

Patient experiences with pre-amputation communication and shared decision-making – a national cross-sectional survey

Katrine R Støvring*¹ MSc Health Science & BSc Prosthetics & Orthotics, **Ane Simony**^{2,3} MD, PhD, Ass. Professor, **Ulla R Madsen**^{1,4}, RN, PhD, Associate Professor, **Charlotte Abrahamsen**^{2,3} RN, PhD, Associate Professor

¹Orthopaedic Department, Holbaek Hospital, Denmark

²Department of Orthopaedic Surgery and Traumatology, Hospital Lillebaelt Kolding, Denmark

³Department of Regional Health Research, University of Southern Denmark, Denmark

⁴The Danish Knowledge Centre for Rehabilitation and Palliative Care (REHPA), Odense University Hospital and Department of Clinical Research, University of Southern Denmark, Odense, Denmark

*Corresponding author email kstov@regionsjaelland.dk

ABSTRACT

Background Shared decision-making (SDM) can be crucial when making sensitive decisions, such as determining the appropriate level of major lower extremity amputation (MLEA). Despite clinicians aiming for SDM and patients wanting active participation, barriers persist to implementation.

Aim To explore patients' experiences with pre-amputation communication and shared decision-making and their attitudes towards a decision-support tool for future amputation decisions.

Methods An electronic survey was distributed between November 2023 and January 2024 to individuals with MLEA, identified via social media, healthcare professionals working with MLEA patients, and a non-profit patient organisation. In total, 49 individuals responded (27% female, 47% living alone, mean age 63, SD=15). The questionnaire covered four themes: experiences of the pre-amputation communication, preferences for SDM, discussion of different amputation levels and respondents' viewpoints on the potential use of a decision-support tool. Descriptive statistics were used to analyse the questionnaire responses.

Results 43% (n=21) of the respondents felt unprepared for a possible amputation, and 80% (n=39) did not know the surgeon beforehand. More than half (59%, n=27) were satisfied with the pre-amputation conversation, while 22% (n=10) were not. Most respondents (73%, n=33) wanted to be involved in the decision about amputation level, and 68% (n=28) believed a decision-support tool would be beneficial.

Conclusions Patients undergoing MLEA generally want to be involved in the complex decision-making process about amputation level and often are, but there is room for improvement. Discussing the risk of amputation earlier allows patients to prepare better and may facilitate easier engagement in SDM.

Keywords decision aid, lower extremity amputation, patient involvement, pre-amputation communication, shared decision making

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INTRODUCTION

Patients who undergo a partial foot amputation (PFA) due to wounds, peripheral artery disease (PAD), and/or diabetes are at high risk of significant complications. These include delayed wound healing, surgical site rupture, infections, and repeated surgical revisions,¹ which can ultimately lead to major lower extremity amputation (MLEA).^{2,3} Some patients lack adequate information about their treatment trajectory and prognosis earlier in the treatment process. They may not be adequately informed about the potential need for revisions, additional toe amputations, prolonged healing due to arteriosclerosis, complication risks, expected immobility, or alternatives like transtibial amputation (TTA).^{1,4} It has been argued, that

patients facing the prospect of PFA might consciously prefer a more invasive TTA if they understand the comparable outcomes in terms of risk for re-amputation, mobility, and quality of life after both procedures, as well as mortality rates following amputation.^{5,6} Additionally, the literature suggests that patients desire an active role in decision-making, even when major amputations are unavoidable.^{7,8}

Despite clinicians' efforts to consider patient preferences in amputation level decisions, obstacles persist, including patients' health issues (such as hearing, vision, cognitive function), emotional distress,⁹ inadequate health literacy,¹⁰ and clinical environmental context.^{9,11} To improve pre-amputation information and facilitate shared decision-making (SDM)

patients and surgeons can use a decision-support tool.^{12,13} Such a tool can facilitate treatment choices by allowing patients to express their expectations and preferences while assisting clinicians in delivering balanced information about risks, pros, and cons among treatment options.^{5,14} Based on existing literature, these tools can employ diverse mediums such as pictograms, flowcharts, and timelines to enhance comprehension.^{5,12–15} Research shows that decision-support tools improve patient knowledge, risk perception accuracy, and active participation.¹² In amputation level decisions, such tools also help address patient fears and clarify personal priorities.¹³ However, implementing SDM requires fundamental changes in mindset and behavior among patients and clinicians.^{16,17}

Systematic implementation and utilisation of SDM in Danish healthcare,¹⁸ including amputation care, is lacking. Given that approximately 1600 MLEAs are performed on 1200 patients in Denmark annually⁶, there is a need to better understand patient experiences with pre-amputation communication and their preferences for shared decision-making.

Therefore, this project aimed to explore patients' experiences with pre-amputation communication and shared decision-making, as well as their attitudes toward a potential decision-support tool for future amputation decisions.

METHODS

A national cross-sectional survey was conducted using an electronic self-administered questionnaire available via www.survey-xact.dk. Data collection lasted from November 2023 to January 2024. Results were reported according to The Checklist for Reporting Results of Internet E-Surveys (CHERRIES).¹⁹ See Table 6.

Respondents and recruitment

A convenience sample of individuals aged 18 years or older, who had undergone a MLEA due to peripheral artery disease (PAD) and were proficient in reading and understanding Danish, was invited to participate. Respondents were recruited nationally through social media, via the e-mail member list and website of a non-profit patient society for individuals living with an amputation (Amputationsforeningen), and face-to-face by healthcare professionals involved in amputation rehabilitation, known by the authors. A link to an open, study-specific questionnaire was distributed. No incentives were offered to participants.

Development of questionnaire

No validated questionnaire exists to explore patients' experiences with pre-amputation communication and the factors influencing SDM in determining the level of amputation. Therefore, we developed a study-specific questionnaire using the guide by Burns and colleagues²⁰ and previous research on factors influencing the implementation of SDM in hospital settings as a framework.¹¹ The initial questionnaire comprised 45 questions, formulated by the first author. Each question was independently evaluated by the co-authors for coherence and relevance. Subsequently, the first author compiled these ratings, followed by a thorough collective discussion of all questions. This iterative process led to the selection and refinement of questions. A paper version of the questionnaire underwent face validation and pilot testing with four recent MLEA patients. Their feedback

led to minor adjustments, including reducing the estimated completion time and revising two questions. Specifically, Question 3 was changed from *"Was the decision about the amputation of your leg sudden/acute?"* to *"Was the decision for amputation made with only a few hours' notice?"*. Additionally, Question 4 was changed from *"Did it feel like a taboo to ask if amputation was a possibility?"* to *"I found that the surgeons were open to talk about amputation as a possibility for me"*.

The final questionnaire and Survey administration

The final questionnaire had 21 questions across four themes, spread over 12 pages (eight pages with one question, three pages with three questions, and one page with four questions) and took approximately 10 minutes to answer. Respondents could navigate back and forth but could not save and complete later. Each question required an answer to proceed, minimising missing responses, though an *"I don't know"* option was available. No completeness check was performed, and there was no randomisation, so all respondents received the same survey version.

The first theme contained 12 questions emphasising patients' experiences of the pre-amputation conversation, received information, and factors related to medical and environmental circumstances known to influence the feasibility and engagement of SDM.^{9,11}

For the second theme conditional logic was applied, so its three questions only appeared if respondents answered *"yes"* to whether the level of amputation was discussed during the conversation. Respondents were asked whether the surgeon inquired about their participation in decision-making, discussed pros and cons, and if they preferred not to be involved in the decision-making process.

The third theme investigated patients' preferences for SDM using the Control Preferences Scale (CPS) instrument; validated and adapted for patients' and clinicians' views of patients' desire for involvement.²¹ The CPS question was modified to ask about preferred involvement in deciding the level of any potential future amputation.

The fourth theme was introduced with a brief explanation of SDM and the potential use of a support tool. It included seven questions regarding a possible decision-support tool, drawing from the content and format of existing SDM support tools^{5,13,14} and its potential use if respondents faced another amputation.

Response options were presented on a five-point Likert scale, ranging from *"I strongly agree"* to *"I strongly disagree,"* with the option to answer, *"I don't know"/"I don't remember"*. Some response options were formulated as *"Yes"*, *"No"* or *"I don't know"*. Additional text response options were added to capture feedback beyond the fixed responses.

Demographic data collected included age, gender, education, marital status, previous amputation level, time since amputation, comorbidities, and amputation location (region).

ETHICS

The aim of the study was clearly outlined in the questionnaire introduction text, together with information about the length of the questionnaire and the contact details of the last author. Respondents were provided with a link to complete the

questionnaire at their discretion. The return of the electronic questionnaire was considered an expression of voluntary consent. No identifying data was collected. As per Danish legislation, this study did not require ethical approval from the National Committee on Health Research Ethics §14, 2 (Committee on Health Research Ethics, 2011). Data collected were securely stored on a server accessible only to the researchers, adhering to the guidelines of the General Data Protection Regulation.²² The study was registered with the Record of Data Process of the Registry of Southern Denmark (journal no. 23/21681).

ANALYSIS

Partially completed questionnaires with full demographic data were included in the analysis. Categorical questionnaire data and patient characteristics are expressed as numbers and proportions. Numeric patient characteristics are shown as means or medians with 25 and 75 percentiles if not normally distributed. For clarity in analysis and interpretation, the five-item Likert scale was consolidated into three categories: "Agree," "Don't know," and "Disagree," by combining the two positive and two negative responses. The simplification enables clearer comparisons and a more straightforward discussion of results. Unanswered questions are marked as "N/A" in the result tables, followed by the count of missing responses. Data are presented according to the four questionnaire themes, following the original question order. Citations from textual responses are provided to elaborate on the corresponding questionnaire theme without any additional qualitative analysis being performed. Data were analysed in IBM SPSS Statistics 21.

RESULTS

A total of 49 respondents participated, with 84% (n=41) completing the questionnaire in full. The respondents had an average age of 63 years (SD=15), 27% (n=13) were female, and 47% (n=23) lived alone (see Table 1). Among the respondents, 51% (n=25) had diabetes, and 70% (n=34) had received treatment for the condition that led to the amputation (for example, foot ulcer or impaired blood supply) within the year preceding the procedure. Additionally, 33% (n=16) had undergone vascular surgery before the amputation, and 31% (n=15) had previously had an amputation on the same leg (see Table 1).

1. Theme: Patients' experiences of pre-amputation communication

Of the 49 respondents, 43% (n=21) reported they were unprepared for the possibility of an amputation. Half of them (54%, n=26) reported that the decision about the amputation was made within a few hours, and the majority (80%, n=39) did not know the surgeon beforehand (see Table 2).

Concerning communication and context, 64% (n=31) of the 48 respondents who answered this section, felt comfortable asking for information to be repeated, while 21% (n=10) did not. Moreover, 56% (n=27) reported receiving sufficient information, while 21% (n=10) felt they had not. Half of the respondents (n=24) had a relative present during the conversations, with 83% (n=20) of these considering this presence an advantage. Regarding the environmental context, 31% (n=15) felt they lacked sufficient time for questions, and 23% (n=11) reported noise or disturbances had affected the conversation.

Of the 46 respondents who rated their overall satisfaction with the conversation, 59% (n=27) reported being "Satisfied" or "Very satisfied" while 22% (n=10) reported being "Dissatisfied" or "Very dissatisfied" (see Table 2).

The text option revealed that respondents experienced a long difficult treatment course up to the amputation, and ultimately faced a choice between amputation or death. One person wrote, "Severe atherosclerosis led to approximately three months of attempted wound treatment [...]. The infection had begun to put internal organs out of action. Without amputation, I would die from it" (Male, 68 years, amputation 2022).

Very different experiences of the conversation with the surgeon were described in the text options. One respondent wrote, "I sat in a four-man room with a crying wife and a doctor who said there was gangrene in my leg and if I didn't give them permission to amputate now; I would lose my whole leg" (Male, 50 years, amputation 2023). Another respondent wrote this about the lack of risk information, "It was a shocking experience as they had not told me that there was a risk that I could be amputated" (Female, 69 years, amputation 2022). Conversely, some respondents wrote about positive experiences such as

Table 1. Respondents' characteristics

(N = 49)	
Age in years (mean ± SD)	63 ± 15
Female, x (%)	13 (27)
Living status, n (%)	
Cohabiting	26 (53)
Living alone	23 (47)
Longest education completed, n (%)	
Elementary school (max 10 years of school)	12 (25)
High school, vocational education/short higher education (2 years),	9 (18)
Tertiary education (2–4 years)	24 (49)
Higher education, (more than 4 years)	4 (8)
Comorbidities, n (%)	
Previous vascular surgery	16 (33)
Diabetes	25 (51)
Previously amputated on the same leg	15 (31)
Time of treatment of the leg, before amputation, n (%)	
0–1 years	34 (70)
1–2 years	5 (10)
> 2 years	8 (16)
Missing	2 (4)
Time since last amputation, n (%)	
1–3 years (Amputation in 2021 through 2023)	24 (49)
3–5 years (Amputation in 2018 through 2020)	11 (22)
> 5 years (Amputation before 2018)	14 (29)
Location of amputation (region), n (%)	
Capital	14 (29)
Zeeland	5 (10)
Southern Denmark	17 (35)
Northern Jutland	6 (12)
Central Jutland	7 (14)

"We talked about the possibility several times. I had considered the possibility due to a minor wound infection earlier in the year [...] and "[I] spent the night thinking about whether it was the right thing to do, agreed with myself that it was, and I have not regretted it" (Male, 63 years, amputation 2023).

2. Theme: Conversation about different amputation levels

Among the 46 respondents who answered this section, 46% (n=21) reported that the conversation included discussions about amputation at different levels. Of these, 48% (n=10) recalled being asked if they wanted to participate in the decision-making process. Additionally, 72% (n=15) reported that the pros and cons of different amputation levels were discussed, and an equal proportion (72%, n=15) expressed a desire to be involved in deciding the specific amputation level (see Table 3). Their experiences with discussing potential amputation levels were elaborated on in the text option by several respondents. For instance, "I have been extremely satisfied with the treatment from the involved doctors, nurses, and other hospital staff. Based on the information I received, I found it very easy to make the decision; the alternative was not appealing." (Male, 63 years, amputation 2023). Another person wrote: "I said from the beginning that they should do what was necessary to stop the infection" (Male, 75 years, amputation 2017), and a third person stated, "Now that a part of my leg

had to be removed due to gangrene, I wanted to avoid repeated amputations, so I asked for plenty to be taken" (Male, 76 years, amputation 2017).

3. Theme: Preferences for SDM

The Control Preferences Scale (CPS) assessed respondents' preferences for SDM in the event of a future amputation, with 45 respondents providing input. Nearly half (47%, n=21) expressed a preference for shared responsibility in the decision-making process (Option C). Meanwhile, 24% (n=11) preferred to make the final decision themselves after considering the doctor's opinion (Option B), and 16% (n=7) preferred to leave the final decision to the doctor, provided the doctor considered the patient's perspective (Option D) (see Table 4). Different perceptions of preferred roles in decision-making were revealed in the comments.

One person wrote: "It must be the doctor who knows best, where to amputate on the leg" (Male, 56 years, amputated 2016), while another one stated: "I felt that I had all the facts laid out by the doctors and based on that I had no qualms about where the amputation should be done." (Male, 75 years, amputation 2017).

4. Theme: A potential decision-support tool

The final theme focused on identifying key features for a decision-support tool to assist patients and doctors in

Table 2. Responses about Theme 1 (n=49)

Theme 1 - Patients' experiences of communication		Responses	n (%)*
Q1	Were you prepared for the possibility of amputation?	Yes	23 (47)
		No	21 (43)
		Don't know	5 (19)
Q2	Did you know the doctor who talked to you about the amputation in advance?	Yes	8 (16)
		No	39 (80)
		Don't know	2 (4)
Q3	Was the decision for amputation made with only a few hours' notice?	Yes	26 (53)
		No	20 (41)
		Don't know	3 (6)
Q4	I found that the surgeons were open to talking about amputation as a possibility for me.	Disagree	14 (29)
		Don't know	12 (25)
		Agree	22 (46)
		N/A	1
Q5	I could freely ask to have the information explained again if there was something I did not understand.	Disagree	10 (21)
		Don't know	7 (15)
		Agree	31 (64)
		N/A	1
Q6	It was okay to disagree with the surgeon.	Disagree	7 (15)
		Don't know	22 (46)
		Agree	19 (39)
		N/A	1
Q7	I received the information that I needed.	Disagree	10 (21)
		Don't know	11 (23)
		Agree	27 (56)
		N/A	1

*Percentages are calculated based on responses provided

Theme 1 - Patients' experiences of communication		Responses	n (%)*
Q8	The surgeon understood that the decision about amputation was difficult for me and had great significance for my future life.	Disagree	11 (23)
		Don't know	8 (17)
		Agree	29 (60)
		N/A	1
Q9	There was time to talk about the topics/questions that I wanted to talk about.	Disagree	15 (31)
		Don't know	11 (23)
		Agree	22 (46)
		N/A	1
Q10	Noise and disturbance from the surroundings affected the conversation.	Disagree	25 (52)
		Don't know	12 (25)
		Agree	11 (23)
		N/A	1
Q11	Patients with relatives present during the conversation.	Yes	24 (50)
		N/A	1
Q11A	The percentages of those who experienced it as an advantage having relatives present (n=24).		20 (83)
Q12	How satisfied are you in general with the conversation you had with the surgeon about the amputation?	Very satisfied	12 (26)
		Satisfied	15 (33)
		Don't know	9 (19)
		Unsatisfied	7 (15)
		Very unsatisfied	3 (7)
	N/A	3	

determining the appropriate amputation level. Among 44 respondents answering this section, 64% (n=28) believed the tool should help them understand the pros and cons of amputations at different levels and clarify the risk of additional amputations if the initial procedure was performed on the foot. Additionally, 80% (n=35) agreed that the tool should help them understand the possibility of being able to walk again. Regarding the tool's format, 48% (n=21) agreed the tool should be digital, while slightly more (60%, n=26) found it should be printable for use during conversations with the surgeon.

Overall, 68% (n=28) of the 41 respondents who completed the full questionnaire thought that a decision-support tool would be beneficial for them as a patient (see Table 5).

DISCUSSION

To our knowledge, this national cross-sectional survey is the first to examine pre-amputation communication and SDM in amputation level decisions, as well as patient views on a potential decision-support tool within Danish amputation care.

Experiences with pre-amputation conversations

The survey respondents reported diverse experiences with their pre-amputation conversations. Some described positive interactions and feeling well-informed, and others felt pressured into deciding and were surprised by the need for amputation. The overall variation in satisfaction with the pre-amputation conversation aligns with the findings by Pedlow et al.²³

Table 3. Responses about Theme 2, with conditional logic applied (n=46)

Theme 2 - Conversation about amputation levels		Responses	n (%)
Q13	Thinking about the process, did you experience that there was a talk about amputation at different levels as an option?	Yes	21 (46)
		No	21 (46)
		Don't remember	4 (8)
Q13-A1*	I was asked if I wanted to be in the decision about the level of the amputation	Disagree	8 (38)
		Don't know	3 (14)
		Agree	10 (48)
Q13-A2*	The pros and cons of amputating different places on the leg were discussed (for example, the risk of multiple operations, the possibility of getting a prosthesis, the risk of complications).	Disagree	4 (19)
		Don't know	2 (9)
		Agree	15 (72)
Q13-A3*	I did not want to participate in the decision about where on the leg I should be amputated.	Disagree	15 (72)
		Don't know	3 (14)
		Agree	3 (14)

*The 21 respondents who answered 'Yes' to Q13 responded to this question (via conditional logic in the electronic questionnaire)

Table 4. Responses about Theme 3 (n=45)

Theme 3: The Control Preferences Scale		n (%)
A	I prefer to make the final treatment decision	1 (2)
B	I prefer to make the final treatment decision after seriously considering my doctor's opinion	11 (24)
C	I prefer that my doctor and I share responsibility for deciding which level of amputation is the best for me	21 (47)
D	I prefer my doctor to make the final treatment decision, but only after my doctor has seriously considered my opinion	7 (16)
E	I prefer to leave all treatment decisions to my doctor	5 (11)

Respondents from our survey had mixed experiences regarding the opportunity to ask questions during their pre-amputation conversations and their comfort in disagreeing (in general) with the doctor. Individuals at risk of amputation have described struggling to discuss potential amputation with healthcare professionals,²⁴ who have been found to explicitly postpone or avoid such discussions.^{8,25} Previous research suggests that social and professional roles, along with patients' prior experiences with healthcare conversations, can influence the dynamics of the conversation and engagement in SDM.¹¹

In previous research, patients expressed a desire for earlier warnings and better information about amputation risks to better prepare and cope with the procedure.^{8,26} Half of our respondents felt prepared for a possible amputation, suggesting that there had been opportunities to discuss the amputation and possibly the level of amputation beforehand. Additionally, just over half reported that they could freely ask for information to be repeated and felt that the surgeon understood their difficult situation. This is particularly positive considering that most respondents did not know the surgeon beforehand. Unfamiliarity may cause patients to hesitate in asking questions and participating in SDM.¹¹ Torbjörnsson et al.²⁷ concluded that forming a partnership with the surgeon is essential for patients' well-being and their sense of involvement in amputation care.

Half of the respondents experienced that the amputation decision was made with a few hours' notice and one respondent wrote "...Without amputation, I would die from it".

This experience corresponds with what other studies have described as a choice between ‘amputation or death’.^{9,28} This complicates the possibilities of engaging in meaningful SDM, which surgeons have described as a clear barrier for SDM in amputation level decisions.²⁹

The environmental context surrounding the patient can also impact how patients experience the conversation with the surgeon and the decision-making process.^{11,30} Although this was not the experience for most respondents in our survey, one respondent described receiving the message about the amputation in a four-man room and another one described it as a shocking experience not being prepared for the risk of amputation. In other studies, patients facing MLEA have described a chaotic situation at the hospital, and that they felt fragile and needed more time for the decision.³⁰

Other studies have emphasised the need for clear and early communication about treatment trajectories and amputation risks for patients with chronic limb-threatening ischemia (CLTI) and/or diabetic foot ulcers.^{31,32} Discussing potential outcomes in advance can help patients psychologically prepare and actively participate in the decision-making process, thereby limiting patient experiences of rushed decisions and inadequate information.

The decision of amputation level and preferences for SDM

In this study, half of the respondents reported that the pre-amputation conversation had included discussions of different amputation levels. However, only half of these reported being asked directly if they wanted to be a part of the decision and 71% reported a wish to participate in the decision. The discrepancy between the desire to be involved and the lack of opportunity to do so was also found in the work of Leonard and colleagues.⁹ This issue may be caused by health professionals’ prejudices or lack of discourse about amputation.²⁵ This survey revealed that most respondents preferred to collaborate with the surgeon in deciding the level of amputation, if they were to undergo another amputation. Only 14% preferred the doctor to decide while considering their opinion. However, when surveying surgeons treating MLEA patients in Denmark, 43% believed that patients preferred the doctor to decide on the amputation level while considering the patient’s opinion (Submitted data). This highlights a disparity between patient’s wishes and doctors’ perceptions, a discrepancy also identified in other studies.³³

Since our sample is somewhat younger than the general population undergoing MLEA,^{6,34} older patients at risk of MLEA may have different preferences regarding SDM and amputation level decisions compared to our survey

Table 5. Responses about Theme 4 (n=45)

Theme 4 - A potential decision-support tool		Responses	n (%)*
Q15	Do you know about decision-support tools in other contexts?	Yes	8 (18)
		No	33 (73)
		Don't know	4 (9)
Q16	If I were to benefit from a decision-support tool, it should help me understand the advantages and disadvantages of amputating at the different places on the leg (e.g. on the foot, below or above the knee).	Disagree	2 (4)
		Don't know	14 (32)
		Agree	28 (64)
		N/A	1
Q17	... help me understand the possibilities for me to be able to walk (again).	Disagree	0 (0)
		Don't know	9 (20)
		Agree	35 (80)
		N/A	1
Q18	...clarify the risk of further amputation by amputating the foot (if applicable).	Disagree	2 (4)
		Don't know	14 (32)
		Agree	28 (64)
		N/A	1
Q19	... be found and used online/digital.	Disagree	3 (7)
		Don't know	20 (45)
		Agree	21 (48)
		N/A	1
Q20	... be printed and brought along for the conversation with the surgeon.	Disagree	2 (4)
		Don't know	16 (36)
		Agree	26 (60)
		N/A	1
Q21	I think a decision-support tool to use in the conversation about where on the leg to amputate would be beneficial to me as a patient.	Disagree	3 (7)
		Don't know	10 (25)
		Agree	28 (68)
		N/A	4

*Percentages were calculated based on responses provided

respondents.¹¹ Older adults with multiple health conditions have been found to more often prefer a passive role in treatment decisions³⁵ and since the population at risk of MLEA is typically older, frail, and affected by multi-morbidity³⁴ this could also be the case in the general population in risk of MLEA.

When patients are unable to engage in treatment decisions themselves, their relatives play a crucial role in the decision-making process.^{11,31} Almost half of the respondents in our study had relatives present during the conversation, and the majority found this presence positive. This highlights the importance of involving patients' relatives in decisions about amputation levels,³⁰ especially when the patient cannot or does not wish to engage in the decision themselves.

Patients and their caregivers find themselves in a difficult and sometimes indecisive position when having to decide actively for amputation.^{26,31} This decision can be made more challenging if clinicians lack an authentic discourse about amputations.³⁰ Clinicians have also reported difficulties engaging some patients in SDM due to emotions, health, and age-related characteristics^{9,11,29,36}. In our study, only three respondents did not wish to be a part of the decision-making process if they were to have another amputation today, supporting the theory behind SDM that all patients should be given the option to participate. This emphasises the need for SDM training for clinicians, with a focus on engaging older adults and their caregivers in the process.³⁷

Decision-support tool

In our study, we asked the respondents' opinions on a potential decision-support tool to support SDM in amputation level decisions. Over half of the respondents could see the advantages of a decision-support tool when deciding the level of amputation and they found that the tool should be available online and printable to bring to the conversation with the surgeon. Most patients agreed on what the tool should assist them in, during the conversation. Even though mortality is included in existing decision-support tools,^{13,14} we intentionally omitted questions regarding mortality discussions. Discussions of mortality after amputation are uncommon,^{37,38} and we aimed to avoid triggering unnecessary thoughts or anxiety in our respondents.⁴⁰ Conversations about mortality when discussing amputation decisions have been found to be meaningful for clinicians and patients³⁸ but are also described as difficult by clinicians.¹³ This points to further investigation of this subject, in the context of Danish amputation care, if a decision-support tool including mortality, is to be implemented.

Method – strengths and weaknesses

The meticulous process when making the questionnaire ensured the questionnaire's validity and appropriateness for investigating patients' perspectives on pre-amputation communication and the decision-making process surrounding the level of amputation, as well as the potential role of decision-support tools therein. Still, some weaknesses might have affected the results of this investigation.

The recruitment of patients was dependent on social media, the patient organisation, and clinicians in contact with patients. With self-selecting samples, there is a risk of selection bias because those who volunteer are primarily people who have strong opinions or a particular interest in what is being

investigated, thus the group of respondents may not reflect the opinions of the majority of those previously having had an amputation.⁴¹

Despite the recruitment method and a small sample size, our sample closely aligns with comparable patient groups on several key characteristics, cohabiting status, educational status, diabetes, and pre-amputation vascular surgery.^{6,34} Our sample consisted of more men than women and was a little bit younger than the general population undergoing MLEA and, as noted earlier, might therefore not include the most fragile and ill individuals who have undergone MLEA.

Pre-amputation communication can be affected by the patient's situation, cognitive state, influence of pain medication, and emotional state.^{9,23,26,30} These factors were not explored in this study design and would therefore need further investigation. Recall bias may have influenced the results, especially since two of the respondents had their last amputation several years ago. Consequently, their responses might not accurately reflect current practice.

CONCLUSION

In conclusion, our survey highlights the experiences of people who have undergone MLEA regarding pre-amputation communication and shared decision-making. Respondents reported both positive and negative experiences, with most not knowing the surgeon who discussed the amputation beforehand. Half of the respondents reported being prepared for the possibility of amputation, suggesting the feasibility of implementing SDM in this population. Discussing the risk of amputation earlier allows patients to prepare and may facilitate easier engagement in SDM. While half of the respondents experienced a discussion of amputation levels, only a few recalled being asked if they wanted to participate in the decision. Most patients expressed a desire for involvement in these decisions and viewed a decision-support tool as beneficial. This study demonstrates that while patients generally want to engage in the complex process of determining amputation levels, there is room for improvement.

Implications for clinical practice

- Most patients undergoing MLEA wish to be included in the decisions regarding amputation levels.
- Patients at risk of MLEA believe the use of a decision-support tool during conversations about amputation levels will be beneficial.
- Discussing the risk of amputation earlier in the treatment trajectory allows patients to prepare for the possibility, facilitating easier engagement in SDM.

FURTHER RESEARCH

- Future research should evaluate the feasibility and effectiveness of SDM tools for this patient population.
- Investigate the experience of patients and family members involved in severe treatment decisions through interviews.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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SUPPLEMENTARY INFORMATION

Table 6. Explanation of the current study formatted on the Checklist for Reporting Results of Internet E-Surveys (CHERRIES)¹⁹

Item Category	Checklist Item	Explanation
Design	Describe survey design	A national cross-sectional open survey using an electronic self-administered questionnaire. The target population was individuals over 18 years with a non-traumatic MLEA. <i>See page 2, lines 13–14 & page 2, lines 18–20.</i>
IRB (Institutional Review Board) approval and informed consent process	IRB approval	As per Danish legislation, this study did not require ethical approval from the National Committee on Health Research Ethics §14, 2 (Committee on Health Research Ethics, 2011). <i>See page 5, lines 11–13.</i>
	Informed consent	The aim of the study was clearly outlined in the introduction text of the questionnaire, together with information about the length of the questionnaire and the contact details of the last author. Respondents were provided with a link to complete the questionnaire at their discretion. The return of the electronic questionnaire was considered an expression of voluntary consent. <i>See page 5, lines 7–11.</i>
	Data protection	No identifying data was collected from the respondents. Data collected were securely stored on a server accessible only to the researchers, adhering to the guidelines of the General Data Protection Regulation. The study was registered with the Record of Data Process of the Registry of Southern Denmark (journal no. 23/21681). <i>See page 5, lines 11–16.</i>
Development and pretesting	Development and pretesting	<i>See 'Development of questionnaire' page 3, lines 4–19.</i>
Recruitment process and description of the sample having access to the questionnaire	Open survey versus closed survey	Open survey. Respondents could answer the survey by opening the link provided in the introduction text and no password was needed. <i>See page 3, lines 1–2.</i>
	Contact mode	Respondents were recruited nationally through social media, via the email member list, and the website of a non-profit patient society for individuals living with an amputation (Amputationsforeningen), and face-to-face by healthcare professionals known by the authors and involved in amputation rehabilitation across Denmark. <i>See page 2, line 20 and page 3, line 1.</i>
	Advertising the survey	The survey was promoted online via the patient society and healthcare professionals engaged in amputation rehabilitation. <i>See page 2, lines 20–22.</i>

Survey administration	Web/email	The link to the online questionnaire was shared by the patient society and healthcare professionals. The survey was published on www.survey-xact.dk which is commonly used by public and private organisations in Denmark. <i>See page 2, lines 20-22.</i>
	Context	Survey-xact specialises in publishing online questionnaires. We only used it for the collection of the data.
	Mandatory/voluntary	Voluntary.
	Incentives	No incentives were offered. <i>See page 3, line 2.</i>
	Time/date	Data was collected from November 2023 to January 2024. <i>See page 2, lines 14-15.</i>
	Randomisation of items or questionnaires	There was no randomisation thus each respondent received the same version of the survey. <i>See page 4, lines 2-3.</i>
	Adaptive questioning	For the second theme, conditional logic was applied in the electronic survey so that the three questions belonging to the second theme only appeared if respondents chose 'yes' when asked whether they experienced that the level of amputation was discussed during the pre-amputation conversation <i>See page 4, lines 8-12.</i>
	Number of Items	21 items in total
	Number of screens	8 pages with one question each, 3 pages with three questions, and 1 page with four questions. <i>See page 3, lines 21-22.</i>
	Completeness check	No completeness check was done. <i>See page 4, line 1.</i>
	Review step	Respondents could navigate back and forth but could not save and complete later. Each question required an answer to proceed, minimising missing responses, though an 'I don't know' option was available. <i>See page 3, line 23, and page 4, line 1.</i>

Response rates	Unique site visitor	N/A
	View rate (ratio of unique survey visitors)	The survey was voluntary. The system used for the survey cannot record the number of unique visitors, so the view rate cannot be calculated.
	Participation rate (ratio of unique visitors who agreed to participate / unique first survey page visitors)	N/A
	Completion rate (Ratio of users who finished the survey/users who agreed to participate).	A total of 49 respondents participated, with 41 (84%) completing the questionnaire in full. <i>See page 6, line 6.</i>

Preventing multiple entries from the same individual	Cookies used	No cookies were used.
	IP check	IP was not checked.
	Log file analysis	N/A
	Registration	N/A

Analysis	Handling of incomplete questionnaires	Questionnaires that were partially answered, but included all demographic data, were included in the analysis. <i>See page 5, lines 18-19.</i>
	Questionnaires submitted with an atypical timestamp	It was not possible to detect atypical timestamps.
	Statistical correction	Numeric patient characteristics will be expressed in means or medians with 25 and 75 percentiles if not normally distributed. <i>See page 5, lines 23-24.</i>