
**The Road to a New Normal - A Qualitative Study on
Relatives' Needs and Roles in Amputation Rehabilitation**

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Abstract

Objective

To explore the roles, experiences, and support needs of relatives of individuals who have undergone major lower extremity amputation during the rehabilitation process.

Design

Qualitative study using focus group interviews and a Research-Driven Photo Elicitation approach.

Setting

A 5-day psychosocial residential rehabilitation program for individuals with lower extremity amputation.

Participants

Thirty-three relatives of individuals with a major lower extremity amputation, recruited through participating patients.

Intervention

Participation in focus group interviews informed by photo elicitation to facilitate reflection and discussion of caregiving experiences.

Main Measures

Data were analysed using Reflexive Thematic Analysis to identify patterns and themes related to relatives' roles and needs.

Results

One overarching theme, *The Road to a New Normal*, described relatives' adaptive processes following amputation. Three subthemes were identified: (1) a gradual realisation of the long-term emotional and practical consequences of amputation; (2) challenges in supporting patients' emotional reactions, including grief and altered identity; and (3) shifting relationship dynamics,

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4 where relatives assumed caregiving roles while striving to maintain their original relational
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6 identity. Many relatives adopted a shared “we-perspective”, emphasising joint adaptation and
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8 coping.
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11 Conclusions

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14 Relatives play a central role in post-amputation rehabilitation, and the findings highlight the
15
16 complexity of relatives’ adaptation following amputation. Their experiences highlight the
17
18 importance of systematically involving relatives in rehabilitation through support for dyadic
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20 coping, emotional preparedness, and shared goal setting to enhance outcomes for both patients
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22 and caregivers
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4 Title page

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8 *The Road to a New Normal - A Qualitative Study on Relatives' Needs and Roles in Amputation*
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10 *Rehabilitation*

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Declaration of Interest

The authors report there are no competing interests to declare.

Ethics

According to the Danish Act on Research Ethics Review of Health Research Projects (Committee Act), ethical approval from the National Committee on Health Research Ethics is required only for studies involving human biological material or biomedical intervention (1). As this study involved interview data only and no human biological material, ethical approval was not required under Danish law. However, the study adhered to the principles of the 1964 Declaration of Helsinki and its subsequent amendments. All participants received oral and written information and provided written informed consent prior to participation. Audio recordings were deleted after transcription. Data storage and processing were approved by the Danish Data Protection Agency, Region Zealand, Denmark (REG-121-2023).

Data availability statement

The data supporting the results and analyses presented in the paper is securely stored on a protected server, accessible only to the authors, adhering to the guidelines of the General Data Protection Regulation (2). Access to the data can be granted upon reasonable request, subject to applicable ethical and confidentiality considerations.

Generative Artificial Intelligence (AI)

The authors declare to have used Generative AI tools ([ChatGPT](#), [Avidnote - AI for Research Writing, Reading & Analysis - Avidnote](#), and [Grammarly: Free AI Writing Assistance](#)) to check the correctness

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4 of wording, grammar, and spelling, and to ensure that the text was concise and without unnecessary
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6 words. This was done since none of the authors are native English speakers.
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10 **Total wordcount:** exclusive references and abstract: **4557**, incl. references, title page, and abstract
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12 **6470**

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15 **Abstract wordcount:** 231

16 Abstract

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21 **Objective:** To explore the roles, experiences, and support needs of relatives of individuals who
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23 have undergone major lower extremity amputation during the early post-amputation period (0–2
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25 years).

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28 **Design:** Qualitative study using focus group interviews and a Research-Driven Photo Elicitation
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30 approach.

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33 **Setting:** A 5-day psychosocial residential rehabilitation program for individuals with lower
34
35 extremity amputation.

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38 **Participants:** Thirty-three relatives of individuals with a major lower extremity amputation,
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40 recruited through participating patients.

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43 **Intervention:** Participation in focus group interviews informed by photo elicitation to facilitate
44
45 reflection and discussion of caregiving experiences.

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48 **Main Measures:** Data were analysed using Reflexive Thematic Analysis to identify patterns and
49
50 themes related to relatives' roles and needs.

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52
53 **Results:** One overarching theme, *The Road to a New Normal*, described relatives' adaptive
54
55 processes following amputation. Three subthemes were identified: (1) a gradual realisation of the
56
57 long-term emotional and practical consequences of amputation; (2) challenges in supporting
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patients' emotional reactions, including grief and altered identity; and (3) shifting relationship dynamics, where relatives assumed caregiving roles while striving to maintain their original relational identity. Many relatives adopted a shared "we-perspective", emphasising joint adaptation and coping.

Conclusions: Relatives play a central role in post-amputation rehabilitation, and the findings highlight the complexity of relatives' adaptation following amputation. Their experiences highlight the importance of systematically involving relatives in rehabilitation through support for dyadic coping, emotional preparedness, and shared goal setting to enhance outcomes for both patients and caregivers

Keywords: Major lower limb amputation, relatives, caregivers, rehabilitation, qualitative study, focus group, thematic analysis

Introduction

Relatives, defined as family members, friends, or others identified by the patient, play a key role in supporting people with chronic conditions (3–5). During hospitalisation and after discharge, they often provide practical care, assist with daily activities, offer emotional support, contribute to decision making, and liaise with healthcare professionals (3–6). These responsibilities can affect relatives' daily lives and well-being, especially as they balance their own needs with those of the patient (4,5).

After a major lower extremity amputation (above the ankle; hereinafter referred to as amputation), the physical and psychological challenges can change significantly during the first year (7). Recovery trajectories vary: some experience a decline in well-being, others adapt to altered life circumstances, while some report stable or improved quality of life (8). The loss of a limb is often likened to bereavement (9–11) and may involve a period of grief while adjusting to new life circumstances (12,13). These diverse pathways and coping strategies (9,14) underscore the dynamic nature of recovery and the need for relatives to adapt to evolving patient needs.

Existing studies show that informal caregiving following amputation can affect relatives' well-being and daily routines, with reported challenges including personal care, mobility support, and reduced social activity (15,16). Emotional responses were often shaped by how the person with limb loss experienced their situation, leading relatives to adopt coping strategies such as seeking support, distraction, or acceptance (17). However, most studies have focused on selected groups or included long and varied timeframes post-amputation (16,17), with limited attention to relatives of patients amputated due to chronic diseases like diabetes (18). This study, therefore, aimed to explore the roles, experiences, and support needs of relatives of individuals who have undergone major lower extremity amputation during the early post-amputation period (0–2 years).

Methods

According to the Danish Act on Research Ethics Review of Health Research Projects (Committee Act), ethical approval from the National Committee on Health Research Ethics is required only for studies involving human biological material or biomedical intervention (1). As this study involved interview data only and no human biological material, ethical approval was not required under Danish law. However, the study adhered to the principles of the 1964 Declaration of Helsinki and its subsequent amendments. All participants received oral and written information and provided written informed consent prior to participation. Audio recordings were deleted after transcription. Data storage and processing were approved by the Danish Data Protection Agency, Region Zealand, Denmark (REG-121-2023).

The study is based on focus group interviews with relatives of patients with amputation who participated in one of four 5-day psychosocial residential rehabilitation stays (see Supplementary file A). Focus group interviews were chosen to encourage dynamic discussions among participants, fostering insights into shared and contrasting experiences (19). This work is reported in accordance with the COREQ checklist (20).

The four residential rehabilitation stays took place at REHPA (The Danish Knowledge Centre for Rehabilitation and Palliative Care Research Clinic) from March 2023 to March 2024, exploring various psychosocial rehabilitation interventions for patients with amputation. The content and outcomes of the stays are evaluated and documented elsewhere (21). This paper reports the results from four focus group interviews with relatives performed on the last day of each stay. The participants for the focus group interviews were close relatives of the 48 patients enrolled in the residential stay, who defined "close relative" according to their criteria.

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4 The relatives needed to be able to make themselves understood in Danish, participate in a group
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6 session with other relatives, and consent to the session being recorded and used for research
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8 purposes. A convenience sample of 33 relatives participated, representing 63% of the 48 patients.
9
10 Most participants were partners/spouses (73%), with 63% being female. The remaining relatives
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12 included adult children, parents, siblings, a social worker, and in-laws. All patients enrolled were
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14 physically independent during the stay, with or without a prosthesis. Two-thirds were men, with an
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16 average age of 64 years (40-90). Most (76%) had an amputation above the knee, on average 10,7
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18 months ago, primarily due to complications from chronic diseases such as critical ischemia, diabetes,
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20 and infection (76%). The rest reported cancer or complicated bone fractures, either acute or over a
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22 longer period, necessitating amputation.
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30 The relatives and patients were invited to join an oral presentation by the second author, who
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32 addressed the challenges that serious illnesses, such as amputations, can pose to interpersonal
33
34 relationships. The subsequent focus group interviews lasted 90-120 minutes and were documented
35
36 using video and audio recordings, supplemented by an observer's on-site notes, who also noted
37
38 what kind of relationship the participant had with the patient. To protect their anonymity, no other
39
40 characteristics about the relatives were collected. An experienced moderator facilitated the
41
42 discussions, ensuring that all participants had the opportunity to contribute.
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48 A variation of the Research Driven Photo Elicitation method (22), inspired by Justesen (23), was used
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50 for the focus group interviews. This method uses visual materials to stimulate reflections on a given
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52 phenomenon, which activates other senses and particularly engages the limbic system, which
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54 processes emotions and is central to memory. Consequently, photographs evoke and recall events,
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56 situations, feelings, and moods more effectively than language and text alone (22). Participants
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4 were asked to select a picture among 60 coloured photo cards that symbolized their answer to the
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7 research question and then share their answers with the group. The photo cards were designed to
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9 support reflections and featured various images, including faces, individuals and groups, hands, road
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11 signs, nature scenes, animals, and buildings (24). The same set of photo cards was used during the
12
13 pilot test and in all focus group interviews.
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16
17 The interview guide was designed and adjusted twice, simultaneously with data collection and initial
18
19 analysis (Figure 1). First, open and neutral questions were developed (by the last author) to
20
21 encourage sharing positive and negative experiences about being a relative to a patient with
22
23 amputation. This preliminary interview guide was pilot-tested with REHPA's user panel (n=10),
24
25 comprising relatives and patients with non-amputation diagnoses. The user panel appreciated using
26
27 the photo cards, which helped focus on what mattered most. However, this pilot revealed that
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29 participants became fatigued after several rounds of questions and card selections, limiting the
30
31 interview guide to include only two of the original six questions.
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38 All interviews began with introductions, during which participants shared their stories from before
39
40 and after the amputation. This sharing created a supportive atmosphere as participants connected
41
42 through relatable experiences and found comfort in being understood. Hereafter, the initial two
43
44 interviews incorporated photo cards for the first two questions (Q1 & Q2). For Q1, participants were
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46 prompted: *"Please choose a card that, for you, represents something important about being a*
47
48 *relative of a person who has undergone a leg amputation..."* For Q2, they were asked: *"Now I would*
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50 *like to ask each of you to take a card that says something about what you would especially like to*
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52 *have known in advance about being a relative of someone who has had their leg amputated."* At
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the end of the interviews, participants were asked to write down three pieces of advice for future relatives.

After reviewing and initially coding data from these first two interviews, the interview guide was refined to probe two emerging themes: (A) relatives' responsibility to seek information post-amputation and (B) balancing support for the patient while fostering their independence. Therefore, the last two interviews only used photocards for Q1. This was followed by a short presentation of the two emerging themes, during which participants were asked to share their experiences with these areas. See the supplementary file B for the translated versions of the interview guide v1+2.

---figure 1 around here---

Data analysis

Reflexive Thematic Analysis was applied according to Braun & Clarke (25,26). The initial data analysis was done by the first and last author, followed by a discussion of the codes and initial themes with other authors. Excel was used for transcription and coding. The photo cards were not systematically included in the data analysis; however, when the photo card prompted the use of a metaphor in the narrative, it was noted in the codes. Metaphors can build bridges between concrete experiences and abstract emotions, which can help uncover deeper layers of meaning (27). For further details on the thematic analysis, coding, and theme generation, see Tables 1&2.

---Table 1 & 2 around here---

The authors, with diverse healthcare research backgrounds and expertise, contributed distinct perspectives to the study. None had prior relationships with the relatives. Minimal personal information was shared during interviews, focusing instead on the project's purpose. The first and

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2
3
4 last authors have extensive experience with patients with amputations, while the second and third
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6 authors brought expertise in supporting relatives of patients with severe illnesses. This diversity
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8 enriched the analysis, providing a multidimensional understanding and strengthening researcher
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10 triangulation.
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13 Findings: The Road to a New Normal

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18 During all interviews, the relatives found joy and recognition in sharing their experiences, from the
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20 events leading to the amputation to the hospital stay and return home. Their focus remained on the
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22 patient, even when asked about their own experiences, highlighting the amputation as a shared
23
24 experience. The reflexive thematic analysis generated one overarching theme, *'The Road to a New*
25
26 *Normal'*, with three subthemes (Figure 2).
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30 --- Figure 2 around here ---
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35 On this road, relatives come to understand, navigate, and adjust to the profound changes that
36
37 amputation brings — not only for the person who has lost a leg, but also for their relationship and
38
39 their own lives. The three themes appeared in all relatives' stories, but with varying impact. One
40
41 relative chose a picture of an iceberg and described:
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45 *"But the iceberg also illustrates that when someone undergoes an amputation, it's just a small part*
46
47 *you can see. Only what's on the surface. A lot of things come up that you must deal with. Life changes*
48
49 *completely."* – (F1, partner)
50
51

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53 The sense that the amputation was merely the tip of the iceberg was also echoed in the written
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55 advice provided by relatives for others in similar situations, though expressed in various ways (See
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57 Table 3 for examples).
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4 **Realising the consequences of limb loss**

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7 The relatives gradually realised the magnitude of the consequences the limb loss had on their loved
8
9 ones and their own lives. A key difference in experiences was whether the amputation was an
10
11 emergency or planned. For some, the realisation began before the amputation, influencing their
12
13 preparedness after the amputation. Some felt relief, viewing it as an end to prolonged suffering and
14
15 a chance to "get their loved one back." In contrast, emergency amputations allowed no time for
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17 adjustment.
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22 Although the physical loss of a limb is most visible, relatives felt unprepared for its huge functional
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24 impact. An intense period of emotional and practical challenges was experienced after returning
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26 home from the hospital, resulting in the relatives putting their own lives on hold to support the
27
28 patient. One relative described feeling a loss of freedom, while another saw work as a "break" from
29
30 these demands.
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35 In this theme, the relatives described certain new roles and needs, highlighting the evolving
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37 responsibilities and adjustments required in their daily lives. A crucial new role for the relatives to
38
39 assume was actively taking on the responsibility of motivating their loved ones, particularly during
40
41 emotionally challenging setbacks. This responsibility, however, placed a significant burden on the
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43 relatives, who felt they had to constantly encourage and "push" their loved ones.
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48 *"She sort of lost her spirit after the operation... We really have to push her to join in with completely*
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50 *ordinary things she used to always take part in... going shopping or heading down to the beach. She*
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52 *loves the beach."* – (A6, partner)
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4 The motivating role involved setting expectations, encouraging independence, and ensuring they
5 felt valued. Setting clear, attainable goals, such as regaining mobility or driving, was emphasised as
6
7 a key motivator for them and their loved ones.
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11
12 *"It's a lot of practical stuff. She actually manages on her own, but I drive her around to training and*
13
14 *so on – yes, she's very active. We've also set ourselves a goal: she's going to be able to drive again.*

15
16
17 *I want my freedom back."* – (B5, partner)
18
19

20 Another important realisation was that relatives had to learn to balance support while fostering
21 independence. Encouraging initiative while resisting the urge to overhelp was highlighted as a
22 delicate and often difficult task. Although driven by love and concern, they acknowledged the
23 importance of allowing their loved one to grow through independence, despite the required
24 patience and effort.
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33 *"Yes, Mum doesn't really want help. It sometimes causes tension between us. I really want to help,*
34
35 *but she won't let me!"* – (B7, child)
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37

38 For the relatives, a part of the realisation phase also covered their process of contemplating that
39 the amputation had caused changes in their shared lives, including the loss of shared interests and
40 hobbies, which was most prominent for those living together.
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46
47 *"There are lots of things we used to do that we can't anymore, like hiking or cycling."* – (H3, partner)
48
49

50 *"It is difficult - what can we do together and what should we do separately? I have attended a*
51 *wedding abroad - without her. I have also gone away with an old colleague. It was nice to get away.*
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53 *I have been on a trip now since my wife was here. I have been wandering around – I can do that."*
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58 – (F8, partner)
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4 More families needed to move to a new place because the previous home was not suitable for
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6 individuals using a wheelchair. Moving was essential for the patient with amputation to gain
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8 independence and for their relatives to regain a sense of freedom. However, for some, the transition
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10 was also connected with feelings of sadness.
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15 *"The house we live in, with the garden, it's been ours, and we wanted to live there until we couldn't*
16
17 *anymore. It's up for sale now. We're moving into a small single-storey house."* – (F5, partner)
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19

20 The introduction of a prosthetic limb was described as a pivotal moment, as daily life significantly
21
22 improved after the patient received a prosthesis, allowing them to regain more independence.
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24 Families worked toward restoring a life that resembled their pre-amputation experience, focusing
25
26 on the patient's ability to do more on their own.
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30 Over time, living with the new situation and its consequences became easier. Relatives were grateful
31
32 they hadn't known the full struggle in advance; however, they wished they had known it would
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34 improve.
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39 *"There is light ahead, we're further away from the amputation itself, and we've started to lead a*
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41 *more normal life. He's got a prosthesis and is getting a car, so we're heading somewhere good. But*
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43 *the road to get here has been tough, and I was close to throwing in the towel."* – (B2, partner)
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46 This sense of things becoming easier with time was also reflected in the written advice. While
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48 expressed in different ways, the advice centred around the themes "There is light at the end of the
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50 tunnel" and "Everything will get easier with time." This perspective was something they particularly
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52 wished they had known during the challenging period immediately following the amputation and
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54 returning home. See Table 3 for the six most common advice themes.
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The patients' emotional reactions

Part of being on 'The Road to a New Normal' involved how relatives were affected by the patient's emotional response to the amputation. Witnessing their loved ones in emotional distress, without the ability to help, was described as particularly challenging, with many relatives expressing a need for more knowledge on how to assist their loved ones in dealing with the emotions and moving forward.

"I did a lot in the period after he came home, trying to lift his spirits. He was very down, maybe even depressed. But everything I did didn't help his low mood." – (B3, partner)

"I'm worried the bubble will burst at some point. He hasn't really reacted to it. ... But I've told him that I'm shaken by his lack of reaction. He's fighting on. And that's brilliant. It rubs off on me." – (F4, partner)

Relatives described the patient's resilience as something that eased both recovery and adaptation for them and their loved one, whereas difficulties in coping left them feeling helpless and uncertain about how to provide support. Grief over losing a leg and their former life also emerged in this theme. One man described how it troubled him that his wife had to go through such a severe experience (losing her leg in an accident):

"What troubles me most is what my wife has gone through; it's been very traumatic. I really feel for her. And sometimes we cry about it together." – (H3, partner)

A part of the emotional reaction was also handling each other's frustrations in the relationship, which was something all relatives recognized and something many described as challenging. Frustrations could arise due to practical things that were hard to do for the patient or when trying to show care for the other.

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4 *"There have been many frustrations – it's hard to handle each other's frustrations, like when she*
5 *wants to manage on her own. I do understand, but I also find it hard... (...) ...As a relative, it's*
6
7 *sometimes easier just to do things yourself."* – (H1, partner)
8
9

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12 For some, the amputation resulted in the loss of employment for the patient, which was hard to
13
14 witness and required families to find new routines in their lives. Two of the relatives described how
15
16 they got sick themselves, and one patient lost his job during the post-amputation time, which put
17
18 even more strain on the relationship.
19

20
21
22 *"He was amputated twice – first his leg, then his job. It's been incredibly hard for him. Work was his*
23 *social life. It's tough watching your husband lose his job – it was such a big part of who he was."* –
24
25 (A4, partner)
26
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29
30 Handling the emotions and consequences of the amputation made some relatives seek support
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32 from outsiders in the form of professional counselling, talking to friends and family, or patient
33
34 organizations, while others described how they had felt very alone with no one to talk to.
35
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39 *"I've spoken to the Danish Cancer Society (support for relatives), and it's been really helpful. I'm not*
40 *finished with that yet."* – (F4, partner)
41
42

43
44 *"Now he's got a prosthesis, and we're heading in a good direction. But I've lacked support. I didn't*
45 *know that relatives could apply for help and guidance."* – (B2, partner)
46
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50 The need to look after yourself as a relative and seek support from others appeared repeatedly in
51
52 the written advice theme "Remember yourself and your needs" and "Seek help, support, and
53
54 comfort for yourself" (Table 3).
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4 **Changing roles in the relationship**

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7 The amputation also brought significant changes to the roles in the existing relationship, regardless
8
9 of whether they were partners, mothers, daughters, or siblings. While these shifts were challenging
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11 and, for some, accompanied by grief, many relatives described how they stood together and worked
12
13 collaboratively to adapt to their new reality.
14
15

16
17 *"We're in this together. We're good at talking about it. His contribution was getting back on his feet,*
18
19 *and I've dealt with everything else. But the balance is there now."* – (F6, partner)

20
21
22 *"My relationship with my dad changed. I sort of became his secretary and took on the 'battle' with*
23
24 *the municipality. I'm surprised at how much we've had to sort out ourselves."* – (A9, child)

25
26
27
28 The return from the hospital constitutes a critical transition period for the relatives, with a great
29
30 need for support from healthcare professionals. Those who experienced well-planned hospital and
31
32 municipal support, such as home modifications before discharge (e.g., ramps and handrails) and
33
34 clear communication, felt prepared for the homecoming.
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39 *"The return home was well organised. The municipality arranged it. First, to a temporary place in a*
40
41 *nursing home, and then home."* – (B7, child)

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44 In contrast, those lacking preparation felt isolated and overwhelmed when returning home.

45
46
47 *"The hardest part has been finding our way through the system... We've been lost in the*
48
49 *communication between the hospital and the municipality... One day he suddenly called and said he*
50
51 *was coming home – but what were we supposed to do? He came home with a wheelchair and a*
52
53 *urine bottle. Luckily, we had already moved to a new house. But we had to get ramps built. That*
54
55 *feeling of uncertainty... We felt completely invisible."* – (F7, partner)
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4 Families with well-planned arrangements managed better, whereas others struggled to navigate
5
6 healthcare and municipal systems for assistance, a process described as stressful and demanding.

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9 The role and responsibility of navigating the healthcare system and municipality, searching for
10
11 information related to amputation, and being proactive in asking questions while settling into the
12
13 new life situation were reflected in the written advice themes “As a relative, you must search for
14
15 information” and “Ask questions and be persistent in getting an answer” (Table 3).

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19 Transportation was described as overwhelming and time-consuming since every trip required a lot
20
21 of planning, i.e., checking wheelchair access and escalators, which the relatives often planned alone.

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24
25 *“Going out and taking trips is completely different now – it takes a lot of planning and thinking in*
26
27 *new ways.”* – (A10, partner)

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29
30 The relatives who lived together with the patient described this handling of transport more often
31
32 than the relatives who did not live together.

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35
36 Relatives described the balance between taking on a caregiving role, comparable to that of a nurse
37
38 in managing intimate and health-related responsibilities, while maintaining their original
39
40 relationship dynamics as particularly difficult and demanding. This was especially hard if the relative
41
42 had provided care during a long illness period before the amputation and/or if the patient remained
43
44 dependent for a prolonged period after the amputation. Initially, relatives actively took the role as
45
46 nurses because they would rather do it themselves than have too many healthcare professionals
47
48 coming along and interrupting or coming at the wrong time, or there was no one else to provide
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50 care.
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57 *“I took on the caregiver role straight after he came home... (...) He had to be lifted around and*
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59 *couldn’t do anything. I had to manage it all. (...) You just do it – help where it’s needed. But you need*
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1 *The Road to a New Normal*

January 2026

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4 *someone from outside to support you as a relative, because you can't see it yourself – that you're*
5
6 *heading down the wrong path. Luckily, a nurse noticed. She told me I needed to take care of myself*
7
8 *– and learn to be a girlfriend again."* – (B2, partner)
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12 In this example, the external intervention helped them realise the need to step back from the
13
14 caregiver role to preserve their pre-amputation relationship.
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17
18 Open communication between the relative and the patient about their feelings and roles was
19
20 described as essential for rebuilding their connection and getting through it together while being on
21
22 *'The road to a New Normal'.*
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26 *"...I don't love him any less because he's lost a leg. We've talked about everything, laughed and cried,*
27
28 *and leaned on each other. We've been able to put it into words."* – (F3, partner)
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32 The need for and importance of nurturing the relationship during the process of adjusting to life
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34 after the amputation was emphasised in the recurring advice theme "Remember to take care of
35
36 your relationship" (Table 3).
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39 --- Table 3 around here ---
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Discussion

This study explored the roles and needs of relatives supporting a person after a major leg amputation. The central theme, "The Road to a New Normal," reflects their adaptation to life changes, emotional strain, and new caregiving responsibilities. While the physical loss is visible, relatives emphasized less expected challenges, especially emotional reactions post-discharge, highlighting the need for better preparation for psychological aspects during rehabilitation. The adaptation process was highly individual and influenced by patient condition, transition to home, and relationship dynamics.

As in earlier studies (17,28–31), returning home was overwhelming for many relatives due to practical burdens and emotional uncertainty. They struggled with navigating the healthcare system and arranging assistive devices and home modifications (31,32).

Our findings reaffirm that relatives often feel unprepared, particularly for the patient's psychological reactions, and express a need for guidance on providing emotional support. While they did not want to know every detail in advance, they wished someone had told them it would get easier. As shown in other studies (28,33), assessing relatives' needs before discharge remains essential. Our study adds that relatives saw themselves as co-responsible for obtaining information and participating in the discharge and rehabilitation process. Besides physical outcomes, they strongly called for more information about likely psychological responses.

Most patients in our study were relatively independent, with 75% using prostheses, yet relatives still faced challenges. Those supporting more frail patients likely require even more guidance (34), particularly on mobility support (16,29).

Amputation affects both the patient and relatives, often triggering grief (11,28,35). While individual coping strategies have been reported (17,28), our study shows how relatives adopt a "we-perspective," seeing the amputation as a shared experience. This aligns with dyadic coping literature, where couples who face illness together often engage in shared problem-solving and emotional regulation (36–38). Relatives in our study supported the patient emotionally and practically, sometimes taking on a motivating role. However, this could become burdensome if the patient's distress exceeded their ability to cope or if the support did not align with patient preferences. Relatives also struggled to balance caregiving with maintaining their identity in the relationship, echoing earlier findings (17,39,40).

Some relatives described shared coping, such as making new plans together or grieving jointly over lost activities. These strategies may enhance both partners' well-being (38), suggesting a benefit to promoting dyadic coping in rehabilitation. Further research should explore how recognizing amputation as a shared, relational event, rather than solely a patient issue, may enhance adaptation.

Communication appeared central to how couples adjusted after discharge, and strained relationships may hinder this process. As noted in prior research, conflict can worsen outcomes for both patients and relatives (41). Our findings also show that being able to step out of the caregiver role—with professional support—helped some relatives reclaim their relational role. Given links between caregiving burden, trauma symptoms, and reduced quality of life (42,43), supporting caregivers in this transition is critical.

Interpretation of the findings requires attention to several methodological considerations inherent in the study design and context. Most participants supported relatively independent patients,

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4 limiting generalizability to those aiding more dependent individuals. However, the amputations
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6 were predominantly related to chronic diseases, which reflects the typical clinical population and
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8 enhances relevance. The pre-interview session on relationship dynamics may have influenced
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10 responses, though balanced with open-ended interview tools. The Danish welfare system may also
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12 explain the lack of financial concerns, which could differ in other contexts (44–47). A strength of the
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14 study is the relatively large and diverse group of participants, including both partners and other
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16 relatives, providing broader insight into different relational dynamics. Furthermore, the study's
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18 strengths include a diverse research team, iterative design, and use of visual methods to enhance
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20 reflection.
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27 In conclusion, being on "The Road to a New Normal" involved emotional, relational, and practical
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29 adaptation for relatives of individuals with amputation. The findings highlight the importance of
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31 including relatives in discharge planning, addressing emotional readiness, and encouraging dyadic
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33 coping strategies. Rehabilitation should not only support the patient but also recognise and
34
35 integrate the needs and roles of relatives. Future studies should test how relationally focused
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37 interventions may improve outcomes for both parties.
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41 42 **Clinical messages**

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46 • **The transition from hospital to home is a high-risk period after amputation.** Discharge planning
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48 should actively involve relatives and address practical needs (e.g. home modifications), as well as
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50 relatives' resources, health, and caregiving capacity.
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4 • **Relatives need preparation for psychological reactions after amputation.** Rehabilitation should
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6 include education for patients and relatives on common emotional responses, such as grief and
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8 identity changes, and guidance on supportive communication.
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12 • **Rehabilitation should target the patient–relative dyad, not the patient alone.** Joint goal setting
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14 and support for shared coping may strengthen collaboration, reduce caregiver burden, and
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16 enhance rehabilitation outcomes.
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For Peer Review

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For Peer Review

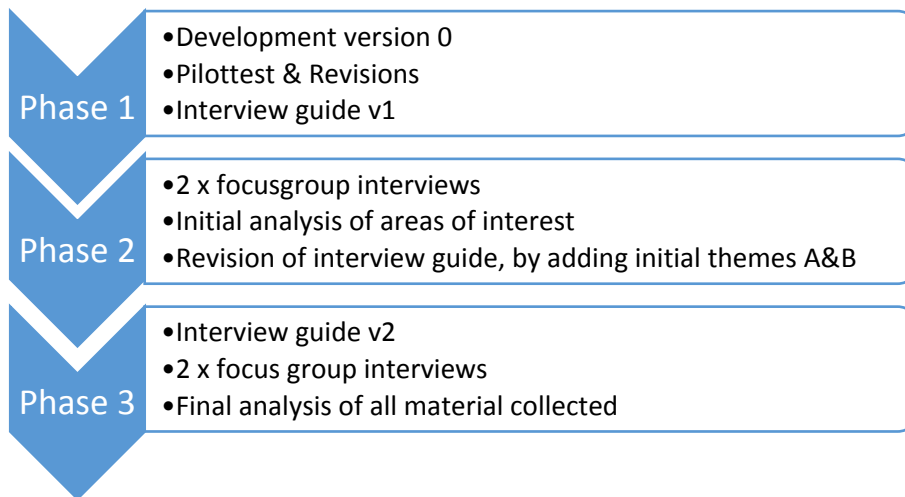


Figure 1: The iterative process of adjusting the interview guide simultaneously with data collection and initial analysis.

Phases	Description of the process in each phase
1. Familiarizing with the data	First author conducted a content transcription of all focus group interviews, noting instances where participants agreed by nodding and any observable mood changes (e.g., smiling, sadness). Additionally, initial ideas and thoughts were documented.
2. Generating initial codes	Features/stories/comments related to the research question were assigned an initial name and colour. The rest of the data was reread and coded, and when a similarity was found, the initial name and colour were added. The data coding was guided by the question, "Which experiences and insights do the participants emphasize concerning their needs and roles?"
3. Searching for themes	Following coding, the process of organizing the codes into potential themes began. Codes with the corresponding informant's ID code were printed on paper, and codes were grouped in themes by the first and last author.
4. Reviewing themes	A Thematic map was made to get an overview of the themes and their relationships, and themes were discussed and evaluated iteratively (by all authors).
5. Defining & naming themes	During the final review of the themes, the data was reread and checked for correspondence with the themes. During this process, saturation was obtained with no new themes identified, but how the themes are associated was adjusted. The written advice was added to the themes that corresponded with the topic of the advice.
6. Producing the report	After analysing and identifying themes, illustrative quotes for each theme were translated from Danish to English, and their meaning was discussed and checked with the Danish version to preserve the intended meaning of the words. Neither transcriptions nor manuscripts were returned to participants for comments.

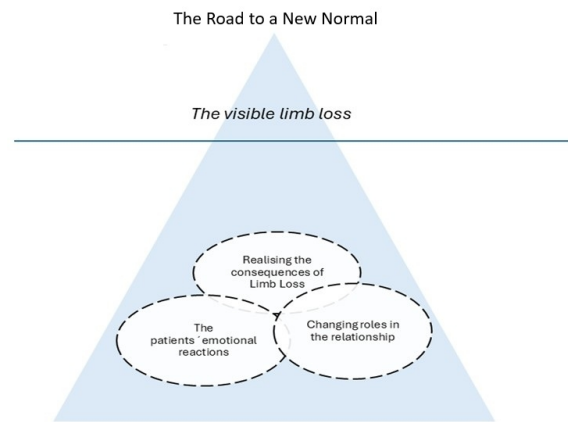
Table 1: Phases in the Reflexive Thematic Analysis

Transcription	Codes	Theme
<p>"There have been many frustrations – It is difficult to handle each other's frustrations" - (H1, partner)</p> <p>"The frustrations have improved; he's not completely down in the dumps anymore." – (H3, partner)</p> <p>"She sometimes gets sad about the things she can no longer do." – (B6, in-law)</p>	<ul style="list-style-type: none"> • Frustrations (because of amputation and its consequences) are difficult to handle • Handling the emotional reactions • Grief over the loss 	<p>The patient's emotional reactions to amputation</p>
<p>"It is difficult to handle each other's frustrations, for example, when she wants to do it herself. Sometimes, it is just easier to do it yourself". (H1, partner)</p> <p>"I found it hard not to help him – very hard." (H3, partner)</p> <p>"Things are moving fast, but she's still afraid of not doing enough at home (after the daughters have started helping more)." (B6, in-law)</p>	<ul style="list-style-type: none"> • 'Difficult to find the balance between helping and letting the amputee do it themselves' 	<p>Realizing the magnitude of the limb loss</p>

Table 2: Examples of coding and the corresponding themes

Advice Themes	Example of what the relatives wrote
Ask questions and be persistent in getting an answer	<p><i>"Remember that there are no stupid questions."</i></p> <p><i>"Ask questions and be persistent in seeking information about what is going to happen, who is involved, and why."</i></p> <p><i>"Be present for all appointments at the hospital, with the doctor, physiotherapist, etc."</i></p>
Remember to take care of your relationship	<p><i>"Agree to be open about challenges and boundaries. It's okay to say both yes and no."</i></p> <p><i>"Remember to share joy over the little things in everyday life."</i></p> <p><i>"Find the balance in your relationship."</i></p>
There is light at the end of the tunnel, & Everything will get easier with time	<p><i>"Remember that there is light at the end and that everyday life will return."</i></p> <p><i>"See possibilities instead of limitations."</i></p> <p><i>"Don't run away, things will get better again."</i></p>
The amputation is only the tip of the iceberg	<p><i>"The physical pain is only one part of it."</i></p> <p><i>"Be patient with your loved one. It's a big shock to their system and mental health to accept the new situation. Your loved one will be angry and frustrated. Remember, it's about them, try to let them know that you are there for them."</i></p> <p><i>"Be prepared for both practical and psychological tasks in supporting the amputee – you may get tired, which is completely natural."</i></p>
As a relative, you must search for information	<p><i>"Search for information at patient organisations and at the hospital."</i></p> <p><i>"Gather plenty of information about having a leg amputated and what it involves."</i></p> <p><i>"Look for information about assistive devices to use in your home or look after a new house."</i></p>
Remember yourself and your needs	<p><i>"Seek help, support, and comfort for yourself".</i></p> <p><i>"Try to get some time to yourself, so everything doesn't end up revolving around illness".</i></p> <p><i>"Do something that makes you happy, so you feel energised".</i></p>

Table 3: The six most common pieces of advice themes with corresponding examples of what the relatives wrote.



21 **Figure 2.** The figure shows that while the physical loss of a limb is the most visible aspect, it can be described as just
22 “the tip of the iceberg”, with many unforeseen challenges and realisations lying beneath the surface. The unexpected
23 challenges are found in the three subthemes encompassed by the overarching theme “The Road to a New Normal”.

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Figure 2. The figure shows that while the physical loss of a limb is the most visible aspect, it can be described as just “the tip of the iceberg”, with many unforeseen challenges and realisations lying beneath the surface. The unexpected challenges are found in the three subthemes encompassed by the overarching theme “The road to a New Normal”.

For Peer Review

Supplementary file A, 5-day psychosocial residential rehabilitation stays

Recruitment of Participants

The participants in the focus group interviews were recruited from a Danish rehabilitation program titled “Videre i livet efter benamputation” (Moving on in Life After Lower Limb Amputation). This program is described in a publicly available Danish report, which includes an English summary (see below) that outlines the context and setting of the rehabilitation initiative.

While the rehabilitation program provided the setting for participant recruitment, the manuscript itself focuses solely on the analysis of the focus group interviews with the relatives and does not further engage with the program or its outcomes.

English Summary: Moving on in life after lower limb amputation (1)

In 2023-2024, REHPA carried out four rehabilitation programs for people with leg amputation. The aim was to collect knowledge about the need for psychosocial rehabilitation and to test various interventions within the framework of REHPA Research Clinic in Nyborg, which could be used in rehabilitation in the municipalities. At the same time, all interventions have had a palliative perspective. The report is aimed at professionals, interest groups, and decision-makers working with people with leg amputations.

Background

It is recognised that the psychosocial challenges of amputation can be at least as great as the physical ones, and there is a need for better psychosocial support in the rehabilitation offered. Internationally, it is recommended to include peer support in rehabilitation programs, but this is not systematically offered in Denmark. Studies show that leg amputees often experience mental problems and social challenges, including stigma and loneliness, but more research is needed on psychosocial problems and effective rehabilitation interventions. A working group of professionals and researchers, together with the Amputation Association, has developed a program based on REHPA's standard rehabilitation program, including a five-day stay, and online follow-up after nine weeks. The program is based on a bio-psycho-social model, is group-based, and involves a multidisciplinary team. Each session builds on top of the other and addresses psychosocial aspects of rehabilitation. In the report, each session is described in detail as an inspiration to professionals.

Main conclusions of the report

Participants had problems of a psychosocial nature like those of patients with cancer or heart disease as they experienced reduced quality of life, reduced function, loneliness, fatigue, sexual problems, depression, and post-traumatic stress. There is a clear need to offer psychosocial rehabilitation programs that participants consider meaningful and relevant. This report presents how a structured psychosocial rehabilitation program after leg amputation can be designed to address the identified psychosocial problems. It is stressed that

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4 social community with peer support is essential and can be a valuable resource. As pointed out in the recent
5 report from the Danish Health Structure Commission, many municipalities will need to cooperate across
6 municipalities to offer qualified rehabilitation at a sufficiently high level. Further research is needed to
7 investigate whether the problems identified can be generalised to the total group of people who have leg
8 amputations. Future studies should also examine the relevance of group-based rehabilitation for the general
9 group of people having a leg amputated.
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14 **Data collection**

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16 The participants were adults with a self-assessed need for help to move forward in life. They should be able
17 to participate in group sessions and not be dependent on physical assistance. The recruitment of participants
18 has been done through social media and in collaboration with relevant organisations. All participants have
19 completed questionnaires that reveal physical, psychological, existential, and social problems. The results are
20 compared in the report with studies involving leg amputees, the background population, or data from
21 previous participants at REHPA Research Clinic (for people with and after cancer or with heart disease). The
22 sessions in the program were evaluated in writing by the participants through an anonymous questionnaire
23 where they assessed the relevance of the topics, the content, the dissemination, and whether they could
24 recommend the session to other leg amputees. The teachers' experience was collected with a similar
25 questionnaire. In addition, the participants' experiences were deepened in a semi-structured online group
26 interview with three to five participants from each program, about 10 days after the stay. The interview guide
27 focused on gaining deeper insight into participants' experiences, including assessments of sessions with a
28 great difference between participants' and teachers' evaluations. Participants were also asked about the
29 possibility of dividing the program into outpatient sessions in a municipal context.
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40 **Results**

41 In total, 48 people carried out one of the four courses. Of these, 62 % were men with an average age of 65
42 years. The youngest participant was 40 years of age, while the oldest was 90 years of age. Amputations were
43 mainly performed above or through the knee (79 %), mostly due to complications from chronic diseases such
44 as infection, diabetes, and critical ischemia (76 %). The rest reported cancer or complicated fractures as a
45 cause. On average, 11 months had passed since the amputation. Many of the participants stated that they
46 were far from living the life they wanted. The most frequently reported problems were physical and practical,
47 including transport, contact with public authorities, and reduced mobility. The participants had significant
48 functional impairments and affected health-related quality of life. A significant proportion showed symptoms
49 of anxiety, depression, and loneliness, as well as reported having pain related to amputation. Fatigue,
50 especially physical, mental, and motivational fatigue, was a problem for many, whereas we did not find that
51 insomnia was a major problem. Participants also reported significant sexual problems. A total of 36 % had
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4 concerns about their role towards family and friends, and 42 % felt that they could not share feelings as
5 desired with their loved ones. The participants generally considered the sessions to be relevant and useful
6 and possible to transfer to a local context. The value of fellowship with like-minded people was highlighted
7 as crucially important. Some sessions were criticised for being less relevant. The participants also wanted
8 relatives to be involved in the process.
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15 Reference

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Supplementary file B

Interview guide version 1

Purpose:

To gather knowledge about the roles and needs of relatives in connection with leg amputation.

- All participants must complete a consent form.
- The workshop will be recorded via Webex for later qualitative analysis.
- The observer serves as an extra set of eyes and ears, assists in managing the Webex recording, ensures that all voices are heard, and takes notes on key discussion points.

Introduction to Participants:

Over the next couple of hours, we would like to talk to you about what it means to be a relative of someone who has undergone a leg amputation. Our goal is to collect knowledge about the roles and needs of relatives, which can be shared with future relatives and the clinicians they encounter.

The session will be recorded to ensure we don't miss any valuable insights. The recording will only be accessed by researchers involved in the project.

Any questions?

Introduction Round:

Please introduce yourself by sharing:

1. Your name
2. Your relationship to the patient with the amputation
3. How long has it been since your relative underwent the amputation

Activity 1: Choosing a Card

As you can see, there are several cards on the table.

1. Please choose a card that, for you, represents something important about being a relative of a person who has undergone a leg amputation.
2. Now I would like you to tell the rest of us about the card you have chosen, and you are welcome to start by describing what you see on the card.

Everyone presents from their card – remember that they must describe what the card represents – ask clarifying questions if necessary and allow other participants to ask questions.

A break may be introduced if needed.

Activity 2: What You Wish You Had Known

1. Now I would like to ask each of you to take a card that says something about what you would especially like to have known in advance about being a relative of someone who has had their leg amputated.
2. Now I would like you to tell the rest of us about the card you have chosen, and again, you would like to start by describing what you see on the card.

Final Activity: Advice for Future Relatives

1. The last thing I would like to ask you is to each take a piece of paper and write down 3 pieces of advice you would give to future relatives of someone who has had their leg amputated.
2. If time allows, participants can share their advice. Otherwise, written responses will be collected.

At the end of the session, participants will be thanked and sent to lunch in the training hall.

Interview guide version 2

Purpose:

To gather knowledge about the roles and needs of relatives in connection with leg amputation.

- All participants must complete a consent form.
- The workshop will be recorded via Webex for later qualitative analysis.
- The observer serves as an extra set of eyes and ears, assists in managing the Webex recording, ensures that all voices are heard, and takes notes on key discussion points.

Introduction to Participants:

Over the couple of hours, we would like to talk to you about what it means to be a relative of someone who has undergone a leg amputation. Our goal is to collect knowledge about the roles and needs of relatives, which can be shared with future relatives and the clinicians they encounter.

The session will be recorded to ensure we don't miss any valuable insights. The recording will only be accessed by researchers involved in the project.

Any questions?

Introduction Round:

Please introduce yourself by sharing:

4. Your name
5. Your relationship to the patient with the amputation

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4 6. How long it has been since your relative underwent the amputation
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7 **Activity 1: Choosing a Card**

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9 As you can see, there are several cards on the table.

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11 1. Please choose a card that, for you, represents something important about being a relative of
12 a person who has undergone a leg amputation.
13 2. Now I would like you to tell the rest of us about the card you have chosen, and you are
14 welcome to start by describing what you see on the card.
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17 Participants will present their chosen cards. The facilitator may ask clarifying questions, and other
18 participants are encouraged to engage.
19

20 Helping questions:

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22 Information: when, in what way. How should you have received that information? What
23 information did you miss? –
24

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26 Left to yourself: what does it mean as a relative? Alone as a relative or just you and your relative?
27

28 *A break may be introduced if needed.*
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30 **Activity 2: Sharing Insights from Previous Workshops**

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32 Over the past spring, we have learned a great deal about what it means to be a relative of someone
33 undergoing a leg amputation. From previous workshops, several recurring themes have emerged
34 among the relatives we have spoken with.
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38 We would like to discuss some of these themes with you—how have you experienced them, and
39 what have they meant for you?
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41 *(Themes to be written on a board)*
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43 **1. Helping the Amputee Without Taking Over (Finding Balance)**

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45 From amputees, we have heard that it can be incredibly difficult to suddenly be in a position where
46 they have to accept help from others. They also express that it can be challenging to practice doing
47 things on their own when the person helping them tends to take over.
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50 **Discussion questions:**

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 - 54 • What has been your experience with balancing helping and receiving help?
 - 55 • Have you talked about this balance before?
 - 56 • Has it ever caused conflicts?
 - 57 • How do you handle situations where your loved one struggles to accept help?
 - 58 • Have you discussed the balance between giving and receiving help?

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2. Access to Information

Many relatives and participants from previous workshops have shared that they felt a lack of information during the amputation process—both for the amputee and for their relatives. We have also heard that it often falls on the relative to seek out this information.

Discussion questions:

- What has been your experience with lacking and searching for information as a relative?
- When have you felt that you were missing crucial information?
- How would you have preferred to receive this information? From whom?
- What information is most important, and at what stage?
- Is this something you can relate to?

If time allows, introduce theme 3.

3. Taking Care of the Relationship

As Nina mentioned in her presentation on being a relative, we know that maintaining the relationship throughout this process is important in ensuring that both partners make it through together. However, past participants have told us that this can be really difficult. Both finding balance in roles and responsibilities after the amputation. But also allowing oneself to put aside the "*protective shield of love*" and speak openly about how the amputation has affected on self.

Discussion questions:

- What have you experienced that the amputation has meant for your relationship?
- What have you done to take care of the relationship?

Final Activity: Advice for Future Relatives

1. The last thing I would like to ask you is to each take a piece of paper and write down 3 pieces of advice you would give to future relatives of someone who has had their leg amputated.
2. If time allows, participants can share their advice. Otherwise, written responses will be collected.

At the end of the session, participants will be thanked and sent to lunch in the training hall.

Key Observations for the Observer:

- Are there viewpoints that remain unexplored? Why?
- Are there facial expressions suggesting a different meaning than what is said?
- Are some participants dominating the discussion?
- Are there participants who barely speak?

The Road to a New Normal

Additional file

- How is the energy between participants?
- What is the group dynamic like?
- Notable non-verbal interactions
- Additional notes to supplement the recorded material

Workshop Methodology

This workshop uses a variation of the Research-Driven Photo Elicitation (RDPE) method (Harper, 2002).

Reference:

Harper, D. (2002). *Talking about pictures: A case for photo elicitation*. *Visual Studies*, 17(1), 13-26.