

Exploring the experiences of amputees with phantom limb

A Report by

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For

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Dedicated to patients and staff at the DSC, Royal Preston Hospital

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Executive Summary

This study attempts to describe what phantom limb is like – from the patient’s perspective – rather than what phantom limb is – from a clinician’s perspective. In doing so, a phenomenological method is employed, suspending as many assumptions and presuppositions as is possible, in order to reveal fundamental descriptions about the meaning of the phantom in the everyday life of the amputee.

In particular this project focuses on the significance of the amputee’s experience and avowal of two simultaneous contradictory realities: the reality of a ‘living’ limb and its destruction. It is argued that what is significant about this ambivalence, in the context of rehabilitation, is that it can be experienced as positive *as well as* negative. That is, instead of seeing the phantom only as a physical and psychological hindrance, in certain circumstances with particular patients, it could be a physical and psychological aid in rehabilitation. This may lead to a number of complementary strategies for rehabilitating amputees.

Background

A few words for readers of this report

To get over the problem of technical language there is an attempt to provide short summaries, in plain English, at the end of each section and/or sub-section when appropriate. For those of you not inclined to read the more technical, philosophically abridged, aspects of the report, I encourage you to either, refer to a glossary of terms provided and/or move on to the end of a section/sub-section and/or, to read heavily abbreviated summaries highlighted in grey. One of the reasons why this report has not been written in jargon free English is because it is aimed at academics as well as non-academics. So, without doing undue violence to the research findings, I have tried to

compromise by writing to two audiences in the space of a single authored report.

All technical concepts are explained and not taken for granted. There are a number of abbreviations of which the reader has to be aware. Namely: LREC = Local Research Ethic Committee; I=Interviewer; AMP= Amputee, sometimes followed by a number – a device for anonymizing interviewees; PLP/PLS= Phantom limb pain, Phantom limb sensation respectively.

A very short literature review

The vast majority of psychosocial research on the effects of lower limb amputation has almost exclusively focused on the negative impact the event has on the person's life and well-being, e.g. depression, anxiety, grief, body image disturbances, and social discomfort (Parkes, 1972; Shukla *et al.*, 1992, Frierson and Lippman, 1987; Hill *et al.*, 1995; Rybarczyk *et al.*, 1992 and 1995; Fisher and Hanspal, 1998; Livneh *et al.*, 1999; Gallagher and MacLaclan 1999). That said, there is an important minority report that critically examines amputation in a more positive light. Dunn (1996) examined the salutary effects of finding positive meaning in a disabling experience and MacLachlan and Gallagher (2000) have focused on positive meaning in amputation and thoughts about the amputated limb.

What set this study apart from the minority report are two things:

- (1) The specificity of the study. Whereas the minority report tends to look at positive meaning in a general sense, focusing in on the disabling experience of amputation per se, this study examines whether or not phantom limb in particular can be understood in a positive way.
- (2) Methodologically. All the studies to date have used fairly traditional clinical methodologies to gather data; questionnaires, statistical analysis

and so forth. This study is not at all like these; being phenomenological in nature it attempts to get at fundamental patient-centered descriptions of what the phantom is really like and how it may help to think about the phantom in a radically new way.

Methodology

What is phenomenology? Using phenomenology in the context of rehabilitating amputees

Phenomenology is about ‘going back to the things in themselves’ (Husserl, 1931). It involves going back to the actuality of brute experience and suspending all metaphysical beliefs about what we think is real, in order to get at the essences of things.

The way phenomenology gets at the essences is through suspending the ‘natural attitude’ – the taken for granted-ness of the way we believe things to be – the common sense view, as it were. It does this through the *epochē* (in Greek), translated as the suspension of belief, which means just that; setting in abeyance beliefs about the existence or non-existence of the phenomena.

For Husserl the suspension of the natural attitude putatively facilitates the phenomenological description of what appears to consciousness *just as it does appear*. Intuitively, Husserl tries to find out *what things are* without deciding *whether they are*. In other words he separates essence from existence.

I, like many other existential phenomenologists before me, do not follow him in this move. Following Merleau-Ponty, I adapt Husserl’s method for my own purposes, viewing ‘essences’ as fundamental existential involvements; how we are in the world. To get at these existential structures, the existential how of our involvement with the world, I, like Merleau-Ponty before me, focus on our corporeal subjectivity. In doing so, I draw heavily on Merleau-Ponty’s classic

phenomenological study *Phenomenology of Perception* (1962). This has influenced understanding of bodily subjectivity in general and the significance of phantom limb in particular. This can be summarized by four related arguments from Merleau-Ponty:

- (1) Merleau-Ponty has a novel way of understanding the subject. For Merleau-Ponty subjectivity is bound up with the body: 'I am my body' – hence, Merleau-Ponty's unusual anti-Cartesian dualistic short-hand for subjectivity, the 'body-subject'. Another way of putting this is that we cannot make sense of the world without it; subjectivity is revealed as a 'being-to-the-world', a 'subject committed to the world,' as subject of perception of behavior as well as cognition and reflection. I have full *access* to the world by way of my corporeality. The body is a *lived* body.
- (2) For Merleau-Ponty subjectivity is not reducible to materialism or idealism, psychology or physiology. This is well demonstrated by the phantom limb, the explanatory force of which cannot be reducible to a mere object in physiology/neurology. Phantom limb for Merleau-Ponty illustrates a fundamental ambivalence and ambiguity on the part of the subject. That is, the amputee avows two contradictory realities simultaneously: the reality of a living limb and the reality of its destruction. These two 'limbs' occupy the same space and time, one the ghostly double of the other's absence. The phantom is therefore 'quasi-present'; its refusal to enter the past, and become a memory, illustrating the body-subject's will to integrity in a lived present.
- (3) Merleau-Ponty lived body thesis is radical because I only have full *access* to knowledge through my lived corporeal situation. For example, space is not something we grasp directly it is something that we understand through our bodily situation. The corporeal schema or body image –

‘the homunculus’ in neurological terms – maintains the integrity of the body’s possibility in relation to the world through an ‘intentional arc’ that is first corporeal rather than mental. The body anticipates *without* reflection. Witness our ability to put one foot in front of the other without thinking about it (what Merleau-Ponty calls ‘corporeal intentionality’).

- (4) Corporeal intentionality helps in further understanding the active as well as the passive presence of the phantom in the ‘life-world’ of the amputees. In other words, it opens up the possibility of thinking about it *as if* it were an ordinary healthy limb, actively anticipating and participating in the body’s situation prior to any cerebral conscious reflection.

In some ways then, the project that I have undertaken repeats some of what Merleau-Ponty has already done. There are, however, very significant differences, where I can afford to go well beyond the scope of his brief remarks about what the phantom is like. The differences arise from the specificity of the rehabilitative context which this project is set.

While Merleau-Ponty is defending a bigger thesis about the lived body, where a fine description of what the phantom limb is, is used as a critical foil to show up inadequacy of thinking about the body as an object of mechanistic physiology (the natural attitude), my context of critical engagement is rather more specific and practical in its anticipated effect on the quality of life of an amputee with phantom limb sensation and/or pain.

Let me briefly outline the significance of this more practical rehabilitative context, before I show why suspending the natural attitude towards phantom limb maybe of practical benefit in rehabilitation.

The sensation of having a limb where one has been amputated is surprisingly common, about eighty percent of amputees have phantom limb sensation/pain. The problems phantom limb causes can be summed up through three common sense clinical perspectives. They are:

- A negative belief in the phantom as a physical aid in rehabilitation. The phantom is painful and deceptive.
- A negative belief in the phantom as a psychological aid in rehabilitation. The phantom is not real and does not really contribute to a sense of bodily integrity.
- A denial of the ambivalent ontological status of the phantom. This leads to a negative view of the phantom as a physical and psychological aid – it should not be acknowledged or reinforced.

It is important to head off any misunderstanding about the natural attitude. First, it is not a wrong belief: it does offer insight into what the phantom is and how to treat it. What can be pernicious about the natural attitude is that it takes for granted that there are no other perspectives and forms of understanding. In short, it is limited in scope. The phenomenological approach redresses this limitation, by trying to describe and understand the natural attitude *as well as* find descriptions and understandings that go beyond it. Summing up it is about a radical plurality of descriptions and understanding, which are truly *complementary* to clinical practice.

Second, the natural attitude is complex and involved: it resists any social or normative classification. There are no easy categorizations because clinical norms and beliefs socially construct how patients come to view their own experience of the phantom and what expectations they may hold in dealing with it. Moreover, there are no simple normative classifications either; the natural attitude that prescribes what is negative about the phantom vis-à-vis

patient experience is not mistaken. It arises out of a genuine problem: physical and psychological suffering. Clinical strategies that alleviate this are good. However, to reiterate, they are not perfect because they overlook other perspectives and treatments that transcend the natural attitude.

Third, it is as important to understand the natural attitude as it is to go beyond it because one logically entails the other. That is, understanding what is beyond the natural attitude is not possible without identifying what is constitutive of the natural attitude in the first place.

To get beyond the natural attitude we need to suspend the received wisdom of what the phantom limb is from a 3rd person objective and clinical point of view and go back to the phenomenon itself as it manifests in the 'life world' of amputees. In short, it is about suspending or bracketing what phantom limb is assumed to be, in order that we may get at what phantom limb is like from a 1st person perspective. As I have already hinted this is no easy task, because patient experience and expectation is deeply embedded within the natural attitude pervasive in the clinic. However, as I go on to demonstrate there are descriptions given by amputees that transcend the natural attitude in important ways. They can be summarized in brief as:

- A positive belief in the phantom as a physical aid in rehabilitation. Phantom pain is a warning, while phantom limb pain/sensation is a useful aid with prosthesis.
- A positive belief in the phantom as a psychological aid in rehabilitation. The phantom helps in giving a sense of bodily integrity.
- A better understanding of the ambivalent ontological status of the phantom. The phantom *can* be perceived as real and helps foster a positive belief in the phantom as a physical/psychological aid.

Having briefly outlined the parameters of my phenomenological approach, I want to say a little about practical methods that help to implement this approach.

Data gathering methods appropriate to phenomenology

Phenomenology allows for a permissive data gathering method. Indeed, it demands it. Two data gathering methods appropriate to phenomenology were used.

An overt form of participant observation was employed in accordance with ethical guidelines laid out in the LREC and protocol. In other words, prior to participant observation the researcher gained permission from the patient to observe a specific aspect of their clinical treatment. The ethos behind participant observation was exploratory rather than confirmatory, holding as few presuppositions as possible when describing patient-clinician interaction. All observations were recorded in a research diary that was kept secure at all times. Patient details were anonymized in accordance with ethical guidelines agreed prior to carrying out research.

After a period of observation 25 in-depth (non-structured) interviews were carried out with amputees suffering from phantom limb sensation and/or pain. A few interviews with amputees who had no phantom limb sensation or pain were also conducted.

An in-depth non-structured approach is congruent with phenomenology because in practice, it meant asking as few questions as possible, therefore limiting any bias in the presuppositions of structured questioning, giving as much space as needed for amputees to provide their own particular perspectives on what the phantom is like and whether or not it is a physical and/or psychological aid to rehabilitation. The interviews were all carried out in accord with ethical protocol; as well as adhering to strict patient confidentiality

all patients were asked to read a patient information sheet before considering whether they wanted to give their consent to be interviewed. Again, the identity of all participants was anonymized – all information being secure and accessible to one principal researcher.

Due to insufficient patient uptake and lack of time, a planned follow up focus group study (built into the research plan from the beginning was not carried out).

Summary Box – methodology or approach

The approach used in this research (phenomenology) is about questioning our assumptions and presuppositions about what we think phantom limb is. It involves carefully listening and suspending – neither believing nor disbelieving – all ‘common sense’ judgments about what medical experts think the phantom limb is and how they should treat it (the natural attitude). In effect this means listening more to what patients with phantom limb have to say about their condition and how it has affected their rehabilitation. The idea of this approach is to complement the considerable amount medical experts already know about the condition, providing a number of alternative ways of thinking about and treating amputees with phantom limb sensation and pain.

Rather than seeing the phantom as only (and wholly) negative, there may be certain patients who experience the phantom as a positive physical and psychological aid to rehabilitation. Indeed, because the phantom is ambiguous, in a sense present and another sense absent, it may prove both positive as well as a negative – depending on the patient’s attitude and circumstances.

The actual research involved observing amputees in a clinical environment and carrying out in-depth interviews. Both practices involved keeping patient information confidential, anonymous and getting patient consent – verbal and informal in the case of participant observation, and written and formal in the case of in-depth interviews.

Analysis of main research findings

The findings section is about describing and analytically understanding how some patients have accepted phantom limb as a negative and a positive force in their lives in general and rehabilitative experience in particular.

Phenomenological analysis I: Phantom limb experience and the natural attitude

The first task is to investigate phantom limb and the natural attitude, which tends towards negative views and beliefs about phantom experience in general and phantom limb experience in the context of prosthetic rehabilitation in particular.

The first perspective within the natural attitude – negative view/belief in phantom as a physical aid to rehabilitation

Some critical observations from research diary (extracts)

It is clear from my observations that by far the most common complaint in the phantom limb experience of amputees is phantom limb pain. More often than not phantom sensation is accompanied by phantom limb pain, which, I have observed, is frequently too difficult to assess and treat satisfactorily. Often many pain-killers are ineffective, only the very strongest tend to have an effect.

Phantom limb pain has been variously described as ‘excruciating’, ‘unbearable’, ‘like electricity’ and sometimes ‘vice like’, often lasting intermittently for days on end. One war veteran described it as the worst pain he had ever experienced, worse than being shot, and worse still than his heart attack in 2002.

Phantom limb pain varies a great deal from patient to patient. Curiously it mimics, almost precisely, the location and quality of the pain pre-amputation. For example, one patient described still feeling the pain of the metal pins in his phantom leg; mimicking the pain he had in his leg before amputation. Such stories are common place. Interestingly patients who found that they were pain free before amputation often do not suffer from phantom limb pain.

It is not hard to understand the natural attitude, in its negative form, when phantom limb pain continues to be a constant reality for many amputees. What is more, any account that dares challenge this needs to be set against the ever present reality of suffering acute phantom limb pain. The problem with severe pain in this form is that it tends to be foremost in the concerns of amputees, overshadowing many minor narratives where the phantom may be experienced as a positive aid to rehabilitation.

Extracts from in-depth amputee interviews

Many phantom limb patients see no advantage in the ‘quasi’ (ambivalent) reality of the phantom, avowing the reality of the stump and the practical uselessness of the phantom as they perceive it. For example

AMP17

I: If there were a pill to get rid of the PLS would you take it?

AMP: Oh yeah, yeah.

I: Why?

AMP: *Because it is something that is not there ...I don't know I just don't want it. You see what is gone is gone. Perhaps if the phantom were useful in some way it would be different.*

AMP7

I: Does PLP/S bother you?

AMP: No it is one of them things...I thought everybody got it. *It is just one of them things you've got to get used to. Once I see it is gone, it leaves with the thought.*

I: Would you say PLS/PLP is a good or a bad thing?

AMP: I wouldn't say it is good thing no, but I wouldn't say it is bad...*I can't see any advantages to it, but neither can I see any disadvantages to it either.*

Phenomenological analysis

- Note the commonsensical character of the natural attitude here. AMP17 acknowledges common sense perception: 'it is something that is not there' and 'you see what is gone is gone'. A very similar kind of response is offered by AMP7 in the phrase 'it is one of them things you've got to get used to.'
- Again, the commonsensical reply of the natural attitude shows up the obvious redundancy of the question about whether the phantom is a good or bad thing. Common sense dictates that if it cannot be useful then it cannot be good or, necessarily bad either.
- The circumstances of these two amputees are significant here. They are both reasonably fit young men who want to get on with their lives. They exhibit very little nostalgia towards the limbs they had, refusing to identify with the phantom, concentrating wholly on the physical accomplishment of rehabilitating with prosthesis.
- These two amputees are model patients because they fit within the natural attitude of a clinical culture that tends toward an avowal and

reinforcement of the reality of the stump over and above that of the phantom (observation taken from research diary). This again makes a lot of practical sense, when one of the prime motives behind rehabilitation is to maximize mobility thus reintegrating patients back into their former lives.

- Note, AMP 7 remark ‘once I see it < the leg> gone, it <the phantom> leaves with the thought. This fits with clinical advice, where patients are not encouraged to recognize the presence of the phantom, because in this way its felt presence will not be reinforced.

Extracts from in-depth amputee interviews

Another reason why the phantom is not seen to be conducive as a physical aid to rehabilitation is because its presence often deceives amputees and leads to accidents. For example

AMP5

AMP: To explain how real it is I suppose a good example would be ...I had an argument with me girlfriend and I just totally forgot that I didn't have a leg and just expected it to be there. It felt like it was there, but it wasn't there. I just went and fell; quite badly actually. That is how real it feels. I have to be consciously aware that it is not there because I think it is...

AMP9

I: Can you remember the PLS?

AMP: Yeah, I was actually facing me bed and I'd lost my first leg and I hadn't got a false limb at that stage and I actually put it down and fell face first on the bed. I mean if I'd been somewhere else...that was the only time it was that distinct. I never got it like that with the second one

I: Did the phantom help you cope at all?

AMP: No I found it *unnerving* actually. It was the other way. *Once I had the sensation and fell on the bed I worried then afterwards whether I'd do it again.*

Phenomenological analysis

- The phantom acts, as it were, before the amputee realizes what has happened: 'I just totally forgot that I didn't have a leg and expected it to be there.' (AMP 5)
- Unsurprisingly this leads to a perfectly natural kind of worry about it happening again: 'Once I had the sensation and fell on the bed I worried then afterwards whether I'd do it again.' (AMP 9)
- Notice the phantom is not only present in some passive sense of the word, it is actively present; part of what Merleau-Ponty calls 'corporeal intentionality' in the 'lived world.' That is, it is still part of the tacit knowledge of the body's subjectivity, where the 'body-subject' already acts before conscious reflection. While this is a good thing if we have two actual limbs – we don't have to think about putting one foot in front of the other – it becomes a major problem when one or more limb is missing and the phantom takes over the role of any normal live limb.
- Because the phantom's active presence leads to accidents, the natural attitude or common sense view of the phantom is to view it negatively as something that deceives, thus hindering rehabilitation.

Summary box

The first perspective within the common sense view (natural attitude) can be summarized as a negative view/belief in the phantom as a physical aid in rehabilitation. The phantom is experienced as painful and deceptive.

The second perspective within the natural attitude – negative view/belief in the phantom as a psychological aid to rehabilitation

Extracts from in-depth amputee interviews

AMP12

AMP: I don't think it is useful psychologically, it doesn't make me feel more whole or complete...I think 'cause I have lived with it <the amputation> for thirty years or more and it is something you accept and get used to ...it's as John Wayne would say 'it goes with the territory.'

AMP5

I: Do you think that the phantom may be of use with the artificial leg?

AMP: No I can't...the trouble is the phantom pain I had wasn't of a good leg, it was of a bad leg...I woke up with this leg that was cold...*I can't remember me leg as it was before the accident and so, no definitely not...I always had a damaged leg and I still have damaged leg.*

Phenomenological analysis

- Amputees with phantom limb who avow their amputee status and come to terms with the loss of one or more limbs, do not see the phantom as psychologically useful. This is illustrated nicely by AMP 12, where the common sense view of acknowledging life without a limb is expressed through phrases like 'living with it' 'accepting and getting used to it' etcetera. While this natural attitude can be a healthy coping strategy, it is not necessarily so for all amputees.
- One major obstacle in the psychological acceptance of the phantom as a psychological aid to well-being, bodily-integrity and full mobility with prosthesis, is that the phantom presence is often a reminder of something, that once flesh was never actually healthy and sound.

Knowing that the phantom tends to mimic the leg as it was, it is hardly surprising that amputees with bad memories of their limb(s) pre-amputation are going to feel anything less than positive about the phantom. This is well illustrated by AMP 5: 'I can't remember me leg as it was before the accident and so, no definitely not...I always had a damaged leg <the leg after the accident> and I still have damaged leg <the phantom of the damaged leg>.'

- As usual circumstances are very important – the amputee's history is crucial in understanding their psychological reaction to the phantom.

Summary Box

The second perspective within the common sense view (natural attitude) can be summarized as a negative view/belief in the phantom as a psychological aid in rehabilitation. The phantom is not real and does not really contribute to a sense of wholeness (bodily integrity).

The third perspective within the natural attitude – tendency to deny the ontological status of the phantom

Extracts from in-depth amputee interviews

AMP10

AMP: It is an *imaginary pain* in some respects, because *obviously* you cannot have pain in a limb that isn't there, but the pain really is intense when it comes and then it feels *real* enough.

AMP3

AMP: The other thing they said to me at Birmingham is try not to do this controlling thing. Yet sometimes when you want to open it up then you do. They said it so that I wouldn't reinforce it. *They think it is bad if you reinforce it.*

They said if I continually moved my thumb in and out as I do like that <illustrates the controlling thing he can do with the phantom by demonstrating with good hand> then I would be reinforcing the brain mechanism that is keeping it going. Errm but *I haven't been able not to do that because there are times when you just want to release it...it can be helpful*. For example, if this <pointing to the chair> were a high arm and I were catching it on it then I'd control my phantom so it wouldn't catch.

Phenomenological analysis

- It is not to be underestimated how bizarre the phantom limb experience must be, because the amputee is avowing two contradictory experiences at the same time, one the ghostly presence of the other's absence. This helps understand AMP 10's contradictory description of the phantom: 'it is imaginary...but it feels real enough'.
- Many amputees first stress the 'imaginary' quality of the phantom, because common sense dictates 'that obviously one cannot have pain in a limb that is not there'. (AMP 10)
- Common sense often wins out, what can be seen (as not being there) is believed more strongly than what is felt to be there (as present). Sight, a very rational sense, often trumps felt experience, a sense that is deemed less trustworthy, partly because it cannot be verified other than by the person having the feelings.
- As we can see from AMP3, the received clinical wisdom is that recognizing the phantom, acknowledging it, is bad because it strengthens, both neurologically and consequently behaviorally, the phantom's presence. This is very categorical advice and tends to be fairly universal.

- It is not clear that this is always good advice. Note, from AMP3's account acknowledging the presence of the phantom and controlling it has its advantages. It is this less commonsensical attitude that I want to talk about next.

Summary box

The third perspective within the common sense view (natural attitude) can be summarized as a tendency to deny or underestimate the ambivalence/ambiguity of the reality of the phantom. In other words, the ambivalent ontological status of the phantom is not fully appreciated. This leads to a negative view of the phantom as a physical and a psychological aid i.e. it should not be acknowledged or reinforced.

Phenomenological analysis II: Phantom limb experience beyond the natural attitude

Having given a phenomenological account of the phantom within the frame of the natural attitude I now turn to descriptions of phantom limb experience that challenge this. What all these experiences and views of the phantom have in common is that they are positive rather than negative – that is, viewing the phantom as having some positive contribution to make in the 'life world' of rehabilitating amputees.

First perspective beyond the natural attitude – a positive belief in the phantom as a physical aid to rehabilitation

Extracts from in-depth amputee interviews

Phantom limb pain, when not overwhelming, is not always bad because it acts as a warning that a limb is no longer there or as a portentous signal that all is well/not well.

AMP4

AMP: I see the phantom as positive because it brings a kind of reality to things. *The pain is warning me not to try and use it.* The phantom pain is saying there is nothing there. So me brain is saying come on you know you can't do that. Quite often I think it is a good job that the pain is there or, I would have dropped that, and that, or, burnt meself or, what have you, you know.

AMP1

AMP: Phantom pains are good in that regard; they're like a warning to something that is happening on your stump ...I found that now. At first I thought they were just an irritant.

AMP12

AMP: If I get it really extreme <the PLP> I say to my wife I'm in for something i.e. a cold or flu or something like that, some bodily malfunction. It gives you a warning that your body is at low level here.

Phenomenological analysis

- Although phantom pain is generally regarded as negative – especially when it is unbearable – amputees learn from it as a warning *not* to use the limb (AMP4); as a sign that the stump must be healthy (AMP 1: this was particularly important for this amputee because it allayed fears that his vascular disease had spread); as a sign that the body is run down (AMP 12: a warning sign that also triggers more severe phantom pain for

this amputee). One thing, therefore, that is not so obvious and actually challenges the natural attitude that all phantom pain is bad, is that the amputee learns to deal with pain in a different way by affirming ‘new found’ body wisdom unique to the circumstances of the amputee.

Extracts from in-depth amputee interviews

Phantom limb pain/sensation helps with physical rehabilitation and the use of prosthesis. For example

AMP2

AMP: Like I was climbing a ladder the other day... When I got to the top where the platform was I became more aware of where both legs were, because I could feel, if you like, ‘inside’ <the prosthesis>, so that made me concentrate on what I was doing and therefore making sure that I really was standing on two feet.

AMP3

AMP: I must have had three months without a piece <the shoulder prosthesis> on and I never caught the wound – for instance getting in and out of the car – when it was bare...my mind must have adjusted to the fact that there was nothing there.

AMP20

AMP: Having the phantom sensation in my prosthesis when driving makes me realize where it <the artificial leg> is, because I have to keep it well away from the other controls... I mean normally with an artificial leg you have to look where it is!

AMP4

AMP: I *know* <feel> I’ve got a foot I can stand on...even though me mind tells I don’t have a foot to stand on, I can walk.

Phenomenological analysis

- If the phantom sometimes deceives, it can also help in certain everyday situations. It aids distribution of weight and balance when climbing (AMP 2 and the walk up the step ladder); it can help in the positioning of the body (AMP 20 and ‘knowing’ where the driving leg is, AMP 3 having a sense of the located-ness of the shoulder, AMP 4 as an aid to walking).
- There is a sense of re-learning how to do simple tasks with the phantom as a positive physical aid in rehabilitation with prosthesis. For example, AMP 2 talks not only of feeling the phantom ‘inside’ the prosthesis when climbing the step ladder, but of ‘needing to concentrate and stand on two feet’. The phantom seems to be working with the amputee in this situation. This sense of re-learning and getting to know the phantom in another way is also a fact for AMP 4, who once realizing that the leg isn’t there learns to trust the feeling of its presence when walking. Once she *knows* she has a foot to stand on (feeling the phantom in the prosthesis), she can walk. Knowing has got to do with feeling rather than looking. She explicitly says elsewhere in the interview: ‘Once I realized that I wasn’t <standing on two feet > although I could *feel* that I was, it did help.’
- It is necessary to understand the limitations of feeling with the phantom. That is, it is about position and balance and not feeling in a tactile sense. This is nicely explained by AMP 2 who elsewhere in the interview talks about it not being a ‘normal’ feeling: ‘I can’t tell when I step on a cat’s tail...except when it wails of course.’
- It is helpful to understand the role of corporeal tacit knowledge, what Merleau-Ponty theorizes in terms of ‘corporeal intentionality’. This helps

us understand AMP 3 whose phantom shoulder ‘protected him’, for example, in getting in and out of the car. In other words, the ‘corporeal schema’ is something active, giving a sense of the position of the body in very concrete lived situations. AMP 20 reinforces this point by knowing where his driving leg is. Note the fact that he does not need to look, as he might have if his artificial leg were not penetrated by the phantom.

- Interestingly the positive use of the phantom as a physical aid to rehabilitation builds confidence in the process. This is what AMP 2 goes on to say when describing the step ladder experience later on in the interview. The physical and psychological can work ‘hand in glove’ in the successful rehabilitation of amputees.

Summary Box

The first perspective beyond the common sense view (natural attitude) can be summarized as a positive belief in the phantom as a physical aid in rehabilitation. Phantom pain is a warning, while phantom pain/sensation is a useful aid with prosthesis.

Second perspective beyond the natural attitude – a positive belief in the phantom as a psychological aid to rehabilitation

Extracts from in-depth amputee interviews

AMP2

AMP: It gives you a feeling of *still being alive*, you know, the leg itself I mean, even though you also know that it isn’t there. And that gives you *confidence* and that is what you need more than anything.

AMP15

AMP: The phantom is positive... just for a moment I feel I've still got my leg. I know I haven't but I feel that I have, so it just gives me a little bit of *comfort* that.

AMP3

AMP: So it is just a way of feeling positive about yourself. There is a sense of *wholeness*.

AMP20

AMP: If I didn't have PLS it would feel as if something were missing...part of me would not be there. *I'm not a whole being <laugh> but I feel as if I've got a whole being.*

AMP23

AMP: Having the phantom pain helps me *accept* the false leg.

AMP22

AMP: It helps me feel still alive and kicking and *it tells me my stump is alright*. If there was no phantom maybe my stump wouldn't be okay.

Phenomenological analysis

- It could be interpreted that all the amputees cited above expressing the phantom as a psychological aid are in actual fact prone to self-deception. This would only be true however, if they were in the natural attitude and trusted what they could see over and above what they could feel. However this is definitely not the case, all of the amputees recognize the ambivalent ontological status of the phantom. That is, they *know* that they are not a whole being, but *choose* to recognize the feeling that they are. For example, this is made explicit by AMP20, 'I *know* that I am not a whole being <laugh> but I *feel* as if I've got a whole being.'
- Notice the language of bodily integrity, and the either explicit or implicit sense of 'wholeness' (contrasted to those amputees where the phantom

acts as reminder of not being well, whole and healthy). Such a sense of bodily integrity affords amputees of this disposition with a ‘feeling of being alive’, of giving ‘confidence’ in the rehabilitation process (AMP2), a feeling of ‘being positive about yourself’ (AMP3) and a sense of it being of some ‘comfort’ (AMP 15).

- A phantom that is perceived as psychologically positive can help in the physical rehabilitation process. Not only does it engender ‘confidence’ in the rehabilitation process (AMP 20) it can help with the psychological acceptance of the phantom (AMP 23). AMP23 goes on to say (in the same interview) that it is because he feels the pain in his phantom foot with the prosthesis on that it helps him accept the artificial leg more.
- As usual it is important to pay close attention to the amputee’s history and circumstances. Younger healthy amputees often see no need for a nostalgic perception of the phantom. Many simply accept the reality of the stump, ignore the phantom and get on with their lives. I’ve observed that many older patients whose limbs have been removed because of disease are more likely to think positively about the phantom as compensating for bodily integrity in some way. Two particular cases stand out here (AMP 15 and 22). Both have had amputations following disease, diabetes and vascular disease respectively. For AMP 15, therefore, the phantom is a ‘comfort’ to a disease that has slowly been robbing her of health and bodily integrity. For AMP 22, the phantom sensation/pain is a reassurance in that it indicates that vascular disease is not spreading.

Summary Box

The second perspective beyond the common sense view (natural attitude) can be summarized as a positive belief in the phantom as a psychological aid in rehabilitation. The phantom helps in giving a sense of wholeness, well-being, sometimes providing awareness inside the prosthesis that aids in a psychological acceptance of prosthesis.

Third perspective beyond the natural attitude - a better understanding of the ambivalent ontological status of the phantom

Extracts from in-depth amputee interviews

AMP1

AMP: But the phantom pains <a derisive hmpff >, there is nothing phantom about them. Don't give me that phantom shit, they are real pains, very real. They are not like a headache when you know it is in your head but you don't know exactly where it is, you can't pin point it – with Phantom pains you can actually mentally and physically pin point pain in your foot, to each bone even. I know damn well it isn't there; it's probably in some furnace in Warrington. They should give 'em back your limbs, you know what I mean, so when you get phantom pains you get it out the freezer and say there it is <laughter>.

AMP1

AMP: I mean, now, I'm pulling me toes back <on the phantom> so what happens is the muscles here <at either side of the knee joint, just above the stump> contract and these expand – *I understand it now whereas I didn't before* – You don't think to yourself now 'I'm going to pull my toes up'. It's good but it is not conscious I can forget about it, because it's like riding a bike you don't

think about keeping upright do you. *Understanding* is one of the main differences to coping with it all.

Phenomenological analysis

- For AMP 1 the phantom is not imaginary, it is a *real feeling*. The tension between the 1st person perspective of feeling pain and the 3rd person verification of seeing where it hurts is captured by the amusing aside of AMP 1: ‘I know damn well it isn’t there; it’s probably in some furnace in Warrington. They should give ‘em back your limbs, you know what I mean, so when you get phantom pains you get it out the freezer and say there it is’.
- For AMP 1 ‘understanding’ how the phantom is working with the prosthesis helps him cope. Notice that he is describing the phantom in tacit mode, as something working with the prosthesis without any need to reflect.
- The recognition and acknowledgement of the quasi-presence (reality) of the phantom-limb could be important for some amputees, both physically as well as psychologically.

Summary Box

The third perspective beyond the common sense view (natural attitude) can be summarized by sensitivity to the ambivalent reality (ontological status) of the phantom. This is important, because it gives amputees the *choice* of whether or not to recognize the presence of the phantom as a possible positive psychological and physical aid in rehabilitation.

Conclusions

Merleau-Ponty's own discussion about phantom limb helped me understand why the natural attitude in the clinic was limited. Doctors/consultants – much more so than nurses, physiotherapists and prosthetists – view the phantom from a 3rd person point of view, *what the phantom is*, from a physiological and neurological point of view. From this perspective, there is a tendency to be less interested in *what the phantom is like* from the point of view of the patient – a 1st person point of view. To end, I review five central conclusions offered by this study.

- (a) By trying to explore patients' own experience through phenomenology it is important to understand that this study is in no way trying to replace the received clinical wisdom. It is simply a *complementary* approach to what is already best clinical practice. The purpose of the study has been about an attempt to widen the rehabilitative *scope* of understanding.
- (b) It is unwise to ignore the significance of the patients' own perspective on phantom limb, by explaining the phantom too narrowly – exclusively within the rubric of physiology and neurology. By ignoring patient experience, many clinicians fail to grasp the significance of the ambivalence of the phantom limb experience. The amputee avows two contradictory realities simultaneously: the reality of a 'living' limb and its destruction. These two limbs occupy the same space and time, one the ghostly double of the others absence. In short the phantom ontological status is 'quasi' real.
- (c) What is significant about the ambiguous and ambivalent quasi-reality of the phantom is that, in the context of rehabilitation, it can be useful. Instead of seeing the phantom only as a physical and psychological

- hindrance, in certain circumstances with particular patients, it could be a physical and psychological aid in rehabilitation.
- (d) This could lead to a plurality of rehabilitative possibilities and treatment strategies fitting the specific psychological type and circumstances of the amputee.
- (e) In order to develop a number of rehabilitative treatment possibilities, there is a need to devise a clinical tool that incorporates a phenomenological method. This will need rigorous research and development, the efficacy of which can only be ascertained through a much more complex methodological rationale, involving larger patient groups across a number of DSC's in the North-West of England.

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