Patient-surgeon decision-making about treatment for very low-risk thyroid cancer

Amanda Doubleday*, Megan C. Saucke#, Maria F. Bates and Susan C. Pitt*

University of Wisconsin School of Medicine and Public Health, 600 Highland Ave., Madison, WI 53792-7375, USA.

ABSTRACT

Patients with very low-risk thyroid cancer are often over-treated with surgery and radioactive iodine. This study aimed to better understand patients’ and surgeons’ decision-making about treatment for very low-risk thyroid cancer that leads to overtreatment. This qualitative study of 10 patients with very low-risk thyroid cancer and 12 surgeons used semi-structured interviews and validated measures of decision preference, control, and satisfaction to characterize decision-making. The majority of patients were white (90.0%) and female (80.0%), with a median age of 47.5 years. Most surgeons were white (91.7%), male (83.3%), and endocrine surgeons (83.3%) who worked at a university or academic institution (91.7%). Patients and surgeons both preferred the patient to make the final treatment decision after considering the surgeon’s opinion. They least preferred to leave the final decision to the surgeon. Patient experiences ranged from deciding on their treatment prior to surgical consultation to a perceived lack of a choice because the surgeon only discussed one option. When asked what was most important in choosing a treatment, patients frequently discussed removing the cancer and trusting their surgeon’s recommendation. Multiple factors influenced surgeons’ treatment recommendations – most commonly clinical data and patients’ anxiety. Surgeons described tailoring their recommendation based on their own perception of patients’ level of fear and risk tolerance, but did not explicitly assess patients’ preferred treatment. When making decisions about treatment for very low-risk thyroid cancer, patients and surgeons prefer a shared model with the patient controlling the final decision. Surgeons’ recommendations appear to heavily influence the decision, but are based on the surgeon’s own perceptions of patients’ preferences, which may not be accurate. To achieve value-concordant patient-centered care, explicit discussion of patients’ preferences in relation to all treatment options and outcomes will be key.

KEYWORDS: thyroid cancer, treatment, decision-making, overtreatment, patient preferences, cancer fear, recommendations.

INTRODUCTION

As healthcare technology and research progress, patients are increasingly faced with multiple treatment options many of which are safer, less invasive, and have improved outcomes compared to traditional management. For patients with malignancies such as thyroid cancer, changes like these have largely occurred because of concerns about overtreatment—which exists when the risk of harm outweighs the potential benefit [1-10]. As a result, patients with very low-risk thyroid cancer now have more treatment options with significant tradeoffs and varying outcomes, but equivalent long-term survival [1-10]. These options include: (1) active surveillance with serial ultrasounds and

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*Corresponding author: pitt@surgery.wisc.edu

#Co-first authors
labs, (2) hemi-thyroidectomy (removal of half the thyroid), and (3) total thyroidectomy (removal of the entire thyroid) [1]. Traditionally, total thyroidectomy has been the treatment of choice, but recent guideline changes now recommend hemi-thyroidectomy for the majority of patients with very low-risk thyroid cancer, such as papillary thyroid microcarcinoma which measure 1 cm or smaller [1].

In situations like this where multiple treatment options exist with similar oncologic outcomes, the decision about which treatment to undergo should be preference-based and reflect the patient’s goals and values [11-15]. Patients should be informed of all available treatment options and actively involved in shared decision-making with their surgeon [16]. However, little is known about the treatment decision-making process for patients with very low-risk thyroid cancer. Because in this setting the need for preference elicitation is new and the disease incidence is increasing, data are needed to evaluate and understand how treatment decisions are made [17, 18]. Therefore, the aim of this study was to better understand how patients and surgeons reach decisions about treatment for very low-risk thyroid cancer. Only after understanding the decision-making process can we develop strategies to ensure patients are informed of their treatment options and make decisions that are aligned with their preferences and values.

MATERIALS AND METHODS

To better understand the treatment decision-making process, we conducted a qualitative study with 22 in-depth, semi-structured interviews. Participants included 12 surgeons who treat patients with very low-risk thyroid cancer and 10 patients with very low-risk papillary thyroid cancer. In addition to the interview, participants completed a questionnaire about the treatment decision-making process. The University of Wisconsin (UW) Institutional Review Board approved this study. All participants signed a written consent form before participation.

Participants

To obtain a geographically and demographically diverse sample of surgeons with a wide range of training backgrounds and practice settings, we recruited surgeons at a national conference—the 2016 American Thyroid Association (ATA) meeting. We sent recruitment emails prior to the meeting and recruited additional participants at the meeting through a combination of flyers and snowball sampling. To be included, participants had to be actively practicing and take care of at least 5 patients with small (≤ 2 cm) low-risk thyroid cancer annually.

To recruit patients with very low-risk thyroid cancer, we identified patients who were diagnosed pre-operatively with papillary thyroid cancer measuring less than 1.5 cm and underwent surgery at the University of Wisconsin within the previous 5 years. Patients with lymph node metastasis were excluded. Eligible subjects (n = 11) were mailed a letter by their surgeon inviting them to participate in the study. If the subjects did not respond and opt out, the study team called two weeks after the mailing and asked to schedule an interview. Both surgeon and patient participants received a cash incentive for participating in the study.

Data collection

Two members of the research team with advanced training in qualitative interviewing (MCS and EMW) conducted semi-structured interviews with participants using open-ended questions and one case-based clinical vignette. Surgeon interviews occurred in September 2016, while patient interviews occurred from November 2016 through April 2017. We planned to conduct additional surgeon interviews if data saturation was not reached, but this was not necessary. Data collection and analysis for patients was concurrent and stopped once data saturation was reached.

We developed interview guides in collaboration with qualitative research experts, as well as an established group of stakeholders that included patients with thyroid cancer, their family members, endocrinologists, and surgeons. Example questions include:

Patient:

• “Tell me about what treatment options you considered.”
• “Tell me more about how the treatment decision was reached.”
Thyroid cancer decision-making: Patients and surgeons

- “How did your surgeon influence your treatment decision?”

Provider:
- “What treatment options do you discuss [for patients with very low-risk thyroid cancer]?”
- “Tell me about how a treatment option is selected and what that looks like?”
- “What would you do if a patient you thought should get a lobectomy, requests a total thyroidectomy instead?”

The interview guides were piloted and revised after initial interviews. The 22 interviews were conducted in-person (n = 18) or via video conferencing (n = 4) and ranged from 30 minutes to 2 hours. Interviews were audio-recorded and transcribed verbatim, with all identifiers removed.

At the conclusion of each interview, all participants filled out a short survey that collected demographic information and included the Control Preferences Scale to assess the level of involvement they prefer to have when making decisions about medical treatments [19]. The surgeon survey also included items from the Provider Decision Process Assessment Instrument and the OPTION scale (Observing Patient InvolveMeNt), regarding how and to what degree physicians elicit patient preferences and how they describe treatment options [20-22]. The patient survey also measured their level of satisfaction with their decision and decision regret using validated measures [23, 24].

Data analysis

We utilized qualitative content analysis to analyze the interviews. Verbatim transcripts were imported into NVivo 11 (QSR International, Melbourne, Australia) which was used to catalog the coding scheme. Three members of the research team with diverse professional backgrounds (sociology, population health, and surgery) independently analyzed the first 3 transcripts for each population (patients and surgeons) using an inductive strategy and open coding to determine the major themes present in the interviews. We then developed initial concepts and categories that reflected salient and recurring themes in the data. We used constant comparison to refine the coding taxonomy. Specifically, for passages under discussion, we compared the identified text to the code description and to data associated with the code in previous transcripts, managing differences by adjusting the meaning of the code or creating new codes to precisely reflect the data. Disagreements between coders were resolved through discussion until consensus was reached.

Group discussion of codes and quotes often inspired ideas about broader patterns and processes in the data. For higher-level analysis, we created concept diagrams, in which we mapped observed relationships between themes and relevant context. Using this technique, we examined how key elements including patient preference and doctor recommendation influenced treatment decisions. These concept diagrams were continually refined as coding progressed until a final model adequately described the data. We also searched the relevant literature for similar themes and models of patient-surgeon decision-making for the treatment of cancer.

RESULTS

Ten patients with very low-risk papillary thyroid cancer and 12 surgeons who treat patients with thyroid cancer participated in semi-structured interviews about treatment decision-making for very low-risk thyroid cancer. Nine patients underwent a total thyroidectomy and one patient underwent hemi-thyroidectomy. The majority of patients were white (90.0%) and female (80.0%) with a median age of 47.5 years (Table 1). Most surgeons were white (91.7%), male (83.3%), worked at university or academic institutions (91.7%), and self-identified as endocrine surgeons (83.3%) as opposed to general surgeons or otolaryngologists (Table 1). Eight of the 10 patient participants’ nodules measured 1 centimeter or smaller; the largest nodule measured 1.3 centimeters on ultrasound.

Overall decision-making process

Patients

When discussing the decision-making process, patients described elements of the process that their surgeon did well and those that were less optimal. Patients relayed a more positive experience when they did not feel rushed and had all their questions answered. Patient 5 said:

“[The surgeon] described the different treatment options, how the surgery was going to go,
the doctors and the surgeons like, I was just like another in and out person.” [Patient 4]  

“[The surgeon] asked me if I had questions... of course I had a lot of questions but I didn’t have any background information, so it’s hard to ask specific questions.” [Patient 2]  

When patients were surveyed about the decision-making process, 20% agreed or strongly agreed that they would have liked more support in making the decision. In addition, 30% did not agree or strongly agree that the decision was easy to make, though 80% strongly agreed that they were satisfied with the decision that was made.  

**Surgeons**  

When surgeons were prompted to discuss the overall decision-making process, surgeons described using multiple techniques to facilitate treatment decisions, including allowing patients time to reflect on the options presented and make the decision (Table 2). For example, Surgeon 4 said:  

“When I sense any hesitation... I usually say... you have time to make the decision...I try not to force [patients] to make a decision during that first consultation if they don’t seem ready.”  

Many surgeons also admitted during interviews that treatment decision-making for very low-risk thyroid cancer can be challenging (Table 2). Surgeons described how patients’ achieving full understanding of all treatment options and outcomes can be difficult and time consuming. Some expressed difficulty performing shared decision-making and finding the right questions to elicit patients’ preferences and values. Surgeons described these challenges:  

“The decision-making process is going to be better informed, more accurate, and more in line with the patient’s true goals and feelings if education is thorough. I’d say the first part is to make sure that the patient understands, and that can take a lot of time and be relatively painful. That’s a skillset a lot of us either don’t have or are having to build in a really kind of painful arduous way... how do you talk to somebody who doesn’t have your background.” [Surgeon 5]  

“Trying to let [patients] speak I think is challenging especially for surgeons. Our  

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**Table 1. Patient and surgeon demographics.**  

<table>
<thead>
<tr>
<th>Surgeons</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (median, range)</td>
<td>41 (34-67)</td>
</tr>
<tr>
<td>Male</td>
<td>10 (83)</td>
</tr>
<tr>
<td>Caucasian</td>
<td>11 (92)</td>
</tr>
<tr>
<td>Academic practice</td>
<td>11 (92)</td>
</tr>
<tr>
<td>Region</td>
<td></td>
</tr>
<tr>
<td>East/Northeast</td>
<td>4 (36)</td>
</tr>
<tr>
<td>South</td>
<td>3 (27)</td>
</tr>
<tr>
<td>Midwest</td>
<td>2 (18)</td>
</tr>
<tr>
<td>West</td>
<td>2 (18)</td>
</tr>
<tr>
<td>Patients</td>
<td>n (%)</td>
</tr>
<tr>
<td>Age (median, range)</td>
<td>48 (21-77)</td>
</tr>
<tr>
<td>Female</td>
<td>8 (80)</td>
</tr>
<tr>
<td>Caucasian</td>
<td>9 (90)</td>
</tr>
<tr>
<td>Currently employed</td>
<td>8 (80)</td>
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<tr>
<td>Education</td>
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<td>High school</td>
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<tr>
<td>Some college/Associates degree</td>
<td>4 (40)</td>
</tr>
<tr>
<td>College degree</td>
<td>3 (30)</td>
</tr>
<tr>
<td>Post-graduate degree</td>
<td>2 (20)</td>
</tr>
</tbody>
</table>

any kind of side effects, medications, what to expect after surgery. It was a good 90-minute or two-hour appointment which was really nice. So [the surgeon] had a lot of information, pretty much every question we had was answered, it was great.”  

Patients also discussed challenges in the decision-making process, such as overuse of medical terminology, lack of diagrams or other tools to explain treatment options, failure to include information important to the treatment decision (i.e. thyroid hormone replacement), not knowing what questions to ask, feeling intimidated, and only being provided one treatment option (Table 2). For example, patients stated:  

“I just remember thinking...that, there wasn’t enough information being sent my way from
When surveyed about the decision-making process, 58% of surgeons agreed or strongly agreed that decisions about treatment for very low-risk thyroid cancer are hard to make. In addition, 67% of personalities are normally more assertive so I think that part is challenging and to really parse out what the patient wants, can be challenging." [Surgeon 6]
surgeons agreed or strongly agreed that a decision support tool, such as a decision aid, would be useful in making treatment decisions with these patients, and 75% would use a decision support tool if it was easy and did not take more time.

**Treatment options and decision control**

**Patients**

When the patients were interviewed about what treatment options they considered for their very low-risk thyroid cancer, some perceived a lack of choice because their surgeon only discussed one option (n = 3) or mentioned alternatives but only recommended one treatment (n = 4). Patient experiences varied in how much control patients felt they actually had over the treatment choice, and some patients did not perceive shared decision responsibility during their consult (Table 2). For example, patients stated:

“I didn’t think that there were any other options. I just thought surgery was it. Because that’s what [the surgeon] said to do. I didn’t know you could even do half of one.” [Patient 4]

“I think [my surgeon] did influence [the decision] a lot because I really trusted his/her opinion on it…[but] s/he didn’t even bring up the partial thyroidectomy.” [Patient 2]

When patients responded to the survey, 20% did not agree that they were adequately informed about the different treatment alternatives available. In addition, 30% agreed or strongly agreed that having more information about their disease would have helped them make the decision. When completing the Controlled Preferences Scale, the majority of patients indicated that they preferred to make the final treatment decision after considering the surgeon’s recommendation.

**Surgeons**

Meanwhile, most surgeons said in interviews that they offered multiple treatment options and left the final decision up to the patient. Many surgeons indicated that they use shared decision-making to reach the treatment decision. The following quotes reflect surgeons’ views about who should control the decision:

“I let the patient choose. I learned long ago that you never talk somebody into surgery... especially for a purely elective operation. The patient has to be happy with their choice of the operation.” [Surgeon 8]

“They have to decide to go through with it. I’m just there to give recommendations and advice.” [Surgeon 10]

Most surgeons also said that they would be flexible if a patient requested a different treatment approach than what they recommended, especially if they felt the alternative was “reasonable” and the patient understood the risks and benefits of all options. Some surgeons also avoided discussing too many options for fear of overwhelming the patient. For example, surgeons said:

“I would talk to them about why [they wanted a different treatment option]...It’s not unreasonable for them to [undergo a total thyroidectomy] as long as they understand that they’re taking a little more risk.” [Surgeon 7]

“I think that it complicates the matter... if you say There’s an...experimental thing---active surveillance—we could look into that, but I don’t do it here...’ It just—it’s overwhelming for the patient.” [Surgeon 9]

In survey responses, most surgeons, similar to patients, indicated on the Controlled Preferences Scale that they preferred the patient to make the final treatment decision after considering their recommendation. Both patients and surgeons least preferred to leave the final decision to the surgeon. However, when surveyed about treatment options offered, only 50% of the surgeons agreed or strongly agreed that they explain active surveillance, which should be a treatment option for many patients with very low-risk thyroid cancer.

**Factors influencing treatment decision-making**

**Patients**

When prompted to discuss factors that influenced their treatment decision in interviews, patients frequently discussed their surgeon’s recommendation and the importance of trusting their surgeon (Table 2). Elements contributing to this trust included the surgeon’s competence, demonstration of knowledge and expertise, and his or her practice being located at a medical center they trusted. For example, patients said:
Patients’ trust appeared to extend to whatever option their surgeon recommended. More specifically, several patients said they would have considered less aggressive treatment if their surgeon recommended it, though some were hesitant about active surveillance. The following patient quotes are examples:

"If I was given that option [hemithyroidectomy], I would’ve gone with that, definitely." [Patient 4]

Interviewer: “What if your doctor recommended this nonsurgical approach?”

Patient: “Oh I’d take their advice!” [Patient 6]

When patients were surveyed about what factors influenced their treatment decision, 70% agreed or strongly agreed that their surgeon’s recommendation was most important. Sixty percent of patients also agreed or strongly agreed that input from their family, friends, or other trusted people influenced their decision. Despite discussing that they would have considered other treatment options, 80% of patients agreed or strongly agreed that they would make the same treatment choice if they had to do it over again, and 70% would recommend the same treatment to a friend or family member. Only 10%, or one patient, agreed that their choice did them a lot of harm.

**Surgeons**

While many clinical factors influenced surgeons’ treatment recommendations, surgeons expressed that the treatment option patients prefer also plays an important role. A common theme among surgeons was the belief that patients have significant fear and anxiety, which leads patients to want the most extensive treatment—a total thyroidectomy. Surgeons described tailoring their discussion of treatment options based on their perception of the patients’ level of fear, anxiety, and risk tolerance, often without explicit discussion of patients’ feelings (Table 2). For example, surgeons described offering more aggressive treatment if they thought the patient would be uncomfortable with the less aggressive treatment. For example, Surgeon 2 stated:

“At a minimum I would recommend a lobectomy, and depending on the patient’s level of comfort…and how much anxiety this diagnosis is giving them, I would offer them a total if they were uncomfortable.”

Many surgeons also shared that some patients wanted them to make the final decision when the patients themselves were unable to decide. In these cases, surgeons again often relied on their impressions of the patient’s anxiety level, leaving room for their own personal biases (Table 2):

“[Patients] say ‘doc, what should I do, you tell me,’ [laughs] and that always puts me in a very awkward position, because it’s hard to be unbiased as a surgeon. I am a surgeon… when you’re a hammer everything’s a nail.” [Surgeon 5]

“… in that case I make my best judgment… I don’t want them to have surgery, have a complication, and regret it; and vice versa. I don’t want them to live with the anxiety so, I try to get a sense from them, where they are and sometimes they push you to make the decision for them and so you do the best you can.” [Surgeon 6]

When surveyed about decision making, only 58% of surgeons strongly agreed that they assess patients’ preferred treatment. However, 75% of surgeons strongly agreed that they explore patients concerns about treatment, and 67% strongly agreed that they explore patients’ expectations or ideas about treatment. Additionally, just 42% of surgeons strongly agreed that they elicit patients’ preferred level of involvement in decision-making or check that the patient understood the information provided.

**Model of treatment decision-making**

Examination of the process of decision-making about very low-risk thyroid cancer reported by patients and surgeons demonstrated gaps in how patients’ preferences are incorporated into treatment decisions and how decisions are made. Figure 1 describes this model and these gaps. Patients in this study reported that their surgeon’s
recommendation was very influential in making a treatment decision. Some patients also reported a lack of input into the decision, and a desire for more support and information about different treatment options to make the decision. On the other hand, surgeons described the importance of determining patients’ preferences, but often did not know how to explicitly elicit or incorporate patients’ preferences. Instead, surgeons described relying on their impression of patients’ anxiety and fear to make recommendations. While this model was not universal, the data indicate that surgeons may be at risk of making recommendations biased by their own beliefs and values and their assumptions about patient preferences. As a result, true shared decision-making may not occur and the treatment received may not reflect patients’ actual treatment goals.

DISCUSSION

This qualitative study of patients with very low-risk thyroid cancer and surgeons who treat this disease demonstrated that both patients and surgeons had an ideal decision-making process in mind whereby the patient makes the final treatment decision after weighing all options and considering the surgeon’s input. However, when discussing their experiences, this ideal often was not reached. Surgeons often did not explicitly elicit patients’ preferences and described tailoring their description of treatment options and recommendation based on their impression of patients’ anxiety and fear or their own personal biases. This process puts patients at risk of having a treatment that may not align with their actual preferences and may facilitate overtreatment.
Similar gaps in the decision-making process have been described for treatment of other malignancies where the treatment decision is preference-sensitive [25]. In a study examining 137 patients undergoing breast cancer treatment, researchers explored the desired level of patient involvement in treatment decision-making, as well as the degree to which these preferences were met. They found that 40% of patients preferred the physician to make the treatment decision, yet only 63% felt their preferred decision-making role was fulfilled. Furthermore, patients who wanted to either make their own decision or have the physician make the decision were more likely to have their preferences met compared to those who wanted to share the decision [26]. In another study assessing decision-making for treatment of prostate cancer, 49% of patients reported difficulty in making the treatment decision, and 45% experienced distress while making treatment decisions [27]. Another study of patients with early stage papillary thyroid carcinoma who underwent adjuvant radioactive iodine treatment showed that patients who perceived that their physician made the final treatment decision experienced significantly more decision regret [28]. When combined with the findings of the current study, these data suggest that better decision-making support is needed for patients with cancer who have multiple or complex management options. Improvements are needed in education about treatment options and actual elicitation and incorporation of patient preferences in the decision-making process for patients with very low-risk thyroid cancer.

Furthermore, our data show that surgeons’ perceptions of patient preferences may not be accurate. The surgeons who participated did not consistently report assessing the preferences of their patients during the decision-making process. Other studies have shown similar results in patients with other cancers. For example, in a study of patients with esophageal cancer following esophagectomy, interviews about the decision-making process demonstrated disparities between patients and their providers. Patients identified cultural beliefs, surgical cure, idealization of the specialist surgeon, and trust in expert opinion as more important than medical information. In contrast, providers emphasized the legal and ethical consent process [29]. In another study of patients undergoing breast cancer treatment for early stage disease, only 38% of patients agreed with the physician’s assessment of how the treatment decision was made [30]. These findings emphasize the need for better patient-surgeon communication and decision-making, particularly with respect to decision control and eliciting patient’s preferences.

There are many possible solutions to these issues. Decision aids and other decision support tools have been developed and used in many medical settings to facilitate the decision-making process [31, 32]. Not only can decision support tools improve patient knowledge and activation, they can be used during decision-making at the preoperative visit. In addition, decision support tools can help providers directly assess patient preferences, cultural differences, and potentially avoid assumptions like those observed in this study [32, 33]. Sawka and colleagues demonstrated these benefits in a randomized control trial of patients who either received or did not receive a decision aid to support decision making about radioactive iodine treatment in patients with thyroid cancer [28]. The decision aid improved patient medical knowledge in comparison to usual care alone and increased confidence in decision-making. A similar approach will likely facilitate decision-making preoperatively, as this is the same patient population.

Other approaches exist to support patient-surgeon decision-making. Increased psychosocial support for patients is one approach shown to facilitate the patient-provider decision-making process [34]. Ensuring adequate time with providers has also been shown to positively influence the ultimate treatment decision. Elwyn and colleagues report that adequate time allowed for shared-decision-making improved patients’ ability to process and reflect on the information received, but also provided both patients and providers more time to ask questions and build relationships [23]. Provider training in shared-decision-making can also positively impact decision outcomes [35]. These approaches have promise to improve patient-surgeon decision-making preoperatively for patients with very low-risk thyroid cancer.

While our findings demonstrate novel observations about thyroid cancer decision making, there are
CONCLUSION

In this study, we found that patient-surgeon decision-making about treatment for very low-risk thyroid cancer may fail to adequately incorporate patients’ preferences. This practice puts patients in jeopardy for undergoing unnecessary treatment that does not reflect their goals and values. Data are needed that more directly examine the actual decision-making process and measure patients’ preferences. This information will facilitate development of tailored decision support tools for patients with very low-risk thyroid cancer.

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CONFLICT OF INTEREST STATEMENT

The authors have no competing financial or other conflicts.

REFERENCES


limitations to this study. In terms of patients, selection bias may exist. The patients were all from a single institution and may have experiences that are not generalizable to other locations. The data collected from patients was also retrospective; their decision and surgical treatment had already been performed. In terms of the surgeons, many were from high-volume, academic or university-affiliated institutions across the country who self-identify as endocrine surgeons. Surgeons with different education and training backgrounds may approach decision-making differently. In addition, recruitment of surgeons was accomplished with a series of emails, flyers and snowball sampling which potentially recruited surgeons with similar biases.