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# The patient experience with shared decision-making in lung cancer: A survey of patients, significant others or care givers

## **Cover Page Footnote**

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## The patient experience with shared decision-making in lung cancer: A survey of patients, significant others or care givers

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### Abstract

A survey (via SurveyMonkey) was sent to lung cancer patients, their caregivers or significant others asking about their experience in making difficult treatment decisions. Of the 198 respondents, 118 (69%) indicated that they had faced a difficult decision with respect to their lung cancer treatment. Of those, 73% indicated that they would have desired that the decision be made with their physician using a shared decision-making process, and 58% perceived that such a process had occurred. In addition, only 23% of respondents indicated that they had had the right amount of information when making the decision. Fortunately, only 9% of respondents expressed regret regarding the decision they ultimately made. A Patient Decision Aid (PDA) was made available to the respondents to view, and opinions were sought regarding the usefulness of this type of format for presenting information. This format was perceived as helpful, unsure if helpful, or not helpful by 62%, 36%, and 2% of respondents, respectively. In summary, the majority of lung cancer patients want to make difficult decisions using a shared decision-making process. The patient perception is that this is not occurring often enough. Even in this fairly well-educated group of respondents, many report that they are not sure that they have all the information necessary to make that difficult decision. Physicians may need help developing their communication and shared decision-making skills. Introducing PDAs into the oncology clinic may represent a way to present complex information and improve the patient experience.

### Keywords

Patient experience, patient decision aids, shared decision-making, lung cancer

### Introduction

Oncologists often ask lung cancer patients to make important decisions regarding their treatment, often within the setting of a single consultation. Patients are presented with treatment options that are sometimes associated with a significant degree of uncertainty as to their risks and benefits. The Institute of Medicine expressed the opinion that shared decision-making was necessary to produce the best clinical outcomes possible.<sup>1</sup> How oncologists present information can be instrumental in what treatment decision is made, the subsequent physician-patient relationship, and the degree of regret experienced by the patient should things not go as well as expected.

When one treatment option is not clearly superior to another, Patient Decision Aids (PDAs) can help present risks and benefits in a simple, visual format.<sup>2</sup> A survey of lung cancer patients or their significant others/caregivers collected information regarding their decision-making experiences, and their perceived usefulness of PDAs.)

### Methods

A survey (via SurveyMonkey) was sent to lung cancer patients, caregivers or significant others who had signed up for email communication from the Bonnie Addario Lung Cancer Foundation (ALCF), Global Resource for Advancing Cancer Education (GRACE), or the University of Colorado. Non-patient respondents were asked to answer the survey, including the demographic information, as they would have anticipated the patient would have answered. In addition to the multiple choice format of the SurveyMonkey questionnaire, all questions provided the option to give freestyle comments. The survey process and questions were approved by the Institutional Review Board of the University of Colorado.

In order to seek opinions regarding the usefulness of PDAs, a representative part of a PDA was shown (Figure 1). The figure provided was typical of how a PDA presents the risks and benefits in a simple way, using numerical and visual formats, combined with a very short narrative.<sup>2</sup> There was also a link to a full PDA for those interested in seeing it.

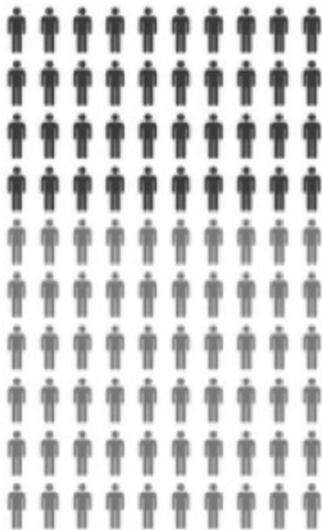
Figure 1. Survey question regarding the usefulness of a PDA

16. There are patient decision aids available that put informational facts about two different treatments side by side, using simple words or pictures. A patient decision aid is usually a few pages long, and tries to point out the benefits and risks of each of the two decisions that you are trying to choose between. An example of a simple picture that is a part of a patient decision aid is below.

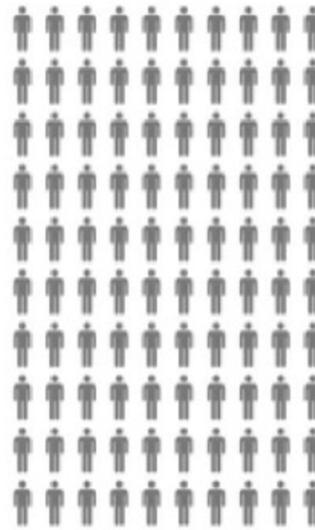
This type of decision aid would have been

- Not helpful
- Helpful
- Don't know
- Prefer not to answer
- Other (please specify) or additional comments

**Treatment A** 40 get memory problem  
60 avoid this



**Treatment B** 0 get memory problems  
100 avoid this



The survey was sent out in January 2016 and by September 2016, 198 completed surveys had been received.

### Results

The demographics of the survey respondents are summarized in Table 1. Given the distribution of the survey through USA-based advocacy associations, it is not surprising that the majority (83%) of respondents were from the USA. The median age of respondents was 51-60 years old but all ages were represented. It was a relatively well-educated group with 83% of respondents having attended at least some college. Sixty-nine percent of the respondents were married. Respondents were more likely

to be white females. There were no Native American, Alaskan Native, Native Hawaiian or Pacific islanders.

Respondents were asked if they had faced a difficult decision regarding their treatment. Sixty-nine percent of the 198 respondents indicated that they had faced a difficult decision. Women were more likely than men to indicate that they had had a difficult decision to make (83% vs 65%,  $p < 0.05$ ).

The stage of lung cancer was Stage I or II (primary tumor in lung without spread to mediastinal lymph or distant organs, Stage III (primary tumor in lung with spread to mediastinal lymph nodes without spread to distant organs), Stage IV (metastatic to distant organs), or not known, in 15%, 14%, 56% and 15% of respondents, respectively.

**Table 1. Demographics of 198 survey respondents**

Demographic variable	N (%)
Respondent	
Patient	127 (64%)
Caregiver/support person	71 (36%)
Country	
United States	163 (83%)
Canada	15 (8%)
Other/No answer	20 (9%)
Age (yrs)	
≤ 30	4 (2%)
31-40	15 (8%)
41-50	30 (15%)
51-60	59 (30%)
61-70	54 (27%)
71-80	20 (10%)
≥ 81	4 (2%)
No answer	12 (6%)
Highest level of school completed	
Elementary or middle school	2 (1%)
High school or equivalent	15 (8%)
Some college but no degree	26 (13%)
Associate or bachelor degree	73 (37%)
Graduate degree	68 (34%)
No answer	14 (7%)
Relationship status	
Married	137 (69%)
Widowed	8 (4%)
Divorced	18 (9%)
Single, never married	13 (8%)
Other/No answer	22 (10%)
Gender	
Male	42 (21%)
Female	128 (65%)
No answer	28 (14%)
Ethnic heritage	
White	150 (76%)
Black	1 (0.5%)
Asian	12 (6%)
Multi-cultural	4 (2%)
No answer	31 (10.5%)

The treatment situations associated with the difficult decision are shown in Table 2. Under the “Other” category respondents commented frequently on the dilemma about joining a clinical trial, seeking a second opinion, or changing treatment course due to toxicities.

When asked why the decision was difficult (again, more than one answer was allowed), the most common answer was that they felt they did not have enough information (44%) or that they had heard conflicting information or recommendations from their doctors (33%). Other cited reasons were that they felt rushed to make the decision (30%), heard conflicting information from non-medical sources such as friends or internet (20%), disagreement with significant other/support team (9%). Additional free style comments alluded to practical issues (e.g., work, expense, insurance, financial) with travelling for treatment or for a second opinion, depression or feelings of futility and helplessness, and difficulty dealing with the unknown.

Respondents used a variety of sources to help make the decision although their physicians and the internet were the most commonly cited sources (81% and 70%, respectively). Table 3 summarizes these responses. Respondents who indicated “Other” had varied comments such as “relying on their gut feelings,” or indicated that they used many of these sources and chose this response as a default.

The amount of information available was categorized as insufficient, just right, too much or difficult to know in 14%, 23%, 2%, 50%. Eleven percent preferred to answer the question with explanations. Most of these comments expressed confusion and uncertainty about the information needed to make the “right” decision. Men were more likely to indicate that they had “just the right amount of information,” 39% vs 14%,  $p < 0.05$ .

Respondents were asked how “they would have liked to make the decision” in terms of collaboration with their physicians and family. The most common answer was that they wanted their doctor(s) to make the decision jointly with them (73%), with half indicating that they wished to also have their family also involved in making the decision. However, only 58% of respondents felt that their decision

**Table 2. Treatment or situation associated with the difficult decision**

Treatment modality or situation	% of respondents
Tests that were done or not done	34%
Surgery	29%
Radiation therapy	29%
Chemotherapy (including targeted therapy)	56%
End of life care	12%
Other*	24%

\*See text

**Table 3. Sources of information utilized by respondents (multiple sources allowed)**

Source of information	Respondent number (%)
Doctors	90 (81%)
Internet	78 (70%)
Books, pamphlets or other written material	35 (31%)
Lung cancer patient advocacy groups or foundations	51 (47%)
Friends or family	53 (47%)
Other people with lung cancer (more informally than patient advocacy group)	28 (25%)
Nurses	24 (21%)
Other	30 (27%)

had been a shared decision with their doctors, with or without their family’s input. Ten percent of respondents indicated that the decision was primarily made by their doctors. Unfortunately, 26% of respondents indicated that they had made the decision by themselves. There was no gender difference identified in the opinion regarding the PDA, or regarding the wish for, or perception of, the degree to which the decision was made jointly with their doctors.

Respondents were asked if they regretted the decision that they had made. Answers were given on a 5-point scale: 1 (strongly agree), 2 (agree), 3 (neither agree or disagree), 4 (disagree) or 5 (strongly disagree). Interestingly only 9% of respondents expressed regret (answered 1 or 2) regarding the decision that they had made. There was no difference in this expression of regret between men and woman. The following freestyle comments were offered by respondents who expressed regret over the decision.

- Regret that even the oncologist glossed over my questions regarding (drug) sequencing
- Not enough tissue obtained for more comprehensive testing
- I still wish my MD was more informative. I am medical, intelligent and aware enough to handle the tough realities. Just talk to me. I’m not in denial or living in an illusion.
- Not given some kind of follow-up PET scan post-surgery. Wonder if preventative chemo might have eradicated the early activity.
- I wish surgeon was more upfront about complications. I got every complication imaginable. Surgeon made it sound like piece of cake.
- Whether to participate in a clinical trial or not.

Respondents were then shown a representative part of a PDA (Figure 1) and asked if this type of decision aid would have been helpful. Of the 91 respondents to this question, 62% felt that a PDA would be helpful, and only

2% felt it would not be helpful. The remainder weren’t sure or offered suggestions regarding modifying the PDA.

At the conclusion of the survey, respondents were given the opportunity to make additional comments. Of the 40 additional comments, many indicated that they had faced multiple difficult decisions throughout their illness. They highlighted the complexity of making personal treatment decisions based on the statistics available. Many were appreciative of having the opportunity to answer the survey, and hoped that further research into shared decision-making would be forthcoming

**Discussion**

The importance of physicians and patients working together to make decisions was highlighted in the Institute of Medicine (IOM) report *Crossing the Quality Chasm*.<sup>1</sup> This IOM report referred to patient-centered care as “care that is respectful of and responsive to individual patient preferences, needs, and values” and that ensures “that patient values guide all clinical decisions.” The IOM expressed the opinion that shared decision-making was necessary to produce the best clinical outcomes possible.

Patients vary in their medical knowledge, but even a patient who has done substantial research prior to the consultation might have difficulty in applying that information to his or her own situation. In addition, patients vary in the extent to which they want to be involved in the decision-making process.<sup>3</sup> This was apparent in our results in which approximately 75% of patients wanted to be involved in making the difficult decision.

Patient education materials are not meant to replace the patient-physician consultation but to improve the decision process. Often patients arrive at consultations or follow-up appointments not knowing the results of tests indicating a need for a change in management, or there may be an actual or perceived need to make a quick

decision during that patient-physician interaction. Patients often look to their health providers to point them to appropriate education sources to support shared decision-making. However, even a patient who has done substantial research prior to the consultation might have difficulty in applying that information to his or her own situation. In addition, patients vary in the extent to which they want to be involved in the decision-making process.<sup>3</sup>

Another way in which oncologists can promote patient-centered care is by providing a written document summarizing the treatment options discussed, and their associated risks and benefits. Providing patients with a visit summary has been designated as a quality indicator by Medicare, part of the Meaningful Use criteria, by which medical facilities can recoup some of their investment in installing an electronic medical record (EMR).<sup>4</sup> Other techniques that have been shown to be effective include the provision of pertinent published literature, tape recordings of the interview, copies of the office notes, and telephone calls before or after the visit.<sup>5</sup> Older lung cancer patients may benefit from written materials that are presented in a particular format. The Centers for Disease Control and Prevention (CDC) has suggested guidelines for oral and written questions with older adults or caregivers (<http://www.cdc.gov/healthliteracy/developmaterials/audiences/olderadults>. Accessed July 23, 2017).

Interestingly, patients are likely to be more satisfied with the decision-making process if the physician communicates the uncertainty associated with their treatment recommendation.<sup>6</sup> Clinicians need to relinquish their role as the single, paternalistic authority and train to become more effective coaches or partners. They have to be comfortable asking, “What matters to you?” or “What is the matter?”<sup>7</sup>

Another validated way of communicating the uncertainty surrounding treatment options is the use of patient decision aids (PDAs).<sup>8</sup> PDAs can be used when there is more than one reasonable option, when no option has a clear advantage in terms of health outcomes, and when each option has benefits and harms that patients may value differently. PDAs may be in the form of written information, videos, or web-based tools that make the decision explicit, summarize the options available, and help people to understand these options as well as their possible benefits and harms.<sup>9</sup> PDAs may contain real patient anecdotes in which one or the other decision was made, with both good and bad outcomes. One expert review concluded that effective PDAs present the risks and benefits in numerical and visual formats, combined with some narrative, and must take into account the ability of the patient to understand the material.<sup>2</sup>

The effectiveness of PDAs in cancer varies from tool to tool, and there is controversy regarding the depth of information that should be presented to the patient.<sup>10-12</sup> However, a Cochrane review regarding shared decision-making concluded that PDAs lead to significant changes in the following variables.<sup>8</sup>

- Increased patient knowledge
- More accurate patient assessments of the treatment risk
- Lower decisional conflict related to feeling uninformed
- Reduced passivity in decision-making
- Reduced number of undecided patients
- Improved effect on patient-practitioner communication

The Cochrane review also concluded that, on average, the use of a PDA only increased the length of consultation by approximately 3 minutes.

Of the 600 plus validated PDAs, less than 60 of these are designed for cancer treatment decisions, and only 10 deal with lung cancer diagnosis or treatment ([www.ohri.ca/decisionaid](http://www.ohri.ca/decisionaid). Accessed July 20, 2017). These can be accessed by patients and oncologists on the internet. Clearly there is room for the development of other lung cancer PDAs.

Unfortunately, the conclusions that can be drawn from this survey are limited by the relatively homogeneous population of respondents, primarily white Caucasian, well-educated patients with access to the internet. A future comparison of these results with other patient populations would be extremely interesting.

In summary, lung cancer patients frequently face difficult treatment decisions, and most, but not all, want to participate in a shared decision-making process with their doctor. However, the patient perception is that this is not occurring as often as it could or should. Even in this fairly well-educated group of respondents with access to many educational resources, many report that they are not sure that they had all the information necessary to make a shared decision. Physicians may need encouragement and education to develop their shared decision-making skills. This could take the form of more open discussion to explore the patient’s values and priorities, for example asking the patient “what really matters to you?”. Introducing more PDAs into the oncology clinic may represent another way to present complex information and enhance the shared decision-making process.

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