, the physician investigator returned to address participant questions. Each focus group was audio-recorded and subsequently transcribed verbatim.

Following each focus group, the investigator team discussed participant reactions and other emerging issues. Investigators compared and contrasted participant attitudes and noted emerging conceptual domains. The team reviewed transcripts and assessed patient issues using an inductive, text-driven approach to thematic content analysis [23, 24]. Investigators collectively identified preliminary themes, leading to theme consolidation and extraction, with subsequent iterative discussion and analysis by the whole team [25, 26].

2. Results

Patients in the three focus groups reported many points of consideration for and against maintenance therapy. We identified five major themes that classify patients' reasoning that we elaborate below. Individual comments are identified by patient case according to Table 1.

2.1 Survival benefits, disease control and “buying time”

Focus group participants considered whether maintenance therapy was associated with a chance of increased life expectancy. One patient stated:

“You know, it’s just a big decision to make, but if it’s more promising or if there’s any way it prolongs life, of course I want to do whichever. That’s what gives us a better chance, you know?” (FG 1, Patient 4)

In general, patients did not focus on maintenance therapy as a “cure” for their lung cancer. Instead they focused on disease control and the increased chance of longer life that maintenance might afford:

“I don’t think it would be any different. Because you want to make sure you get well. I know you’re not going to get well, but at least contain the cancer. So you have to think on those terms. You want to live longer, that’s the main thing. You want to live longer” (FG 3, Patient 3)

The chance for longer life was also associated with the opportunity for hope and new treatment possibilities. Two patients described the maintenance as a chance to be eligible for future treatments:

“So I know there are lots of interesting things going on. If you’re doing maintenance it will buy you a little time and maybe... Something that will come along that will make everything—get everything barely back to normal.... Keeping options open. Keeping future options, the possibility of future options open.” (FG 2, Patient 1)

“Now, if the maintenance chemotherapy with other lines of drugs that are already out in the market, or...producing new medicines as the months and days go by...if we get that chance to grab onto that medicine, of course that will be really helpful to all of us, in especially prolonging our life.” (FG 2, Patient 4)

The same patient later described the “hope” that a limit of disease progression could afford:

“But other than that it helps stop—if it can help to stop the progression of the disease then, you know, I’m really positive about it. So, it helps that there’s still hope, you know, continuously hope.” (FG 2, Patient 4)

2.2 The importance of “doing something”

Distinct from the theme of disease control and survival benefits, some patients focused on maintenance therapy as a chance to keep “doing something” instead of taking a wait-and-see approach. Two patients equated the action of maintenance therapy with an opportunity to keep up the “fight” against cancer:

“...I just think, God, you know—but I’m just not going to give into it. I’m going to fight it, and I’m going to fight it with whatever y’all have to give me. And I’m going to win.... So I’m definitely a candidate for the maintenance chemo.” (FG 3, Patient 1)

“... as far as being on board with the experimental treatment, I’ve been on board with it since day one. If you can’t give me anything that’s helping, give me something else.” (FG 3, Patient 3)

The same patient described a reliance on treatment and fear of recurrence during a treatment break:

“As long as I was getting some sort of medication, I would feel better about it. I don’t know if I’m at the point where I would just take it away and let me see how I’m doing.” (FG 3, Patient 3)

Another patient concurred, saying:

“...you know, as long as the side effects weren’t too bad I think I would rather continue on with—I’d be afraid it’d start growing again once we stop” (FG 2, Patient 3)

A final patient connected the general lack of available lung cancer treatments with an enthusiasm for maintenance treatment, stating:

“... that’s one thing that we have to accept as lung cancer patients is that we take into consideration whatever opportunity we have.” (FG 2, Patient 4)

2.3 Quality of life concerns

The ability to engage in meaningful activities and not be a burden to others during maintenance therapy was a strong theme of the patient discussions. In their consideration of maintenance treatment, multiple patients discussed the impact of potential treatment side effects on their quality of life:

“Just, with the maintenance are we going to be able to go on with life, so not just be totally ill all the time, or do we want to take a chance and be with our family and loved ones and have some quality of life left?” (FG 1, Patient 4)

“Well, I guess I have mixed emotions about it. Yes, I would push through and continue, but a lot of it would depend on what quality of life am I going to have continuing.” (FG 1, Patient 4)

“...I just have one daughter and one grandchild, and they live in New York, and I don’t want to be a big burden... if it’s going to be something where I’ve got to have live-in nurses, or she’s got to come down here and watch me — I’d rather die and not put her through it.” (FG 1, Patient 2)

One patient, in particular, suggested that the limited survival benefit was not worth undergoing treatment if patient quality of life during that time was likely to be poor:

“... the quality of life is a pretty important — I don’t know any other way to put this, but to prolong a few months, if you can’t do anything — “ (FG 1, Patient 2)

For a number of patients, their current treatment experiences played a large role in their attitudes toward the quality of life associated with maintenance therapy. Patients who noted few side effects from their current chemotherapy were more enthusiastic about maintenance therapy. For example, two patients describing their perspectives of maintenance stated:

“I’m going to do it. Unless something dramatically happens to where—but as I say, my experience before is I did keep walking five miles every day, and I didn’t have any trouble getting my breath.... But as long as I can get up and walk my five miles I want to do the maintenance, and I can live with it forever. And if I’m going to be out of town I’m just going to arrange to have it at another hospital.” (FG 1, Patient 2)

“I’ve had a pretty good experience with the chemo. I didn’t get sick at all, not once, not once in the first round, second round nauseated, third round a little more nauseated which has brought me to now which I feel lousy. But I had expected that in the beginning instead of later. Other than that, though, I’ll keep taking chemo as long as you’ll give it to me. (FG 3, Patient 3)

“...if you’re on maintenance therapy all the time are you never going to get your hair back? I mean because that’s really the only symptom I’ve had is I’ve lost my hair.” (FG 3, Patient 2)

In contrast, other patients who experienced more severe side effects of chemotherapy appeared less enthusiastic or at least conflicted about maintenance therapy:

“If maintenance therapy made me feel the way that last round of chemo did, I don’t know if I could handle it all the time.” (FG 2, Patient 3)

“Right now it’s like I’m doing this every three weeks, but I don’t think I’d want to do something every three weeks, if the first week you’re too tired to get out of bed, and the second week you’re feeling good, and then the third you’re not feeling so good again—I don’t think I’d just want to keep doing that forever and ever.” (FG 2, Patient 1)

“...my son is coming to visit from Virginia this month, and I’ve always liked to cook, and his family, they’re all coming, and —[laughs] I had to tell my daughter-in-law she’s got to cook. And, you know, things like that that—that bothers me.... But, no, I will continue with the maintenance. (FG 3, Patient 1)

Two patients discussed the potential quality of life benefits associated with a “break” from chemotherapy:

“If the break allowed me to feel good enough that I could iron, go to the grocery store, go have a cup of coffee at Starbucks with friends, then I’d like to have that break. Right now—I mean it’s, again, my legs is what’s keeping me basically in bed most of the time... I wouldn’t want to do that year after year after year.” (FG 2, Patient 1)

“I’m thinking of being able to cook meals, being able to go to the grocery store, being able to just do general, tidy up around the house—not house cleaning, but just have energy to do something. Because at this particular point I have very little energy.” (FG 3, Patient 1)

2.4 Role of provider opinion/preference

A number of patients verbalized a trust in their providers' attitudes toward maintenance therapy as a driving factor in their potential decision. For these patients, a physician's recommendation about maintenance therapy appeared to be a primary force in their potential decision:

"...you trust your physician. You know, the trust that you build with him or her, so once you get that trust you learn from each other on how to deal and how to treat the disease. So I think the way a physician is recommending us in any type of treatments that we are undergoing, then you have that trust in him that you built already that is a big, big percentage, where we believe in him or her." (FG 2, Patient 4)

"I don't know if I'm that brave yet, but if my doctors assured me this was a good move, this was a good move for me, I feel confident enough in [my doctor] to follow his advice." (FG 3, Patient 3)

"I'm going to pretty much rely on what [my doctor] tells me." (FG 1, Patient 2)

"See it's not a big deal to me because I know [my doctor] wants me to live as long as I can. That's the easy part. I know he's got my best interest at heart. He doesn't want to see me just roll over and die. He wants to see me make it as long as I can make." (FG 3, Patient 3)

For other patients provider opinion was important, but was tempered by other factors such as quality of life and caregiver preferences:

"I would like [my doctor] to go through all the options, and then make my decision, I don't know, based on probably mostly his recommendations, but certainly, like I said, I don't want to just have to lie in bed." (FG 2, Patient 1)

"It's not hard for me to say, but I'd rather wait on the girl who see after me [patient's caregiver] – I'd rather ask her and see what is her opinion and then I know more because I don't want to do nothing when it's gonna hurt me." (FG 3, Patient 5)

2.5 Importance of logistics

Focus group members identified transportation and distance as logistic barriers to treatment that involved multiple visits to the medical center. For some patients, these concerns tempered their enthusiasm for maintenance therapy:

"To me it's nice not to be here every week or every two weeks. If you can make it once a month or one and a half or whatever...I mean it would be on me because the reason why – I don't have a way to get out here. I'm paying for the go backwards and forwards. Because that old taxi cab, he will eat your lunch." (FG 2, Patient 2)

"I live alone as well, and every time I come for chemo or transfusions I have to have someone bring me. So that would — if I had to come real frequently that would put a hardship on me. If it's more like the traditional cycle, I manage pretty good with that. But I mean it would be difficult to come a whole lot." (FG 3, Patient 1)

Other patients found themselves weighing the "cons" of travel and time spent in clinic with the potential "pros" of maintenance therapy:

"So I mean I would rather come, you know, as long as it's not every day. [laughs] I don't know about every day, because I live an hour and a half away. But if it meant

prolonging my life and me feeling well enough to do some of the things that I like, I'd be willing to make the trip." (FG 2, Patient 3)

"But basically my thoughts here regarding the time that you spend with maintenance chemotherapy, basically coming back and forth here to the clinic, is that, yes, it does take a lot of your time probably, and also it might hurt your time with your family as well, or with friends. The only thing is that, like I go back again to the cancer progression, where if it can help the cancer progressing, I mean at least keep it down from being in a progressive state, then the time that you spent here coming back and forth might be worthwhile." (FG 2, Patient 4)

3. Discussion and conclusion

3.1 Discussion

Using focus groups, this qualitative study identified a range of patient concerns related to an emerging therapeutic paradigm in lung cancer care. The principal limitation—small sample size—reflects the inherent challenge of capturing patients at a specific treatment window. Our requirement that patients be undergoing first-line chemotherapy at the time of participation also results in selection bias. Only approximately 25 percent of potential subjects identified eventually attended a focus group. This sample represents those patients who felt well enough to participate on a given day. Given the logistic challenges and toxicities of chemotherapy, these participants may have tolerated chemotherapy particularly well, or may have been particularly motivated. However, we believe that only patients currently receiving first-line therapy could have addressed issues surrounding maintenance chemotherapy adequately. Newly diagnosed, untreated patients may have less understanding of the details and adverse effects of cancer therapy. Patients receiving second- or subsequent lines of treatment are no longer eligible for a maintenance paradigm. Thus, they may not consider maintenance chemotherapy as an issue of potential personal importance or may question why they had not received it themselves. All patients were currently receiving care, which may explain minimal discussion of access or costs of maintenance therapy, even in our safety-net setting. Despite the relatively small number of participants, data analysis revealed sufficient thematic repetition to suggest saturation whereby major patient concerns were identified during the three focus groups.

We also faced some limitations inherent to the focus group design. Group dynamics may suppress objections or disagreements; however, moderator tactics can be used to establish group rapport through experiential commonalities, especially in a small group setting ($n < 6$). To this end, the moderator deliberately prepared participants for contrasting answers and encouraged participants to compare their experiences among themselves. There is also a risk of the Hawthorne effect (patients observed responding in a manner they believe their clinicians desire). We sought to minimize this effect by explicitly excluding the medical oncologist investigators from the focus group discussions.

Results from our three focus groups indicate that patients were able to understand a brief presentation about maintenance therapy and thoughtfully weigh the pros and cons of such an approach. A major consideration of maintenance therapy was its potential impact on survival and disease control. A number of patients discussed how maintenance chemotherapy could positively impact hope and opportunity for new treatments. Another theme focused on action versus inaction, with somewhat unexpected reasoning. Where we initially expected patients would perceive the off-treatment period between first and second-line therapy as a "treatment break," focus group participants more commonly perceived it as taking a wait-and-see approach. As patients have equated "watchful waiting" as "doing nothing" in the context of prostate cancer uncertainty, these NSCLC patients seemed to perceive the idea of maintenance chemotherapy as actively "doing something". As in the case of prostate cancer,

this need to “do something” by engaging in active treatment could play an important role in decisions about maintenance therapy [27–29]. Consistent with other treatment preference studies, quality of life and the ability to engage in meaningful activities (e.g., socializing, cooking, cleaning) were important considerations of maintenance therapy [21]. For many patients, the extent and severity of current treatment-related side effects also played a large role in their attitudes, with those who had difficult symptom burdens less enthusiastic about continuing chemotherapy without a break.

Provider recommendation is important to patient decision-making [30], and our study found similar considerations. Nevertheless, respondents tempered the importance of provider recommendations with quality of life and caregiver burden considerations. Finally, the logistics of travel and clinic time potentially associated with maintenance were carefully weighed against the potential benefits of treatment. Such findings suggest that the clinical team should address treatment time burden with patients in any discussion of maintenance therapy, particularly since approved regimens may be administered orally (i.e., erlotinib) or with relatively short infusions (i.e., pemetrexed).

3.2 Conclusion

Our study demonstrates that patients with advanced NSCLC currently receiving first-line chemotherapy are able to understand the concept of maintenance chemotherapy, distinguish it from traditional treatment paradigms, identify pros and cons of this approach, and convey reasons for considering it. Key patient themes include (1) survival benefits, disease control, and “buying time”; (2) the importance of “doing something”; (3) quality of life concerns; (4) the role of provider opinion/preference; and (5) the importance of logistics. Future research should explore potential differences among between English and non-English speaking patients, perhaps through more in-depth individual interviews.

3.3 Practice implications

As the study and use of maintenance therapy expands in other advanced cancers, the themes identified in our study will likely be salient beyond lung cancer [9, 10, 31]. The present work highlights the impact that advances in oncology care, including new therapy modalities and delivery patterns, can have on patient perceptions and treatment experiences. While a study of this nature is not definitive, our analysis suggests clinical team members may wish to elicit treatment considerations and preferences of first-line patients through collaborative clinical discussions. In the case of maintenance chemotherapy, such discussions may be important in determining interest in and potential adherence to specific regimen options.

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References

1. Ciuleanu T, Brodowicz T, Zielinski C, Kim JH, Krzakowski M, Laack E, et al. Maintenance pemetrexed plus best supportive care versus placebo plus best supportive care for non-small-cell lung cancer: a randomised, double-blind, phase 3 study. *Lancet*. 2009; 374:1432–40. [PubMed: 19767093]

2. Cappuzzo F, Ciuleanu T, Stelmakh L, Cicenias S, Szczesna A, Juhasz E, et al. Erlotinib as maintenance treatment in advanced non-small-cell lung cancer: a multicentre, randomised, placebo-controlled phase 3 study. *Lancet Oncol.* 11:521–9. [PubMed: 20493771]
3. Klein R, Wielage R, Muehlenbein C, Liepa AM, Babineaux S, Lawson A, et al. Cost-effectiveness of pemetrexed as first-line maintenance therapy for advanced nonsquamous non-small cell lung cancer. *J Thorac Oncol.* 2010; 5:1263–72. [PubMed: 20581708]
4. Fidias PM, Dakhil SR, Lyss AP, Loesch DM, Waterhouse DM, Bromund JL, et al. Phase III study of immediate compared with delayed docetaxel after front-line therapy with gemcitabine plus carboplatin in advanced non-small-cell lung cancer. *J Clin Oncol.* 2009; 27:591–8. [PubMed: 19075278]
5. Belani CP, Waterhouse DM, Ghazal H, Ramalingam SS, Bordoni R, Greenberg R, et al. Phase III study of maintenance gemcitabine (G) and best supportive care (BSC) versus BSC, following standard combination therapy with gemcitabine-carboplatin (G-Cb) for patients with advanced non-small cell lung cancer (NSCLC). *J Clin Oncol.* 2010; 28:abstr 7506.
6. Perol M, Chouaid C, Milleron BJ, Gervais R, Barlesi F, Westeel V, et al. Maintenance with either gemcitabine or erlotinib versus observation with predefined second-line treatment after cisplatin-gemcitabine induction chemotherapy in advanced NSCLC: IFCT-GFPC 0502 phase III study. *J Clin Oncol.* 2010; 28:abstr 7507.
7. Sun JM, Park JO, Won YW, Kim JH, Yun J, Lee J, et al. Who are less likely to receive subsequent chemotherapy beyond first-line therapy for advanced non-small cell lung cancer? Implications for selection of patients for maintenance therapy. *J Thorac Oncol.* 5:540–5. [PubMed: 20195170]
8. Gerber DE, Rasco DW, Le P, Yan J, Dowell JE, Xie Y. Predictors and impact of second-line chemotherapy for advanced non-small cell lung cancer in the United States: real-world considerations for maintenance therapy. *J Thorac Oncol.* 2011; 6:365–71. [PubMed: 21173713]
9. Haines I. Rituximab maintenance therapy for follicular lymphoma. *The Lancet.* 2011; 377:1151.
10. Murphy C, Khasraw M, Seidman A. Holding back the sea: the role for maintenance chemotherapy in metastatic breast cancer. *Breast Cancer Research and Treatment.* 2010; 122:177–9. [PubMed: 20458530]
11. Stinchcombe TE, Socinski MA. Maintenance therapy in advanced non-small cell lung cancer: current status and future implications. *J Thorac Oncol.* 2011; 6:174–82. [PubMed: 21127437]
12. Jalal SI, Ademuyiwa FO, Hanna NH. The role of maintenance chemotherapy in advanced nonsmall cell lung cancer. *Curr Opin Oncol.* 2009; 21:110–5. [PubMed: 19532011]
13. Cappuzzo F, Coudert BP, Wierzbicki R, Wu Y-L, Gonzalez EE, Davidson N, et al. Efficacy and safety of erlotinib as first-line maintenance in NSCLC following non-progression with chemotherapy: results from the phase III SATURN study. *J Thorac Oncol.* 2009; 4:S289. (Abstract A2.1).
14. Barbour RS. Making sense of focus groups. *Med Educ.* 2005; 39:742–50. [PubMed: 15960795]
15. Krueger, R.; Casey, M. *Focus Groups: A practical guide for applied research.* Thousand Oaks, California: Sage Publications; 2000.
16. Nelson JE, Gay EB, Berman AR, Powell CA, Salazar-Schicchi J, Wisnivesky JP. Patients rate physician communication about lung cancer. *Cancer.* 2011
17. [Accessed February 21, 2012.] US Census State and County QuickFacts: Dallas County, TX. Available at: <http://quickfacts.census.gov/qfd/states/48/48113.html>
18. Rasco DW, Yan J, Xie Y, Dowell JE, Gerber DE. Looking beyond Surveillance, Epidemiology, and End Results: Patterns of Chemotherapy Administration for Advanced Non-small Cell Lung Cancer in A Contemporary, Diverse Population. *Journal of Thoracic Oncology.* 2010; 5:1529–35. [PubMed: 20631635]
19. Ritchie JE, Herscovitch F, Norfor JB. Beliefs of blue collar workers regarding coronary risk behaviors. *Health Edu Res.* 1994; 9:95–103.
20. George M, Margolis ML. Race and lung cancer surgery--a qualitative analysis of relevant beliefs and management preferences. *Oncol Nurs Forum.* 2010; 37:740–8. [PubMed: 21059585]
21. Silvestri G, Pritchard R, Welch HG. Preferences for chemotherapy in patients with advanced non-small cell lung cancer: descriptive study based on scripted interviews. *Brit Med J.* 1998; 317:771–5. [PubMed: 9740561]

22. Yorio JT, Xie Y, Yan J, Gerber DE. Lung Cancer Diagnostic and Treatment Intervals in the United States: A Health Care Disparity? *Journal of Thoracic Oncology*. 2009; 4:1322–30. [PubMed: 19752757]
23. Miles, MB.; Huberman, AM. *Qualitative data analysis*. Newbury Park, California: Sage; 1994.
24. Creswell, J. *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, California: Sage Publications; 1988.
25. Mays N, Pope C. Rigour and qualitative research. *Brit Med J*. 1995; 311:109–12. [PubMed: 7613363]
26. Cohen DJ, Crabtree BF. Evaluative criteria for qualitative research in health care: controversies and recommendations. *Ann Fam Med*. 2008; 6:331–9. [PubMed: 18626033]
27. Zeliadt SB, Ramsey SD, Penson DF, Hall IJ, Ekwueme DU, Stroud L, et al. Why do men choose one treatment over another? *Cancer*. 2006; 106:1865–74. [PubMed: 16568450]
28. Holmboe ES, Concato J. Treatment Decisions for Localized Prostate Cancer. *J Gen Intern Med*. 2000; 15:694–701. [PubMed: 11089712]
29. Chapple A, Ziebland S, Herxheimer A, McPherson A, Shepperd S, Miller R. Is 'watchful waiting' a real choice for men with prostate cancer? A qualitative study. *Brit J Urol Int*. 2002; 90:257–64.
30. Jagsi R, Abrahamse P, Morrow M, Griggs JJ, Schwartz K, Katz SJ. Postmastectomy radiotherapy for breast cancer: patterns, correlates, communication, and insights into the decision process. *Cancer*. 2009; 115:1185–93. [PubMed: 19180636]
31. Salles G, Seymour JF, Offner F, López-Guillermo A, Belada D, Xerri L, et al. Rituximab maintenance for 2 years in patients with high tumour burden follicular lymphoma responding to rituximab plus chemotherapy (PRIMA): a phase 3, randomised controlled trial. *The Lancet*. 2011; 377:42–51.

Figure 1. Schematic of “traditional” and “maintenance” chemotherapy for advanced NSCLC displayed at throughout each focus group session.

Table 1

Participant Socio-demographics and Clinical Status

FG #	Patient	Age	Sex	Race	Treatment	# Cycles	Best response to date	More first-line chemo planned?
1	1	57	M	White	WBRT, SRS → carboplatin-paclitaxel	2	Stable disease	Y
1	2	69	M	White	Carboplatin-pemetrexed + bevacizumab	3	Minor response	Y
1	3	69	M	White	Surgery and chemo for prior stage III → stage IV recurrence: SRS → carboplatin-pemetrexed	1	Not yet determined	Y
1	4	64	F	White	Carboplatin-paclitaxel + study drug	2	Minor response	Y
2	1	67	F	White	Carboplatin-pemetrexed	2	Mixed response	Y
2	2	53	M	Black	Carboplatin-paclitaxel	3	Minor response	Y
2	3	58	F	White	SRS → carboplatin-pemetrexed → palliative RT to spine	2	Minor response	Y
2	4	39	M	Asian	Resection of brain metastasis → erlotinib x 6 months → carboplatin- pemetrexed	1	Not yet determined	Y
3	1	69	F	White	Carboplatin-gemcitabine	4	Mixed response	Unknown
3	2	45	F	White	Carboplatin-paclitaxel + bevacizumab	2	Minor response	Y
3	3	62	F	White	Carboplatin-paclitaxel	3	Minor response	Y
3	4	64	M	White	Palliative RT to bones → carboplatin-paclitaxel	3	Not yet determined	Unknown
3	5	62	M	Black	WBRT → carboplatin-paclitaxel	6	Partial response	N

SRS, stereotactic radiosurgery (eg, Gamma Knife); WBRT, whole brain radiation therapy

Table 2**Focus Group Questions and Probes**

Based on the information presented, what is your understanding of “maintenance chemotherapy” for lung cancer? What do you understand it is <i>intended</i> to do?
What do you think of “maintenance chemotherapy”? Can you tell me what “pros and cons” there might be to this kind of approach?
<i>Prompt:</i> degree to which it could extend life, side effects, time commitment, other barriers
What does “quality of life” mean to you in the context of your diagnosis?
How important is your “quality of life” during treatment?
How important is it for you to feel like you have “completed” treatment?
Does the end of treatment signify something important?
Would you consider maintenance chemotherapy for yourself?
How would you go about making a decision like this?
<i>Prompt:</i> How might your physician’s recommendation affect your thoughts?
What has your current experience with treatment been like?
How might your current experience affect your potential interest in maintenance therapy?
What is the goal of [your] lung cancer treatment?
How do you make your decisions about treatment? Have you been “aggressive” in your treatment?
<i>Prompt:</i> Is it most important to shrink/remove as much tumor as possible?
How important is it for you to minimize side effects during treatment?