Increasing patients’ awareness of their own health: Experiences of participating in follow-up programs after surgical treatment for intermittent claudication

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Introduction: Claudication is the most usual symptom of peripheral artery disease, it is described as painful contractions in the leg when walking and alleviated upon resting. People with claudication have an added risk of cardiocerebrovascular events, amputation, and death. Adherence to medical treatment and changes in lifestyles can lower this risk, but this secondary prevention therapy requires engagement, participation, and adherence from the patient.

Objective: To explore patients’ experiences of participating in a 1-year multicentre clinical trial with two follow-up programs evaluating a nurse-led, patient-centered health-promoting programme after surgical treatment for claudication, the FASTIC study.

Methods: A descriptive design with qualitative semi-structured interviews was used among participants in the FASTIC study. The study was conducted at two centres for vascular surgery in the city of Stockholm, Sweden. In all, 17 patients (nine men and eight women) who had completed the FASTIC study participated. Data was analysed using qualitative content analysis with an inductive approach.

Results: Two main categories were identified, ‘Patient-Professional collaboration’ and ‘Experience of one’s health’, which were associated with four subcategories: facing opportunities and obstacles, cooperating based on the illness experience, increasing awareness of one’s own health, and maintaining a healthy lifestyle.

Conclusions: Patients’ participation in follow-up programs after surgical treatment for claudication is highly valuable for an increased awareness of one’s own health. A person-centered care with patient-professional collaboration is experienced as important for maintaining a health-promoting lifestyle.

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Introduction

Peripheral artery disease is a major public health problem and its prevalence increases consistently with age. Known risk factors are hypertension, smoking, hypercholesterolemia, and diabetes. The most usual symptom of peripheral artery disease, claudication, also named as intermittent claudication in the literature, affects approximately seven percent of all adult individuals aged older than 60 years.

Claudication is described as painful contractions in the leg when walking, which are alleviated upon resting. People with claudication have an added risk of cardiocerebrovascular events, amputation, and death. Management of claudication should include best medical treatment as well as lifestyle changes, most importantly smoking cessation and increased physical exercise. According to guidelines, using supervised exercise programs is the first-line treatment and the positive effects of walking exercise on limb symptoms in claudication has been described. In some cases, revascularisation through surgery or endovascular methods could be an essential treatment. Those diagnosed with claudication should be provided with secondary preventive measures including best medical treatment and risk-factor modification to reduce the risk for cardiocerebrovascular events and prevent progression of disease. Claudication reduces the individual’s health-related quality of life with respect to impaired physical health and could be...
expressed as an emotional, physical, and social burden.\textsuperscript{12} The illness could be experienced differently dependent on the individuals’ level of activity.\textsuperscript{13}

Previous studies have found that one year after surgical treatment, quality of life can be improved\textsuperscript{14,15}. However, a recent long-term follow-up study found no improvement in health-related quality of life after five years.\textsuperscript{16}

A systematic review identified important symptoms from the perspective of individuals living with peripheral artery disease including fatigue, pain, cold extremities, limited mobility, impaired sexual function, and non-healing ulcers.\textsuperscript{17} Substantial symptoms can be experienced to varying degrees even after surgical intervention.\textsuperscript{17,18} Experience of burden due to physical limitations, feeling of powerlessness, and sense of dependency has also been reported.\textsuperscript{19}

Patients generally lack understanding of claudication which could lead to delay in diagnosis and treatment.\textsuperscript{19} Patients’ misunderstanding of the aetiology of claudication seems to hinder lifestyle changes.\textsuperscript{20,21} Experiences of pain when walking can lead to beliefs that exercise is harmful.\textsuperscript{18} Another barrier is that patients can have doubts about walking as a treatment and be hesitant to follow recommendations to walk through the pain.\textsuperscript{19}

Secondary prevention therapy necessitates patient engagement, participation, and adherence.\textsuperscript{20} Person-centered care is an important element of care in which the individual’s views about their life situation are placed at the centre of care.\textsuperscript{22} The care is based on the patient’s narrative about their life situation, experience of health, and illness or injury. This approach focusses on building relationships and includes sharing of both information, planning, and decision-making. Thereafter, the patient and healthcare professionals can work together in developing a personal health plan based on the patient’s resources, capabilities, and needs.\textsuperscript{22} Rehabilitation outcomes has shown to be improved through person-centered care.\textsuperscript{23} However, more research with rigorous designs is needed to provide evidence-based guidelines for person-centered care regarding rehabilitation. The Follow-up After Surgical Treatment for Intermittent Claudication (FASTIC) study, described by Haile et al.\textsuperscript{24} aims to evaluate if a health-promoting and person-centered program led by nurses would improve patient’s adherence to recommended treatment and patient related outcome measures for patients with claudication. The current study is conducted as a process evaluation of this multicentre clinical trial.

Process evaluations can help to explain for whom, how, and why a complex intervention has a particular impact.\textsuperscript{25} Furthermore, process evaluation can be used to evaluate the quality of the intervention and help researchers in interpreting and understanding outcomes. The aim of process evaluation can include exploring the views of study participants on the intervention, investigate the contextual aspects, and components of the intervention.\textsuperscript{26} In the present study, we report the findings of a qualitative exploration of patients’ experiences of participating in the FASTIC study.

Materials and methods

Design

A descriptive study design with qualitative semi-structured interviews was used among participants in the FASTIC study. The Consolidated criteria for reporting qualitative research (COREQ) has been followed.\textsuperscript{27}

Brief description of the FASTIC study

The inclusion criteria for the FASTIC study were adult patients (18 years and older) diagnosed with claudication by a vascular surgeon using International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) code I70.2 or I739B, absence of signs of critical limb ischaemia, and awaiting revascularisation through surgery and/or endovascular methods. Exclusion criteria were having a dementia diagnosis, planned discharged to a nursing home, and an expected survival less than one year. The participants were recruited from two vascular surgery centres in Stockholm, Sweden during their stay for revascularisation. Those who meet inclusion criteria were allocated either to intervention or control group using secure computer-generated random numbers. The allocating study nurses had no insight to factors behind the sequence generation process.\textsuperscript{24}

Participants in the intervention group underwent a nurse-led health-promoting follow-up program in accordance with the person-centered care model described by Ekman et al.\textsuperscript{22} The nurses involved in taking care of the participants had received an introduction to person-centered care and basic training in motivational interviewing. The interviewing method addresses the patient’s perspective and focuses on promoting change of behaviours through identifying strength, ambivalence, barriers, and resources.\textsuperscript{28} The nurse initiates partnership with the patient during the first meeting in the ward lasting 30–60 minutes prior to discharge. After revascularisation, participants saw the nurse for three visits in the outpatient clinic at 4–6 weeks, 6 months, and 1 year after revascularisation (for 45–60 minutes in each visit) and had two telephone calls at 2 weeks and 9 months (≤15 minutes each). All visits except two telephone calls were attended. Participants in the control group received oral and written information about their medication, surgical procedure, and secondary prevention from the discharging physician. They were then scheduled for two follow-up visits (4–8 weeks and one year after discharge) at the outpatient clinic. At the first visit the participants met with a vascular surgeon (for 20–30 minutes) and at the second visit they met a vascular nurse (for 45 minutes). For detailed description of the FASTIC study, see Haile et al.\textsuperscript{24}

Participants

Participants who completed the FASTIC study, a total of 191 persons, were given written information about the aim and procedure of this study and asked for their consent to eventually be contacted for interview. Of those, 94 participants gave their consent and stated in the form how they wished to be contacted (telephone or mail). A purposeful sampling procedure was used to obtain a wide range of variations in the dimensions of interest as well as by age and sex until data saturation was obtained. Data Collection

An interview guide was developed based on experience of the research team in which the second, third, and last author have designed and performed several qualitative studies using inductive approach. The interview guide was pilot-tested through two researchers performing two interviews each. The answers from the four interviews were then assessed and found to answer the aim of the study, which confirmed the interview guide to have a high level of usefulness (Table 1).

The individual interviews were conducted between June 2018 and November 2019 at a location chosen by the participant, usually at the participant’s home or in an undisturbed room at the hospital. The interviewing researchers are both female and had no established relationship with the participants prior to the interview. The interviewers were named as contact persons in case of queries in the written information participants received about the study before inclusion. All interviews took place after completion of the follow-up period. During the interview, supplementary questions were asked if needed following topics mentioned by the
conducted Ethical analysis therefore, inductive described interviews. The semi-structured interview guide.

- Can you tell us about your experience of participating in the FASTIC study?
- You were assigned to participate in the intervention or control group, and what did you think about this?
- How has the follow-up program affected your daily life? (e.g., by changing living habits, health perception etc.)
- Is there anything that has been particularly helpful or positive during study participation? (e.g., return visits, phone calls)
- Has anything been particularly obstructive or negative during your participation?
- Is there anything else that you want to add or share?

interviewees and no repeat interviews were carried out. The recorded interviews lasted between 12–37 minutes (median 21 minutes). The interviews were tape-recorded and transcribed verbatim by three researchers.

Data analysis

We performed qualitative content analysis with an inductive approach, and we focused on the manifest content of text, according to Elo, Kyngäs. The motive for using the inductive approach in this study was that there were no previous studies dealing with this phenomenon.

The analysis process involved several steps. First, three researchers independently listened to the recorded interviews and read the entire transcribed interview text. This was done to acquire an overall understanding of the content. The authors used open coding and words, meaning/s, or sentences were noted in the margin of the text of each interview. Among all 17 interviews, 220 meaning units were identified that reflected the overall aim of the study. The text in the meaning units was condensed and then coded according to what was communicated in the text in relation to the study aim. The main categories and associated subcategories covering all the codes were finally determined. To verify the categorization, the entire text of each interview was re-read, the codes and categories were compared with each other. All authors read and discussed the results and concluded them to be consistent with the data analyzed.

Trustworthiness

The authors discussed and reached consensus regarding the chosen categories. The authors collaborated during several scheduled meetings in choosing the quotations that best represented the findings. Interviews and content analysis were performed in Swedish. The quotes were translated to English after the analysis, using a professional language service. The research group discussed and concluded that data saturation was obtained after 17 interviews. Transcription validity was ensured by reading the transcribed text while listening to the audio recordings. When an inductive approach was chosen, each researcher’s pre-understanding was described and discussed within the research group and during the entire analysis process. The analysis had to be transparent; therefore, bracketing our assumptions were important during the analysis process. Nevertheless, according to Granheim and Lundman the reader must finally decide if the findings are trustworthy.

Ethical considerations

This study was approved by the Regional Ethical Review Board in Stockholm (registration number: 2015/2346-31/2). The trial was conducted in accordance with the latest Helsinki Declaration.

Table 1

<table>
<thead>
<tr>
<th>Participant number</th>
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<th>Sex</th>
<th>Age</th>
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</thead>
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<tr>
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</tr>
<tr>
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<tr>
<td>3</td>
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<td>Female</td>
<td>73</td>
</tr>
<tr>
<td>4</td>
<td>Control</td>
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</tr>
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<td>Control</td>
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<td>Control</td>
<td>Female</td>
<td>78</td>
</tr>
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</table>

Written and oral information was given to all participants about both the FASTIC and the current interview study. Written informed consent was obtained prior to their inclusion.

Results

The final study sample consisted of 17 participants, nine from the intervention group and eight from the control group. Table 2 presents the background data of study participants by group assignment. Fourteen of the participants were treated with unilateral revascularisation while three were treated bilateral. The most common method was endovascular with only two participants treated through surgery. Three of the participants had a history of previous revascularisation.

The current results describe patients’ experiences of participating in a research study with two different follow-up programs after surgical treatment for claudication. The results showed similarities but also some differences between the experiences of the two groups.

In the first part of the results, the presented text describes how participants experienced being randomised into either intervention or control group. In the second part of the results, the findings are presented as two main categories: ‘Patient-Professional collaboration’ and ‘Experience of one’s health’; these are associated with four subcategories: facing opportunities and obstacles, cooperating based on the illness experience, increasing awareness of one’s own health, and maintaining a healthy lifestyle (Figure 1).

Of those allocated to the intervention group, many described the allocation as a positive experience. They understood they would receive more frequent follow-ups and/or more opportunities to schedule appointments during the study period. Some participants assigned to the control group pointed out their disappointment at not having been allocated to the intervention group. These individuals expressed a need for a greater support or more follow-up visits, preferably with a professional caregiver such as a registered nurse or vascular surgeon. Meeting the professional caregiver and getting adequate answers about the illness and the treatment were important in relation to the participants wellbeing. One person in the control group expressed satisfaction being in that group as he had to travel often and thus would have difficulty participating in an intervention that involved several follow-up visits. Some participants did not have any direct thoughts about the group assignment, and some did not even recall much about the procedure. These beliefs were more evident for participants in the control group.
Patient-Professional collaboration

Patient-professional collaboration was considered a process in which participants could feel they contributed to research and improvement of future care via their participation. The dialogue typically included a friendly but professional attitude, with a willingness to offer as much help as possible. Working together with professionals over a longer time in the treatment process based on participants’ experiences of illness symptoms was considered crucial, describing the importance of patient-professional collaborating in the treatment and follow-up of patients with claudication. Various opportunities, as well as obstacles, were also described regarding the cooperation between patients and healthcare professionals.

Facing opportunities and obstacles

There was a clear desire among the participants in both groups to take part in contributing and sharing personal experiences in a follow-up program after surgery for claudication. They described the study period in terms of providing the researchers with valuable and meaningful information which in the future can help other people living with claudication. Overall, the collaboration during the study was considered positive, as an opportunity that was given to them. The participants noted that the gains achieved from their collaboration in the study far outweighed the drawbacks. One participant in the control group expressed: ‘I think that if you can help and do something for other people, as I found in this study, that’s perfectly OK with me.’ The significance of the dialogue was well noted by those in the intervention group, particularly regarding the importance of receiving professional answers to their questions and they expressed they were highly involved in the dialogues that took place during the study. When they needed to talk to a nurse, they felt that the nurses were most often available and always took the time required to understand each person’s unique situation, which was appreciated.

The participants in the intervention group also mentioned that more appointment times were available if needed, which gave them a feeling of security that they would be well taken care of and that was much appreciated. As one participant communicated, ‘But it felt like I was getting a little closer to care, in some way. I was also very surprised that there were so many visits during the follow-up.’ A strong desire for greater collaboration, partnership, and communication between themselves and healthcare professionals was explicitly conveyed among those in the control group.

Aspects that both groups had described as obstacles related to such matters as having to wait for surgery or having to undergo several surgeries during the ongoing study period. For some participants, this waiting time created anxiety and fear about the future. Being involved in well-functioning patient-professional collaboration concerning the individual’s treatment was then considered an important factor in alleviating suffering and fostering hope for the future. The importance of being included in a partnership in collaboration with professional caregivers, was highlighted.

Some descriptions indicated that the intervention of the FAS-TIC study demanded a good deal of time and energy (e.g. traveling to and from the hospital). Furthermore, some participants felt that it was difficult to coordinate time for the appointments at the outpatient clinic because of all their daily activities. A few participants felt that the questionnaires were difficult to complete in that some questions were hard to interpret. Several participants in the control group experienced having only a single follow-up visit as a disappointment because they thought it was important to have further conversations with a vascular surgeon or nurse. For some participants, what mattered most were questions that progressively emerged over time and that were related to the surgical procedure. Their questions typically concerned the outcome of surgery or persisting symptoms, but they were also worried if new symptoms had appeared (e.g. pain in the other leg). This raised a lot of new concerns and new questions about the illness.

Cooperating based on the illness experience

Participants in both groups reported having many thoughts about sharing their illness experience, including their knowledge about living with a long-term disease. For a few participants, however, the encounter with the health-care staff during the follow-up generated some emotional triggers (anxiety, anger or sadness) when receiving a lot of information or talking about the disease and surgical procedure. One participant in the control group said, ‘I get angry very often. I’ve never been that way before. I do not know if it’s the medication or? Maybe it’s because I’ve been very sad actually. Because I’ve got this. Because I’ve got claudication…’

Within both groups, patients’ illness symptoms had a negative influence on their life and daily physical activities. Moreover, some participants reported that their status could quickly change, and

![Fig. 1. Main categories and subcategories.](image-url)
symptoms suddenly worsen. They often characterized their condition as one filled with anxiety and fear that was associated with sudden symptom onset, leading to reduced participation in physical activities and a need for social support for maintenance of physical activities. The need for and importance of having many follow-up visits was expressed in both groups. The importance of being able to obtain access to care and to receive prompt treatment for their long-term illness was also frequently mentioned.

**Experience of one’s health**

Participating in the FASTIC study contributed to an increased awareness about claudication as well as more general issues related to health and prevention. One major benefit of participating in the study was that the individual’s attention to health promotion increased. The follow-up programs were described as a reminder of previous knowledge in relation to health and self-care that the participants had. However, the desire to change their lifestyle habits and maintenance shifted among the groups.

**Increasing awareness of one’s health**

Several participants in both groups stated that they felt motivated to initiate healthy lifestyle habits, and some of them had already done so. Both groups described study participation as a motivating factor or stimulus toward increased awareness about health and health prevention at home. Some of the participants had previous experiences regarding health awareness and knowledge as to diet, exercise, and alcohol/nicotine use. This information had been obtained via mass media or other information channels, but also through previous care and claudication treatment.

Thoughts and feelings, as well as new knowledge, regarding the importance of health promotion strategies in everyday life was pronounced in the intervention group. However, differences in experiences varied, with some identifying an increased awareness of living habits, as well as those who experienced a real change in their lifestyle and standard of living. These changes in everyday life were mainly expressed as derived from new knowledge gained through the follow-up programme. One participant in the intervention group said, ‘Yes, definitely, I am more aware today after the follow-up program. I have stopped smoking, reduced my alcohol intake almost 100% and changed my diet, and I exercise more.’

In the control group, participants focused mainly on describing information about medical and surgical treatment, including follow-up of disease symptoms, drugs, and surgery. Above all, many recounted the importance of the surgery, the notable reduction in pain, improved walking, and leg mobility. They reported a big difference from their previous condition and great relief to have the ability to walk with ease again and without pain. Some participants in the control group also stated that they had been given information about increasing their physical activity or that they had previously been active and that with the surgical intervention, they hoped they would be able to be more active physically.

**Maintaining a healthy lifestyle**

Living with a long-term illness that involves pain and movement impairments entails to face numerous challenges in daily life. Receiving support with respect to adopting a healthy diet or reducing the consumption of alcohol or nicotine was much appreciated in participants’ effort to maintain a healthy lifestyle, in both groups.

The descriptions regarding their knowledge and understanding of maintaining good living habits were different in the two groups. In the intervention group, thoughts and feelings regarding the importance of health promotion strategies in everyday life were expressed and highlighted. Their will to improve, their understanding, and their desire to make changes in their daily behaviors were partly reflected in the support they received during the follow-up program.

Several aspects illustrating the importance of person-centered care was mentioned in the intervention group. Support from the FASTIC nurses had been vital to their success in committing and sustaining a change in lifestyle habits, together with appropriate weight reduction. The participants described actual lifestyle changes that they had made during their transformation, including healthier cooking at home, an increase in daily exercise, and lower consumption of alcohol and nicotine. They also emphasized having follow-up visits over a long period of time (one year) facilitated maintaining their healthier habits. The descriptions of the self-care process ranged from increasing perceived knowledge to developing a comprehensive understanding of adaptive self-care strategies, with a focus on health prevention in everyday life. This understanding of the importance of engaging in a healthy lifestyle was most pronounced in the intervention group, together with notions of maintaining control of one’s own health in daily life.

Most participants’ satisfaction level with the self-care support for better health and improved living habits was rated high. One participant in the intervention group said, ‘You were suddenly more important. You were asked questions and listened to, and I have been at the centre! Yes, I felt that I was in the centre, and it has been interesting and something important.’ They expressed that they had a high level of trust and confidence in the healthcare professionals who they felt were willing to provide support and care from a long-term perspective.

In contrast, some of the participants in the control group indicated a lack of motivation or no real desire to change their lifestyle habits. They were aware that maintaining a healthy lifestyle is valuable, but these participants saw no need for any major lifestyle changes for the moment. This reasoning was compatible with their medical records showing good results post-surgery.

Some participants in the control group reported that they were aware of healthy living habits but that it was difficult to adopt these because it was easy to revert to their old habits. In this respect, one participant in the control group said, ‘Then I can admit that I live a little unhealthy too, wine and stuff like that. Sometimes I smoke a cig, although I know, I know, it’s just so stupid.’ Without professional support, it could be easy to fail to maintain a healthy lifestyle.

**Discussion**

Herein, we report the results of a qualitative exploration of patients’ experiences of participating in a research study with two follow-up programs after surgical treatment for claudication. Professional collaboration and experience of one’s health were identified as two main categories. The need for close collaboration with healthcare professionals was perceived as vital, considering the patients’ long-term illness and symptoms, which hindered them from carrying out simple everyday activities. This is in line with previous studies of patients with claudication, where information about the disease and support were found to be important facilitating factors for being able to handle and follow recommendations regarding changes of behaviour[20] and to handle a new life situation and live with long-term illness[32]. The result that participants in the intervention group were more likely to experience not only awareness but also a real change in lifestyle could be associated to the collaboration with professionals regarding information about disease and support. These could have minimized the inconsistency
described by Cunningham et al. between a persons’ beliefs about the illness and the recommended treatment. In that study, the patients were aware that they need to exercise but some lacked confidence in their ability to walk and associated walking with negative outcomes like pain and possible damage on their legs.18 When applying a person-centered approach, the care can be adapted to persons’ expectations and wishes, and empower them to make lifestyle changes.

Some participants in the intervention group mentioned experiencing obstacles to participation in the FASTIC study, which demanded a good deal of time and energy (e.g., traveling to and from the hospital). A further development of the FASTIC follow-up program would be to offer both face-to-face meetings and digital follow-up meetings. Compared with a traditional healthcare, digital health can make data available to both health-caregivers and patients. It can provide collaborative and democratic relationships which promotes joint decisions.33

The attention to health promotion was increased during the study through awareness of health, and the participants described the support from the nurses as a motivating factor, vital to their success in committing to and sustaining a change in lifestyle habits. Health promotion is essential within nursing practice, and nurses have a vital role as facilitators for the empowerment of the patients’ own health promotion efforts. Lopez-Dicastillo et al. express that nurses have the possibility to move between the clinical tasks and health promotion when necessary, and that nurses’ health promotion activities should be seen as a long-term investment for the society and the health care system.34

A person-centered care should emphasis a dualistic perspective, since it should include cooperation between both the patients and the health-professionals.32 The importance of dialogue between healthcare personnel and patients was well noted by participants in the intervention group, who were highly involved in the dialogues. The key components of person-centeredness in providing positive outcomes from a meeting with the healthcare are the ability of the professional to evoke individuals’ beliefs and to motivate the individual to steer the dialogue.35 The competency of the healthcare giver is therefore of utmost importance.

Strengths and limitations of the work

To our knowledge, this is the first study to report results of a qualitative exploration of patients’ experiences of follow-up programs after surgical treatment for claudication. A strength of this study is that the authors have varied levels of previous understanding and involvement in the intervention, which improved the discussion and analysis. In addition, credibility was established through broad experiences and knowledge regarding qualitative interview studies and conducting content analysis in the research group. The two researchers who conducted the semi-structured interviews were not involved in providing usual care or the intervention. Purposeful sampling was used to provide a wide range of variations regarding age and sex and thus increase the generalizability of the findings. The lack of ethnic diversity in our sample could be a limitation. Moreover, the transferability of the findings in this study is limited owing to the small number of participants and the settings in which the study was undertaken.

Conclusion

Patients’ participation in follow-up programs after surgical treatment for claudication is highly valuable for an increased awareness of one’s own health. A person-centered care with patient-professional collaboration is experienced as important for maintaining a health-promoting lifestyle. This research project is expected to contribute to knowledge about implementation of preventive measures for patients with claudication, from patient’s perspective. Vascular surgical units should consider collaboration between patients and health professionals with a person-centered approach during treatment and follow-up.

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Declaration of Competing Interest

None

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