Mirror Visual Feedback for Phantom Pain: International experience on modalities and side effects discussed by expert panel. A Delphi Study

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No funding was received for the study.

The material was presented at the scientific meeting of the Physiotherapy Research Society in Cardiff on 9th April 2013 and the abstract is visible on the homepage of the PRS:

Title: Mirror Visual Feedback for Phantom Pain: International experience on modalities and side effects discussed by expert panel. A Delphi Study

Abstract

Background: MVF (mirror therapy) is practised worldwide in very different ways to alleviate phantom pain; no study has compared these variations yet or researched risk and harm.

Objectives: To establish usage and justification of a generally accepted MVF treatment plan after amputation, to explore occurrence and handling of side effects, and to increase knowledge on contributing factors.

Methods: Experiential knowledge of 13 experienced practitioners from six countries and five professions was explored with a three round Delphi technique.

Results: Experience with the use of five different treatment plans was described of which one has never been mentioned in the literature: an intense one-off plan where the illusion was carefully set up before the patient was left to the experience with no interference, resolving pain as well as side effects. In the four known
treatment plans, the expectations of response time varied which influenced the
definition of responders/non-responders, the set-ups, control and use of material
reflected the professional background of the practitioners. Contraindications were
also defined according to the professional confidence to deal with the side effects.
Side effects were reported including emotional reactions, pain increase, sensory
changes, freezing of the phantom limb, and dizziness and sweating. The attitude
toward and the handling of side effects varied in patients as in practitioners
according to their professional background. A tool to fine-tune the experience was
reported with covering the limb during therapy. Full consensus was reached on
several treatment modalities.

Conclusion:
The results suggest that the different treatment plans suit different patients and
practitioners. Matching these could enhance effectiveness and compliance.
Knowledge about side effects needs to inform treatment decisions. These findings
triggered the development of a MVF gateway to guide patients to the treatment
plan for their needs and collect data from the practitioners to enhance
neuroscientific understanding and inform practice.
Introduction

Phantom pain is a well-known and frequently experienced problem after amputation and often occurs in connection to altered or non-existent movement abilities of the phantom limb. In 1993 Ramachandran and colleagues first discovered mirror visual feedback (MVF) to be able to address the issue of phantom pain by creating an illusion with a mirror in a box which was placed in front of the patient in such a way that the missing limb could be seen as a reflection of the remaining limb. This visual input resulted in pain relief. Twenty years later, a number of professions use the principles of MVF (also known as mirror therapy or mirror box therapy) in treating chronic pain and learned non-use. Research has been conducted on the effectiveness of MVF with the identified problem of heterogeneous study designs. The treatment plans vary to a great extent (see table1). These have never been compared and researched. Side effects are only rarely mentioned (see table2). They are by no means thoroughly researched. Only one paper based on retrospective evaluation of patient records, specifically discusses the frequent side effects of MVF experienced during treatment which resulted in withdrawal from MVF. Thus, the questions about side effects of MVF – at which point in the treatment do they occur and why, and how to resolve these – remain unanswered in the current literature.
Overall, there is considerable interest and clinical support for the use of MVF in treating phantom pain, and this treatment approach is practised and taught in many countries in many different, possibly contradictory ways and without informing on risk and harm. This study sought to address the question: “How is MVF best practised in treating phantom pain and what are the risks?” Secondary objectives included: To explore how MVF is used, the rationale underpinning clinical decision-making and the occurrence and management of side effects.

Research has been very limited and we decided to do a Delphi Study to further define the area. This study design can access the experiential knowledge of those who have seen and managed the patients to identify underlying principles. Three rounds of consecutive questionnaires are conducted with an expert panel of experienced practitioners. Practitioners’ experience represents one of the three components of evidence-based practice, namely, clinical expertise (29). The outcome can then guide further research and practical application.

**Method**

The Delphi method is defined as “a systematic and interactive research technique for obtaining the judgment of a panel of independent experts on a specific topic” p.99. It follows an iterative process of data collection, analysis and feedback and is particularly useful when there is a lack of empirical evidence or conflicting evidence.
A panel of experts are selected, according to the criteria for expertise defined within the study context, and asked to participate in two or more rounds of structured questionnaires progressing to more specifically focussed questions. After each round, the researcher provides an anonymous summary of the experts’ input from the previous questionnaire that also forms part of the subsequent questionnaire content \(^{17,18}\). The aim of the Delphi Method is, through a process of initially open-ended questions to more specifically focused questions, to decrease the variability of responses and achieve a predetermined level of group consensus \(^ {17,18}\). A number of advantages contributed to the choice of the Delphi Method in this study: feeding back the experts’ responses from previous rounds validates and enlarges the data and rapid clarification can be obtained \(^{19}\). Also the use of email was convenient for the practitioners and could be assimilated more easily into their daily schedules \(^{20}\).

The risk of bias is acknowledged. Practitioners were required to recall effects that occurred in the past from memory. In conducting a Delphi study, the researcher may unconsciously impose own interests and opinions on the emerging data \(^ {18}\). However, the authors’ interest was to understand the matter in depth instead of seeking support for a specific protocol or assumption. This was reflected in the search of the widest possible range of treatment plans practised and side effects experienced with no limitation to profession or site. Every effort was made to limit bias through reflection on assumptions held about MVF, discussion at each phase with the second author, and the use of a research journal.
Practitioner bias was addressed through anonymity to eliminate competition between the various treatment plans, continuous encouragement to report all observations and to comment wherever they wished on the open-ended questionnaires.

Rigorous selection of experts in the Delphi Method is fundamental. The main inclusion criterion for this study was practical experience with patients in MVF after amputation. It was assumed that practitioners, who present this experience in public such as, the literature, online forums, conferences, interest groups, or in teaching professional development courses, would fulfil this criterion. A strategy of purposive sampling was applied with the aim to cover the widest variety of treatment plans used and the widest variety of professions offering these:

(I) Authors of the key literature were contacted,

(II) A letter of invitation was posted onto the Amputee Rehabilitation Network of the interactive site of the Chartered Society of Physiotherapists (iCSP); amputation support groups (Amputierten-Initiative, Berlin and Empowering Amputees, USA) were contacted,

(III) internet search engines, such as Google, and the video-sharing website YouTube were searched and we identified and contacted these practitioners,
(IV) twelve centres for artificial limb or pain services in UK and Germany were contacted.

These strategies resulted in eight participating practitioners with experience in MVF after amputation who agreed to participate.

Subsequently, in order to increase the sample size, a snowball sampling approach was used, i.e., the identified practitioners were asked to suggest further practitioners with experience in treating patients after amputation with MVF. Fifteen further contacts were made; five felt confident to have enough experience (on request, an aim of around 10 cases was given) or had limited experience but an unusual experience to report, and agreed to participate. Of all the 36 MVF practitioners identified and contacted, 12 never replied, 3 gave lack of time as reason not to participate, 6 reported to have no or very low experience in treating phantom pain and therefore did not feel they should participate as experts, and two never returned the first questionnaire despite reminders and were therefore not included. No practitioner who felt experienced in treating phantom pain with MVF and wished to participate was refused participation.

The panel therefore consisted of 13 practitioners from six countries and five professions: medicine, psychology, physiotherapy (PT), occupational therapy (OT) and nursing.
Two practitioners, who treated a relatively low number of patients with amputations and felt unable to contribute with further data, withdrew after the first round. Eleven practitioners completed the study.

Anonymity is a key component of the Delphi technique. This was guaranteed to the practitioners. Informed consent was assumed when practitioners returned the first completed questionnaire. All practitioners were assigned a code. Identifying features were removed from responses before being shared in subsequent rounds. The study received ethical approval from the Coventry University Research Ethics Committee.

A pilot test of the first questionnaire was conducted involving three health professionals who were familiar with MVF but had not enough experience to meet the inclusion criteria. Minor changes were made to the first questionnaire based on the feedback obtained about the questionnaire design, the clarity of the questions and content.

As the Delphi technique requires data analysis and partial data presentation during each round, data collection and partial data presentation constitute an interwoven process. In round one, the Delphi approach customarily asks open questions to ascertain the nature, scope and breadth of the topic being explored leading to very specific questions for clarification, cross-checking for verification, and further exploration of knowledge in subsequent rounds. Questions in the first round focused on how
treatment was organised in terms of length, duration and frequency of sessions.

Side effects were explored in respect to nature, frequency and severity of occurrence, management of the side effects, and how (or if) they were resolved, and questions about experiences of non-response to MVF were included. The first round was concluded when all practitioners had returned the questionnaire. Each round had a deadline of 2-3 weeks for return of the completed questionnaire and reminder email messages were sent to the practitioners as needed. After each round the responses were reviewed by the first author, collated and presented in tables.

As a result of this process, the second round consisted of data presented for comment or rating on a 5-point Likert scale: clarification questions and new questions that arose from the emerging information about MVF related to treatment outcomes, use of sensory materials or manual techniques, timeframes, and other factors. In the second round, practitioner responses were added to the pooled data. Consensus, in this study, was defined as 100% agreement (agree or strongly agree) of those who responded to the particular statement within a table of 12 statements (see table 3). The third round focused on acquiring information and clarification about specific topics, such as, experience of phantom limb shrinking and awareness, restoring a lost illusion and the effect that covering a limb with cloths during MVF has on the intensiveness of the experience.

Once questionnaires from the third round had been received another document was produced using a cross-sectional ‘code and retrieve’ method to collate the
data \cite{p203}. This means, the data from all questionnaires were labelled and brought together under various categories under recognition of their source whereupon analysis was performed within the categories as well as across sections, e.g., with regard to the professional background of the practitioners and the number of patients they had seen. The data analysis was discussed with the second author after each round.

**Results**

**Equipment and the illusion**

The mirror equipment used comprised:

- simple, cheap mirrors from discount stores,
- mirror tiles from bathroom stores glued to the side of a cardboard box,
- large, plain wall-style or long free-standing mirrors,
- wooden stands with acrylic glass,
- commercially produced mirror boxes,
- E-shaped construction with a reversible mirror in the middle or a projection system with a mirror.
The therapists did not consider the nature of the equipment important, nor the angle at which the mirror was set up as long as a strong and vivid illusion could be achieved in a relaxed position. The illusion could be spoilt by patients' lapse of concentration, forgetting to move the phantom limb, or moving the two limbs at different speeds or through different ranges. Jewelry, watches or tattoos spoiled the mirror illusion in some cases but not in others. An unusually high percentage (40%) of non-responders to MVF was reported by a practitioner who defined three week as the response time.

Treatment plans

The different treatment plans can be categorised as follows:

A. Remote MVF: instruction via leaflet and DVD, focussing on patient education, with remote follow up. This plan is apt for highly motivated and educated patients.

B. Intense MVF: One lengthy session up to 3 hours in length. After the assessment and development of the specific treatment plan the mirror illusion was set up. Once the process was underway, there was no interference from the practitioner and the patient was left to explore the experience on their own. This approach often resulted in resolution of pain for several days which could then often be permanently resolved after regular or as-needed self-administered sessions. Follow up was conducted remotely. This approach has been effective for
patients who had previously experienced no success with another MVF treatment plan.

C. Graded MVF: In this approach MVF was preceded by up to two weeks of laterality training (distinguishing left from right with flashcards) and up to two weeks of imagery training of positions and movements of the phantom limb before MVF was introduced. This structure was based on Graded Motor Imagery (GMI) and controlled and monitored by the practitioner in usually one or two face-to-face sessions per week. It required self-administration of short sessions several times a day.

D. Structured MVF: This approach involved highly structured sessions using the mirror from the beginning. The various structures described here are summarised in figure 2.

E. Pre-recorded MVF: This approach used pre-recorded movements of the sound limb or of another person’s limb projected onto the mirror. This allowed unilateral movement but was restricted to the treatment setting.

Consensus

All the practitioners (100%) agreed that thorough patient education and preparation, individual set-up, face-to-face guidance and re-assessment are key factors in MVF after amputation.
The majority of practitioners agreed on the need of a quiet setting and on the importance of individual triggers of patients’ phantom pain. Other statements on observations were more ambiguous (see table 3).

It was agreed that it took patients 1-10 minutes to become immersed in the illusion and the session length was usually determined by the patient’s ability to concentrate and tolerate the programme. The frequency of practising was mostly limited by time constraints.

No consensus was reached on the optimal length of MVF sessions (the range was from under 5 minutes to 120-180 minutes) or the frequency of sessions (the range was a single session to six or more times a day). A minority of practitioners felt strongly that practising little and often is more beneficial than longer and less frequent sessions. There was no consensus on the causes of non-response but suggestions included a lack of remapping phenomena (referred sensations to locations on other body parts, e.g., touch on ipsilateral cheek, neck, upper arm or genitals felt on phantom limb), effort sensation (felt level of effort when moving phantom limb), sensory referral (touch of same location in other person felt on phantom limb) of tactile sensation (when touching an object), telescoping (perceived shift of position of phantom limb into its proximal parts or stump) and poor technique.

Side effects
A variety of side effects were identified; these comprised emotional reactions, pain increase, sensory changes, dizziness, nausea, telescoping and residual limb spasms, freezing of the phantom limb, overall sweating, sweating of the phantom limb, and spontaneous movements of the phantom limb.

Emotional reactions, described by 85% of the practitioners, were associated with suddenly “seeing” the limb and sometimes with “taking it away again”. These reactions, observed in the first and second session only, ranged in severity from ‘amazement’ to, in rare cases, significant depression. PTs and OTs generally chose to stop the MVF if emotional reactions occurred and some classified them as contraindication for MVF. Remarkably, those practitioners with psychological training saw a necessity in accepting emotional reactions as long as post-traumatic stress disorder was treated before commencing MVF.

When pain increase occurred, it was, according to two thirds of the practitioners, limited to the duration of the MVF session. Individual practitioners, however, reported delayed onset briefly after the session or pain increase lasting after the session and spreading in location. Most practitioners advised not to tolerate pain increase. Residual limb spasms associated with irritated neuromata and increased or excessive activity were mostly held responsible and resolved with relaxation techniques, looking without moving, minimal session time or slower movements without moving the stump muscles, a quiet setting and comfortable positioning.
Manual techniques were also applied to either the stump or to the unaffected limb. Pain increase was regarded as a reason to stop MVF for the moment and alter posture, relax the residual limb, or reduce intensity or duration of the session. Yet, a minority regarded effort related pain increase for the duration of the session as the norm. Sensory changes in the phantom limb were common and were generally perceived as enjoyable. Locking or freezing of a phantom limb is a phenomenon that can typically be resolved with MVF. Interestingly, two practitioners witnessed this as a side effect from MVF treatment. In one case, the locked position was not resolvable with movement imagery and the patient left in distress. Another practitioner described the same effect as a worrying and dramatic experience which was resolved by the patient himself during the long session. On follow up the patient rated it as one of the most exciting experiences of his life with complete and permanent pain resolution as a result. Dizziness and nausea were reported as occasional mild effects except in one patient who subsequently withdrew from MVF. Subtle eye problems were made accountable and it was recommended to cover the affected limb during MVF as a means of refining the MVF experience. Sweating in general, spontaneous movements or “odd” behaviours of the phantom limb occurred as transient phenomena.
Boredom during therapy was associated with monotonous exercise programs and sleep-deprivation; it was addressed with exercise variety and progression, short breaks, incorporating music and meaningful functional tasks, and shorter sessions.

**Discussion**

Defining non-response after three weeks seems too early when others reported improvement after 5 months confirming the possible need of longer practice (3). Mirror therapy was successful despite patient scepticism and vice versa which questions the need to believe in the illusion (13). The variety of treatment approaches and attitudes (outlined earlier) reflects the practitioners’ professional experience and confidence and supports Ramachandran and Altschuler’s suggestion that different treatments may suit different patients³.

The low incidence of dizziness and nausea reported in the current study is in contrast to the high incidence reported in Casale, Damiani and Rosati’s study, a note evaluation with a high withdrawal rate from MVF treatment ¹⁶. The authors assumed a conflict of body schema (image of normal limb versus prosthesis) to be responsible for their high incidence. Whether boredom of flexing and extending a limb for 30 minutes, or subtle eye problems in a mostly elderly inpatient cohort may have played a role remains to be seen in further research.
As a precaution, careful management is advised, especially as literature mentioned vomiting as possible outcome (11). Whether the use of clothing can help avoid these exacerbations needs to be investigated.

**Conclusion**

Important insights have been gained about the practice and side effects of MVF as a result of using a Delphi Technique to access experts’ knowledge. Five different treatment approaches were described, one of which (B) has not been described in the literature. This approach, being longer and more intense, was successful in cases who had previously failed with other MVF treatment. This indicates an area for further research. Each treatment plan has specific advantages related to the professional background of the practitioner and individual patient needs; therefore best practice seems to be to match these.

Side effects have been identified and described here, and while they were generally mild, some severe side effects occurred. These were freezing of the phantom limb and severe nausea. Practitioners and patients interested in using MVF should be informed of these risks. Tools to address the side effects have been described by the practitioners.

The findings of this study will contribute to the development of an MVF Gateway project that will provide guidance for patients in choosing the treatment plan which
best meets their needs, and collect anonymous treatment data to enhance understanding of the underlying principles.
Acknowledgements

Many thanks are directed to Jessica Aldis and Richard Catlow, to the colleagues who pilot tested the first questionnaire, and to the participating practitioners for their time and commitment to sharing their experiential knowledge.

Declaration of conflicting interest

The authors declare that there is no conflict of interest.

This research received no funding.
References:


Table 1: Treatment plans of mirror visual feedback in the literature

<table>
<thead>
<tr>
<th>Author</th>
<th>Name of treatment plan</th>
<th>Structure</th>
<th>Frequency and duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moseley 2006 RCT</td>
<td>Graded Motor Imagery</td>
<td>Three phases: limb laterality recognition, imagined movements, mirror therapy</td>
<td>2 weeks each phase with hourly home exercise programme</td>
</tr>
<tr>
<td>Grünert-Plüss 2008 Case series</td>
<td>St Gallen protocol</td>
<td>Looking first</td>
<td>5-6 times a day, not more than 5-10 min</td>
</tr>
<tr>
<td>McCabe 2010 Background and protocol</td>
<td>Bath MVF treatment protocol</td>
<td>Body schema, imagining movements first</td>
<td></td>
</tr>
<tr>
<td>MacLachlan et al. 2004 Case study</td>
<td>Not specified</td>
<td>Fading out of therapist-mediated intervention over three weeks</td>
<td>Practising 2-4 times a day, 10 exercises x 10</td>
</tr>
<tr>
<td>Chan et al. 2007 RCT</td>
<td>Not specified</td>
<td>Movements, not specified</td>
<td>15 min a day for 6 weeks</td>
</tr>
<tr>
<td>Darnall and Li 2012</td>
<td>Self-delivered mirror therapy</td>
<td>7-minute DVD and written instructions, diary</td>
<td>25 min a day for 8 weeks</td>
</tr>
<tr>
<td>Mercier and Sirigu 2009 8-cases study</td>
<td>Visual Virtual Feedback</td>
<td>10 unilateral movements 10 repetitions each</td>
<td>2 sessions per week for 8 weeks, lasting 30-60 min</td>
</tr>
<tr>
<td>Kawashima and Mita 2009 Case study</td>
<td>Not specified</td>
<td>Synchronous and periodic wrist movements, smoothly and in as large a range as possible</td>
<td>1 hour per week for 3 months</td>
</tr>
</tbody>
</table>
Table 2: side effects of mirror visual feedback in the literature

<table>
<thead>
<tr>
<th>Study</th>
<th>Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ramachandran and Rogers-Ramachandran 1996</td>
<td>Telescoping (perceived as beneficial as pain disappeared together with phantom limb)</td>
</tr>
<tr>
<td>Chan et al. 2007</td>
<td>Two brief grief reactions</td>
</tr>
<tr>
<td>Grünert-Plüss et al. 2008</td>
<td>Pain increase possible</td>
</tr>
<tr>
<td>Casale et al. 2009</td>
<td>Dizziness, irritation, uneasiness</td>
</tr>
<tr>
<td>Kawashima and Mita 2009</td>
<td>Client vomited after increasing feeling of nausea during first session</td>
</tr>
<tr>
<td>Darnall and Li 2012</td>
<td>Boredom, increased depression, increase of phantom limb awareness and phantom limb pain</td>
</tr>
</tbody>
</table>
Table 3: Consensus on statements about mirror visual feedback

<table>
<thead>
<tr>
<th>Statement</th>
<th>Agreement</th>
<th>Disagreement</th>
<th>Consensus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good education/preparation for mirror therapy is a key factor</td>
<td>100%</td>
<td>0%</td>
<td>Full</td>
</tr>
<tr>
<td>Individual set up of mirror therapy is most important</td>
<td>100%</td>
<td>0%</td>
<td>Full</td>
</tr>
<tr>
<td>Face-to-face guidance is most important</td>
<td>100%</td>
<td>0%</td>
<td>Full</td>
</tr>
<tr>
<td>Re-assessing is most important as some patients do not use the mirror correctly and therefore do not succeed</td>
<td>100%</td>
<td>0%</td>
<td>Full</td>
</tr>
<tr>
<td>The setting must be quiet</td>
<td>91%</td>
<td>9%</td>
<td>Most</td>
</tr>
<tr>
<td>Finding triggers which cause phantom pain is most important</td>
<td>80%</td>
<td>20%</td>
<td>Most</td>
</tr>
<tr>
<td>Sensory changes were seen as positive by the patients</td>
<td>90%</td>
<td>10%</td>
<td>Most</td>
</tr>
<tr>
<td>Mirror therapy requires a lot of concentration and emotional energy</td>
<td>73%</td>
<td>27%</td>
<td>Tendency</td>
</tr>
<tr>
<td>Time since amputation plays a role</td>
<td>66%</td>
<td>33%</td>
<td>Tendency</td>
</tr>
<tr>
<td>The repeated use of the mirror shrinks the phantom size</td>
<td>63%</td>
<td>37%</td>
<td>Ambiguous</td>
</tr>
</tbody>
</table>
**Very analytical right hemisphere dominated patients have difficulties with mirror therapy**

<table>
<thead>
<tr>
<th></th>
<th>50%</th>
<th>50%</th>
<th>Ambiguous</th>
</tr>
</thead>
<tbody>
<tr>
<td>It does not matter if a patient &quot;believes&quot; in the mirror illusion, the brain just works this way</td>
<td>40%</td>
<td>60%</td>
<td>Ambiguous</td>
</tr>
</tbody>
</table>
Figure 1: treatment plans used by expert panel

Figure 2: structures used within treatment plan D of this study

Figure 3: number of practitioners reporting side effects that occurred with mirror visual feedback
<table>
<thead>
<tr>
<th>Mirror Therapy Treatment Plans</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A</strong> instruction only, home-based, can be remote</td>
</tr>
<tr>
<td><strong>B</strong> one intense, long, client-led, supervised session, starting with tiny movements</td>
</tr>
<tr>
<td><strong>C</strong> gradual approach (GMI), laterality, imagery, mirror therapy</td>
</tr>
<tr>
<td><strong>D</strong> structured, controlled mirror therapy</td>
</tr>
<tr>
<td><strong>E</strong> projector system of mirror therapy</td>
</tr>
</tbody>
</table>
Treatment plans D

Individual structure of mirror therapy designed for the client

Structure of course:
1. Motor execution without objects
2. Sensory exercises with objects (hedgehog ball, bowl with peas etc)
3. Motor exercises with objects (ball, cups etc)
4. Mental practice

10 min relaxation
2 min looking in mirror
5 min of moving different joints for 1 min each
2 min just looking
19 min

1. Positioning, adopting position of phantom limb
2. Rubbing a painful place on the sound limb, using heat or ice
3. Movement individualised
4. Rest and repeat
Number of practitioners reporting side effects