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RESEARCH ARTICLE



Reducing phantom limb pain using phantom motor execution enabled by augmented and virtual reality: participants' perspectives on an innovative treatment

Els Keesom^{a†}, Kajsa Lidström-Holmqvist^{b,c†} , Max Ortiz-Catalan^{d,e,f,g} , Monika Pilch^{h,i} , Eva Lendaro^{d,e} , Liselotte Hermansson^{c,j#}  and Corry K. van der Sluis^{a#} 

^aDepartment of Rehabilitation Medicine, University of Groningen, University Medical Center Groningen, Groningen, Netherlands; ^bDepartment of Neurology and Rehabilitation Medicine, Faculty of Medicine and Health, Örebro University Hospital, Örebro, Sweden; ^cUniversity Health Care Research Centre, Faculty of Medicine and Health, Örebro University, Örebro, Sweden; ^dCenter for Bionics and Pain Research, Mölndal, Sweden; ^eDepartment of Electrical Engineering, Chalmers University of Technology, Gothenburg, Sweden; ^fOperational Area 3, Sahlgrenska University Hospital, Mölndal, Sweden; ^gDepartment of Orthopaedics, Institute of Clinical Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden; ^hCentre for Health Policy and Management, School of Medicine, Trinity College Dublin, Ireland; ⁱSchool of Psychology, University of Galway, Ireland; ^jDepartment of Prosthetics and Orthotics, Faculty of Medicine and Health, Örebro University Hospital, Örebro, Sweden

ABSTRACT

Purpose: Phantom limb pain (PLP) is a condition that greatly diminishes quality of life. Phantom motor execution (PME), enabled by myoelectric pattern recognition combined with virtual and augmented reality, is a novel treatment for PLP. Here we, aimed to describe patients' experiences of this treatment.

Material and Methods: Qualitative, using semi-structured interviews one month after completed PME treatment. Twenty-one Swedish and Dutch patients (mean age 57, 16 males, 16 lower limb amputations) participated. The analysis followed the framework approach.

Results: The main themes were 1) treatment effects on the perception of the phantom limb, 2) living with PLP before and after treatment, and 3) facilitators and barriers to treatment. Most participants learned to control their phantom limb, perceived it more positively and as more complete. This control over the phantom limb became a tool for managing PLP. Most participants' outlook on life and energy levels improved after treatment. Being mentally focused during treatment was important. Therapists were pivotal to the success of the treatment.

Conclusion: Controlling the phantom limb improved their perception of it and pain management, self-agency, and quality of life. The therapists' role was invaluable. We suggest training for patients in phantom limb control before and after amputation.

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Pain management; qualitative research; therapeutic approach; social participation; activities of daily Living

► IMPLICATIONS FOR REHABILITATION

- Phantom limb pain is a common and chronic problem after amputation. When informing patients about the phantom limb phenomenon it is important to use positive wording and to acknowledge its existence as normal.
- Controlling the phantom limb is a key for the success of the phantom motor execution (PME) treatment and should therefore receive clinicians' attention from the early stages after surgery and onwards.
- The role of the therapist is invaluable in teaching, supporting and coaching patients receiving PME treatment.
- In order to facilitate successful outcome of the PME treatment it is important to consider and reduce potential barriers to patient adherence to the treatment.

Introduction


Phantom limb pain (PLP) is a debilitating syndrome in which patients feel pain at the site of their amputated limb [1]. PLP occurs in 60–80% of all individuals with an amputation and can adversely affect their quality of life [2,3].

PLP can manifest itself in qualitatively different ways, which include but are not limited to stabbing, burning, and cramping pains [3]. The onset, duration and frequency of PLP vary, and whereas some patients experience PLP directly on regaining consciousness after their amputation surgery, others find that it does not start until years after the amputation. However, not all sensations felt in the

CONTACT Kajsa Lidström-Holmqvist  kajsa.lidstrom-holmqvist@regionorebrolan.se 

[†]These two authors contributed equally to this work.

[#]These two authors contributed equally to this work.

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phantom limb are painful, and it is important to make a clear distinction between PLP and phantom limb sensations [3].

Phantom limb sensations can be divided into three categories: kinetic, kinesthetic or exteroceptive [4]. *Kinetic sensations* relate to the way a person perceives the movements of their phantom limb, which can be voluntary or involuntary. *Kinesthetic sensations* relate to the perception of the form and size of the phantom limb but also its position, where for instance, fingers can be fully extended or flexed. Lastly, *exteroceptive sensations* are those sensations that would normally be associated with an external stimulus such as touch, pressure or warmth [4].

Despite being common, PLP has proven difficult to treat, with over 60 different treatments available but no clear recommendations [5]. Pharmacological treatment, mirror therapy, eye movement desensitization and reprocessing (EMDR), use of a prosthesis, neuromodulation and surgical interventions have all been used as PLP treatment options [6,7]. More recently, virtual reality and other technologies have been introduced as promising tools for treatment [8]. One recent approach incorporating technological tools is phantom motor execution (PME) [8], in which a person produces movements of their phantom limb that result in synergistic contractions of the muscle remnant of the amputation [9–11]. The activity of the muscles in the residual limb is picked up by electrodes placed on the surface of the skin and this is used to train a machine learning algorithm to decode the intended phantom movements; the algorithm can be used to control a variety of virtual environments [9,10].

PME treatment consists of three elements. In the first element, the virtual limb is projected on to the participant's residual limb. Participants see themselves on a monitor and can move their projected virtual limb when they contract muscles in their residual limb. The second element is the Target Achievement Control test (TAC test) [12] in which participants must match their phantom limb with a projected limb position on the screen. If this is done correctly, the limb on the screen turns green and a new position is projected. The participant gets a score for this element. The third element is a game in which the phantom limb is used to steer and accelerate a virtual racing car. The muscles in the residual limb are used to control this car [9–11,13].

To research PME as a working treatment for PLP, a large international randomized controlled trial (RCT) has been conducted [13,14]. A total of eight clinics participated in this trial and 77 participants were included. The participants underwent 15 treatment sessions of two hours and were then followed up at one, three and six months after finishing the treatment, including a qualitative interview at the one-month follow-up.

Research exploring the experience of people undergoing a treatment for PLP is rare, especially so for treatments integrating virtual or augmented reality [15]. Qualitative methods are ideal for gaining insight into patients' experiences of treatment [16]. These methods can bridge the gap between quantitative research and clinical practice [17]. The aim of this study was to investigate the patients' experiences with their phantom limb, PLP and phantom limb sensations before, during and after the PME treatment, and their perspectives on daily functioning one month after finishing the treatment. Furthermore, we aimed to gather patients' opinions on facilitators and barriers related to the elements of the PME treatment.

Materials and methods

Design

The study had a multicenter descriptive design belonging in the interpretivist paradigm with a deductive and inductive qualitative

approach guided by the Framework Method [18]. Face-to-face or phone interviews were conducted using a semi-structured interview guide. The COREQ guidelines were followed to ensure comprehensive reporting [19]. Ethical approval was obtained in Sweden (approval number 041-17) and the Netherlands (UMCG METc 2017/109).

Recruitment and participant characteristics

Participants were recruited from a larger sample of patients included in the RCT evaluating the PME treatment [13]. The eligibility criteria for the RCT comprised 15 requirements whereof these were central: a minimum age of 18, amputation at least 6 months ago, a stable prosthetic, pharmacological and PLP situation, voluntary control over at least an agonist and antagonist muscle in the residual limb with no pain in that same residual limb, and cognitive ability to follow instructions. The full eligibility criteria can be found in Lendaro et al. [13]. All consecutively eligible patients were informed about the qualitative study and its procedure, and they signed informed consent before inclusion in this interview study. Three Swedish units (Örebro, Gothenburg and Stockholm) and one Dutch unit (Groningen) recruited participants for the current study. The participants were interviewed during, or close to, the one-month follow-up in the RCT.

A total of 24 participants agreed to be interviewed, 12 from Sweden and 12 from the Netherlands, 18 men and 6 women. All participants had lived with PLP for years, with a median of 5 years. All Dutch patients who participated in the RCT agreed to be interviewed at the one-month follow-up. Two of the Swedish participants at first agreed to be interviewed but withdrew their participation before the interview took place; both were men of working age with lower limb amputations, and the reason they gave was time constraints.

In total, 22 participants were interviewed; however, one interview was excluded from the analysis due to poor sound quality of the recording, meaning that 21 were included in the analysis. The excluded interview was held with a woman of working age with a lower limb amputation; due to long travel distance, she was interviewed using an online meeting platform. The mean age of the 21 participants was 57 years (range 19–84 years). Details of each participant's characteristics are presented in Table 1.

Table 1. Participant characteristics (n=21).

Participant ID	Sex	Level of amputation	Laterality
1-NL	Male	UL, above elbow	Unilateral
2-NL	Male	LL, below knee	Unilateral
3-NL	Male	UL, above elbow	Unilateral
4-NL	Male	UL, above elbow	Unilateral
5-NL	Male	LL, above knee	Unilateral
6-NL	Male	LL, above knee	Unilateral
7-NL	Male	UL, above elbow	Unilateral
8-NL	Female	LL, above knee	Unilateral
9-NL	Female	LL, below knee	Unilateral
10-NL	Male	LL, below knee	Unilateral
11-NL	Male	LL, below knee	Bilateral
12-NL	Female	LL, above knee	Unilateral
13-Sw	Male	LL, above knee	Unilateral
14-Sw	Female	LL, above knee	Unilateral
15-Sw	Male	LL, below knee	Unilateral
16-Sw	Male	LL, above knee	Unilateral
17-Sw	Female	LL, above knee	Unilateral
18-Sw	Male	LL, below knee	Unilateral
19-Sw	Male	LL, above knee	Bilateral
20-Sw	Male	LL, below knee	Unilateral
21-Sw	Male	UL, above elbow	Unilateral

NL: The Netherlands; Sw: Sweden; UL: upper limb; LL: lower limb.

Data collection

Interviews were conducted using a semi-structured interview guide that was jointly developed by Swedish, Dutch and Irish researchers, all involved in the execution of the RCT. The interview guide was developed before the participants entered the RCT, and it covered the topics phantom limb symptoms, effects of PME treatment on phantom pain and everyday activities, perceptions of the different elements of the treatment, control of the phantom limb and general perceptions of the treatment. Each topic had subquestions or probes to encourage the participants to give rich descriptions. Examples of such questions were: *Did the PME treatment change something in your daily life? - If so, in what way?, To what extent, and in what way, did the treatment affect your life?, Was any part of the treatment more effective than the others in affecting phantom pain or phantom sensations?* and *Can you describe why you feel this way?* The complete interview guide can be found in [Appendix A](#).

Since the two patient groups spoke different languages, it was decided to perform the interviews in the participant's native language, using a Swedish or Dutch translation of the original English interview guide. The interview guide was initially piloted for relevance, understandability and content, with one Swedish and one Dutch participant, after which no revisions were needed, and therefore both participants were included in the study.

Nine interviews were conducted in Swedish and twelve in Dutch. Each participant was interviewed during a single session. To conduct the interviews with suitable background knowledge, the researchers were introduced to the PME treatment prior to the start of the interview study. The Swedish researcher (KLH) who performed the Swedish interviews was a registered occupational therapist within neurorehabilitation. She was experienced in qualitative research methods and in performing interviews; she had no previous relationship, or contact, with the participants. Two Dutch researchers, one a resident in rehabilitation medicine (EK) and the other a PhD student in Orthopedics (SB), carried out the interviews. EK conducted 10 interviews and SB conducted 2 interviews. EK had no prior experience in qualitative research but was involved in the inclusion of patients in the main RCT study. In the RCT, she conducted questionnaires during treatment and follow-ups and had contact with the participants during their treatment and prior to their interviews. SB is an experienced interviewer who also had experience of qualitative research and had no previous relationship, or contact, with the participants outside the interview. The epistemological and ontological stance of the researchers was that reality can be experienced from different views and knowledge can be obtained through the experiences of the participants [20].

Interviews were held at the unit where the participant had received the PME treatment, or in their own home ($n=19$) or by phone ($n=2$). Only the participant and the interviewer were present during the interview. The mean length of the interviews was 44 min (range 19–68 min). Saturation was discussed between the researchers and no new information regarding the aims occurred after seven Swedish and eight Dutch interviews. All interviews were audio-recorded. No field notes were taken during the interviews.

Data analysis

The framework method was used for data analysis, using the seven steps outlined by Gale et al. [18], as shown below.

Step 1: Verbatim transcription of interviews in the native language after which participants received the transcription of their own interview and were invited to comment on them. No participants' feedback was received. The Swedish interviews were transcribed by a professional transcriber in Sweden and the Dutch interviews were transcribed by EK.

Step 2: Data familiarization, meaning that the transcripts (in the language of the interview) were read repeatedly to get to know the data. The number of repetitions was subjectively determined by the researcher, who finalized reading as soon as they had a good sense of the whole content of the interview. This implies that not all transcripts were read the same number of times.

Step 3: Six randomly chosen interviews were translated into English by authors EK and KLH (three Dutch and three Swedish). No back translation was made to avoid losing any meaning due to translation. Subsequently, all interviews were deductively and inductively coded independently by both authors by labeling and coding parts of the text that were relevant to the aim. Notes and ideas on patterns, possible explanations or questions were noted for each label, after which EK and KLH exchanged the coded transcripts and coded them again. Multiple discussions among four of the researchers (EK, KLH, LH, CS) followed scrutinizing each other's notes, patterns, explanations, and ideas for codes in order to reach consensus.

Step 4: An analytical framework was developed after discussing the labels and reasons for finding them meaningful, together with explanations and interpretations. A set of codes was agreed on and a brief explanation of each code was made. Using Microsoft Excel, a working analytical framework was developed, and similar codes were merged. This framework was then discussed by KLH, EK, CS, and LH. CS and LH who had not developed the framework read the transcripts to familiarize themselves with the data, after which the framework was discussed again, refined and consensus was reached. It was tested on two more transcripts to identify eventual need for further refinement. No such need was identified, and the framework was used in step 5 to code all interviews in their original language.

Step 5: NVivo release 1.3 (QSR International), a qualitative data analysis computer software package, was used to apply the analytical framework, and all transcripts were coded by EK and KLH. All coding was conducted in the original language of the interview, to minimize loss of meaning due to translation [21]. Interviews previously translated into English were thus recoded in their original language.

Step 6: All data was manually sorted into the framework matrix by KLH and EK, summarized first in original language and then translated into English for each code, with one English summary for Swedish transcripts and one for Dutch transcripts. These summaries were compared and discussed by KLH, EK, CS and LH. The summaries of the Swedish and Dutch transcripts turned out to be very similar and a common summary was formulated for each code.

Step 7: Data interpretation was carried out by comparing similarities and differences, deviant cases, and different perspectives. This was done in a process of multiple joint discussions by KLH, EK, CS, and LH after which the final themes and subthemes were formulated and agreed on. Participants did not provide feedback on these findings. See [Table 2](#) for an illustration of the analysis process.

Table 3. Main themes with underlying Sub-themes.

Themes	Treatment effects on phantom limb pain	Living with phantom limb pain before and after treatment	Facilitators and barriers to treatment
Sub-themes	Perceptions of the phantom limb and phantom limb pain Self-agency and movement control as strategies for handling pain	Acceptance and personal attitude to phantom limb pain Activity performance in daily life Effects on state of mind and sense of self	Mental demands and attitudes to treatment The therapeutic approach External conditions Factors within treatment

Findings

The participants' experiences can be described in three main themes with underlying sub-themes (Table 3). Below each theme, the sub-themes are described in more detail.

Treatment effects on phantom limb pain

Most participants experienced a positive change in how they perceived both their phantom limb and PLP after treatment; some became completely pain free and described it as almost "miraculous." However, there were also participants who did not experience any change and some expressed disappointment.

Perceptions of the phantom limb and phantom limb pain

Participants described how their perception of the phantom limb changed because of the treatment. Before treatment, they described their phantom limb as partially present, that parts could be missing, or they experienced a telescoping effect (shortening of the phantom limb over time).

Some described the phantom limb as a lump with an undefined shape. After treatment, the phantom limb was described as more normal in length and size, such as the number of fingers that were present on a phantom hand. A feeling of being more complete was highlighted as important, as it led to a more positive attitude toward both the phantom limb and PLP.

By making all movements it [the phantom limb] became bigger, so the ankle, shin and calf were there now, they weren't before. And I felt it too, normally these parts were missing. It was just the foot. (Participant 8)

Most participants, but not all, found the PLP easier to deal with after treatment, due to a greater sense of control over phantom limb movements. Another outcome was that the participants developed an ability to distinguish and classify PLP from other phantom limb sensations, which they considered helpful in pain management.

Instead of it just being something that sits there and hurts like hell, I can influence how it hurts, but I can't influence it so that it goes away. (Participant 14)

Self-agency and movement control as strategies for handling pain

Before treatment, participants experienced a lack of pain management strategies. They described using passive strategies such as doing nothing, hoping it would disappear spontaneously, taking medication, wearing a transcutaneous electrical nerve stimulation (TENS) device, having acupuncture or searching the internet for solutions. More active strategies were to try to distract themselves from the pain by keeping themselves occupied, practising relaxation or donning and doffing the prosthesis. The participants' level of movement control over their phantom limb before treatment varied, and it was most common to have no control or partial control. They described their phantom limb as inactive or stated that they did not know how to produce movements in it.

During treatment, participants gained movement control over their phantom limb, although this was to varying degrees and not applicable to all. Most described how the feeling of having control over their phantom limb was valuable for pain management, self-esteem, and the feeling of having a complete body. Participants strived for a natural feeling and preferred compound movements. On the other hand, some also described learning to tense a single muscle and elicit a response on the screen, without feeling it as a real movement. Their degree of control could vary between sessions according to their concentration, their tiredness, or the electrode placement.

After treatment, more participants described applying an active pain management strategy instead of a passive strategy. The dominant strategy was to use the movement control gained during treatment. They valued their ability to vary the intensity and severity of their PLP by relaxing and moving the residual stump muscles, and this gave them a sense of control.

After treatment, participants reported that the phantom limb felt more complete, less painful, or not painful at all. Others described still feeling PLP, but they were able to relax and felt more complete. Some participants found it hard to move the phantom limb without the feedback from the PME system and they would have liked a home system; others had no problems with maintaining movement control after treatment and they continued the exercises at home.

I can steer it. I have more grip and when I feel it I move it and that works. I feel I can make it less painful by exercising. There is less pain and it goes away faster. (Participant 5)

Living with phantom limb pain before and after treatment

Acceptance and personal attitude to phantom limb pain

Before treatment, participants expressed a degree of self-doubt that led them to question their sanity because they perceived pain in a non-existing body part. This led to a lack of confidence in their ability to accomplish their tasks at work, due to fear that mental problems would affect their performance. The treatment reassured these participants that their phantom limb was not a figment of their imagination but rather, a neurological response to the amputation. Together with the improved ability to perform movements, this enabled them to accept their phantom limb as a body part. This acceptance changed their attitude toward PLP indicating an understanding that, as all body parts hurt sometimes, the phantom limb can hurt as well. This line of thoughts made it easier to handle PLP, and it was no longer considered a mental problem in the same way. As one participant put it:

We (the phantom and I) are practically buddies now... it was not good before. Our relationship was no picnic. (Participant 19)

Activity performance in daily life

The participants' perceptions of how PLP affected their activity performance before treatment varied. They all described PLP as having a negative impact on their activity patterns. They were not always referring to the number of activities that they could carry

out, but in many cases, they also talked in terms of the quality of their participation. The pain affected their concentration, sleep, energy, mood, and they had to adapt their daily life in various ways. Some described engaging in a deliberately overactive lifestyle to distract themselves from the pain. This also left them sufficiently exhausted to sleep at night. In contrast, others described a more restricted life with more rest, fewer social contacts and difficulties sleeping. Social life was the area affected most negatively. Many social activities, such as having dinner with friends, are performed sitting down, which was described as a position that worsens PLP. Lack of concentration, lack of sleep, mental fatigue and a high intake of pain killers made it difficult to follow conversations and to actively take part in social life. Furthermore, mood changes such as depressive mood or irritability affected their interaction with others. Altogether, this resulted in participants having to prioritize between or opt out of activities, particularly social activities.

...and I could not be nice to the grandchildren, even dropping a pencil would set me off. So if they came around I would just go to bed. (Participant 2)

After treatment, there were only small changes in actual activity performance regarding work, household or leisure activities, even though some participants also described working more or engaging in more leisure activities.

However, some participants experienced that their everyday life had been affected in a positive way, which made them see a brighter future for themselves. As one participant reasoned:

Yes, I'm thinking of other things. More positive about everything so to speak. Because as I say now, it feels like now my body is intact in some way. And then I find myself wanting to do things more too. (Participant 15)

Some participants described how the treatment had been life-broaden, making it possible to enjoy life again and enabling them to change their social activities. Others described having more energy, being more patient, and feeling a will to plan things with others, such as being with their grandchildren. Sleep was still a problem for many participants, even though some slept better.

I am awake longer during the day, and the grandchildren, it is perfect, lovely, I can enjoy them again. Yes really, it gave me so much. (Participant 2)

Effects on state of mind and sense of self

After the onset of PLP many, but not all, participants perceived that their sense of self had been affected. They saw themselves as a person who was less fun to be with. Changes in emotions and mood, such as being more easily irritated, led to changes in behavior such as yelling at people in a way that they had to apologize for afterwards. Some described being ashamed of their own behavior.

My mood is closer to the surface, there is an increasing risk of exploding with emotion when there is a lot of pain. (Participant 19)

Some participants described depression and existential questioning such as whether their life was worth living. However, they only occasionally had these thoughts.

After treatment, several participants described improvements in their sense of self and state of mind. They did not feel that they had changed as a person but rather that they had regained their former self because their mental fatigue had reduced, and their energy levels increased. This improvement meant that they could focus better and feel less irritable. They expressed a better outlook on life, with feelings of hope and confidence about the

future. Participants described how these changes had given them new desires, such as traveling, trying new leisure activities, trying new prostheses, or exploring new job opportunities. They reported that they had a better, or much better, quality of life.

On the other hand, those participants who did not experience any changes in PLP or did not develop strategies for pain management expressed disappointment with the treatment and painted a bleak picture of the prospect of being forced to grow old with PLP.

I see the future a bit too negatively. There are of course energetic pensioners, but there are also very tired newly retired pensioners. And if you have problems like this now, how the hell will it be then? So I try to avoid (thinking about it)... Yes. We'll have to deal with that when the time comes. (Participant 13)

Facilitators and barriers to treatment

The participants described both facilitators and barriers regarding the PME treatment. The following sub-themes were identified and encompassed both facilitators and barriers: *Mental demands and personal attitudes to treatment*, *The therapeutic approach*, *External conditions* and *Factors within treatment*.

Mental demands and personal attitudes to treatment

Most participants were highly motivated to complete the treatment. Their belief in the treatment was regarded as a facilitating factor. However, the participants' belief in the treatment, and thereby their motivation, could decrease, or even be lost when they did not achieve results. The treatment was mentally demanding and required mental strength to facilitate an effect. This could be a barrier in treatment for those who could not maintain focus or who for different reasons were tired during treatment, but it could also act as distraction from pain.

I think that it asked so much of my concentration and that was so distracting that it caused less pain (Participant 12)

Whereas a certain degree of competitive personality seemed to be a facilitator, a personality that was too competitive could be a barrier because focusing too much on high scores diverted attention away from the real goal of the exercises, namely, to learn to move the phantom limb in a natural and relaxed way. Focusing on natural movements of the phantom limb in a relaxed way, instead of reaching high scores on the exercises and tests and putting too much strain on oneself, seemed to be facilitating.

The therapeutic approach

The therapeutic approach used by the therapist was important for how the participants experienced the session and managed to achieve the movements. Several facilitators were described, related both to an approach that focuses on creating mutuality and to one that focuses on facilitating performance. The therapist's approach when coaching the participants was crucial. Approaches described were: instructive, in which the therapist gave guidance in how to make the movements; encouraging, in which the therapist used humor and cues to make the participant push and try harder; collaborative, in which the therapist and participant collaborated in finding solutions; and, problem-solving, in which the therapist gathered facts and suggested solutions based on those facts.

Halfway through I really had a tough moment. And then it is really nice to have someone knowledgeable that helps you. It felt really pleasant to have those with the expertise right next to you. They had a really positive effect. (Participant 1)

Barriers to treatment could occur when the participants perceived that the therapist's approach did not match their needs or maturity, such as treating them as children. Other barriers described were when different therapists gave conflicting instructions for how to perform the exercises, or for what to focus on.

External conditions

External conditions, such as individual needs regarding treatment intensity, were perceived as facilitators when they were met with flexibility.

I got very tired afterwards... so that if I were to do this every day then I probably wouldn't be able to do it. But twice a week was perfect (Participant 21)

The participants also described the necessity of a proper treatment environment and structure of the sessions, such as a prepared room, quietness, and regular breaks in order to have enough energy for the exercises. An external condition that contributed to increased fatigue, and thereby constituted a barrier regarding mental strength, was long travel time to and from treatment. Mental tiredness after treatment was a particular problem in this context. Participants also described that they needed enough time and energy for all their commitments in life and that adding a demanding treatment could contribute to stress.

Factors within treatment

A facilitating factor, irrespective of the perceptions of the technique per se, was that most, but not all, participants found that seeing themselves with the virtual limb was initially emotional as they then felt complete. The virtual limb exercise allowed them to move the limb freely and naturally and to learn how to relax, at the same time receiving feedback on the movements on the screen. This was important to have an effect on their PLP and learning how to relax was especially important for those experiencing PLP when trying too hard.

The TAC test was described as fun and challenging, and it helped the participants to try to improve their performance. As with the virtual limb exercise, the visual feedback was a facilitating factor in the TAC test.

It felt really real when you saw it. And it helped me let my phantom become part of myself. It made me more complete. Even if only virtually. It felt good. (Participant 5)

Some participants experienced that the requirements for coordination of movements were too high and that combined movements were therefore too exhausting. One such exercise was the car race game, which even triggered pain for some.

Several participants described the placement of the electrodes as a barrier; it took valuable time from the treatment, and sometimes the therapist did not manage to place them well enough to get the most out of the exercises. Further, some participants found the graphical design of the virtual limb not natural enough. For them this was a barrier, as it distracted their attention. Another comment on the design of the treatment programme was that not all exercises were adapted to the level of the participant's amputation, which made it feel unnatural when, for example, steering a virtual car with the phantom leg.

Discussion

Using a qualitative study design, we revealed that most of the participants who underwent PME treatment gained a more

positive view of their phantom limb, learned to control it and perceived it as more complete. Most participants were able to change their pain management strategy from passive to active, and the treatment had positive effects on their sense of self, quality of life, sleep, and energy. Their mental focus and perseverance and the therapeutic relationship appeared to be important facilitators for a positive effect from the treatment. However, there were also participants who reported no effect on PLP from the treatment. Fatigue, insufficient muscle relaxation and external conditions were the main barriers to success.

Executing phantom motor movements has been reported to successfully reduce PLP in lower limb amputees [2,22]. In a randomized controlled trial, graded motor imagery treatment (a three-step process including mirror therapy and imagery movements) had a positive effect on PLP reduction compared to routine physiotherapy [2]. Others found that participants who used phantom motor exercises combined with motor imagery exercises to reduce their PLP had significantly better results compared to the control group treated with mirror therapy and routine physiotherapy. The former group also showed significant improvement in all quality-of-life domains [22]. A significant advantage of our PME treatment over imagery exercises might be that our participants moved their now visible virtual phantom limb on the screen, providing direct feedback to themselves and to the therapist on their phantom movements, whereas in motor imagery treatments, direct feedback is lacking. Receiving such feedback allows the therapist to adjust the treatment to the individual's needs.

Even though all our participants had experienced PLP for years (Md = 5 years), most of them reported that the PME treatment proved to be successful in reducing even chronic PLP. The PME exercises became the dominant, active strategy for managing PLP, instead of the more passive pain management strategy that the participants had used before PME treatment. It would therefore be interesting to explore the preventive effect of the PME treatment directly after a limb amputation. However, it is important to note that some participants experienced no effect of the treatment on PLP. Furthermore, there were participants who experienced barriers to treatment, regarding their attitude to the treatment or their ability to focus. Therapists should consider such barriers to help patients to overcome or reduce them.

One striking effect that our participants pointed out, regardless of the effect on PLP, was that by gaining active motor control over their phantom limb movements, the size and shape of the phantom limb normalized. Interestingly, a correlation has been found between PLP and changes in the limb's cortical representation [23,24]. Furthermore, participants described a change in their attitude toward their phantom limb, from being something undefined to being a natural part of their body and making them feel more bodily complete. They also experienced their phantom limb in a positive way for the first time in years. This can be interpreted as a positive development of their body image because of the PME treatment, which might have contributed to a reduction in PLP due to better psycho-emotional appreciation. Amputees suffering from PLP have previously been shown to have a more negative body image than those without PLP, and mind-body treatment targeting this area has been highlighted as crucial in reducing PLP [25,26]. We therefore propose a programme of education and training for individuals with an amputation about actively using their phantom limb from the early stages after surgery and onwards, to enable them to experience the phantom limb as complete and controllable.

Participants perceived changes attributable to the PME treatment beyond the reduction of PLP and normalizing the phantom limb sensations. Even though many participants described not letting their PLP influence their performance of daily life activities,

many experienced an improvement in energy levels, mood, participation in social life and having a brighter outlook on the future after treatment. These beneficial effects of pain treatment were also found in research on patients with chronic pain [27,28]. This confirms the impact chronic PLP has on quality of life, outlook on the future and day-to-day activities, and stresses the importance of finding an effective treatment.

Our participants described how, after the PME treatment, their sense of self and state of mind improved. Not only did the gain in motor control help them to accept their phantom limb as part of their body, but also the acknowledgement, by the treatment team, that their phantom limb was real and normal was pivotal, even among participants who reported that the PME treatment had no effect or limited effect on their PLP. This finding implies that in clinical practice it might be important for therapists to be aware of the language they use when they first inform patients about PLP and phantom limb sensations, to avoid negative connotations and ideas related to the phantom limb; a positive attitude to the phantom limb appears to be crucial for the patients. This is also supported by studies about language and pain experience [29,30]. These studies reported that when individuals are in constant pain, they respond more strongly to specific words used to describe pain; this is in part influenced by personality and culture, but more so by thoughts and emotions, because language can produce a negative memory [29]. They conclude that the use of appropriate language is helpful in the management of chronic pain patients [29]. Regarding the people suffering from PLP, our research suggests that it is important to use positive language from the early stages after amputation.

In general, it can be said that the success of any treatment is dependent on the patient's adherence to treatment [31]. Patients need to be able to focus on their therapy to stay involved [32]. The PME treatment asked patients to be focused on the goal of making movements with their phantom limb. It proved to be a mentally demanding treatment and the ability to maintain focus was vital for a successful experience of pain reduction, and for the feeling of having control over the situation. Both internal and external factors were identified for a successful or reduced ability to focus: if participants were tired, distracted by day-to-day problems or annoyed by system failures or the unrealistic graphical design of the virtual limb, they found it harder to focus. Given that the ability to focus proved to be important, patients who find this difficult due to problems related to work, sports, family, high doses of medication such as opiates, or who have cognitive problems, might not be suitable for treatment with the PME system.

An important facilitator proved to be the relationship with the therapists, which confirmed previous studies on facilitating factors for effective treatment [33]. Participants felt understood, valued, and taken seriously about their PLP, and they appreciated the therapists' professional expertise on this rare phenomenon. Different therapeutic approaches can be used to meet a patient's training needs, such as an instructive, encouraging, advocating, collaborative or problem-solving approach [34–36]. In our interviews, the participants described the therapists as being mostly person centered and using mostly approaches, they described as instructive, encouraging and problem solving. This result is not surprising, as the content of the PME treatment demands these types of therapeutic approaches rather than, for example, efforts to convince participants of the benefits of the programme; these efforts would be unnecessary, since nearly all participants were highly motivated to try PME treatment from the beginning [36]. In the PME treatment, learning plays an important role, as the participants are asked to control increasingly difficult movements. Learning can be facilitated in different ways, such as by trial and error or by errorless learning [34]. Trial-and-error learning is learning by making mistakes, whereas

in errorless learning the therapist guides the learning process to minimize mistakes and thereby cancel out any negative experience, because failures can be more salient in memory than successes are. Even though the PME treatment has clear elements of trial and error, errorless learning also seemed to be important in the treatment process, as it helped the participants to focus on remembering the correct action instead of remembering their mistakes [36]. Errorless learning helps the individual to focus on performing specific movements, without stress and without a high cognitive load on episodic memory [37]. In combination with a strong therapeutic alliance, errorless learning is found to be important in improving treatment adherence, quality of life and satisfaction with treatment [33,36,38–41]. Treatment with the PME system seems to be more than just learning to move the phantom limb, since the therapist's role was seen as invaluable.

Participants also experienced some barriers to the PME treatment. These were related to travel time, suboptimal placement of the electrodes, finding it hard to fit the treatment sessions around daily life and having trouble focusing. It proved important to have a stable environment for PME treatment. Until now, the PME training has been an outpatient clinical training in specialized centers. A home treatment system might be an answer to some of the barriers and it could be a helpful addition to the outpatient clinical training with specialized therapists [42].

Future research directions and clinical implications

The results of this study show that many, but not all, participants had several positive effects of the PME treatment, however the effects need to be further evaluated from different perspectives. To investigate eventual differences in characteristics of participants can gain insight in which patients benefit most from the PME treatment. In this study, the participants had lived with PLP for some years, and it would be valuable to study if PME treatment shortly after surgery can prevent the development of PLP. For some of the experienced barriers to treatment a home training version of the PME treatment may be a solution. However, this needs to be studied to verify a potential effect of this version of the treatment. Further, when developing a home training program, it is important to take the interaction between therapist and participant, and the therapists' expertise in consideration as it seems to be of great value for a positive outcome.

In clinical practice, the therapeutic relationship seems to have a substantial impact on the outcome. A person-centered approach, where the therapist adapts both treatment and difficulty in the exercises to the patient's living situation and mental ability for the day, is important. Further, to create a stable physical environment without distractions can help the patient overcome the mental demands needed during the training session.

Strengths and limitations

A limitation of this study is that one of the Dutch interviewers was involved in both the inclusion of patients and conducting questionnaires during the RCT, as well as doing the interviews at the one-month follow-up. The fact that participants knew who the interviewer was might have enhanced the participants' willingness to participate, or reduced their will to decline the interview, as there were no dropouts among the Dutch participants. It might also have affected the duration of the interviews, because the Dutch interviewer knew these participants better than the Swedish interviewer knew the Swedish participants. It may pose a risk not to ask further questions because the interviewer understood what the participants meant, meaning a risk that some

content was not verbally expressed and thus not included in the analyses.

The interview guide had some closed questions, which can be considered a study limitation. However, all such questions were followed up with further questions on “how” and “why” to deepen the answers and thus get rich data. In addition, the interview guide was indicative but the questions were adapted to the participants’ answers and their narrative style. This means that questions could differ in order and formulation depending on the participant.

We only included Dutch and Swedish participants, which limits the generalizability of our findings to an international context. However, although we expected certain cultural differences between the two populations, the results of both groups of participants were strikingly similar. This leads us to suggest that the inclusion of two different European participant groups did not influence the results, and that the generalizability to other western countries will probably be high.

Another limitation could be the fact that we translated quotes into English. It can be argued that, for complete transparency, both translated and native language quotes should be included [43]. To avoid losing relevant information and following the guidelines of van Nes [21], we coded in both native languages as far as possible.

The interviews were taken in different forms: most were face to face, but others were by telephone. There is a risk of missing data due to not being able to see nonverbal cues during telephone interviews [44]. In contrast, participants might find it easier to speak over the phone when talking about sensitive subjects, and therefore phone interviews can be just as valuable as face-to-face interviews [45].

Conclusions

Most participants with a limb amputation suffering from chronic PLP described the PME treatment to be a valuable addition to their strategies for reducing PLP. The PME treatment changed passive pain management into an active strategy, and had positive effects on quality of life, sleep, and energy levels. Learning to control the phantom limb and normalization of its size were found to contribute to successful treatment. The participants’ mental focus and therapeutic bonding were important facilitators for reducing PLP. Barriers were distracting events in the participants’ lives or a distracting treatment environment.

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Disclosure statement

MOC has consulted for a company commercializing a device to deliver PME. He is also the originator, but not the owner, of a patent on augmented reality to facilitate PME. All the other authors declare no competing interests.

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ORCID

Kajsa Lidström-Holmqvist  <http://orcid.org/0000-0002-5799-3045>

Max Ortiz-Catalan  <http://orcid.org/0000-0002-6084-3865>

Monika Pilch  <http://orcid.org/0000-0002-0610-0593>

Eva Lendaro  <http://orcid.org/0000-0001-9545-7633>

Liselotte Hermansson  <http://orcid.org/0000-0003-4247-2236>

Corry K. van der Sluis  <http://orcid.org/0000-0003-2141-8214>

Data availability statement

Due to the nature of this research, participants in this study did not agree to their data being shared publicly, so supporting data is not available.

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