



Decision-making experiences of patients and partners opting for active surveillance in esophageal cancer treatment

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ABSTRACT

Objectives: This study explored the decision-making experiences of patients and their partners or primary caregiver who opted for experimental active surveillance (instead of standard surgery) for the treatment of esophageal cancer.

Methods: Seventeen couples participated. Semi-structured interviews were conducted on couples' joint experiences as well as their individual experiences. Preferred and perceived role in the treatment decision-making process was assessed using the adjusted version of the Control Preferences Scale, and perceived influence on the treatment decision was measured using a visual analog scale.

Results: Couples reflected on the decision-making process as a positive collaboration, where patients retain their autonomy by making the final decision, and partners offer emotional support. Couples reported about an overwhelming amount and sometimes conflicting information about treatments among different hospitals and healthcare providers.

Conclusions: Patients often involve their partner in decision-making, which they report to have enhanced their ability to cope with the disease. The amount and sometimes conflicting information during the decision-making process provide opportunities for improvement.

Practice implications: Couples can benefit from an overview of what they can expect during treatment course. If active surveillance becomes an established treatment option in the future, provision of such overviews and consistent information should become more streamlined.

1. Background

Patients with locally advanced esophageal cancer who have a clinical complete response (cCR) after neoadjuvant chemoradiotherapy (nCRT) may benefit from an organ sparing approach. [1,2] Instead of planned surgery, an active surveillance strategy may be a safe and effective treatment alternative for patients with a cCR. During active surveillance, patients undergo frequent clinical response evaluations using endoscopy and imaging to assess tumor response after nCRT. Only when locoregional regrowth is histologically proven or highly suspected without any signs of distant metastases, surgery will be offered. Active surveillance for locally advanced esophageal cancer **after neoadjuvant chemoradiotherapy** is an experimental treatment. The benefit and harm of active surveillance is currently under study within the SANO study, a

multicenter prospective cohort study [3].

Currently, active surveillance for esophageal cancer is only available within an experimental context as the (long-term) results from prospective studies are pending. This makes the decision process between active surveillance and standard surgery quite complex. For example, a previous study conducted by our research group demonstrated that patient treatment preferences in the decision between active surveillance and surgery for esophageal cancer are highly individualized, which makes it a challenge to anticipate on this. [4] To illustrate: patients opting for active surveillance often express confidence in positive outcomes, questioning the need for surgery when no cancer is detected. They prioritize living in the present moment, while maintaining their quality of life. Conversely, patients preferring surgery respond to the disease threat by choosing an active approach focused on seeking

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certainty. Undergoing surgery contributes to their sense of having done everything possible to survive. The current context of a novel experimental approach wherein data on long-term treatment outcomes is not yet available, necessitates clinicians to discuss patient preferences.

Such preference-sensitive decisions are not easily navigated alone. Patients often adapt their personal preferences to the needs and desires of those whose interests are intertwined with their own thereby forming an integral part of the patients' autonomy. [5] This probably also applies to esophageal cancer patients, as we found that they value support from loved ones and take their partner's opinions into consideration when choosing active surveillance. [6].

In the processes of coming to terms with illness, digesting information and making treatment decisions, family members often play an important role in providing support and guidance. [7] Patients' partners are often included in cancer treatment decision-making. [8] Their involvement can help patients to experience greater treatment satisfaction, higher treatment adherence and better quality of life. [9] **It also aids partners in better coping with the disease and being more actively engaged in the treatment journey. [10]. Moreover, partners' satisfaction with dyadic coping is linked to improved emotional functioning, such as reduced feelings of tension, worry, irritability, and sadness, for both themselves and patients facing an advanced cancer diagnosis. [11].**

Couples may experience an array of emotions that lead to uncertainty about what is the "right treatment". [12] It can occur that patient and partner have different perceptions on what treatment is best, which may lead to discussion or conflict. [13] Furthermore, patients can feel pressured to opt for a treatment that is less burdensome to the family. [14] Hence, it is important to consider family members' role in decision-making and the influence they can have on treatment decisions. **Studies that have examined decision-making on 'active surveillance' are mostly limited to prostate cancer. These studies show that having a partner's support for active surveillance can help a man feel more comfortable with choosing and adhering to this approach, while a lack of partner involvement can be a predictor of lower quality of life for men on active surveillance. [15–17] However, the consideration of active surveillance for prostate cancer is of a different nature than for esophageal cancer. Prostate cancer generally has a slower progression, lower morbidity, and better survival rates compared to esophageal cancer, which is known for its aggressiveness and poorer prognosis. [18,19] Moreover, active surveillance is already considered a safe alternative to immediate treatment for men with low-risk prostate cancer. [20].**

The objective of this study is to understand how patients with esophageal cancer and their partners or primary caregiver reflect on the treatment decision-making process on experimental active surveillance. Additionally, we explored patients' and partners' preferred roles in treatment decision-making. This information may optimize guidance of future patients and partners who are facing such a treatment decision.

2. Methods

2.1. Design

This study was a qualitative sub-study of the SANO-2 study. [21] The SANO-2 study is a multicenter prospective observational cohort study designed to monitor the safety and effectiveness of active surveillance in patients with locally advanced esophageal cancer who achieved a cCR following nCRT. The study has been approved by the Medical Ethical Committee of the Erasmus MC (MEC 2021–0068) and has been registered at ClinicalTrials.gov (NCT04886635). [22] COREQ checklist was used as a reporting guideline for this study (see Appendix). [23].

Participants in SANO-2 undergo two clinical response evaluations (CREs) after nCRT. During CRE-1 at 5–6 weeks after nCRT patients will undergo esophagogastroduodenoscopy (EGD) with biopsies. During CRE-2 performed at 10–12 weeks after completion of nCRT, patients will

undergo positron emission tomography with computed tomography (PET-CT), endoscopy with biopsies and endoscopic ultrasonography (EUS) plus fine-needle aspiration (FNA). Patients who achieve a cCR at CRE-2 will undergo active surveillance. During active surveillance regular CREs (including endoscopy, EUS and PET-CT at each CRE) are performed to detect regrowth of cancer: every 3 months in the first year after completion of neoadjuvant treatment, every 4 months in the second year, every 6 months in the third year and yearly in the 4th and 5th year of follow up. Surgery is considered only when there is high suspicion or confirmation of locoregional regrowth without distant dissemination [2].

2.2. Participants

This qualitative study included patients who participated in the SANO-2 study and their partners or primary caregiver. The inclusion criteria for the patients were: cCR 10–12 weeks after nCRT and undergoing active surveillance within SANO-2. Partners were identified based on patient referral, and they were approached for participation in the study only after the patient consented to their involvement. One partner per patient was allowed. The inclusion criteria for partners were: individuals who were involved in the treatment decision-making process of the patient, such as spouses, children or close friends, as long as this person has a solid attachment to the patient, aged ≥ 18 . We will refer to these participants as 'partner'.

2.3. Procedure

Recruitment took place in Erasmus University Medical Center Rotterdam, The Netherlands. Patients were recruited from June 2022 until May 2023. All consecutive SANO-2 patients who were eligible were approached. Patients were contacted by female researcher MH, either in person after their appointment with the clinician or via telephone to inform them about the study **and the reasons for doing the research**. Patients and partners received a letter providing study information. Interviews were carried out either at the hospital, the patients' home or via telephone, depending on the participants' preference. The first two couples were interviewed by LK (female senior psychologist) and MH together. The other 15 couples were interviewed by MH. All participants gave written informed consent.

2.4. Measures

Semi-structured interviews were performed. Interviews consisted of two parts and took approximately 1 h in total. First, the dyadic interview was conducted to explore how patient and partner collectively navigated the decision-making process. The following topics were covered to explore their experiences: treatment options offered; treatment preferences; information provision; involvement in decision-making; feedback to health care professionals to improve guidance for future patients. Subsequently, separate interviews were conducted. Participants got the opportunity to privately (without their partner) elaborate on topics that were being discussed in the dyadic interview. Additionally, the preferred and perceived role of each participant in the decision-making process were explored. For this purpose, we used an adjusted version of the Control Preferences Scale [24,25]. Additionally, the perceived influence each participant had on the treatment decision was measured using a visual analog scale (VAS) ranging from 0 (no influence at all) to 10 (a lot of influence). Interview questions are listed in Table 1.

There were set response categories for most questions, except for two questions in the joint interview that allowed participants to provide open-ended responses regarding when and by whom the final treatment decision was made. The interviewer took notes during the interview and summarized the participant's explanations, who was then invited to adjust this summary for accuracy and completeness. Furthermore, the interviewer was allowed to reschedule the order of questions during the

Table 1
Interview questions and answers (translated from Dutch) N = 17.

Respondents	Questions asked (response categories in italics)
Couple	General questions about the decision
	(1) Which treatments were offered? (<i>Surgery (17) /AS (17) /doing nothing/other response</i>)
	(2a) Did you had an immediate preference for one of the treatments? (<i>yes (13) /no (4) /other response</i>)
	(2b) Did this preference differ between you both? (<i>yes (1) /no (16) /other response</i>)
	(3) Who were involved in the decision?* <i>Patient + partner (10) / Patient + partner + children (5) / Patient + doctor (1) / Patient + partner + children + doctor (1)</i>
	(4) Have you had any doubts about the final decision? (<i>patient yes, partner yes (2) /patients yes, partner no (1) /patient no, partner no (14) /patient no, partner yes</i>)
	Information provision
	(1) What did think you of the information about the treatments?* <i>Good (12) / Good but too much (5)</i>
	(2) Was the information sufficient to make a decision?* <i>Yes (17)</i>
	Final decision
(1) When was the choice for treatment definite for you?* <i>Directly (13) / after a little while (2) / after discussing with family (2)</i>	
(2) Who made the final decision?* <i>Patient (13) / Patient and partner (3) / patient and doctor (1)</i>	
(3) Do you regret the choice of treatment, at this moment? (<i>patient yes, partner yes/patients yes, partner no/patient no, partner no (17) /patient no, partner yes</i>)	
Tips for guidance* <i>None (5) / one contact person (4) / better information provision/communication (8) / overview of trajectory (4)</i>	
Patient only	Perceived role in decision-making
	(1) How was the decision about your treatment made? (<i>only by me (6) /by my partner/by me and my partner (3) /by the doctor/by me and the doctor (1) /by me, doctor and partner together (7) /other response</i>).
	(2a) What do you think of the level of your involvement? (<i>sufficient (17) /insufficient</i>)
	(2b) Would you have liked to see this differently? (<i>yes/no (17) /other response</i>)
	(3) Do you think your partner is satisfied with your level of involvement? (<i>yes (17) /no/other response</i>)
	Preferred role in decision-making (with partner)
	(1) Which statement best describes how you would like to see a decision made about your treatment? (<i>I prefer to make the final decision by myself (2) /I prefer to make the final decision by myself after considering my partners opinion (12) /I prefer my partner and myself to share responsibility for the decision (3) /I prefer my partner to make the final decision, after considering my opinion/I prefer to leave all decisions about treatment to my partner</i>)
	(2) Looking back on how it really went, is that also the case? (<i>yes (17) /no/other response</i>)
	Preferred role in decision-making (with doctor)
	(1) Which statement best describes how you would like to see a decision made about your treatment? (<i>I prefer to make the final decision by myself (3) /I prefer to make the final decision by myself after considering my doctors opinion (9) /I prefer my doctor and myself to share responsibility for the decision (3) /I prefer my doctor to make the final decision, after considering my opinion (2) /I prefer to leave all decisions about treatment to my doctor</i>)
(2) Looking back on how it really went, is that also the case? (<i>yes (17) /no/other response</i>)	
Influence on the decision	
(1) On a scale of 0 to 10: how much influence did you have on your treatment decision? (<i>0 =no influence/10 =very much influence</i>) M = 9.4; SD = 1.	
Partner only	Perceived role in decision-making
	(1) How was the decision about the treatment of your partner made? (<i>only by my partner (6) /only by me/by me and my partner (6) /by the doctor/by the doctor and my partner together (1) /by the doctor, my partner and myself together (4) /other response</i>)
	(2a) What do you think of the level of your involvement? (<i>sufficient (16) /insufficient (1)</i>)
	(2b) Would you have liked to see this differently? (<i>yes (1) /no (16) /other response</i>)
	(3) Do you think your partner is satisfied with your level of involvement? (<i>yes (17) /no/other response</i>)
	Preferred role in decision-making

Table 1 (continued)

Respondents	Questions asked (response categories in italics)
	(1) Which statement best describes how you would like to see a decision is made about the treatment of your partner? (<i>I prefer to make the final decision about the treatment of my partner/I prefer to make the final decision after considering my partners' opinion/I prefer my partner and myself to share responsibility for the decision (1) /I prefer my partner to make the final decision about their treatment after considering my opinion (12) /I prefer to leave all decisions about my partners treatment to my partner (4)</i>)
	(2) Looking back to how it really went, is that also the case? (<i>yes (17) /no/other response</i>)
	Influence on the decision
	(1) On a scale of 0 to 10: how much influence did you have on the decision of your partners' treatment? (<i>0 =no influence/10 =very much influence</i>) M = 6.2; SD = 3.3.

* Response categories on open-questions

interview, in situations where this occurred more logical and/or more in line with what one would perceive as natural conversation. Data was analyzed by frequency counts for the answers to the set response categories by researcher MH under supervision of senior psychologist LK. Additionally, the interviewer asked participants to elaborate on their answers. Responses to open-ended questions were clustered into thematic categories based on the interpretation of the contents.

3. Results

3.1. Participants characteristics

A total of 24 patients were invited to participate, 7 declined participation. Reasons for non-participation were: not having a decision partner or not wanting to participate. In total 17 patients with their 17 partners were included. Fourteen out of 17 partners or primary caregiver were spouses, 2 were children, and 1 was a close friend of the patient. See Table 2 for participant characteristics. At time of the interview, all patients were enrolled in the SANO-2 study and had recently (between 1 and 31 days) heard that there were no signs of progression and that they could continue the active surveillance program.

3.2. Interviews

See Table 2 for answers to the interview questions.

Table 2
Baseline characteristics of participants.

Characteristics	Patients (n = 17)	Partners (n = 17)
Sex	11 (65 %)	6 (55 %)
Male		
Relationship type		14
– Spouse		2
– Child		1
– Close friend		
Median age in years (min-max)	72 (60 – 83)	
Tumor type	14 (82 %)	
Adenocarcinoma	3 (18 %)	
Squamous cell carcinoma		
Clinical T-category	6 (35 %)	
cT2	10 (59 %)	
cT3	1 (6 %)	
cTx		
Clinical N-category	9 (53 %)	
cN0	4 (23 %)	
cN1	3 (18 %)	
cN2	1. (6 %)	
cN3		

3.3. Couples' joint experiences

3.3.1. Treatment options, preferences and doubts

All patients were offered a choice between standard surgery and experimental active surveillance (SANO-2) as treatment options for esophageal cancer, and all opted for active surveillance. The majority of couples (13/17) expressed an immediate preference for this last approach. This preference was driven by factors such as anxiety related to surgery, the desire to preserve the esophagus and to maintain quality of life. One patient expressed a desire to contribute to science by participating in the SANO-2 study: *"I am familiar with the hospital, and by participating in this study I also feel like 'giving back' (patient #10).* In one case, a patient initially preferred surgery: *"I first wanted to go for surgery, but my husband and my daughters convinced me to participate in SANO-2" (patient #15).*

A few (4/17) couples had no immediate treatment preference, and encountered doubts that were driven by factors such as fear of potential metastases if opting for an active surveillance approach; or a perceived lack of guidance from health professionals in making the treatment decision. *"We would have preferred some kind of advice or suggestions from the doctor, this would ease the decision making" (patient #8).* Overall, treatment preferences did not differ between couples, with one exception where the patient initially considered surgery and the partner active surveillance.

3.3.2. Treatment information

Couples frequently felt overwhelmed by the amount of information they received: *"It was a lot of information at once, it all goes 'in the one ear and out the other', so I was happy my partner was there with me" (patient #9).* Some indicated that information provision could be better organized: *"We had too much different conversations, with too many different specialists, this was very overwhelming, especially for people my age" (patient #12); "not all specialist gave the same information, so that was also confusing" (patient #14).* One patient stated: *"there was nothing wrong with the actual information they give, but you just cannot process the information correctly. It is better if the doctor just tells you the information instead of having to read all the paperwork" (patient #15).*

Despite feeling overwhelmed at some stage(s), couples reported that they were able to make a treatment decision based on the information provided.

3.3.3. Decision for active surveillance

Couples indicated that the decision for active surveillance was often made promptly after its introduction. Couples who required more time to finalize the decision, used this time to discuss with their children, or to process the extensive information that was provided to them.

The majority of couples (15/17) stated that both patient and partner were jointly involved in the decision, occasionally with the inclusion of their children: *"We do everything together, so we also made this decision together, we are in this thing together" (patient #2).* The other 2/17 couples indicated an active involvement of the clinician.

In most cases (12/17) the patient had the final say over the decision. Sometimes the final say was collaboratively with partner (4/17): *"He [close friend of the patient] read a lot of information, and he strongly advised me to participate in SANO-2, he gave me a lot of advice" (patient #11),* or with the clinician (1/17): *"I followed my intuition, and also what the doctor told me" (patient #1).* Once the final decision was made, no regrets were reported regarding the choice for active surveillance.

3.3.4. Suggestions for guidance

Couples expressed they would benefit from an overview of what to expect in the upcoming months, to ease the overwhelming experience. They suggested a designated contact person: *"It would be very nice if there was one specific person you can always turn to with your questions" (patient #3); "More personal guidance would be nice" (patient #15).* Furthermore, consistent information provision was desired, for example by improving

the coordination among healthcare professionals from different hospitals. Some partners would appreciate more attention focused on partners.

3.4. Patient individual experiences

3.4.1. Involvement in the final decision

7/17 patients reported that both their partner and clinician were involved in the final decision for active surveillance. 3/17 stated that only their partner was involved in the decision, and 1/17 stated that only the clinician was involved. The remaining 6/17 patients reported they made the final decision alone.

Patients considered their partner's involvement sufficient: *"I was happy with his involvement, I can trust him, and I appreciated that he does research and read a lot about the disease and treatment options" (patient #1).* Patients believed that their partner was also satisfied with the kind and extent of their own involvement.

3.4.2. Patients' preferred role in decision-making with partner

14/17 patients preferred an active role for themselves in decision-making with their partner, that is, patients preferred to decide themselves about treatment. Of these 14 patients, most (n = 12) preferred to consider their partners' opinion: *"It is nice to hear dissent, I put my 'mind to zero' and I made the choice on the advice of my partner, I trust him" (patient #11),* and 2 preferred to make the decision without considering their partners' opinion: *"imagine if it goes wrong, then I will have the responsibility" (patient #9).* 3/17 preferred a collaborative role, and to equally share responsibility with their partner for deciding which treatment is best.

3.4.3. Patients' preferred role in decision-making with clinician

12/17 patients preferred an active role for themselves in decision-making with the clinician, that is, patients preferred to decide themselves about treatment. Of these 12, most (n = 9) preferred to consider their clinicians' opinion when making a decision, *"It is of influence how the doctor himself regards active surveillance" (patient #12),* and 3 preferred to make the decision without considering their clinicians' opinion: *"But suppose the doctor would have given advice, this would weigh into the decision. Now, this was not the case and this was totally fine" (patient #25).* 3/17 patients preferred a collaborative role, and equally sharing responsibility with their clinician for deciding which treatment is best: *"It not pleasant when the choice lies completely in the patient's hands" (patient #11).* Few patients (2/17) prefer a passive role, and leaving all decisions regarding treatment to their clinician: *"He is the doctor" (patient #13).*

3.4.4. Patients' perceived roles in decision-making

Patients indicated that their preferred roles in decision-making with both their partner and their clinician, corresponds with the roles they indeed perceived to have in making the decision for active surveillance.

Patients felt they had a lot of influence of the final decision. They reported an average rating of 9.4 on a scale of 0 to 10, where 0 = no influence at all, and 10 = a lot of influence.

3.5. Partner individual experiences

3.5.1. Involvement in the final decision

10/17 partners felt they were involved in the final decision. Of these, 6 reported that only they were involved in the final decision, and 4 reported that also the clinician was involved.

"I did feel like I was taking some kind of lead, because it was too much information for my partner [i.e. the patient] to process at once" (partner #11).

7/17 partners felt not involved in the final decision. Of these, 1 stated the decision was made by patient and clinician and 6 stated the decision

was made solely by the patient.

Partners were satisfied with their kind and degree of involvement, and believed the patient was also satisfied with this. There was one exception: *“My husband expects something I can't give him. He expects involvement but I can't live up to it. He told me that it seems like as if it all does not get through to me. I guess I am more introverted than him”* (partner #35).

One partner would have liked to be more involved by the clinician: *“The doctor mainly paid attention to my husband and did not really involve me in the conversation. I understand that my husband is the patient, but it would be nice if the doctor also asks me as a partner how I am feeling about the situation”* (partner #16).

3.5.2. Partners' preferred role in decision-making with patient

16/17 partners preferred a passive role regarding treatment for the patient, that is, to leave the decision up to the patient. Most of these partners ($n = 12$) preferred the patient to seriously consider the partners view and opinions, and only few ($n = 4$) preferred the patient to make the decision on their own. 1/17 partner preferred a collaborative role, and to equally share responsibility with the patient for deciding which treatment is best.

3.5.3. Partners' perceived role in decision-making with patient

Partners reported that their preferred role in decision-making with the patient corresponded to their perceived role in the decision for active surveillance.

Partners rated their degree of influence on the final decision with an average of 6.2, on a scale of 0 to 10, where 0 = no influence at all, and 10 = a lot of influence.

4. Discussion

We explored decision-making experiences of patients and their partner who opted for experimental active surveillance instead of standard surgery for the treatment of esophageal cancer. Couples reflect on the decision-making process as a positive collaboration between the two of them, wherein both patient and partner were satisfied with their perceived roles they had throughout this process. There was minimal discrepancy observed between the joint and individual interviews, as the statements provided by patients and partners in the joint interview harmonized with those made in the separate interviews.

At the moment of the interviews, patients were cancer-free and continued with active surveillance: their treatment of choice. Consequently, it is not so surprising that they did not report decisional regret, as their decision turns out as hoped for, at least at the moment of the interview. This optimistic outlook is observed in couples' experiences as well. Despite encountering challenges, such as feeling overwhelmed by the abundance of information, couples manage to give a positive spin on this experience by feeling adequately informed to make a treatment decision. However, in the event of cancer recurrence, couples might perceive the decision-making process differently in hindsight. In such a scenario, decision regret could arise, causing a more critical appraisal of the entire process by both patient and partner. In our study, we found no outcomes that have led us to believe that there were major differences between patients and partners in this respect.

The results show that partners were actively involved throughout the decision-making process, providing emotional support to the patient. Partners seem to have less influence on the final treatment decision. This is perhaps not surprising considering the preferred roles in decision-making: patients prefer an active role, indicating their willingness to take the lead in decision-making, and partners prefer a passive role, indicating their comfort with the patient taking the lead in decision-making. This finding is in line with a recent study from our research group, showing that patients highly value support from their partners during decision-making, while emphasizing that they prefer to make the final decision themselves. [26] This finding on preferred roles is also

underscored in a systematic review on caregiver involvement in cancer decision-making. [27] According to this review, it is important to target caregiver-patient dyads rather than individuals, since a supported relationship could have a protective effect on the couples' psychological distress and quality of life.

It is without question that patients should be allowed and enabled to make a decision about their health care. Especially in this case, wherein patient preferences for active surveillance are shown to be highly individual. [7] However, patient autonomy can be at stake when partners manipulate patients, compromising their autonomy, or vice versa, when patients oblige partners to decide in place of them, transferring their autonomy. [28] At the same time, that the patients' autonomy should be respected does not mean that there is no space for patients to make decisions based on considering consultation with others. The concept of 'relational autonomy', is of relevance here. It holds that autonomous decisions are made by people whose identities and interests are always also shaped by their relations to others. [5] So, autonomy is inherently relational: most patients make decisions influenced by their social network and within the context of a specific the healthcare system; whatever is important to the patient is affected by their relationships and social environment. [29,30] Indeed, we found that patients prefer to make the final decision, but not without considering the opinion of their partner. At the same time, partners also express a preference for patients to make the final decision while taking their opinions into consideration. In one case, a patient indicated to be 'persuaded' by her family to opt for active surveillance instead of her initial preference for surgery, and still this couple reported that the patient was the one who made the final decision. This highlights the complex dynamics involved in decision-making, where it may not always be easy to entangle who has the final say.

The overwhelming amount of information and the sometimes conflicting information about treatments among different hospitals and different healthcare providers, provide opportunities to improve the decision-making process. The current experimental context of active surveillance, probably contributes to the sense of overwhelming and inconsistent information as crucial questions about safety and efficacy of active surveillance cannot be answered yet. If active surveillance becomes an established treatment option, updated clinical guidelines will facilitate consistent information provision. Furthermore, healthcare providers can enhance the decision-making experience by offering more tailored support and guidance during the decision-making process. A tool that may be helpful in this, is the 'Metro Mapping' method. This is a service to support shared decision-making in oncology that literally maps the complexity of a medical care path. This method addresses all topics that seem relevant for the present treatment decision for esophageal cancer: the current experiences of patients, significant others and clinicians; the metroline visualization of the entire care trajectory, and the persons involved in care and decision-making. [31].

4.1. Strengths and limitations

The relatively small sample size of 17 couples may limit the generalizability of the findings. Participants were selected based on their SANO-2 study participation, meaning that only those who opted for active surveillance were included in this present study. In addition, only patients were included who had a partner closely involved in the treatment decision-making process. Possibly, patients who opted for surgery instead of active surveillance, and/or patients without a partner, may have different experiences regarding the treatment decision.

The strength of this study lies in the exploration of both patient and partner perspectives, by conducting both joint and individual interviews to counter the possibility that participants provided responses they believed were desired by their partner.

4.2. Clinical implications

Within the context of locally advanced esophageal cancer and the decision between active surveillance and surgery, partners should be recognized as valued participants for patients throughout the disease trajectory. The inclusion of partners in the decision-making process most likely supports the couple's ability to cope with and adapt to this life-changing experience of cancer. Patients and partners can benefit in decision-making from an overview of what they can expect during the course of different treatments. As discussed above, a metro-map service can serve this need. If active surveillance becomes an established treatment option in the future, the provision of such overviews and consistent information should become more streamlined.

4.3. Conclusion

Patients often involve their partner in decision-making, which illustrates that decision-making is not a solo cognitive process, but rather a process that is inextricably connected to social relations. Patients may have the final say over the treatment decision, but whatever is important to the patients is affected by their relationships and social environment. Therefore, with respect for patient autonomy, the supporting role of partners in decision-making should be recognized.

Ethics approval statement

This study was performed in line with the principles of the Declaration of Helsinki. The Erasmus MC Medical Ethical Committee approved the study (MEC 2021–0068).

Patient consent statement

All participants provided written informed consent.

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CRedit authorship contribution statement

Bas Wijnhoven: Writing – review & editing, Supervision, Data curation, Conceptualization. **Pieter van der Sluis:** Writing – review & editing, Data curation. **Merel Hermus:** Writing – original draft, Resources, Project administration, Methodology, Formal analysis, Data curation, Conceptualization. **Charlene van der Zijden:** Writing – review & editing, Conceptualization. **Jan van Busschbach:** Writing – review & editing, Visualization, Supervision, Conceptualization. **Sjoerd Lagarde:** Writing – review & editing, Supervision, Funding acquisition, Data curation, Conceptualization. **Leonieke Kranenburg:** Writing – review & editing, Visualization, Supervision, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data Availability

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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