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Informed Consent for AAA Repair: The Patient's Perspective

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Abstract

BACKGROUND—Although information about risks, benefits and alternatives to intervention is central to ensuring adequate informed consent, patients are often not well-informed about potential adverse outcomes when they are considering whether to have surgery. Whether or not to undergo surgery for abdominal aortic aneurysm (AAA), and whether to have open or endovascular repair (EVAR), is a complex decision that relies heavily on patient preferences, and yet little is known about the patient perspective on informed consent in this context. Understanding patients' views on their decision-making processes and the quality of surgeon-patient communication could inform improvements in informed consent for AAA repair.

METHODS—We conducted in-depth interviews with AAA patients (n=20) who underwent open AAA repair, endovascular repair, or declined surgery. Data were independently transcribed and analyzed by a team of individuals with diverse backgrounds, using the constant comparative method of analysis and systematic coding procedures.

RESULTS—We identified four central themes characterizing patients' experiences with informed consent for AAA repair: 1) some patients perceived that there was no choice regarding whether or not to have surgery; 2) some patients did not feel adequately informed prior to making a decision; 3) patients differed in the scope and content of information they desired during informed consent; and 4) trust in the surgeon had an impact on the informed consent process.

CONCLUSION—Our research highlights the limitations of the informed consent encounter in the current clinical context, and points to several ways in which informed consent could be improved. Adapting the informed consent encounter to incorporate the patient's perspective is critical in order to ensure that the decision regarding AAA repair is consistent with the patient's informed preference.

Patients with abdominal aortic aneurysms (AAAs) face a difficult decision: whether or not they should undergo surgery for a condition that is usually asymptomatic, and for which the natural history is uncertain. The decision whether to have surgery, and if so, whether to have an open repair or endovascular aneurysm repair (EVAR), relies heavily on patients' preferences.¹ In order to make decisions that are consistent with individual preferences, patients must fully understand the distinct risks and benefits of each alternative as presented during informed consent.² When patients are fully engaged in the informed consent process, they are likely to be more satisfied with their decision and may experience better outcomes.³

Studies have shown that patients are not always well-informed about potential outcomes when they consider whether or not to have surgery.^{4–9} Stanley *et al* found that 25% of patients undergoing lower extremity bypass or carotid surgery had a poor understanding of the risks and complications of the procedure,⁶ and Vohra *et al* found that only 78% of cardiac surgery patients were informed about risk.⁸ Little is known about informed consent in patients undergoing AAA repair. One study evaluating post-operative functional status found that 18%

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of patients would not have had the operation if they had understood the difficulty of the recovery process,¹⁰ suggesting that informed consent was not adequate in these patients. Although we have previously reported surgeons' opinions on the content of informed consent for AAA repair,¹¹ no prior studies have explored the patient perspective regarding the content, scope and quality of informed consent in this context.

Key to assessing the degree to which patients are making informed choices is to understand patients' perspectives regarding their own decision-making process, their perceptions as to the adequacy of the information conveyed by the surgeon, and the quality of the surgeon-patient communication process.¹² Therefore, we sought to explore how patients approach AAA decisions, including what information was important to them in making the decision and how effectively that information was conveyed during the informed consent encounter. We performed in-depth interviews with individual patients, because this approach is best-suited to explore complex phenomena that are difficult to measure quantitatively, such as individual preferences regarding surgeon-patient communication and personal reflections on decision-making processes.¹³ In contrast to quantitative studies which require large numbers of participants, in-depth interview studies generally require 20–30 participants, depending on the nature of the research question.¹⁴

METHODS

Study design and sample

We conducted a qualitative study using in-depth interviews^{14 15} with patients with AAA who had undergone open repair or EVAR or declined surgical intervention in the previous three to six months at Yale-New Haven Hospital or the West Haven VA Hospital. Consistent with established procedures for sample development in qualitative research, we drew a purposeful sample of 'information rich' participants¹⁴ from six different surgeons' practices in order to ensure representation of patients with a range of characteristics that are potentially relevant to AAA surgery decisions (gender, age, and positive and adverse outcomes from both open and EVAR). Information rich participants are those who have direct experience with the phenomenon of interest and are able to provide unique insights of central importance to the study's purpose. We asked patients whether another individual (such as a friend or family member) was present during the informed consent discussion and played a significant role in their decision-making process, and if so, the concluding segment of the interview included a supplemental interview with that individual. The final sample size was determined by the criterion of 'theoretical saturation,' or the point at which no novel concepts emerge from subsequent interviews.^{16 17} In this study, theoretical saturation was achieved upon completion of 20 interviews. The research procedures were approved by the institutional review boards at the Yale University School of Medicine and the VA Connecticut Healthcare System, West Haven Campus.

Data Collection

We collected data through in-depth interviews, a qualitative research technique designed to elicit individual perceptions and experiences through open, non-directive, questions. The interview used broad 'grand tour' questions¹⁸ to explore patient perspectives regarding the nature and extent of information desired, as well as aspects of patient-surgeon communication during informed consent. Scripted probes were used to elicit detailed narratives from participants.^{18 19} The interview guide is included in the appendix. Consistent with standard qualitative research techniques,^{14 15} the interview guide evolved as interviews progressed through an iterative process to ensure that the questions captured all relevant emerging themes.

The primary investigator (L.B.) contacted all patients by mail and then with a follow-up phone call. All interviews were conducted in person by the primary investigator. Family members were invited to participate in the interview only if they were defined by the patient to be present during the informed consent encounter and actively engaged in the decision-making process. Patients were initially interviewed alone, and family members were invited to join at the end of the session, at which time selected questions were repeated. Interviews were audio-taped and transcribed by an independent, professional service. A brief questionnaire was administered at the close of the interview to obtain demographic information.

Data Analysis

Data analysis was guided by the constant comparative method, a systematic data coding and analysis procedure.^{16,20,21} This method is an approach to analyzing qualitative data during which specific quotes from participants are categorized into themes with the use of codes developed iteratively to reflect the data. A code structure is developed initially after review of the first few interview transcripts, and as additional transcripts are reviewed, sections are constantly compared with previously coded transcripts to ensure consistent assignment of codes. This approach helps to develop and adapt the existing code structure and identify new codes to fit emerging concepts as they are identified. Following the process recommended by experts in qualitative research,²² transcripts were reviewed and coded independently by three individuals from diverse backgrounds including surgery, qualitative and health services research, and medical decision-making. All transcripts were coded independently, and then in group sessions to resolve discrepancies through discussion until we reached consensus. We used Atlas software (ATLAS.ti, 5.0) to assist with management, coding, and analysis of data.²³ We systematically reapplied the final code structure to all transcripts to articulate common themes to describe the patient perspective on AAA informed consent.

RESULTS

Out of the 22 patients who were initially contacted for interviews, 20 agreed to participate. The characteristics of interview participants are shown in Table 1. Participants ranged in age from 59 to 90, and the vast majority was male. Most participants were married and retired. There were 12 patients who had open repair, 8 who had EVAR, and 1 who declined surgery. A total of 7 patients reported experiencing a complicated post-operative course. A complicated post-operative course was defined as having a complication which led to a prolonged hospital or ICU stay and substantially impacted overall recovery. Examples of such complications include wound infection requiring readmission for wound exploration and home care upon discharge, myocardial infarction leading to prolonged ICU stay and recovery, and femoral artery pseudoaneurysm after EVAR requiring open reintervention.

We identified 4 central themes (Table 2) that characterize how patients with AAA experienced the informed consent process: 1) some patients perceived that there was no choice regarding whether or not to have surgery; 2) some patients did not feel adequately informed prior to making a decision; 3) patients differed in the scope and content of information they desired during informed consent; and 4) trust in the surgeon had an impact on the informed consent process.

Theme #1: Some patients perceived that there was no choice regarding whether or not to have surgery

Some patients described feeling that there was no choice regarding whether or not to have surgery for their AAA. Upon learning about their diagnosis, they were terrified by the consequences of refusing surgery and saw surgery as their only option. For example, a 67 year-old man who had an open repair described his approach to the decision as follows:

“There was no other option other than the surgery. It was either that or live on a daily basis knowing that you could die at any second, and you can’t live that way.”

- Interview #3

Participants’ opinions were often based on misperceptions about potential precipitants of rupture, or lack of knowledge of the risks related to the intervention. An example of the former is this 70-year-old female who had an open repair and mistakenly believed that her regular daily activities might lead to rupture of the aneurysm:

“I felt like all of a sudden I was going to bump into something, I’m just going to bleed out like a stuck pig, and it was terrifying.”

- Interview #7

Underestimation of the risks of surgery was also expressed by some patients. When asked about the risks associated with surgery, this 67-year-old who had open surgery responded:

“The risks? They told me they were minimal.”

- Interview #20

The patients who linked likelihood of rupture to individual behavior tended to lack understanding of the risks related to surgery. For instance, a 73-year-old man who had open repair said:

“We felt like we’re walking on eggshells for fear the thing would burst.”

When asked about the risks of surgery, he responded: “I don’t know. I said, hey, I got to have it done.”

- Interview #17

In contrast, other patients did perceive having a choice regarding surgery. An 82-year-old man who had an EVAR described his decision-making process and interaction with his surgeon as follows:

“He painted the picture very clean. He left me the choice to make. He told me the choices. He did not hold anything back. I could have refused the surgery. He would not have said anything. He would have let it go and he still treated me until it broke I guess. He did not pressure me at all.”

- Interview #5

However, even in this case where the patient did perceive a choice, he nonetheless lacked understanding of the risks related to surgery as illustrated by this response:

“[Surgery is] not really a risk. The risk was if I did not have it done.”

- Interview #5

Theme #2: Some patients did not feel adequately informed prior to making a decision

Patients did not always feel adequately informed prior to making a decision regarding intervention. Some patients wanted to better understand the magnitude of risk associated with surgery and how risks could vary according to comorbidities, as illustrated by this 72 year-old man who had an open repair.

“I was thinking well maybe I could have known what the odds say of waking up... Maybe I could have asked more questions along that line... In other words, the fact that something could happen when I was on the table ... that risk part of it, my age, and the fact that I am being treated for a heart condition.”

- Interview #4

Other patients indicated they did not know what to expect, as demonstrated by this 82-year-old EVAR patient's response when asked about his understanding of the risks associated with surgery:

“The heart doctor explained that because I have a blocked artery here so they might have to open an artery someplace up in here (points to neck) and go in to keep blood flowing to the brain. They had me pretty confused by the day I went in.”

- Interview #5

Similarly, this 59-year-old man was unprepared for his prolonged hospital course after having open surgery:

“All I knew is, I thought I'd wake up and it would be recovery, you know, surgery, abdominal surgery, and then it seemed like a complicated thing. I was very confused because I was intubated for a week so I was out of it for a week so I was hallucinating a lot. Not in a horrible way but like I didn't really know what was going on. And I was asking [my wife], like, how did I get here. Like what's this all about?”

- Interview #19

Some patients wanted to know about the technical aspects of surgery, for example this 68-year-old man who had an EVAR:

“I think if I would have understood, in fact I still don't understand what they did... did they go in through groin, through the artery? I have no idea how they could repair the damage, or the aneurysm. I don't know how they did it. Technically, I'm sure that, you know, that's a doctor's point of view, but if there was something that would explain in more laymen's terms you know, what the procedure would be or how they did it. It may have made you feel a little bit more understanding... the not knowing what's going on is kind of difficult to handle. You lay there and say hmm... what's happening?”

- Interview #10

Others did feel adequately informed before undergoing surgery, as illustrated by the following quote:

“He took it from step one all the way through to the final step. He told us the risks, the benefits, and what the operation would consist of. He was very thorough.”

However, even though this patient perceived that he was well-informed, he did not actually have a good understanding of risk, as illustrated by this exchange:

Interviewer: “Do you remember what the surgeon told you about the possible complications of the procedure?” Interviewee: “No. He did not seem to think there was going to be any.”

- Interview #2

There were significant consequences when patients did not feel fully informed. Some patients opted out of the decision-making process because they did not feel that they had enough information to be able to actively participate:

“Not being really knowledgeable of what the heck this all was all about I just put myself in their hands really because I didn't know what to ask.”

- Interview #6

Other patients expressed regret regarding their decision to undergo surgery, as they were unaware of a potential adverse outcome that they ultimately experienced. For example, one patient who underwent EVAR described his dissatisfaction and questioned whether he should have had surgery in the first place:

“Seven and a half hours on the operating table is not much pleasure and then I don’t move my leg for six hours. There was a lot of stuff that I went through. I don’t know if it was worth any of it but as I sit here right now, the trouble I’ve gone through, I question whether it was worth it or not.”

- Interview #11

Theme #3: Patients differed in the scope and content of information they desired

Patients expressed a broad range of preferences regarding the scope and content of the information they desired. Some patients wanted to know extensive details about each of their options and the risks associated with each option. The following quote is from the wife of a patient who desired full disclosure:

“There are some people that don’t want to know anything. They don’t want to know what your insides look like. We wanted to know everything. Where it was. What connected to what.”

- Interview #1

This patient commented that being informed helped him prepare for the surgery and thus decreased his anxiety:

“I remember leaving here, being in the house and going into the hospital, and I did not have any of that anxiety like I did prior to January 10th coming. You know what I mean? We were getting in the car, we were going and I felt fine. I knew what was going to go on.”

- Interview #1

In contrast, other patients preferred less information, and in some cases chose to delegate the role of engaging in the informed consent process to a family member. For example, one 71 year-old man who had open repair stated:

“At the time I really didn’t want to know too much about [the risks of surgery] ... Now my daughter was pretty good. My daughter was there and, and there were some conversations that I didn’t hear that they might have had. As a patient I was probably better off not knowing all those things like, you know, you’re going to have dialysis.”

- Interview #6

This same patient’s daughter also noted the importance of having support from family members during the informed consent process:

“That’s where the extra pair of ears and eyes come into the scenario. You need somebody else, so it isn’t as stressful. You’ve got all this information coming at you and I think it’s important to have someone, whether it be a patient advocate or a family member or someone you know, to not be alone for something like that.”

- Interview #6

Theme #4: Trust had an impact on the informed consent process

Patients' trust in their surgeon was an important concept which was discussed by almost all participants. There was variation in whether or not trust was present in the relationship, how it evolved over time, and how it impacted informed consent.

In some cases patients expressed that their trust in the surgeon had been established prior to the informed consent encounter, after doing background research on the qualifications and reputation of the surgeon:

“We had done a lot of research before we ever went to [the hospital] and knew that [the surgeon] had a fabulous reputation. He had done a lot of the surgeries and that it was our philosophy that the person that had done three thousand versus three is where you want to get your experience. This is the kind of hospital that does a lot of this kind of surgery. They have the best equipment, the best trained people. So that goes a long way to helping you make your decision.”

- Interview #1

Other patients' trust in the surgeon developed through the interpersonal interactions that occurred during the informed consent process:

“I could see it in their eyes that they were concerned and they were, you know, they looked genuine, they had a genuine concern.”

- Interview #15

“He explained what he would do if it were his own father, so I felt more comfortable with that because a lot of times I don't think doctors give you that aspect.”

- Interview #17

In some cases, trust evolved as a result of effective communication of risks related to surgery:

“Number 1, I trusted the doctor. I had faith in him and he would tell you point blank. He explained everything and made me come back 2 or 3 times before it was done.”

- Interview #2

“I would have liked them to say, it's going to work and I'm going to come out this thing, you know, but they did the honesty thing. Told me the truth and I appreciated that.”

- Interview #12

In contrast, other patients' trust resulted from the surgeon's confidence that the outcome of the surgery would be positive, as opposed to disclosure of the possibility of adverse events:

“The doctor was a big factor in how he treated me and the way he explained it to my family and to me and gave me an assurance that everything was going to be okay. He didn't look down at me and say ‘Oh well you know this is going to be a serious surgery,’ he said ‘We're going to fix you up. Don't worry about it. Everything is going to be fine,’ and I kind of got the confidence in him that he was going to be able to do the job.”

- Interview #10

Trust had an unexpected impact on the patient's role in informed consent. Some patients suggested that because they trusted their surgeon, they chose defer to the surgeon during the informed consent discussion:

“I just left it in their hands. I’m that kind of a person anyway. I have faith in them, you know?”

- Interview #15

Patients who expressed lack of trust in the surgeon described feeling threatened or pressured:

“I think that I felt threatened when [he said], ‘hey if you don’t do it now it might be too late later.’ Well that’s a threat, isn’t it? ... I checked on the computer to see what experiences other people have had and other [aneurysms] growing and stuff like that, and I felt that they were rushing me.”

- Interview #11

“This other surgeon was going to jump right in and put that thing in there... this turkey did not even look to see that I had the blocked artery.”

- Interview #5

DISCUSSION

This is the first study we are aware of which has investigated the patient’s perspective on informed consent for AAA surgical repair. Using established research procedures^{14–16} for data collection and analysis, we characterized how patients approach AAA treatment decisions and identified areas of potential deficit in the nature, scope and communication of information during informed consent that can be targeted for improvement.

We found that many patients perceived that they had no option other than surgery. This is not necessarily surprising given the life-threatening nature of the diagnosis of an AAA. Some patients learned about their aneurysm, felt that they had a “ticking time bomb” inside them, and decided that they would pursue whatever intervention was required to fix it, regardless of risk, since the alternative (risk of rupture) was unacceptable. Some patients mistakenly believed that they had to “walk on eggshells” so as not to precipitate rupture, which led to an unfounded sense of urgency in their approach to the decision about surgery. Many patients, such as those who have had a family member or friend die of a ruptured aneurysm, make the decision to have surgery even before they begin the informed consent discussion with their surgeon. This may make it difficult for surgeons to explain that non-intervention may be a reasonable course of action for patients who are unlikely to outlive their aneurysms, have a high risk of developing a serious complication, or are more likely to experience long term disability following surgery.

We found that patients had a poor understanding of the potential risks related to surgery. Studies that have quantitatively examined the information that patients recall after informed consent for laparoscopic cholecystectomy,³ CABG,⁴ joint replacement,⁷ and other vascular procedures⁶ have found similar gaps regarding knowledge about risk. In all studies of informed consent, lack of knowledge may be related to poor recall, but in the case of AAA, it is also possible that patients who have already made a decision to have surgery are less likely to be open to hearing information about potential complications. This hypothesis is supported by the minimization or complete dismissal of risk that was verbalized during the interviews, as well as the surprise and disappointment voiced by those who had experienced adverse events.

Some patients consented to having AAA repair because of misperceptions related to the consequences of not having surgery, while others consented without appreciation of the risks related to either open or endovascular repair. As a result, adverse outcomes were met with surprise and even regret. Part of reshaping the informed consent encounter so that patients can make truly informed choices includes effectively communicating information about potential adverse outcomes.

The importance of open exchange of information during informed consent should be interpreted with caution, as we found that there was substantial variation in the amount of information desired by individual patients prior to making a decision. Some patients said that hearing about risks related to surgery increased their anxiety, while others felt that knowing more helped them prepare for their surgery. It is difficult to convey information about risk and non-intervention when patients are experiencing high levels of anxiety about their diagnosis, and their only priority is to have the aneurysm repaired. In these fairly unique circumstances, patients may be unable to process complex information about their options and formulate appropriate questions. In many cases, family members were felt to be invaluable participants in the informed consent process, as they were able to provide support and process information when patients were overwhelmed by the stress of the situation. It is important for surgeons to communicate a certain baseline amount of information to patients and family members so that they can make an informed decision, but do not feel overwhelmed, and to be able to tailor the amount of information provided to an individual patient's preferences.

Informed consent can be seen as an opportunity for surgeons to gain the trust of their patients. Our participants described several ways in which their trust in their surgeon evolved, both prior to and during the informed consent encounter. During informed consent, some patients expressed trust related to the openness with which information was provided to them, and others appreciated being sheltered from information and reassured by the surgeon that "everything was going to be okay."

Patients' level of trust had important implications regarding their role in the informed consent process. Some patients stated that because they trusted their surgeon, they required less information. In contrast, other patients who expressed a lack of trust in their surgeon frequently chose to seek more information through a second opinion. This inverse relationship between degree of trust and preference for information is not necessarily intuitive, but it has been described in other studies.^{24,25} Although it is essential for surgeons to gain patients' trust during informed consent, it is important to be aware that patients' trust in the surgeon may lead to a decreased desire for information which can result in inaccurate expectations and dissatisfaction with outcomes.

We designed this study in order to explore patients' perspectives on the AAA decision-making process and generate hypotheses about how this process might be improved. We interviewed patients from private and academic practice settings, with a broad age range and complicated and uncomplicated postoperative courses in order to create a sample diverse in characteristics potentially relevant to patients' views on AAA informed consent. All but two patients who were approached for an interview agreed to participate. We used several recommended strategies to ensure candid responses, including conducting the interviews in person, in locations and at times determined by the patient, and using specific techniques for in-depth interviewing. We also used several recommended strategies to ensure the reliability of the data, including use of an interview guide and independent transcription service, standardized coding and analysis of data, and maintenance of an audit trail to document analytic decisions.²⁶ However, findings should be considered in light of several limitations. All of the patients who were interviewed were seen by one of six surgeons and were treated at one of two hospitals, so these findings may not apply to patients in other settings. This qualitative study is intentionally descriptive in nature, proposing themes that characterize the experiences of patients contemplating AAA repair. Further quantitative studies are needed to determine the prevalence of views expressed in these interviews among patients at large, or to make associations between patient characteristics such as age, gender, or level of education and patient views.

CONCLUSION

In summary, we found that many of the patients who were interviewed perceived that they had no choice as to whether or not to have elective AAA repair. In addition, to some extent, all patients interviewed in this study lacked full understanding of the potential adverse outcomes of intervention. Our findings suggest that there is a need to better educate patients about the nature of the diagnosis of AAA and their surgical options so that they can make an informed choice, not only about whether or not to have surgery but also whether to have open or endovascular repair. The themes that were raised in these interviews point to several ways in which this education might be achieved during informed consent.

First, patients' misperceptions about the nature of death from a ruptured aneurysm should be corrected, and the sense of urgency removed from the decision. Second, a baseline amount of information about the risks of intervention should be communicated clearly and consistently, with the flexibility of providing more information as desired by the patient. Open communication about risk not only adheres to the principles of informed consent but also may build patients' trust in their surgeon. Finally, family members should be engaged when possible to help with information-processing. Adapting the informed consent encounter to incorporate the patient's perspective is critical in order to ensure that the decision regarding AAA repair is consistent with the patient's informed preference.

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References

1. Brewster DC, Cronenwett JL, Hallett JW Jr, Johnston KW, Krupski WC, Matsumura JS. Guidelines for the treatment of abdominal aortic aneurysms. Report of a subcommittee of the Joint Council of the American Association for Vascular Surgery and Society for Vascular Surgery. *J Vasc Surg* 2003;37(5):1106–17. [PubMed: 12756363]
2. Beauchamp, T.; Childress, J. *Principles of Biomedical Ethics*. 5. New York, NY: Oxford University Press; 2001.
3. Whitney SN, McGuire AL, McCullough LB. A typology of shared decision making, informed consent, and simple consent. *Ann Intern Med* 2004;140(1):54–9. [PubMed: 14706973]
4. Kriwanek S, Armbruster C, Beckerhinn P, Blauensteier W, Gschwantler M. Patients' assessment and recall of surgical information after laparoscopic cholecystectomy. *Dig Surg* 1998;15(6):669–73. [PubMed: 9845634]
5. Mishra PK, Ozalp F, Gardner RS, Arangannal A, Murday A. Informed consent in cardiac surgery: is it truly informed? *J Cardiovasc Med (Hagerstown)* 2006;7(9):675–81. [PubMed: 16932081]
6. Stanley BM, Walters DJ, Maddern GJ. Informed consent: how much information is enough? *Aust N Z J Surg* 1998;68(11):788–91. [PubMed: 9814743]
7. Turner P, Williams C. Informed consent: patients listen and read, but what information do they retain? *N Z Med J* 2002;115(1164):U218. [PubMed: 12552294]
8. Vohra HA, Ledsham J, Vohra H, Patel RL. Issues concerning consent in patients undergoing cardiac surgery—the need for patient-directed improvements: a UK perspective. *Cardiovasc Surg* 2003;11(1):64–9. [PubMed: 12543575]
9. Braddock CH 3rd, Edwards KA, Hasenberg NM, Laidley TL, Levinson W. Informed decision making in outpatient practice: time to get back to basics. *Jama* 1999;282(24):2313–20. [PubMed: 10612318]

10. Williamson WK, Nicoloff AD, Taylor LM Jr, Moneta GL, Landry GJ, Porter JM. Functional outcome after open repair of abdominal aortic aneurysm. *J Vasc Surg* 2001;33(5):913–20. [PubMed: 11331828]
11. Berman L, Dardik A, Bradley EH, Gusberg R, Fraenkel L. Informed consent for AAA repair: Assessing variations in expert opinion through a national survey. *Journal of Vascular Surgery*. in press
12. Kasper JF, Mulley AG Jr, Wennberg JE. Developing shared decision-making programs to improve the quality of health care. *QRB Qual Rev Bull* 1992;18(6):183–90. [PubMed: 1379705]
13. Malterud K. The art and science of clinical knowledge: evidence beyond measures and numbers. *Lancet* 2001;358(9279):397–400. [PubMed: 11502338]
14. Patton, M. *Qualitative Research and Methods*. Thousand Oaks, CA: Sage Publications; 2002.
15. Britten N. Qualitative interviews in medical research. *Bmj* 1995;311(6999):251–3. [PubMed: 7627048]
16. Glaser, BG.; Strauss, AL. *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine; 1967.
17. Morse J. The significance of saturation. *Qualitative Health Research* 1995;5(2):147–149.
18. Crabtree, B.; Miller, W. *Doing Qualitative Research*. 2. Thousand Oaks, CA: Sage Publications; 1999.
19. Merton, RK.; Fiske, M.; Kendall, P. *The Focused Interview: A Manual of Problems and Procedures*. Glencoe: Free Press; 1990.
20. Miles, MB.; Huberman, AM. *Qualitative Data Analysis: An Expanded Sourcebook*. 2. Thousand Oaks, CA: Sage Publications; 1994.
21. Strauss, AL.; Corbin, J. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. London: Sage Publications; 1998.
22. Bradley EH, Curry LA, Devers KJ. Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health Serv Res* 2007;42(4):1758–72. [PubMed: 17286625]
23. Muhr, T. *User's Manual for ATLAS.ti. 5.0* [computer program]. Version 5. Berlin, Germany: Scientific Software Development GmbH; 2004.
24. Fraenkel L, McGraw S. What are the essential elements to enable patient participation in medical decision making? *J Gen Intern Med* 2007;22(5):614–9. [PubMed: 17443368]
25. Kraetschmer N, Sharpe N, Urowitz S, Deber RB. How does trust affect patient preferences for participation in decision-making? *Health Expect* 2004;7(4):317–26. [PubMed: 15544684]
26. Mays N, Pope C. Rigour and qualitative research. *Bmj* 1995;311(6997):109–12. [PubMed: 7613363]

Appendix: Interview guide

We asked questions 1 through 9 with the patient alone, then we repeated questions 5 through 9 with family present. For patients who declined surgery, we skipped questions 7 and 8.

1. When you found out you had an aneurysm, what did that diagnosis mean to you?
2. What did you think your options were at that time?
3. After meeting with the surgeon, what did the diagnosis mean to you?
4. What did you think your options were at that time?
5. Please tell me a little about what it was like for you talking to the surgeon.
6. How much information did you feel that you needed to be able to make a decision about whether or not to have the operation?
7. Once you had made the decision, how did it make you feel to hear about the risks of the surgery?
8. Looking back on your experience of having the operation and recovering from it, is there anything that happened to you that you were not prepared for?

9. What would you tell someone who was trying to decide if they should have this operation?

Table 1
Participant characteristics

Characteristic	Number (%)
Gender	
Male	17 (85%)
Female	3 (15%)
Type of surgery	
Open repair	11 (55%)
EVAR	8 (40%)
Declined surgery	1 (5%)
Education	
Less than high school	4 (20%)
High school	9 (45%)
College	4 (20%)
Graduate/professional school	3 (15%)
Marital status	
Single	1 (5%)
Married	13 (65%)
Separated/divorced	3 (15%)
Widowed	3 (15%)
Employment status	
Employed	3 (15%)
Retired	16 (80%)
Disabled	1 (5%)
Surgeon practice setting	
Academic	7 (35%)
Private practice	3 (15%)
VA	10 (50%)
Interview participants	
Patient alone	10 (50%)
Patient with family	10 (50%)
Post-operative course	
Complicated	7 (37%)
Uncomplicated	12 (63%)

Table 2
Themes and Sub-themes

1. Some patients perceived that there was no choice regarding whether or not to have surgery. Those who perceived they did not have a choice often had misperceptions related to the natural history of an AAA and the risks of surgery.
2. Some patients did not feel adequately informed prior to making a decision. Being inadequately informed had consequences ranging from opting out of the decision-making process to regret about the choice that was made.
3. Patients differed in the scope and content of information they desired. Family members played an important role in obtaining and processing information.
4. Trust had an impact on the informed consent process. Trust in the surgeon evolved in the context of disclosure of surgical risk as well as reassurance that the surgical outcome would be positive. Patients who expressed trust in the surgeon required less information and tended to defer to the surgeon in the decision-making process.