Complex aortic aneurysm management: from technical outcomes to patient-centered insights

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PART 3

Lessons learned fr interviews and pat regarding aortic a

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CHAPTER 5

Perspectives of pat professionals on p complex endovasc

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ABSTRACT

Objectives

Misinterpretation of patient preferences in perioperative education can lead to an undesired treatment decision. This explorative interview study presents differences in perspectives of patients and professionals on patient education in complex endovascular aortic aneurysm management.

Methods

Using convenience sampling, a cross-sectional interview study was performed among patients who were in various stages of the decision-making process for complex endovascular aortic repair. Five physicians were interviewed, representing the main providers of clinical information. Interviews were transcribed verbatim and analyzed inductively.

Results

Twelve patients (mean age 76.6 (SD: 6.4), 83% male) were interviewed. Ten (83%) felt like they had no other realistic option besides undergoing surgery, whereas all professionals (5/5) stressed the importance of delicate patient selection. Five patients out of 10 (50%) who commented on their preferred decisional role, considered the professional's advice as decisive. All but one patient (11/12) reported that the information was easy to understand, whereas four out of five professionals (80%) doubted whether patients could fully comprehend everything. Patients experienced a lack of information on the recovery process, although professionals stated that this was addressed during consultation.

Conclusions

Several differences were found in the perspective of patients and professionals on information provision in complex aortic aneurysm management. In order to optimize patient involvement in decision-making, professionals should be aware of these possible discrepancies and address them during consultation. Future research could focus on these differences in more detail, by including more patients in different treatment- and decision stages.

INTRODUCTION

Since the publication of *Charles et al.*, shared decision-making has been embraced as the preferred model of decision-making in healthcare.[1] Involving the patient in decision-making and discussing patient-specific treatment preferences minimizes the risk of a so-called 'preference misdiagnosis', which can potentially lead to an undesired treatment decision.[2-3] This is particularly important when there are multiple treatment options, each with their pros and cons, without one necessarily being superior.[4]

In vascular surgery, complex aortic aneurysm management is such a subject par excellence.[5] Complex aneurysms contain visceral side branches that need to be preserved during treatment, in order to maintain blood flow to their target organs. Although cut-off points vary, the yearly risk of rupture is generally considered to exceed the risk of non-emergent surgery once a complex aneurysm reaches 6.0 cm.[6] Previously, open repair (OR) was the only modality of treatment, which is often ill suited for frail patients. Building on experience in conventional aneurysm management, complex endovascular aortic repair (complex EVAR) was developed as a less invasive treatment option.[7] This requires far smaller incisions, has less hemodynamic impact, and lower short-term mortality. Nonetheless, it is still associated with considerable risks, requires life-long surveillance, and carries higher surgical risks compared to conventional EVAR.[8-14] A third option would be not to treat the aneurysm and choose a conservative approach.

The introduction of complex EVAR not only provides surgical challenges, but challenges in patient education as well. Frailer patients for whom different considerations might be relevant are considered for surgery, and this highly technical procedure needs to be explained in an understandable manner. Previous research has highlighted challenges that may arise during patient-involvement in decision-making for conventional aortic aneurysm surgery, such as the lack of feeling involved (*Santema et al.*), or an inadequate understanding of complications after surgery (*De Mik et al., Jones et al.*).[15-17] Our explorative interview study aims to present potential differences in perspectives of patients and professionals on patient education in *complex* endovascular aortic aneurysm management. In addition, we aim to visualize the care pathway of complex EVAR patients in our institution by constructing a patient journey.[18] The aim is to improve medical professionals' understanding of the decisional process the patient goes through. Recommendations will be provided, aiming to improve the perioperative information provision and patient satisfaction.

METHODS

Design

This is a cross-sectional explorative interview study, performed at the department of vascular surgery in the Leiden University Medical Center (LUMC). Ethical approval was obtained from the local medical ethics committee (protocol number: N20.174), and written informed consent was obtained from all interviewees.

Current information provision

Currently at the LUMC, when patients are diagnosed with a (non-emergent) complex aortic aneurysm, they are referred to a vascular surgeon. Depending on aneurysm size, a surveillance plan is drafted. Once the aneurysm reaches or approximates the treatment threshold of 6.0 cm, the treatment modalities are discussed in further detail. As of 2017, complex aneurysm patients are routinely referred for geriatric, physical, and dietetic screening. The goal is to disclose possible indicators of frailty and to identify targets for (p)rehabilitation. Thereafter, the patient is discussed in a multidisciplinary meeting, in which a patient-specific provisional treatment plan is drafted. Participants in this meeting are vascular surgeons, interventional radiologists, thoracic surgeons, and anesthesiologists. The outcome of this meeting is discussed with the patient, and the patient is given approximately two weeks to deliberate. Additional appointments are made at the patient's request, and each patient is provided with a printed informational folder.

Study population

Patients for whom complex EVAR was considered and patients who had already undergone complex EVAR were invited to participate in the study. Patients were selected using convenience sampling. This often-used method is a form of non-probability sampling, which consists of including patients that are easily accessible in the clinical setting.[19] To determine sample size, thematic saturation was aspired. At the start of our study, it was not clear how many patients would need to be included. The initially envisioned patient sample size consisted of fifteen patients, based on previous research.[20] Inclusion came to a halt when coding of the interview transcripts showed that no new thematic insights arose, which meant that including more patients was not expected to provide additional information on the subjects of interest. Saturation was reached after interviewing twelve patients and inclusion was ended.

The character of our study is explorative. Therefore, we included patients in different stages of the treatment- and decision-making process in order to create a broad view. To explore the professional's view on patient education and information provision, five medical professionals were interviewed. They represent the main stakeholders of complex EVAR education in our institution: three vascular surgeons (working at the LUMC and the affiliated HagaZiekenhuis hospital), one interventional radiologist, and

one geriatrician. Because of the limited number of professionals involved in information provision on complex aneurysm management, saturation was not aspired.

Interviews

Semi structured interviews were conducted by author FO. Semi structured means that a framework of questions (Appendix A and B) was used, but interviewees themselves eventually directed the topics that were discussed. Due to the leading role of the interviewee and our inductive approach, not every question was featured in each interview. Prior to the interview, patients received an introductory booklet via (e-) mail, to provide a better understanding of what the interview would entail. Baseline characteristics such as age, gender and comorbidities were obtained from patients' medical records. It was estimated that interviews would last approximately 60 minutes, but no time limit was set in advance. All interviews were recorded using a recording device provided by the LUMC. Data were stored using a secured server in the LUMC.

Coding and analysis

Audio recordings were transcribed verbatim. To ensure anonymity of the interviewees, authors that were involved in patient care did not listen to the audio tapes, nor did they read the interview transcripts, except for the (translated) anonymous quotes included in this manuscript. Transcriptions were coded inductively, using Atlas.ti as supporting software. Codes were analyzed into groups, which were divided into themes. Subsequently, themes were categorized. This was performed based on consensus agreement between two researchers (WW and FO).[21-23] Our coding focused on the interviewees' perspectives on three main themes in the interview framework, but was not limited to these subjects.

Patient journey

To visualize the care pathway of complex EVAR patients in our institution, a patient journey was constructed. Patient journey mapping is a commonly used method in human-centered design engineering (customer journey), but is relatively new in health care.[24] It combines several methods in order to best understand the patient experience. Our patient journey was created based on the interviews, combined with additional observations during visits at the outpatient clinic, and the standard elements of the complex aortic aneurysm care pathway. Data were analyzed using the process mapping approach, in which these elements are combined to depict the patient experience in consecutive steps of events. It includes the key informants, channels of information, considerations of patients and professionals, and emotions involved. [25-26]

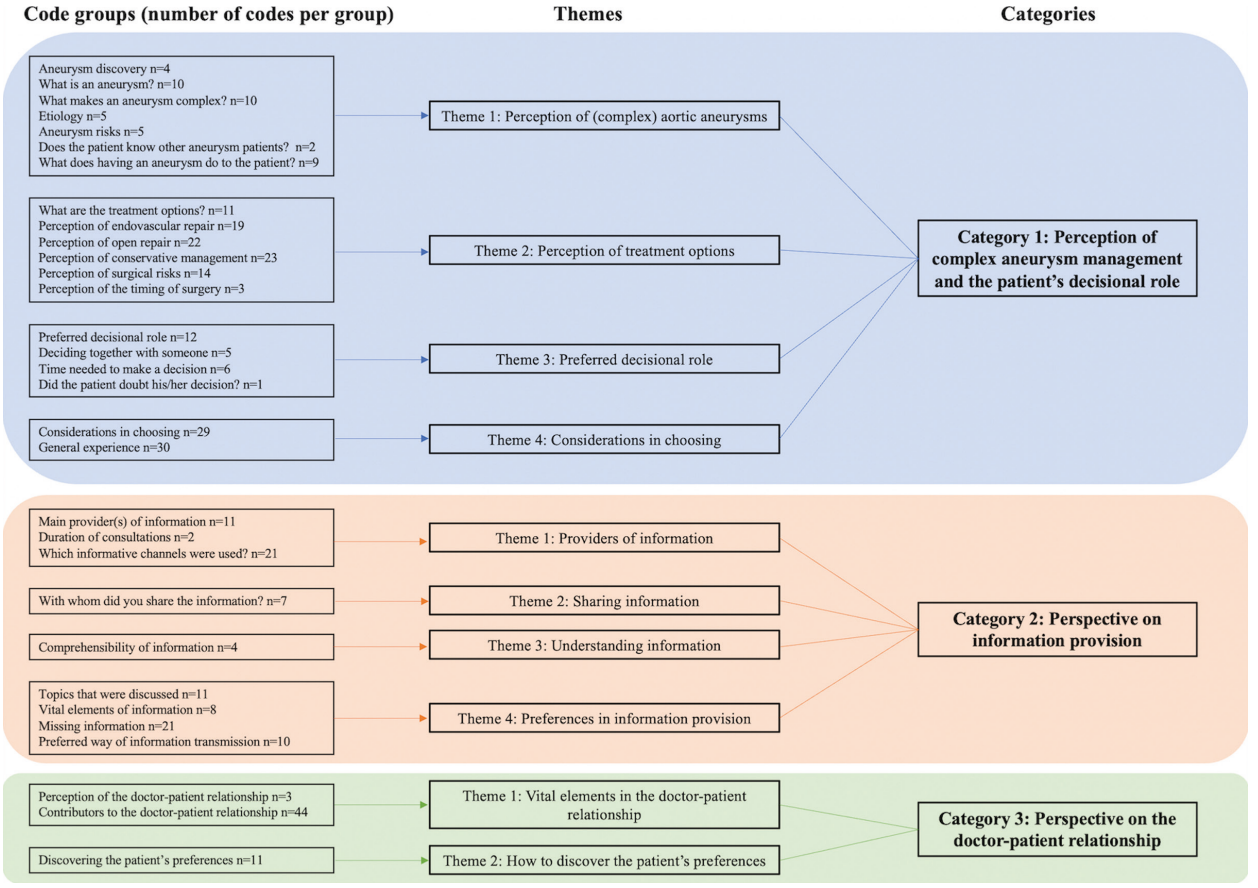


Figure 1: Coding tree of the patient-centered interviews.

RESULTS

Demographics and coding

Table 1a and 1b show the patient-specific and baseline characteristics of the twelve patients, including timing of the interview. Mean age was 76.6 (SD: 6.4), and 83% of participants was male. At the time of the interview, four patients were still scheduled to undergo complex EVAR, and for one patient the treatment modality had not yet been decided. One patient chose conservative management. Patient interviews lasted between 32 and 77 minutes, with a mean duration of 55 minutes (SD: 13.2). One patient interview was conducted by phone, all other interviews were performed face-to-face. One interview was performed in English, all other interviews in Dutch. Six patients were accompanied by their partner, one by his son, and one patient brought a friend. For the patient interviews, 366 codes were analyzed into 31 code groups, which were divided into ten themes. Subsequently, themes were categorized into three categories. Figure 1 shows the coding tree for the patient interviews.

The patient perspective

Category 1: Perception of complex aortic aneurysms and management

Theme 1: Perception of complex aneurysms

When asked to define an aneurysm, patients described a 'broadening', 'enlargement', 'widening', and 'bulging' of the aorta or 'the body's main artery'. Five participants (42%) knew other aortic aneurysm patients. Patients commented on the complex configuration of their aneurysm by mentioning that the surgeon had to make side branches to the kidneys and the intestines, and by stating that the stent had to be custom-made. When asked about the potential causes of an aneurysm, patients considered hypertension, hypercholesterolemia, 'calcification', and smoking as contributors. In eight out of the ten non-emergent patients, the diagnosis caused (great) feelings of fear, due to the potential risk of rupture (*Quote 1, Table 2*). Two patients mentioned that it felt like living with a 'time bomb' which could go off at any time.

Theme 2: Perception of treatment options

One patient chose not to undergo surgery. Only one other patient considered the option of not undergoing surgery and awaiting the natural course of the aneurysm. All other patients (10/12, 83%) did not consider the conservative approach as a realistic option.

All patients considered the open procedure as more invasive compared to endovascular repair. Three patients regarded open repair as an old-fashioned procedure (*Quote 2*), and one partner thought that open repair was always the secondary choice of treatment (*Quote 3*). Patients perceived various disadvantages of open repair compared to endovascular surgery: longer hospital stay, extensive recovery time, a larger wound, and a higher risk of complications. Patients mentioned cardiac complications, pneumonia, infection, ending up in a wheel chair, brain damage due to embolisms, and 'leg

problems'. One patient considered it an advantage of open repair that doctors are more experienced with this procedure. Although all patients considered the endovascular procedure to be less invasive, they did mention several surgical risks: kidney failure, spinal cord injury, paralysis, and 'scars inside the body' instead of a large skin incision. Four patients added that the risks of such complications were small (*Quote 4*).

Theme 3: Preferred decisional role

Ten patients commented on their preferred decisional role in the decision-making process. Five patients (50%) wanted the doctor or the medical team to make the treatment decision regarding when and how to treat the complex aneurysm (*Quote 5*). One of these patients wanted to be involved, but considered the decision of the vascular surgeon as decisive. Four patients appreciated that they were able to decide together with their doctor (40%). Two of these patients added that they felt relieved when the surgeon seemed to agree with their decision to undergo complex EVAR. One patient (10%) presented with the decision between surgical or conservative treatment claimed that patients need to decide for themselves, because a doctor cannot be burdened with this responsibility (*Quote 6*).

Theme 4: Considerations when choosing

The patient who chose conservative management considered himself unfit for surgery. For other patients, the main reasons for not considering conservative treatment were the will to live (n=6, *Quote 7*) and not wanting to live with the fear of possible rupture (n=7). One patient described that he felt like he could take control over the situation by deciding to undergo surgery, even though the outcome could be bad (*Quote 8*). When presented with the fact that complex aneurysm surgery can lead to serious complications, six patients put this into perspective by stating that any surgical procedure carries risks. In addition, for five patients the feeling of being fit enough to successfully undergo a surgical procedure played a role. Main concerns with undergoing surgery were: not wanting to end up in a nursing home, not wanting to become disabled, and being scared of losing independence.

Category 2: Perspective on information provision

Theme 1 and 2: Providing and sharing information

Table 3 shows by whom information was provided and with whom information was shared.

Theme 3: Understanding information

Only one patient mentioned that he did not understand all information (*Quote 9*), without further explaining why. For all other patients (11/12, 92%), the information on complex aneurysm management shared by the medical professional was easy to understand. However, two patients remarked that doctors should avoid using medical jargon (*Quote*

10). All nine patients that commented on the length of the consultations were satisfied with the duration of the conversations and felt no rush during appointments.

Theme 4: Preferences in information provision
The main subjects of interest for patients were the potential surgical risks, although four patients stressed that they did not want to know every detail. Other subjects of interest were: the aneurysm growth rate, length of hospital stay, necessary medication, and the success rate of the procedure. Two participants emphasized that doctors are inclined to inform the patient about possible complications, in order to avoid accusations or legal claims. When asked about preferred channels of information provision, in addition to the consultations with their doctor, seven patients commented that the informational folder was a positive contribution. Seven patients thought that a drawing they received, clarified their understanding of the aneurysm.

Patients were asked whether any information was lacking during or after the decision-making process. Four patients would have wanted to receive more information about the recovery process. They encountered unexpected complaints such as skin numbness, muscle weakness, and long-lasting fatigue. One patient mentioned he would have liked an additional appointment between making the decision to treat and the surgery itself, to discuss possible insecurities that might arise during this time. Additional subjects patients wanted to receive more information about were: updates about the planned date of surgery, what to expect after deciding not to undergo surgery, and information about parking facilities and route directions at the hospital.

Category 3: Perspective on the doctor-patient relationship
Theme 1: Vital elements in the doctor-patient relationship
All patients were satisfied with the doctor-patient relationship (12/12, 100%). Patients and their accompaniment mentioned 44 elements that, in their experience, contributed or could contribute to a successful doctor-patient relationship. Codes that were mentioned twice or more are included in Table 4, with corresponding quotations.

Theme 2: How to discover the patient's perspective
Eight participants commented on exploring the patient perspective. One patient thought it was not possible for a doctor to investigate patient preferences and felt like this was a subject for the field of psychology (*Quote 11*). Three participants thought it was the patient's responsibility to talk openly about his/her preferences. Three patients commented that doctors should actively ask about the patient's lifestyle, in order to explore his/her preferences (*Quote 12*). One participant believed that doctors need 'people skills' in order to adequately support a patient in the decision-making process (*Quote 13*).

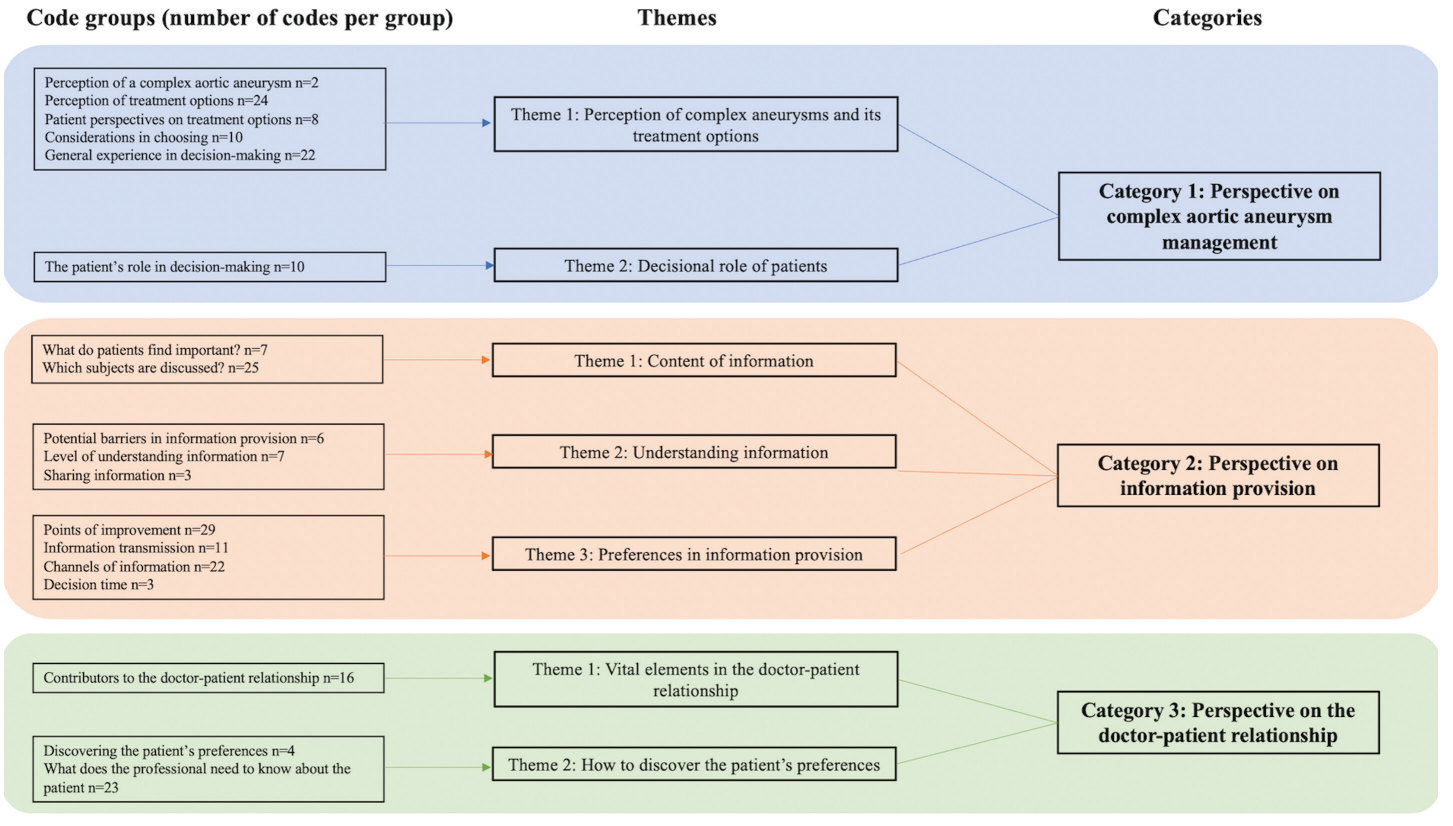


Figure 2: Coding tree of the professional-centered interviews.

The professional's perspective

The interviews with professionals were all conducted in person and lasted between 34 and 75 minutes. From these interviews, 232 codes were analyzed into 18 code groups, which were divided into 7 themes. Subsequently, themes were categorized into three categories. Figure 2 shows the coding tree for the interviews with professionals.

Category 1: Perspective on complex aortic aneurysm management

Theme 1: Perception of complex aneurysms and its treatment options

Two professionals commented that an aneurysm itself usually does not cause physical complaints. Therefore, they believed that treating an aneurysm essentially entails treating the threat or fear of potential rupture in the future. When asked about complex aneurysm treatment options, all professionals mentioned the option of complex EVAR and open repair, as well as conservative management. All professionals (5/5, 100%) commented that the decision to treat a complex aneurysm, either via open or endovascular repair, should be made carefully. Especially in older or frail patients, the option of conservative management should be discussed (*Quote 14, Table 5*). Three professionals addressed the high costs of custom-made stents in this equation.

Perceived disadvantages of open repair compared to complex EVAR were: bigger scars, a longer duration of recovery, and a higher rate of complications. One participant highlighted the long-term advantages of open repair for younger patients. A perceived downside of endovascular repair was the fact that the long-term outcomes are less known.

Theme 2: Decisional role of patients

Each professional believed that the patient should be involved in the decision-making process. The extent to which they thought patients should be able to make a treatment decision slightly differed among the interviewees. Four out of the five professionals (80%) commented that the decision whether to treat endovascularly or using open repair was mainly up to the medical team, and that patient involvement played a role in deciding whether to undergo surgery or to choose conservative management. In addition, three of these professionals (3/4, 75%) saw a guiding role for the doctor if, from a medical point of view, they thought the patient was too frail to undergo surgery. However, all participants (5/5, 100%) believed patients should be informed in-depth about the medical team's considerations in choosing between open or endovascular repair. One professional (1/5, 20%) thought the treatment decision should ultimately be left up to the patient, unless there is a definite contraindication (*Quote 15*).

Category 2: Perspective on information provision

Theme 1: Content of information

All professionals mentioned that patients should be informed about the surgical risks and possible consequences. Examples were: spinal ischemia causing paralysis, endoleaks

needing reintervention, kidney failure, and pulmonary complications. Other subjects of information were: the definition of an aneurysm, aneurysm size, the risk of rupture, risk factors (hypertension, smoking, diabetes, hyperlipidemia), technicalities of the procedure, hospital admission, medication, duration of recovery, and the possibility of necessary reinterventions.

Three interviewees mentioned that they got the impression most patients do not want to know every detail (*Quote 16*). According to the professionals, subjects that matter most to patients are: the surgical risks, the chances of success, postoperative functioning and rehabilitation, and the potential heredity of aneurysms. Subjects the interviewees considered to be underexposed during consultation were: the option of conservative treatment, the fact that an aneurysm might not rupture during the patient's lifetime, and erectile dysfunction as a surgical complication.

Theme 2: Understanding information

Four professionals commented on the patients' understanding of information; they all thought that patients are not able to understand all information that is offered, or that they cannot fully comprehend the situation they are in. These professionals therefore suggested that the patient is accompanied by someone to each consultation. Three professionals believed that patients needed the provided multiple consultations in order to make a decision. Two interviewees thought that patients needed several weeks to decide after the initial consultation in which the treatment options are presented (*Quote 17*). Although professionals did not often experience difficulties in transferring information themselves, they did mention potential barriers doctors might encounter: a different cultural or religious background, cognitive impairment, language barriers, a different educational background, and memory problems.

Theme 3: Preferences in information provision

Interviewees were asked to come up with additional ideas that might improve current decision-making and information provision. Suggestions consisted of: improving the inter-professional communication, establishing predictive tools in order to improve patient selection, hiring a physician assistant to support patients, a combined consultation with a vascular surgeon, interventional radiologist and geriatrician, implementing a supportive decision-tool, providing online additional information for patients who wish to receive more details, and visualizing the patient journey.

Category 3: Perspective on the doctor-patient relationship

Theme 1: Vital elements in the doctor-patient relationship

Table 4 shows which elements of the doctor-patient relationship were mentioned by both professionals and patients. All elements mentioned by professionals were also reported by patients. However, there were various additional elements mentioned by patients, which were not expressed by the medical professionals.

Theme 2: How to discover the patient's preferences?
In order to support a patient in the decision-making process, professionals wanted to know about objective characteristics such as: comorbidities, living status, physical functioning, cognitive functioning, the patient's support network, and his/her level of independence. These parameters could be questioned during consultation or tested via geriatric, physiotherapeutic, and dietetic screening. In addition, professionals were interested in more subjective characteristics, such as: the patient's vision on life (*Quote 18*), a patient's general mood, his/her quality of life and understanding of the disease, and the impact of having an aneurysm on the patient's quality of life (*Quote 19*). Two interviewees commented that they sometimes find it hard to objectify patient preferences. Three professionals mentioned that they explicitly ask patients about their preferences.

Patient journey
Figure 3 (supplementary material) depicts the patient journey that was construed based on the interview data. It shows the phases patients go through between receiving the diagnosis and their treatment (decision). The professionals in the patient journey correspond with the professionals included in this interview study. In addition, the dietician, anesthesiologist and physiotherapist are included in the patient journey. The emotional curve shows an initial decline in mental well-being due to receiving the diagnosis. Because of satisfaction with the doctor-patient relationship, the emotional curve rises during the consultation process. During the waiting period and directly after surgery it drops again, due to feelings of uncertainty and physical recovery with sometimes unexpected symptoms respectively.

DISCUSSION

In this interview study the greatest majority of patients felt like they had no other choice than to undergo surgery, either in order to stay alive, or because they could not live with the threat of aneurysm rupture. However, all professionals stressed the importance of adequate patient selection for surgery. Patients and professionals grossly agreed on the most important topics of information. In addition, most patients agreed with a leading role of the professional in decision-making. However, several important differences were detected between the patient and professional's perspective, which will be discussed below, including recommendations to avoid miscommunication.

Perception of a complex aneurysm and its treatment options
The finding that most patients considered surgery as the only realistic option is in accordance with *Berman et al.*, who reported that conventional aortic aneurysm patients considered surgery as their only option.[27] Here, there seems to be a discrepancy with the professional's perspective. All professionals believed that conservative management

should be discussed and considered, especially in older and frail patients. They emphasized that in some cases the risks of surgery might not weigh against its potential survival gain, and that for some patients other health conditions are more likely to lead to the death of the patient before aneurysm rupture.

The difference in the patient and professional's perspective could indicate that the professional's considerations on conservative management do not come across during consultations. It is important to address possible misperceptions of the risks of aneurysm rupture and the risks of surgery, as several patients considered the chances of surgical complications as minor, whereas they thought the aneurysm would definitely rupture. It is also possible that professionals underestimate the impact of living with an aneurysm on a patient's quality of life, and therefore perceive the option of conservative management as more realistic compared to most patients.

The information provision and the exploration of individual considerations on this subject could be improved in consultations by addressing these differences when informing patients. In addition, more attention could be paid to the guidance of patients with respect to the psychological impact of living with an aneurysm, for example by consulting a medical psychologist during preoperative screening or following the decision not to treat, and by gaining advice from a geriatric specialist. The patient journey supports these improvements by providing insight, to professionals as well as patients, in the needs and emotions of patients during the decision-making process.

Perception of the patient's role in decision-making

Unlike *Santema et al.*, we did not find that patients prefer a more active role in decision-making.[15] Most patients preferred the professional to have a leading role, whereas professionals were convinced patients should have a leading role in deciding whether to undergo surgery or not. Professionals estimated that patients needed multiple appointments or several weeks to come to a decision. Patients stated that they were able to make this decision either directly after consultation, or within a few days. Adhering to these shorter terms could limit the lead time between diagnosis and treatment.

Perception of information provision

Patients stated that they wanted to receive more information about the period of recovery. The informational folder, which most patients found useful, does address the fact that surgery has a considerate effect on the patient's physical condition and mentions that total recovery might take up to 6 months after complex EVAR. In addition, professionals mentioned the duration of recovery as one of the topics they discussed during consultation. This discrepancy might be caused by a bias towards short-term thinking.[16,28] Interestingly, *Faggioli et al.* found that the recovery time was considered significantly important by treated patients, but not by untreated patients prior to surgery.[29] To prevent dissatisfaction regarding the provided information, professionals

could emphasize this subject during pre-surgical consultation and could mention the expected period of recovery again prior to hospital discharge. In addition, a patient expert could provide patients with information on their own experience with the postoperative period.

All but one patient stated that the information was easy to understand, whereas professionals felt like patients were not able to comprehend all information. Based on our data, it is not possible to define the level of understanding among patients. However, previous research has established the Dunning-Kruger Effect, due to which people tend to overestimate their medical knowledge. It is important to be aware of this phenomenon, because of its potential negative impact on decision-making.[30]

Perception of the doctor-patient relationship

The subject of 'contributors to the doctor-patient relationship' received the highest number of codes. Contributors mentioned by professionals were in accordance with codes mentioned by patients. However, several additional important elements were mentioned by patients, which professionals should take into consideration when caring for their patients (Table 4).

Limitations

The character of our study is explorative. Therefore, we included various professionals and patients in different stages of the treatment- and decision-making process by convenience sampling. This causes heterogeneity and can limit the external validity.[19] In addition, the type of health care system might be of influence on the complex aneurysm pathway, which could limit the generalization of our results with regards to other countries. However, this approach best fitted our aim of exploring different visions of patients and caregivers involved. An additional study could be performed, in which patients are divided into different groups based on the decision-making phase they are in, in order to investigate their needs in greater detail.

An inductive approach was used to analyze interview data, which meant that the interviewees directed the extent to which topics were discussed. Therefore, not every question was featured in each interview. In order to quantify results, a questionnaire study could be performed, although these are limited in their in-depth analysis. In addition, quantified observations during consultation could be added in order to objectify results.

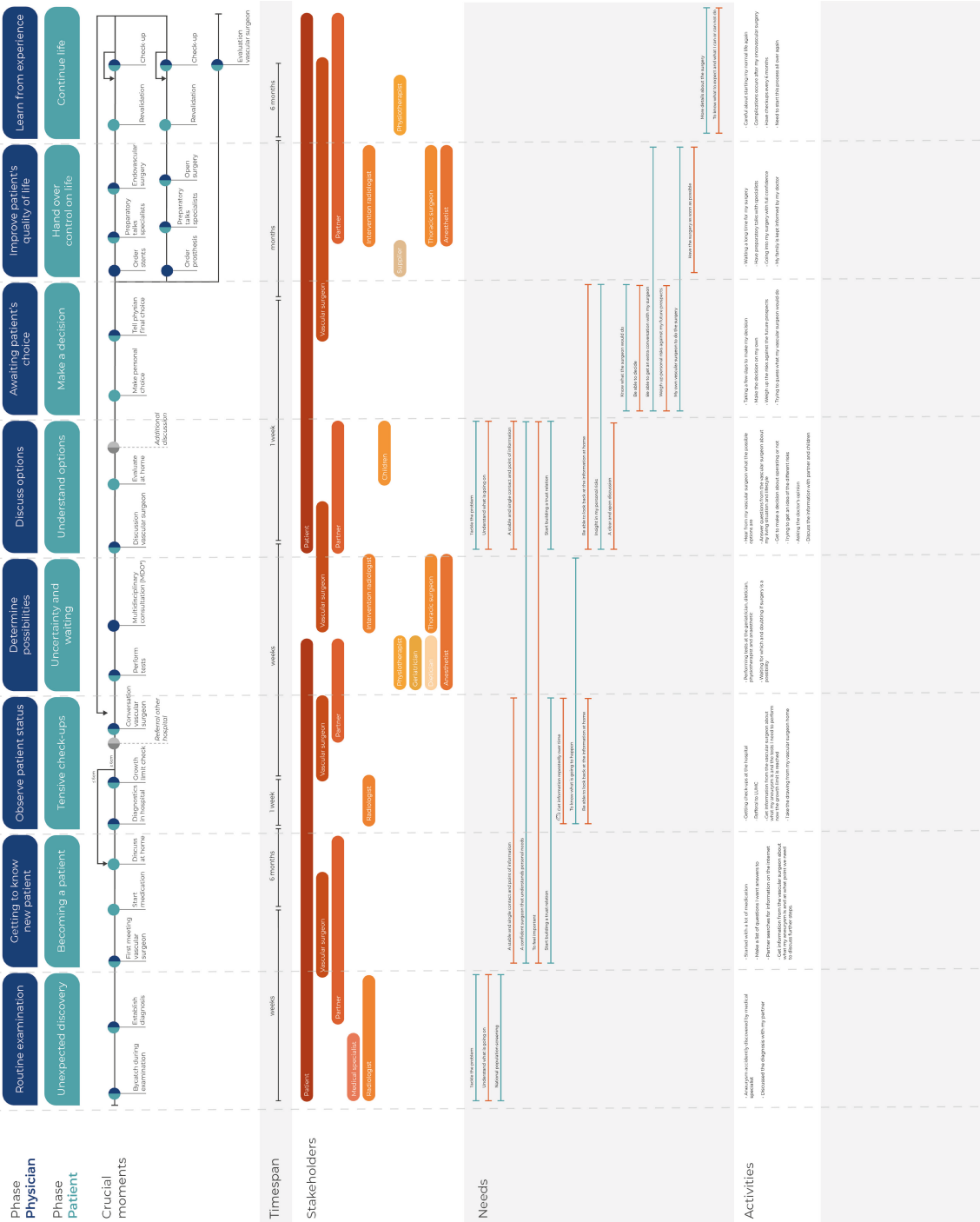
CONCLUSIONS

Several important differences were detected between the patient and professional's perspective. Patients felt like they had no other choice than to undergo surgery, whereas all professionals stressed the importance of adequate patient selection for surgery. Secondly, patients experienced a lack of information on the postoperative recovery period, although this was addressed in the informational folder and, according to professionals, mentioned during consultations. Professionals should be aware of these discrepancies and address them during consultations, in order to optimize patient involvement and satisfaction with information provision on complex aneurysm management. Future research could focus on further detailing the needs of patients in different phases of the decision-making process by including a larger patient cohort and by adding additional quantifying methods.

INTERIM SUMMARY

This chapter showed that patients and professionals have a different understanding of the possibility of conservative management. Professionals stress the importance of addressing this option, whereas patients do not seem to regard it as a realistic treatment option, mainly due to their fear of aneurysm rupture. Patients experienced a lack of information on the recovery period, although the professionals stated this is something they address during consultation, and it is mentioned in the informational flyer. This could be due to a bias towards short-term thinking. The fact that patients were very prone to talk about their (positive) experience of the doctor-patient relationship indicates that this is something they perceive as highly important. In the current chapter, overall, patients seemed to be satisfied with information provision and the doctor-patient relationship. However, patient dissatisfaction does occur. In the next chapter we will identify factors underlying patient dissatisfaction, by analyzing Dutch medical disciplinary complaints.

TABLES AND SUPPLEMENTARY FIGURES



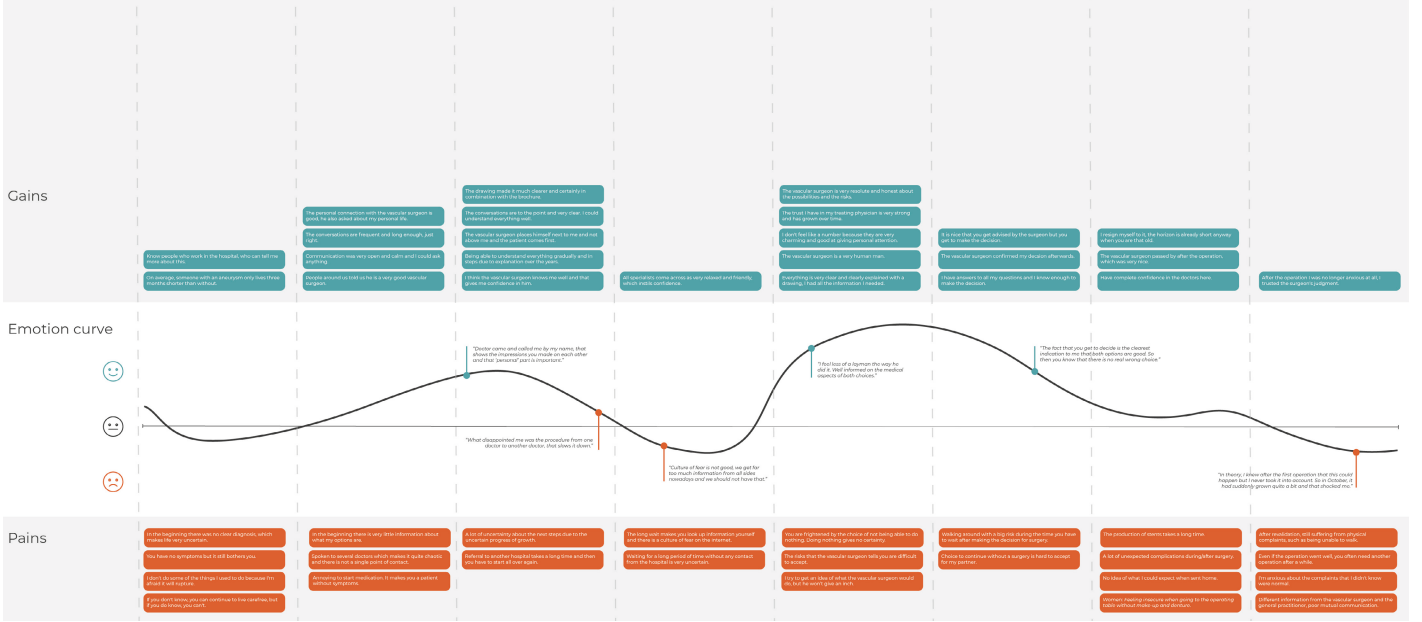


Figure 3: The patient journey of complex aortic aneurysm patients in the Leiden University Medical Center. Available online: https://www.annalsofvascularsurgery.com/article/S0890-5096(23)00327-8/fulltext

Table 1a: Patient-specific characteristics

Patient	Age	Gender	Treatment	Timing of interview
1.	77	male	not yet decided	weeks after diagnosis
2.	84	male	FEVAR	pre-surgery
3.	74	male	BEVAR	pre-surgery
4.	81	male	BEVAR	pre-surgery
5.	84	male	Arch-EVAR	pre-surgery
6.	77	female	FEVAR	months post-surgery
7.	72	female	emergency BEVAR	months post-surgery
8.	85	male	FEVAR	1 year post-surgery
9.	87	male	FEVAR	1 year post-surgery
10.	71	male	emergency BEVAR	5 years post-surgery
11.	74	male	FEVAR	5 years post-surgery
12.	75	male	conservative treatment	months after decision

FEVAR; fenestrated endovascular aortic repair, BEVAR; branched endovascular aortic repair

Table 1b: Baseline characteristics

Variable	
Age, mean (SD)	76.6 (6.4)
Male gender, n (%)	10 (83%)
Aneurysm size in mm, mean (SD)	68.9 (12.6)
ASA-score	
2	3 (25%)
3	8 (67%)
4	1 (8%)
Comorbidities, n (%)	
Hypertension	10 (83%)
Hyperlipidemia	3 (25%)
Type 2 diabetes	2 (17%)
MI/ACS	2 (17%)
AF	1 (8%)
Other cardiac comorbidities	6 (50%)
COPD/other pulmonal comorbidities	3 (25%)
Previous AAA repair	5 (42%)

SD: standard deviation, ASA-score: American Society of Anesthesiologists-score, MI/ACS: Myocardial Infarction/Acute Coronary Syndrome, AF: atrial fibrillation, COPD: Chronic Obstructive Pulmonary Disease, AAA: abdominal aortic aneurysm

Table 2: Quotes of patients

Quote number	Category	Theme	*Quote*
1	1	1	*You're happy that you're still walking around, but you start to wonder; How much longer will I be around? How much risk do I have?*
2	1	2	*The first conversation was with an older doctor, who would soon retire. He still performed that old-fashioned treatment, which was a horrible procedure.*
3	1	2	*If they think that it's possible via the groin, they will choose to do so. If there really is no other way, then they will…I don't think they're jumping up and down to perform an open [procedure].*
4	1	2	*There is always a risk, but it's only small percentages.*
5	1	3	*I found it quite surprising [that the doctor didn't want to decide for me]. It feels a bit like theoretically implemented democracy in health care. Back in the day, the patient was silenced; 'This is what we're going to do sir, shut up.' Of course, that wasn't good either, but now it's a bit overdone. As long as it's nuanced, then it's ok.*
6	1	3	*You can't expect the doctor to decide for you; he's not going to take that responsibility. So, it's very simple: you just need to make your own decision.*
7	1	4	*'It can also go wrong, so yeah… What do you want'?, [the doctor asked]. Because some people do not want to undergo surgery. I said: 'I still want to live for a while. I'm not that old yet.'*
8	1	4	*If you decide to do nothing, then [aneurysm rupture] will happen. You just don't know when. But it will happen, and you have no power over it. I really don't like that idea. It's better to know where you stand, don't you think?*
9	2	3	*I think a lot of it just went over my head. I heard what was being said, but I didn't understand it.*
10	2	3	*In the online patient portal, you can read a lot about what's going on. But in order to understand it, you would have to know Latin. That was disappointing. So many things are in Latin, which is impossible to understand.*
11	3	2	*I think [discovering the patient's perspective] is a subject for the field of psychology. There are so many factors that can play a role (…) You would have to dig into someone's existence: Are you married? Do you have children? Are you still having fun? (…) What are your hobbies? (…) But they see so many patients each year.*
12	3	2	*They should get to know the patient a little bit, to guide them in the right direction (…) [They should know about] someone's vision on life, if you're still active… If you only stay at home looking outside the window, that's a very different life compared to when you're still active, going on a holiday…*
13	3	2	*The more they get to know the patient, the better [doctors] are able decide wat to do. One doctor will have more people skills than the other; there are people who are very interested in others, and people who are absolutely not. The latter should not become a doctor, right? [laughing]*

Category 1: Perception of complex aortic aneurysms and management
Theme 1: Perception of complex aneurysms as an anatomic entity
Theme 2: Perception of treatment options
Theme 3: Preferred decisional role
Theme 4: Considerations when choosing
Category 2: Perspective on information provision
Theme 3: Understanding information
Category 3: Perspective on the doctor-patient relationship
Theme 2: How to discover the patient's perspective

Table 3: Providing and sharing information

Information provided by	**Mentioned by number of patients**
Vascular surgeon	12
The internet	5
Befriended medical specialist	2
Home care nurse	1
Online hospital portal	1
Family member	1
Acquaintance	1
Information shared with	**Mentioned by number of patients**
Child(ren)	8
Friends/family	5
Partner	3
General practitioner	2
Home care nurse	1

Table 4: Quotes and codes of patients and professionals regarding the doctor-patient relationship.

Code	Mentioned by number of patients	Quotes of patients	Mentioned by professional(s)	Quotes of professionals
The doctor and other hospital staff were kind.	9	*There was also a very kind medical receptionist behind the counter. That really helps.*		
Personal aspect in the doctor-patient relationship.	8	Interviewer: *What is your overall opinion of the conversations with your doctor?* Patient: *Well, good, useful, efficient. Uhm...he is also engaged personally.* Interviewer: *How can you tell?* Patient: *By his demeanor, his way of talking (...), like he is interested.*	yes	*Why should it be impersonal? You don't go to the doctor to receive something impersonal.*
Doctor was not authoritative.	6	*He was not like; you're the patient and I'm the doctor, so shut up. I'm saying it a bit black-and-white. No that was really not the case.*	yes	*Doctors used to be placed on a pedestal. People were like 'yes if you say so doctor'. That's very different now, and I think that's a good thing.*
Doctor should be available to ask questions.	6	*I picked up the phone and got an appointment in no time. He took care of that. That makes me think; this is someone I can trust.*		
The patient felt like the doctor was trust-worthy.	5	*Feeling that you are in good hands, that's most important. (...) And I fully trusted him.*	yes	*You have to build trust.*
Doctor took the necessary time for consultations.	5	*No as I said, the character of people that seem to be working here...uhm you never got the sense of well let's get this over with very quickly (...) There was no rush to get out.*	yes	*In my experience, patients appreciate (...) a doctor taking the time to explain the treatment options.*
It is important that the patient can see the same doctor.	3	Interviewer: *Was it nice to see the same doctor?* Patient: *Well, there's no guarantee because it's an academic hospital, so these people have to go somewhere else sometimes. (...) That is something I find unfortunate, but that's the way it is.*	yes	*It would be best if there was continuity in [the professional that] patients get to see.*
A doctor should keep his promises.	3	*He does what he says, that's important.*		

Table 4: Quotes and codes of patients and professionals regarding the doctor-patient relationship. *(continued)*

Code	Mentioned by number of patients	Quotes of patients	Mentioned by professional(s)	Quotes of professionals
Doctor came across as confident.	2	*He came across as very confident. That's important.*		
Doctor should treat you as a human being, not just as a patient.	2	*(...) They treat you as a person, not just as a patient.*		
Doctor needs to be honest.	2	*He was honest and explained it all very well.*	yes	*You need to tell it like it is.*
Doctor should reassure the patient.	2	*What the doctor tells you and how he responds, is very important. To a patient, that is very important and reassuring.*	yes	*(...) I will try to reassure them (...)*
The surgeon that provides the information should perform the surgery himself.	2	*(...) I wanted to be absolutely sure that [name doctor] would perform the surgery himself, and not a doctor in training (...)*		
The doctor showed compassion.	2	*(...) if someone shows interest and compassion.*	yes	*It's about the way you engage with someone; showing compassion.*
The surgeon was a modern doctor.	2	*A modern doctor, I must say.*		
The doctor used humor.	2	*He used a bit of humor as well. I liked that.*		
The surgeon personally called family members after surgery.	2	*Well, I found it very pleasant that [name doctor] called [my husband by name]. That is something I really appreciate. I didn't expect that. Everything is so impersonal nowadays.*		

Table 5: Quotes of professionals

Quote number	Category	Theme	Quote
14	1	1	*(...) We do suggest [conservative management] if we think the remedy might be worse than the disease. In older patients, or someone with a lot of comorbidities, you should wonder if you should still perform surgery. But with a relatively healthy 65-year-old patient, I usually don't discuss the option of doing nothing.*
15	1	2	*Eventually, it is not up to us to decide what a patient wants. (...) Of course, it's a different scenario if the surgeon says 'if I perform the surgery, then I will kill the patient'. That's a medical contra-indication. Then the patient can bend over backwards, but the surgery won't happen. That doesn't happen a lot.*
16	2	1	*(...) [Patients] say; 'That may be the case doctor, but [the surgery] has to happen anyway'. So, they react quite dismissive towards detailed information.*
17	2	2	*That process takes several weeks, and I think patients need that time.*
18	3	2	*(...) And also a patient's vision on life; how long do you want to live, and with what quality of life?*
19	3	2	*In deciding whether to perform surgery or not, especially in older patients, it is very important to know (...) whether someone can handle the idea of not treating something that might cause a problem in the future.*

Category 1: Perspective on complex aortic aneurysm management
Theme 1: Perception of complex aneurysms and its treatment options
Theme 2: Decisional role of patients
Category 2: Perspective on information provision
Theme 2: Understanding information
Category 3: Perspective on the doctor-patient relationship
Theme 2: How to discover the patient's perspective?

Appendix A and B available online via:

https://www.annalsofvascularsurgery.com/article/S0890-5096(23)00327-8/fulltext

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