... and then there comes this madmen of 'Who's afraid...' with his stanley knife...

Phantoms and the body: Experiences of phantom pain
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Preface

In September 1999 I saw an interesting documentary on Dutch television about a new treatment for people who suffered from phantom pain. In this documentary a man was telling about the recurrent sensations of pain he felt in his phantom arm. This documentary triggered off a lot of questions. I wondered how people experience this pain in daily live. I also became very interested in chronic pain after reading about it during the chronic illness module of the AMMA course. I thought people’s experiences of phantom pain would be an interesting topic for my thesis. Members of the Dutch foundation Landelijke Werkgroep voor Beenprothese-gebruikers were willing to talk about their experiences, for which I want to express my gratitude. Furthermore I also want to thank the informants involved in the treatment of phantom pain for sharing with me their experiences and views on this subject.

Krista Coppoolse
August 2000.

1 This documentary was broadcasted by the VPRO on the 21st of September in a program titled ‘Noorderlicht’. It showed the famous mirror-box experiment of V. Ramachandran.
1. Introduction

There are approximately twenty thousand leg-amputees in the Netherlands. Every year two to three thousand people have their leg(s) surgically removed (Cats, 1999:1). More than 85% of the leg amputations are the result of problems with the blood vessels, like arteriosclerosis or obstruction of the smaller vessels in case of diabetes. The remaining causes of amputations are accidents, malignant tumours in the leg or congenital deformity (Van der Meij, 1999:89).

As many as 70 percent of (all) amputees are said to suffer from phantom pain. Phantom pain is the feeling of pain in a limb that has been surgically removed. It is often described as burning, cramping or shooting (see Annex I) and may vary from being occasional and mild to continuous and severe. It usually starts shortly after amputation but sometimes appears weeks, months or years later (Melzack, 1992:90). Seven years after the amputation half of the amputees still suffer from phantom pain (Broers, 1996:36).

Phantom pain is an intriguing mystery that has captured the imagination of health care providers and the public alike. How is it possible to feel pain in a limb that has been surgically removed? Sherman (1997:143) has shown that there are about 68 treatments for phantom pain in recent or current use. They range from highly invasive interventions such as lobotomies through spinal surgery and re-amputation to more innocuous treatments such as ‘phantom exercises’, injection of the stump with local anaesthetics and relaxation training’ (p. 143). All surgical procedures have proven to be unsuccessful; phantoms persist and the pain usually returns. According to Sherman these invasive procedures have caused severe disability.

Currently, there are no medications which are capable of reducing phantom pain. Nowadays one is restricted to techniques like acupuncture and electrical stimulation of the residual limb. Some patients benefit from medications, normally prescribed for epilepsy and depression. Another way to decrease the intensity of phantom pain is the combined administering before the operation of a general anaesthetic and of more local anaesthetics which work on the spinal cord. In this way it is prevented that pain signals which arise during the amputation, are passed on through the spinal cord to the brain (Broers, 1996: 37).

In the next paragraph some of the main mechanisms, which have been used to define phantom pain, are described. These different etiologies could be mostly considered biomedical and explaining the cause of phantom pain.
1.1. Etiologies of phantom limbs

I presume that most biomedical theories underlying the various etiologies of phantom pain are part of the same 'biomedical tendency to create a purely biological metaphor for pain (Kleinman & Kleinman 1998:202)', in which mind and body are mostly separated or treated as two distinct entities. This mind-body dualism is implicitly used in medical classifications of distress. For example, the healthy mind is quick, active, powerful and rational. Used in a metaphor, it stands for what is essentially human – the domain of intelligence, responsibility and freedom. In contrast, the body is ultimately irrational, governed, not by human will but by the inexorable rules of the material world (Kirmayer, 1988: 76). In their search for causes of phantom pain, biomedical scientists have tried to look for clues in the nervous system. In the next subparagraph I will describe that they first looked at the Peripheral part of the Nervous System.

1.1.1. The traditional peripheralist view

Melzack states that ‘the oldest [biomedical] explanation for phantom limbs and their associated pain is that the remaining nerves in the stump, which grow at the cut end into nodules called neuromas, continue to generate impulses. The impulses flow up through the spinal cord and parts of the thalamus (which is a central way station in the brain) to the somatosensory areas of the cortex (Melzack: 1992:91).’

According to this traditional view the Central Nervous System (CNS) cannot operate on its own, it has to be triggered by the Peripheral Nervous System (PNS) for the real perception of phantom limb to be generated. The peripheral nerves are sometimes represented as ‘inanimate telephone wires (Devor, 1997:57, italics are mine),’ living a life on their own, firing spontaneously and thereby fooling the brain. Rational treatment from this view requires silencing the firing neuromas. In attempts to relieve phantom pain surgeons have been surgically cutting the nerves from the neuromas, either just above the neuromas or at the roots, next to the spinal cord. Although there is some temporary relief, the phantoms persist and the pain usually returns (Sheldrake, 1994:190). Since this kind of therapy clearly did not work, the biomedical scientist’s next explanation was to move upwards in the nervous system. They ended up in the workings of the brain: the Central Nervous System. The theories described below all consider phantom pain to be caused in this system, but they differ in the degree to which the brain is hard-wired or not.
1.1.2. Theory of the hard-wired brain

To understand how the brain works, scientists have among other things tried to 'look closely at how various body parts such as limbs are mapped onto the cerebral cortex, the great (...) mantle on the surface of the brain (Ramachandran and Blakeslee, 1998:25).' This is thought to be especially important in the case of phantom pain, because in this way one can understand the emergence of a phantom limb, it is said. The homunculus (see Annex I) is draped across the surface of the cerebral cortex. He is 'upside down for the most part, and his feet are tucked onto the medial surface (inner surface) of the parietal lobe, near the very top, whereas the face is down near the bottom of the outer surface (Ramachandran and Blakeslee, 1998:26). There is a place on the homunculus for each nerve coming from the body surface.

In the Amputee's Guide to the Amputation and Recovery Process, Sherman and Casey Jones demonstrate that the homunculus has the same structure as 'a hard-wired telephone switchboard (1997:199, see Annex I).' They state that the homunculus 'is not part of our conscious brain (...) we do not think it can learn or change much after childhood. It has no way of knowing where the signals reaching it actually started from [for example from nerves in the stump] (p.199).' The homunculus has no way of knowing that the limb is missing, even though one would know perfectly well that it is gone. Anything that causes the nerves that once served the amputated limb to start a signal will cause a sensation that seems to come from the amputed limb, the homunculus tells the conscious part of the brain that the sensations actually came from that limb. Thus, people with an amputated limb cannot consciously convince the brain that the limb is lost: 'the wiring does not change much as the years go by (Sherman and Jones, 1997:200).'

But, again, this theory has also been refuted by the fact that radical treatments directed to 'remove areas of the thalamus and the cerebral cortex that receive impulses from the affected limb (...) in order to stop the pain have also failed (Sheldrake, 1994:191).' Thus the possible source of phantom limb pain still had to be found somewhere else in the brain.

In the next subparagraph I will describe the current theories of phantom pain. They deal with possible sources deeper into the tissues of the brain. It seems that these theories 'do not consider the peripheral nerve processes all that important in the emergence of phantom pain. These theories define phantom pain to be entirely caused in the brain.'
1.1.3. Plasticity theories

Ramachandran, a neuroscientist, was wondering if body maps are fixed on the surface of the brain (on the homunculus), which is believed by scientists who adhere to the hard-wired brain theory, or if they could change with experience.

What he did found out during an experiment with a blinded subject (who was experiencing phantom pain in his amputated arm, especially the hand) was that when he stroked the subject's face using a simple Q-tip, he could generate phantom sensations in the subject's phantom arm. He found a complete map (representing all the fingers) of his subject's phantom hand on his face (Ramachandran and Blakeslee, 1998: 28-29). This and other experiments he did with amputee's lead him to the following 'staggering implications ( ... ).

[First] they suggest that body maps can change, sometimes with astonishing rapidity ( ... ); new, highly precise and functionally effective pathways can emerge in the adult brain as early as four weeks after injury. Second, the findings may help explain the very existence of phantom limbs (p.31). The phantom exists in the more central parts of the brain were the remapping has occurred. Ramachandran has two possible explanations for this remapping to occur on the cellular level. One is that 'sensory input from the face and upper arm activates brain areas that correspond to the hand. Second, each time the motor command center sends signals to the missing arm, information about the commands is also sent to the parietal lobe containing our body image. The convergence of information from these two sources results in a dynamic, vibrant image of the phantom arm at any given moment (p.45).

Ramachandran has also linked this story back to the homunculus. In this map the face is located near the hand, so the input from the face area could be invading the territory vacated by the hand (p.36), giving the impression that the hand still exists.

But how does Ramachandran explain phantom pain? He supposes that it has to do with abnormal remapping. Some touch input is hooked up accidentally to pain centers or that volume control centers (that allows us to alter our responses to pain in response to changing demands) have gone awry as a result of remapping. But Ramachandran does say that 'we really don't know how the brain translates patterns of nerve activity into our conscious experience, be it pain, pleasure or color (p.51, italics are mine).'

But still the question remains: can the phantom be ‘unlearned”? For this Ramachandran developed his famous ‘mirror-box experiment': a mirror is placed in the middle of a box. The front of the box has to wholes in it, through which the patient insert his ‘good hand' and the phantom hand. The patient is seeing the mirror reflection of her intact hand, hereby creating 'the illusion of observing two hands (p.46). If the patient sends motor commands to both arms to make symmetric movement [clenching and unclenching the hand], the patient 'sees' her phantom moving as well.' Ramachandran did several of these experiments; his patients
The neuromatrix is able to independently produce an activity pattern characteristic of pain, for example a burning feeling. Other forms of pain, like cramp, arise when the neuromatrix independently produces impulses to move a limb. Because that would be impossible with an amputated limb, the neuromatrix sends even stronger impulses to the limb (Broers, 1996: 37). These theories have in common that phantom pain experiences arise in the brain. In the next subparagraph these experiences are altogether denied and are considered to be a product of someone’s ‘psyche’.

1.1.4. Psychosomatic explanations

Amputees requesting treatment for phantom pain have also been sent to psychiatrists and psychologists. Some authors discussing the origins of phantom limb sensations have expressed ‘that they are akin to hallucinations and arise in the psyche (Devor, 1996:33).’ ‘The practice of relegating certain inexplicable phenomena to the psychological or emotional realm may free theorists from considering them further, but it changes how the amputee is viewed and treated and implicitly blames him or her for the pain (Katz, 1996:106, italics are mine).’ This means that amputees suffering from phantom pain have sometimes been presented as ‘somatizers’. When nothing physically wrong can be found and treatments do not work it is sometimes said that there is an underlying psychological problem in the mind, which presents itself physically. ‘Personal and social distress, along with those mysteries of the body that have not yet yielded to biological explanation, are challenges to the rational order. The treat that unexplained or uncontrolled sickness presents to the authority of biomedicine is neutralized by making the patient accountable for the illness (Kirmayer, 1988:24).’

1.2. Theories of embodiment

It seems that both biomedical and psychogenic theories of phantom pain view phantom pain as caused in either the brain or in the psyche. I suggest that by using a more embodying theory one could try to overcome this mind-body dualism. This perspective is described by Davis (1997:15) and conceptualises the body as ‘embedded in the immediacies of everyday lived experience. Embodied theory requires interaction between theories about the body and analyses of the particularities of embodied experiences and practises. It needs to explicitly tackle the relationship between the symbolic and the material, between embodiment as experience or social practise in concrete social, cultural and historical contexts.’
Jackson (1994) describes that pain is 'something quintessentially lived and experienced in the body. The experience of chronic pain is simultaneously sensation and emotion, neither preceding the other (p.210).’ Jackson critically examines our model of chronic pain as first *caused* (in either the body or the mind) and then *experienced*.

Jackson states that to speak of the experience of pain one must objectify pain in order to 'give meaning' to it and this requires distorting the experience – in a sense, betraying it (1994:221). One must objectify one's body or one's pain when using everyday language (as an object 'out there', this can refer to inside the body; pain is seen as an object). Thus patients who objectify their pain speak in terms of 'getting a grip on it'. Pain itself is sometimes conceptualized in terms of the presence of a physical object inside oneself. We also try to objectify our pain in order to understand and control the difference between painful and painless states. On the other hand, one can move toward greater subjectification of pain - not to attempt to decrease the power of one's pain by saying it does not exist - but rather attempt to merge the pain more with one's selves. The crucial element seems to be how pain sufferers connect pain to their bodies and to their identity. If one claims it, accepts it, does not fight it, then, paradoxically, one better controls it. The subject – object dichotomy is essentially about the presumed cause of a pain, and while this is certainly an important factor in how one experiences pain, it is not the same thing as the experience of pain (p.204).

'Patients speak of their pain at times in terms of an identification of self apart from pain; at other times they use terms revealing an identification of self with pain. Knowing where the sufferer positions himself or herself on this continuum helps us to understand how an individual experiences the body (...) (1994:209).’

1.3. Study objectives

In this study I intend to explore what kind of experiences of phantom pain people have. I am also going to explore what kind of explanations of the body people adhere to when talking about their experiences of phantom pain. Part of these explanations can be derived from biomedical explanations of phantom pain; from what they have heard from their physicians and other people or from what they have read about the causes of phantom pain, for example representations of the nervous system. Beyond this I presume that people’s experiences go deeper than just biomedical explanations. I suppose biomedical explanations interact with all kinds of other explanations people derive from themselves and all kinds of sources; like near-others and fellow-suffers, etcetera. I would like for my final research to come to a more embody-ing approach, in which pain is experienced and lived in the body in a social, cultural and historical context.
1.3.1. General Objective

The aim of my research will be to explore and describe the informants’ own experiences and explanations of phantom feeling, sensation and pain in relation to their body and how these explanations fit in with biomedical theories of phantom pain.

1.3.2. Research questions

1. How do people experience their phantom feeling, phantom sensations and phantom pain?
   - How do they make a distinction between their phantom feeling, phantom sensations and phantom pain?
   - How would they describe (terms used) their phantom feeling, sensation and pain?
   - How do they experience painful and painless states?
   - How could they experience their painless phantom as functional?
2. How do people experience their pain in relation to their body?
3. How do they relate the origins of phantom feeling, sensation and pain to biomedical explanations (physical and psychological) of the body (e.g. representations of nervous system)?
4. How could the amputation and the circumstances around it have influenced the experience (e.g. duration and frequency) of phantom pain?
5. What kind of other factors people experience as influencing phantom pain and phantom sensations?
6. What kind of treatment experiences (of phantom pain and sensations) did they have?
   - How do people experience their current treatment practices?
   - How did people experience former treatment practices?
   - How do they cope with treatment failures?
   - How do people experience the influence of medical doctors?
   - What kind of treatments have they tried outside biomedical treatments and how do they experience them?
7. How do people experience pain in daily life?
   - How do people experience the influence of others in coping with pain in daily life?
   - How do people experience support of the fellow-sufferers group and other networks?
2. Methodology

In the theories described in the first chapter the mind is mostly portrayed as the center where we get a sense of our body. However, I presume that the way we get a sense of our body is dependent on how we experience our body but also on our emotions; these seem almost to be left out in these theories. Not explained is for example, how 'neural networks' generate the (felt) experience of phantom pain.

Jackson has stated that pain is lived and experienced in the body and that experience of chronic pain is simultaneously sensation and emotion, neither preceding the other (1994:210). The focus of this research is not to look for causes of phantom pain, but to describe what people who experience phantom pain think about what is involved in phantom pain. I will try to describe what kind of theories of the body they adhere to and how this is connected to their experiences of phantom pain. This kind of focus requires a research method which is open to people's own views, which will be described in the next paragraph.

2.1. Study type

The general objective of this study is to explore and describe people's experiences. The research method employed in this research will be the qualitative method. This method 'is the basic strategy of social research that usually involves in-depth examination of a relatively small number of cases. Cases are examined intensively with techniques designed to facilitate the clarification of theoretical concepts and empirical categories (Ragin, 1994: 1990).

Within this strategy of qualitative research a combination of study types will be used; a mixture of an exploratory and descriptive study type. I would like to explore and describe 'the characteristics of a limited number of cases extensively' (Hardon et al., 1994:117) and these will be derived from the meanings people give to their experiences of pain. I have developed a number of specific topics based on the research questions above (see Annex II). These are discussed with my informants in an open-ended fashion. After each interview this topic list will be reviewed in order to develop concepts that are relevant to respondents' everyday lives (Hardon et al., 1994:117).
2.2. Study population

In order to find informants for my research I have contacted the national secretariat of the Dutch patient organization for people with a leg prosthesis (Stichting Landelijke Werkgroep voor Beenprothese-gebruikers). This organization has been established in 1982. The initiative was taken by the Dutch foundation Warenonderzoek Medische Hulpmiddelen and the Consumers organization and several users of leg prostheses. The reason for its foundation was that at that time there were complaints about the available leg prostheses as well as a lack of information. There was insufficient mutual understanding between healthcare providers and users during the period in which prostheses had to be fitted and measurements had to be taken. There were also complaints about quality, maintenance and fitting. Most of these complaints were disposed of with arguments like: 'it is the users fault', 'it is all in the head' and 'that it could not be done differently'. This treatment often was the consequence of incapacity or insufficient interest or knowledge. These were often painful remarks made by rehabilitation doctors or leg prosthesis makers. Users often had the feeling that decisions were made for them but not with them. The relationship between users of leg prosthesis and healthcare providers has improved gradually. But misunderstandings still happen. Important in the relationship between healthcare provider and client is that the user of a leg prosthesis wants to be kept informed about all the possible alternatives in prosthesiology and that he/she want to pass his/hers experiences as a user on to workplaces, manufactures and health insurers. This has been stimulated by the foundation from its beginnings.

The foundation also informs and advises leg amputees concerning their rights as such and concerning their problems connected with the use of prosthesis. The SLWB organizes contact meetings for fellow sufferers and is helpful in maintaining the regional and/or local groups/associations of users of leg prostheses.

To conclude, the foundation protects the interests of users by representing them in official bodies or persons, such as medical doctors and prostheses makers (Biermans and de Boer et al).

Through the secretariat I was brought into contact with the coordinator of the fellow sufferers contact group of the organization. This contact group is there for people who are about to undergo an amputation or have recently undergone an amputation and want to talk about their situation. The coordinator brought me into contact with other members of the organization. I phoned them and asked them if they would like to be interviewed about phantom pain. Subsequently I asked my key-informant if she knew other persons who are suffering from phantom pain and/or sensations; this is called 'snowball or chain sampling (Hordon et al. 2000:7)"
Thirteen members agreed to be interviewed, of which seven females and six males. The informants’ ages ranged from 23 up to 73. One informant had undergone an amputation of the leg and a part of the pelvis. Two informants had an upper leg amputation and one informant had two upper leg amputations. Nine had undergone a lower leg amputation. According to Van Acker (1999:113) however, the sex and age of an amputee and the level of amputation does not have any influence on acquiring phantom pain. The time since amputation ranged from 1 up to 60 years.

The secretariat of the organization also referred me to an anesthesiologist. Informants indirectly referred me to the neuroscientist and the acupuncturist I interviewed. I also wanted to see and describe their views on phantom pain.

2.3. Data collection techniques and analysis

The main data collection technique I use in my study will be interviewing, with a high degree of flexibility (semi-structured or unstructured interviews). I will use a topic list or research themes based on the specific research questions, to ensure that all issues are discussed (Hardon et al., 1994:149). The sequence of questioning will not be rigid and the questions will not be formulated in a fixed manner in advance. But the questions should be truly open-ended (’What’ en ’How’), it ‘allows the person being interviewed to select from among that person’s full repertoire of possible responses (...) In qualitative inquiry one of the things the evaluator is trying to determine is what dimensions, and images, themes (...) feelings, thoughts, and experiences [people use] (Patton, 1990:296).’

I plan to ask each informant the same question in the beginning of the interview. With this question I intend that informants will begin talking from the point where it all started (the amputation and the first experiences of phantoms) and by then asking ‘how’ and ‘what’ questions, enable them to ‘historicize their current existence (Nijhof, 2000:9).’ Nijhof further states that life stories are interpretations of interpreted events (p.27). But the researcher also interprets the life stories (p.31). This process starts when all the interviews are transcribed from tape and read very carefully. ‘At this stage the aim is to use the data to think with. One looks to see whether interesting patterns stands out as surprising or puzzling (...) and whether there are any apparent contradictions among the views of different groups or individuals (Hammersly & Atkinson, 1983:178).’
'You have created this beautiful piece of embroidery for all these years, and then there comes this madman of 'who's afraid', and cuts through your embroidery with a stanley knife…'

3. Phantoms and the Body

This chapter contains statements of my informants' own experiences of phantom pain. The statements of people who treat and approach phantom pain scientifically and biomedically will also be taken into consideration. I will try to interpret the relationships between their various experiences, perspectives, etiologies and practices, for example how peoples own explanations about factors influencing phantom pain correlates with what they do about phantom pain and the body. As I already explained in the two preceding chapters, I will try to establish the infinite nuances in my informants' stories, which are part and parcel of the experience of phantoms. This implies analysing my data in a corresponding way. Not only descriptions of phantom pain were eminent in my informants stories, but also descriptions of phantom feelings, which among other things contains feelings of movement and of all kinds of sensations in amputated limbs. These different experiences will be included in all the paragraphs of this chapter.

In the first paragraph I will try to depict the words or metaphors or comparisons my informants' used to describe what phantom feeling, sensation and pain and their different qualities encompasses. In the second paragraph the explanations or etiologies of phantom feeling, sensation or pain predominate. Peoples practises to deal with, find relief, and cope with their phantom pain, sensations and feeling is discussed in the third paragraph. At the end of each paragraph the findings will be briefly summarized.

3.1. Giving meaning and making comparisons: images of phantom limbs

Phantom feeling, sensations and pain is just like any other bodily sensation difficult to describe and explain. It requires objectifying the experience by using common everyday language. From my informants' stories it seemed that words to describe phantoms are used to make comparisons, thereby making the experience concrete and understandable for laypersons. Giving meaning to phantom experiences is not an easy task, I could sense from what my informants told me, because phantoms are not easy to grasp and understand for people who have never experienced them. In the following subparagraph I will describe how my informants described phantom feeling.
3.1.1. Phantom feeling

Almost every amputee is familiar with and recognizes phantom feelings; sometimes they are so strong, that the phantom is sometimes felt clearer than the healthy extremity (Van Acker, 1985:21). In my informants’ stories it is clearly distinguished from phantom pain and sensations. It is used to distinguish between painless and painful states in the case of phantom pain and sometimes phantom sensations. Phantom feeling is almost always described as non-painful, sometimes not totally unpleasant and even functional.

In one case an interviewee who lost her leg age at 15, 25 years ago, told me that she wasn’t even aware of the fact that she had the feeling of a phantom after her brother made her conscious of it:

I was in my sixth form when I had the accident... and they had changed my parents bedroom into a bedroom for me, so I could study and sleep there... because I couldn’t manage to walk up the stairs... and at one point a brother of mine came in and he said: ‘what are you doing?’... I was scratching the leg that wasn’t there anymore... I didn’t notice it myself, because I was studying... but I found it very peculiar... so the feeling is there indeed.

First (conscious) experiences of phantom pain can be, just like the one above, very confronting. Two informants told me that their first experiences of phantom feeling, not long after the amputation, were very fundamental. One interviewee (55, above the knee amputation) told me that after her operation, she had the feeling her leg was sticking through the mattress:

When you come to realize that you are lying in bed... and your leg is hanging there, through the mattress... then it’s not very logical... and then the dream came that that leg was amputated below the knee... It took a whole week when I finally realized what was going on... that is wasn’t below the knee, and I asked continuously: ‘I’m shorter’, they answered ‘no you’re not shorter’... for a long time a thought: ‘It will grow back again’... I pushed everything away... it will grow back again and that is that... and I didn’t want to talk to anyone about it.

The next informant (52, hemipelvectomy) also told me what happened after the operation 23 years ago:

When you’re just amputated... you can have ten blankets pulled over you... but that leg... it floats... it sticks somewhere in the air... so you’re lying there constantly... with your legs wide apart... for your own feeling... and then I said: ‘don’t you have anything heavy?’... ‘a sandbag or anything?’... only then I had the feeling I was lying in my bed with closed legs... then I got the sandbag from the nurses and that made my legs close again.
Ever since they experienced this kind of phantom feeling, they did not have these kind of experiences anymore, but it seemed that they were fundamental and still present in their stories about phantoms.

Other feelings of phantoms contain the moving of the amputated limb. One interviewee (52) told me that whenever a part of the body is taken away, the feeling of that part is still present, and is accompanied by the moving of the amputated limb:

*It doesn’t matter if it’s your finger of your leg that has been taken away... I think the feeling of it... is still there... I can move my heel; I can move my whole feet...*

This informant (73) emphasises that the phantom limb does not move uncontrollably:

*These toes... which since sixty years I haven’t got anymore... I can move them on command... this ankle I can move on command... everybody can stand on my left foot of course... I don’t say au... but you notice... how you feel it... I don’t know how to fine-tune these terms...*

One informant however did not experience a phantom leg at all. He was the victim of an industrial accident 20 years ago. In the period after the amputation he began to reject his leg, which was amputated below the knee. He told me that he didn’t have a leg from his groin onwards. With the help of a haptonomist they tried to build up the leg again:

*Then we began to stretch the leg... and now I actually feel my foot in my shoe... before that I didn’t feel a foot in my shoes (...) I did everything on one leg... I danced on one leg... I exercised on one leg... I was lawn mowing on one leg... but when I walk now... and they have trained me in that very well... I walk on my feet and I feel my tows.*

Examining the latter statement it seems that phantom feeling can be useful for walking. This informant (41) who is a physiotherapist and amputee, says that you need phantom feelings to walk properly:

*I think you need phantom feelings to be able to walk well... it sounds a little strange... but is pleasant to know roughly... that it is nice to have a little bit of a blueprint of your body schema and I think a little phantom feeling can help with that... that that body part is not really there... but still is a kind of extension piece of yourself.*

But to be able to walk well, just like the latter interviewee says, you need the phantom to exactly coincide with the leg prosthesis. And this is not always the case according to what two informants told me.
In the case of this informant who had to undergo a 'high' amputation [hemipelvectomie] 23 years ago due to a tumour in her pelvis, talks about the experience of the 'telescope phenomenon':

What they say about the telescope phenomenon... that the leg becomes shorter... he sticks into my (wheel) chair... and my foot is in strange cramping position... a little upright... and you can do nothing about it... when I move this way... then it moves also... it is so incomprehensible... and that is phantom feeling I feel right now... on every chair... and also when I wear my prosthesis... it doesn't matter... my leg used to be of normal length... but now it's shorter... I can feel my toes... my [middenvoet], ankle, heel, my shin is gone a little bit then there is a bend and then my upper leg.

The telescoping phenomena is the 'telescoping of phantom limbs into the distal end of the residual limb (stump), while progressively losing detail from proximal to distal (Sherman, 1997:1-2). Telescoping is not always the cause of the phantom limb to 'shorten' as is seen in the following statement by this informant (55):

I always feel my leg... always on really strange places... but it's never integrated into my prosthesis... well, sometimes until my knee, but then my foot sticks out strangely... in a very confusing way... but slowly you are able to handle it... but it's still very confusing especially as you walk with your prosthesis... you do walk but you have the idea that your foot is behind you, since I have had correctional surgery and two centimetres were taken of the bone from my upper leg (or stump), my phantom foot became two centimetres shorter and is not standing on the ground... probably it's the piece that was removed (that I'm now missing).

According to the latter interviewee it can be a rather confusing experience when the phantom limb is not integrated into the leg prosthesis. A neuroscientist I interviewed explained that life could be much more complicated when your prosthesis is one thing and the phantom is another and when it is difficult to relate the two:

The prosthesis belongs like a hammer or fork into your body schema... just like a tennis racket... you do not feel the ball on your racket but through the extension piece... for example a blind man with his stick... he feels a curb stone at the end of the stick... we can extend our projections through helping aids... but the problem is that phantom patients already have a different schema of that body part and on top of that you bring in a prosthesis... these two can be at odds with each other.
When I asked some of my informants if phantom feeling means 'the experience of two legs', rather clumsy it seemed afterwards, they quickly corrected me. It seems that this is what a layperson imagines phantoms to be like.

It seemed that most of my informants at one point in time have had the experience of two legs while missing one, but that was totally different from phantom feeling and occurs very rarely.

With the following statement this interviewee (40) explains that she in a particular situation must have thought that she had two legs. This is the only experience of this kind she has ever had, she told me.

'A couple of years ago I could not walk for a time because I had a wound on my stump... I stood in the shower... I had my daughter on this (healthy) leg to wash her hands... and I fell through that leg while trying to put my other (amputated) leg onto the ground... I found it rather strange that my leg wouldn't stand... that is the first time I had that experience.

The next informant (36), suffered from severe complications after his leg was broken. These complications were so severe that his lower leg had to be amputated. He had a similar experience as the one in the previous statement. From what he could remember is that it occurred only once. He told me that he was very fortunate because he did not hurt himself:

I once made the mistake... I didn't wear my prosthesis in those times because I had these infections in my stump... and I was used to walk with my prosthesis for a long time... I once got up from a chair at my friends place... and I forgot that I did not had a prosthesis on... I fell vertically... on my stump... it was really painful, luckily it wasn't damaged...

I suppose the crucial element here is the difference between 'feeling' in the case of phantoms and 'thinking' in the case of the 'experience of two legs'. While these experiences do not occur very much, one informant told me that she still had to get used to her missing one limb (above the knee) which happened eight years ago.

It has something to do with what happens in the brain:

In the beginning I have had incredible difficulties to not dry the leg, which I was missing, with a towel... then you dried one foot and then you wanted to do the other one... 'o, no... I don't have that anymore... and still out of some habit... some programme in the brain system... that you think... now I must... but you don't... but that is getting less... it's been programmed on two legs for 48 years... and then you miss something... and in what sense these things will go out (of the system)... I don't know... but currently I re-programme myself again and again...
Another interviewee (23) said that he sometimes had 'the experience of two legs' while walking with his prosthesis on.

*Sometimes when I walk... with my prosthesis... and you have that feeling... then you think hé... I've got two legs... then you're walking agreeably and you feel good... and then everything goes okay and then it's good to feel your leg...*

One informant, who is a neuroscientist said about 'the experience of two legs':

*The feeling of presence (of the amputated leg) is the basis of the body schema... the feeling that says to me: I am complete... that's here (in the brain) and that's independent of what's here (the body).*

In this subparagraph I have tried to show the very many nuances of phantom feelings in people's stories. Some informants had very emotional and confronting first experiences of phantom feeling. Luckily these were mostly non-recurring and the majority of the informants developed a kind of phantom feeling in the sense that they were able to move and feel and exactly locate the phantom toes and feet, ankle and sometimes the knee. But some informants were less lucky because the phantom limb (especially the feet) did not coincide with their prosthesis. One interviewee, who is a physiotherapist as well, discussed the fact that phantom feeling of a limb that coincides with the prostheses is very useful to be able to walk well and to adjust and build up new body schemas or blueprints (in the brain), which was emphasized by the neuroscientist as well.

When the informants talked about the 'experience of two legs', they distinguished it from phantom feeling, which is mainly 'felt'. These experiences did not occur very often and could sometimes be very painful for the stump. Thinking about 'two legs' had to do with build in patterns in the brain of 'having two legs', which in a sense resembles the body schema and blueprint theories the physiotherapist and neuroscientist talked about. In the next subparagraph descriptions of phantom sensations and pain are given and the association between the two is made.
3.1.2. Phantom sensations and Phantom pain

Very eminent in my informant's stories was that almost everybody told me that every amputee has totally different phantom experiences, not one story is the same. Thus the labels people use (common labels such as phantom pain and phantom sensations) to generalize their experiences thus clarifying for outsiders what they mean, is almost always insufficient and more or less diminishes the richness of their experiences.

Not all of my informants have had experiences of phantom sensations. But when they did most of them clearly made distinctions between phantom sensations and pain, in order to clarify the many nuances in their stories. For only a few informants this differentiation is important to discriminate between painless and painful states (phantom pain). For others the boundary between the two in not very distinct and severe phantom sensations can, under particular circumstances, develop into phantom pain. Only one informant said that before (and after) he was treated for severe phantom sensations, never experienced phantom pain. This means that what one informant would call phantom sensations or in Dutch [zware tintelingen] others would call phantom pain and this again emphasizes the individuality of phantom experiences.

This informant (55) lost both her legs during a car accident 18 years ago. Very characteristic in her story is the unremitting presence of [tintelingen] and when she concentrates she feels them through her lower leg and her feet and toes, which she can move. She uses the following comparison to describe what it is she feels continuously:

For example, when you used to ice-skate and almost had dead toes and then went of the ice... those [zware tintelingen]... which you felt then... those chilblains [wintertenen] that some people had in those days... those thick swollen toes... that feeling... that is really what I mean... that kind of sensation... or you used to place your feet against a stove or fire... and when you pulled them away... that gives such a [tintelend gevoel].

The subsequent story is also characterized by the continual presence of phantom sensations, they are accompanied by a warm sensation in the informant's (52) phantom limb, and it is explained like this:

When you bang your elbow against the wall you have these [prikkelingen] thousands of [prikkelingen]... that's a feeling you have constantly, all day... they won't go away... thus, it's always these [prikkelingen] and it's completely warm.
One interviewee (38, underwent below the knee amputation one year ago), who since he was four years old had to go through radiation treatments due to a tumour in his leg, only experienced phantom sensations.

Before he was treated for phantom sensations he could exactly feel where they were situated:

*I was able to point out those [tintelingen] very specifically... on the inside of my big toe just until the cuticle... now I am only bothered by overall, very global phantoms... they float a little bit across my leg... but I only feel the parts that were not radiated, that is my foot... I never had much feeling in the radiated area, and that also means that I don't have phantom sensations in that part... it seems like my body image... that a certain part of my leg does not exist in the body image...*

Phantom sensations can turn out to be very uncomfortable. This informant (23) says:

*And sometimes it's just like feeling your leg, your tows... and then it starts to itch... that can be just as annoying as that pain...*

Another interviewee (49, lost his lower leg due to an industrial accident) explains that there is dissemination, of what entails a sensation and what is involved in phantom pain:

*I mean... for me the boundary is not so sharp... when I feel a sensation in my toes and I fear that the one will cross the other [dat de ene teen over de andere schuift] and I will get a cramp... then it quickly becomes a (painful) phantom... and also when you're walking sometimes I get these sensation pains, [prikkelingen] which I feel in my foot and tows...*

But for this informant (55) who lost both her legs in a car accident 18 years ago, the distinction between phantom sensations and phantom pain is more clear-cut.

For her it has to do with the fact that you can evoke phantom sensations, but not phantom pain which can appear suddenly:

*You can evoke those tingling sensations. If I go back deep into myself, then the tingling sensations emerge... then I feel my foot... the instep... my ankle... But a phantom (pain) is totally different from it. That is the real pain, it lasts about thirty seconds, but it is very intense.*

Informants, who experienced phantom sensations, such as the continuous [prikkelingen] described by some interviewees, could very clearly point out where they felt these sensations. It seems that whilst these sensations are felt in the phantom limb, they simultaneously feel the existence of the phantom feet and toes. The same is true for phantom pain.

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But the relationship between phantom feeling and phantom pain is more complicated in the case of this informant who lost her lower leg 25 years ago, age 15, while she was hit by a car:

I miss a piece... only with phantom feeling... I feel my foot... but that piece in between... the calf and my shinbone... I feel that (part) rarely if ever... but with phantom pain I do... In the beginning... I experience a kind of shooting pain [pijnscheut] in the non-existing part and I can feel everything there... and it can hurt terribly.

Most of my informants said that phantom pain is mostly felt in different places on and in the phantom limb. And distinctions are made for example, between muscle pains (such as cramps) and nerve pains (such as shooting pain), between pains which are felt more on the surface of the phantom limb and the more deep pains. It seems that everything from which a limb is build up (e.g. nerves, muscle and blood), also exists in the phantom limb.

The following interviewee (55, lost both her legs) clarified it like this:

When you have phantom pains... you do not always have them at the same spots... in your toes or under the ball of your foot, like your nail has been pulled out... and in the calves... that feels like a cramp... sometimes is seems like your blood is clogged... it's swirling [kolkig] or something like that...

The next informant had an accident when she was 16, 13 years and 20 operations later, her leg was amputated, because it's condition worsened. She has episodes of phantom pain nearly once a month, mostly at night and it continues for a couple of hours. She compares her phantom pain with a very painful treatment she once had at her dentist's:

I once had a root-canal treatment... then you also get these stabbing [stekende] pains... just like a needle that has been stuck in... but then a lot worse... that's why I was thinking again about nerve pains [zenuwpijn]

The subsequent statement is from an informant (55) who lost both her legs during a car accident 18 years ago. She also lost the little finger of her right hand in which she also has got phantom pains.
She compares phantom pain with labour pains:

It is difficult to put into words... what you feel exactly... it's difficult for a layperson to imagine what it's like... it's just a contraction (labour pain)... you can compare it with that... that goes through everything... not in your belly but in your leg... I've also got it in my hand... and then it goes down below... like a stab of pain [scheut]... wham...

The neuroscientist I interviewed said that all the neurological disorders, can also exist in the phantom:

And the crazy thing is... all disorders there are in neurology can also exist in the phantom... someone can have a paresis of a non existent limb... what is mostly described, is that the phantom limb is in a cramp... that is a spastic paresis... There are neurological diseases were your foot is [dystonisch]... in such an extreme position that it becomes painful. And when you constantly have contractions in that direction... the muscles become stronger... and it becomes worse and worse... but a [dystonie] can reside in the phantom... and that just as awful (as in a non-ampulated limb)... the awfulness of course is in the brain...

The next interviewee (55, lost her upper leg almost 8 years ago) told me about how her pain resembles the stabbing of knitting needles:

I've never had a knitting needle in my leg... look, when you see someone approaching you with this, then you can brace yourself... but now you can't... it's the same when someone unexpectedly pushes you in your side, then you also have that reaction... but it's very sharp, intense and very mean.

From this statement one could say that the unexpectedness and suddenness of the emergence of phantom pain is very eminent. Other informants underscore this assertion by saying that phantom pain is accompanied by a flash, [wham], or stabs [scheuten] of pain.

In the following statement, the informant (46, who lost her leg after a bone tumour was which discovered 20 years ago), said that her pain comes (and goes) very unexpectedly:

When it happens... you're like this [sound of sharp intake of breath]... then suddenly you can have such pain... unexpectedly... like a laser beam... and then all of a sudden it's gone... but when I get these stabs [scheuten]... you want to grab, but there's nothing to grab... but when it takes some time, you get sick of it... it's like there's been an attack... in your head also... a little dizzy.
This informant who is 41, he underwent an amputation when he was 18 years old. He is a physiotherapist and also treats amputees. He used to experience phantom pain not very often, and it would come and go: he explained that phantom pain as ghostly [spookachtig]. With this statement he also seems to underwrite the significance of the unexpectedness and swiftness of phantom pain:

The phantom pains came sporadically... as swiftly as they came, they disappeared... the mysterious thing about phantom pain is that it's ghostly [spookachtig].

The next this informant (52, who lost her leg from the pelvis at age 29) compares phantom pain with 'toothache in your leg':

It's like toothache in your leg... you can't do much about a toothache... your teeth may be extracted... and then it's like the tooth is still there... my husband hasn't got his teeth anymore... and he sometimes says: 'I've got a toothache'... [...] You've got pain in an ankle that isn't there anymore... it's like stabbing... they're doing something with knives... it's like an infected toenail... it's like an splinter I once had underneath a nail... that you have the feeling that it's festering... that you haven't got any nails... and you can't grasp it...

From the previous statement it seems that phantom pain can sometimes resemble pre-amputation pains.

Past experiences of having blisters, splinters, infected toenails or cuticles, callosities, etc. are now pertaining to pains in the phantom limb. In the case of this informant (38) who suffered from severe phantom sensations told me that:

What struck me about [fantoomtintelingen]... once in a while I experienced these cramps which were pretty inconvenient... that my leg really was in a cramp... most of the time I had these very specific [tintelingen]... pain which I used to have... returned... that is suggestive of the fact that it does not only have to do with nerves being cut, but also with that what is laid down in your head... and comes to the surface again... these very specific sensations [tintelingen].

Not only very specific pre-amputation pains can persevere into the phantom limb, but also pain felt in the limbs prior to amputation can persist as phantom pain. The subsequent statement is from an informant (49) who was the victim of an industrial accident 20 years ago. He was carrying out activities in the workplace, when others were working on a machine. They rolled this machine into a tackle (for repairing) and when he happened to walk under it, in that split second, the tackle burned through and he came under the machine.
The machine was on fire and his legs burned. He was in hospital for six weeks, from which he can't remember anything because he was under morphine. In that period they amputated his leg below his knee. From the story he told me the accident and the severe pains, which were the result of it, were later experienced in the form of phantom pain:

If you're talking about real pains that return... then these are the pains which I had after that block was lifted from my leg... And when you look at what happens after that... then these pains diminish... and then on the other side these [prikkelingen] begin to emerge... like a thrust of a knife [messteken]... that's the way I feel it... it hurts terribly... [waar 'm dat in zit]... according too me, these are pains...

One other informant who lost her left upper leg when she was 48 years old, which is now almost 8 years ago, cannot recollect anything from the accident. She was told that she had been waiting on her bike in front of a traffic light to cross the street straight on. At the same time a bus was waiting next too her, which she didn't see. The bus made a turn too the right and she drove into the wheel of the bus. Afterwards she was told that the bus driver had said that she was in his 'blind spot'.

She told me that she has been trying to recollect the accident to find out where her phantom pain came from:

I can exactly point out where it (phantom pain) is... one time it's in the ball of your foot, the other time it's in the heel of your foot... and sometimes on top of your instep... I then say very taciturn: 'again a bus is driving over my foot'... maybe I've stored [opgeslagen] it... but I don't know that... because I can't remember anything... but I did look for it...

She conveyed subsequently that a psychiatrist advised her not to search for any memories of the accident, because he had told her that the film of the accident would then constantly 'run through her brain':

So now I don't look any further... but I am still sometimes reminded about the leg which I don't have anymore... that is the crazy thing and it's very double [tweeslachtig]...
In the first part of this subparagraph I have tried to reflect on the complex relationship between phantom sensation and phantom pain. Nearly half of my informants experienced phantom sensations [zware tintelingen/ prikkelingen]. They are characterized by their continuous presence and very exact location.

But sometimes phantom sensations can become very uncomfortable and it was very hard for some informants to make very clear distinctions between phantom sensations and phantom pain. For other informants however, it was very important to distinguish between painful ('real' phantom pain) and painless states, which were experienced as mere sensations; some informants were able to evoke them through concentration. Phantom pain is felt in very different locations, and is characterized by its sudden (like a flash) and unexpected appearance. In some cases more of the phantom limb is felt during phantom pain then in the case of phantom feeling (often only the foot). Phantom pain can also be felt in the different parts from which a leg is build up (nerve, muscle, blood and bone). For example, sharp shooting or stabbing pain is associated with nerves. One informant compared these pains with 'nerve pain', others with the 'stabbing of knitting needles', 'toothache in your leg' and 'the trust of a knife'. Cramping pains were associated with muscles, these pains were compared by one informant with 'labour pains'.

According to a neuroscientist all kinds of neurological disorders, like extreme positions of the limb or joints [dystoniën], could also exist in the phantom limb.

From some of my informants' descriptions it seemed that very specific pre-amputation pains resembled their phantom pain, such as blisters, infected toenails or cuticles. One informant experienced phantom pain that resembled pain felt prior to amputation. Another informant had tried to find out if her phantom pain resembled the pain she felt prior to amputation, but this was very difficult because she didn't have any recollections of the accident.

Very central in my informants stories was that they tried to look back and find patterns of how and when phantom pain started and what kind of factors were influencing phantom feeling, pain and sensations. To this I will turn in the next paragraph.
3.2. Etiologies of phantom limbs

When people talked about their experiences of phantoms, they not only tried to describe them, but they also tried to explain what things influenced phantoms or what had lead to a (sudden) manifestation of phantoms. From the stories it seems that people develop their own patterns of 'phantom' experiences. But the problem is that this is only possible in retrospect. This is especially this case with phantom pain, because from almost all my informants' stories it seemed that phantom pain occurs unexpectedly, and nothing can prepare someone for it. This is slightly different in the case of phantom feeling and sensation. As will be shown in the subparagraphs, phantom feeling and sensation could be in some way avoided, or handled with.

Very essential in the informants' stories is the fact that my informants' explained that different factors could bring about phantom pain, feeling and sensation. Thus different etiologies can exist next to each other and can complement each other. In the next subparagraph I will try to show, according to my informants, what is involved in phantom feeling.

3.2.1. Etiologies of phantom feeling

Phantom feeling is not just a fact, it is not just 'out there'. From the stories people told me, intensity of phantom feeling seems to be subject to someone's state of mind, to the level of concentration on phantom feeling, to bodily processes and to the actions of other people. It is something that could be evoked by people themselves or by external factors. The next statement is from an informant (40) who was 15 years old when she crossed the street nearby her house. She saw a car coming and could easily mange to cross the street, but the driver of another car was overtaking the other; the driver did not see her coming. She said about phantom feeling:

*I can evoke my phantom feeling by contracting my muscles... but I don’t find that annoying... it goes with it [het hoort erbij]... but it seems that it’s very hard to imagine, for someone who can never feel it... it’s a very intangible thing... you feel something which isn’t there anymore...*
Other informants could evoke phantom feeling by thinking about it or by concentrating on it. This informant (52, who lost her left leg from the pelvis) explained it like this:

> When you constantly think about phantom pain... when I think about it now... it's phantom feeling that you then evoke... but it's very difficult to say when that pain springs up.... I don't have a stump... they've closed the buttock... the wound... with skin from the buttock... so, when I scratch... I am touching my behind [dan zit ik aan m'n achterwerk]... that's really strange... it's of course a shifting of feeling...

This informant (46, who lost her left upper leg, due to a tumor) said about thinking of phantom feeling:

> When you think about it, then it could be that it's there constantly... I don't know that... when you think about it, then you do feel it... but when I am busy with something I don't feel it. I think that when you think about it, you can always evoke phantom feeling... but if you should ask... do you have phantom feeling all the time... then I would think... that your are always occupied with it.

Not only thinking about it evokes phantom feeling but also talking about it. This is very familiar in almost all my informants’ stories. One informant (52, who was hit by a bus when she was 13 years old and lost her lower leg as a consequence), said that talking about phantom feeling is difficult for amputees, because it evokes these feelings:

> I've never come up with an explanation why... why it's (phantom feeling) now and not then... but, I have noticed that when I talk about the subject... then the feeling intensifies... and that's why I think a lot of people who are amputated avoid the subject... they are in a coping process [verwerkingsproces]... but also talking about it strengthens phantom feeling... then you do it to yourself... and now... I talk about it... it becomes stronger... but it's always there...

From the last two statements it seems that talking about phantom feeling can evoke it. And the informant in the last statement said that this might be a reason why some amputees avoid the subject. An anesthesiologist who I interviewed also explained that there is not much talk about phantoms. He also has had contacts with the foundation (SLWB):

> In the years I've followed the association... phantoms... there they don't talk about it much... since it's an emotionally charged [beladen] subject.
All these things made me aware of the fact that for some people I interviewed it wasn’t an easy subject, not only because while talking about it could evoke phantom feelings (and sometimes sensations) but also because it could bring back feelings connected to the circumstances that had to do with the amputation and other affecting subjects (like problems with prostheses).

For some interviewees it was a long time ago since the amputation and they had talked about their situation and phantom pain often, but for some it was more recent and more emotional to talk about it.

Not all of the informants mentioned the fact that talking and thinking about and concentrating on phantom feeling influenced it.

One informant (73, who lost his leg 60 years ago) explained that phantom feeling is just commonsense: although the nerves have been cut, everything is still there:

*Phantom feeling... yes, it is there... it’s logical [dat kan ook niet anders]... because... these nerve bundles... they are still there... although they have been cut... but the rest is there...*

One informant said that specific processes in the body could evoke phantom feeling. This was hard to understand for the informant. It seemed difficult at first to establish a connection between these bodily processes and the emergence of intensified phantom feeling. This informant (55) who was hit by a bus 8 years ago and had to miss her left upper leg as a consequence, said that:

*When you have to pee, or when you defecate... especially when you have to use some force... then you feel these [prikkelingen]... then you also think... the first time... have I gone mad... what is this?... The second time you know... o, that’s the connection... but it’s difficult to understand...*

Another informant (52) who lost her leg from the pelvis when she was 29, experienced strong phantoms while she had her menstruation:

*When you also experience it very strongly... and I had asked about it when I was only just amputated... what was so striking... was that during menstruation... it was very strong...*
The neuroscientist I interviewed explained that these kinds of experiences, like the one that is depicted above, are often described (in literature) in the case of phantoms. But it has not always been this way:

Yes... full bladders and erections... that is all described... and people were afraid to say this... out of fear of being called insane...

The informant who stated that urinating or defecating could evoke phantom feeling, explained that when someone would stroke her on the left part of her body this could also evoke strong phantom feeling:

I also experience it when someone tabs me on the shoulder or when my husband strokes me... that had been a very great inconvenience [stoomis]... the moment my husband touched me on the left side of my body, my phantom feeling played up terribly... thus that’s a disturbance in the perception of your sexuality you could say... but now you know what happens... but first you have a reaction like: ‘don’t do it’... and then you relax somewhat... and then someone can stroke you... But I keep feeling this [prikkeling] in my foot... and that really becomes activated... from my shoulder till my buttock... the moment someone strokes... then I am loaded with phantom feeling [dan sta ik stijf van de fantoom gevoel].

It is not only when someone touches a part of her body, that she experiences intensified phantom feeling, but there are also other things influencing this feeling. When she for example would walk through rough terrain, her prosthesis could smack against sensitive points in her leg:

Some time ago I've walked on grassland... there I am always very careful... when you stumble into a hole, which you can't see... then you smack against that small point in your groin... these are things which don’t feel very comfortable... no... and after that I have this really strong phantom feeling for a long time.

The next informant (44, who has a left lower leg prosthesis) said that she normally walks absent – minded with her prosthesis. But this changes when there are obstacles. That also has got to do with the fact she does not feel her prosthesis foot that good:

You don’t feel your prosthesis foot that good when you place it... when stumble on a marble... when the children were small and they were playing marbles... then I really had to warn them... don’t leave any marbles on the floor... normally you feel it when you step on it... but I don’t... and then you slide [dan schuif/ val je wel]...you really have to take these sort of things into account...
In this subparagraph I have tried to show, through the informants stories, what is involved in phantom feeling. It seemed that people themselves had some influence on phantom feeling. Phantom feeling could be evoked by contracting muscles. But also by thinking of the phantom limb. One informant said that if you experience phantom feeling all the time, you must have thought about it all the time. But another informant said that it is always there, but that it strengthens when you talk about it. She also explained that talking about it could be a reason why some people who are amputated and are also coping with their amputation avoid the subject. An anesthesiologist said that it is an emotional charged subject. In some interviews I also experienced this, because talking about it could also be connected with the feelings about the amputation itself and other sensitive issues. Some informants explained that bodily processes like urinating, defecating and the menstruation could evoke phantom feeling. The neuroscientist I interviewed said that this is often described in literature and that people used not to talk about it in fear of being called insane. The same informant who talked about these bodily processes, said that parts of her body (skin) were very sensitive and stroking these areas could also evoke phantom feeling. This has been a concern for her in her relationships with near others. As I will try to show in the next subparagraph, these kind of bodily processes could also evoke phantom pain and sensations. According to my informants, a range of other things could also influence phantom sensations and pain.

3.2.2. Etiologies of Phantom sensation and Phantom pain

In the previous subparagraph I have tried to explain that phantom feeling could be evoked through the workings of several related factors (concentration, thinking, talking) and through the workings of the body.

Phantom sensations could also be evoked through concentration and thinking and through bodily processes. According to some informants, intensified phantom sensations also had something to do with dealing with the consequences of the amputation. Concerning phantom pain, most of the informants had said that it cannot be evoked through concentration or by talking about it. Phantom pain almost overtakes someone. Phantom pain etiologies are quite different compared to those etiologies related to phantom feeling and phantom sensations. Some people emphasised that phantom pain is something, which is very intangible. In some situations someone may have known what influenced a (sudden) intensification of phantom pain, in other situations other influences are involved or it remains inexplicable. Thus different etiologies of phantom pain can also exist next to each other.
But first I will turn to people’s explanations of the workings of phantom sensations. As I described in the previous subparagraph bodily processes, like urinating could influence the experience of phantom feeling. This informant (38) told me that he had only experienced severe phantom sensations in his foot. He never had much feeling in the part below his knee down to his ankle before amputation, because this part was periodically radiated since he was a child (because of a tumour in his leg). He said that he had experienced an extraordinary feeling:

*But what is quite unusual... sometimes when I... have to pee... then... I sometimes get these [tintelingen] in my feet... by which urinating [plassen]... (has a) connection... maybe some parts of the body are connected through nerve bundles [zenuwbanen]... that could be an explanation.*

Very eminent in peoples’ stories was that phantom sensation could be evoked by concentrating on these (severe) [tintelingen]. The next informant (55) who lost both her legs and a part of her right hand, during a car accident, said that when she enters deep into herself, then [tintelingen] emerge:

*When I go deep into myself [als ik diep naar binnen ga]... as it were... then the [tintelingen] emerge... then I feel the underside of my feet... against the ball of my feet... on my instep... yes, that very remarkable [frappant].*

One informant (of 44 years old, who was 16 when she had a motorbike accident) said that talking about phantom sensation could also evoke it:

*When you talk about it now, then you just feel this [tinteling]... but in itself that’s not painful... and when I think about it I can just move my toes...*

In a previous statement an informant (55) had spoken about the fact that she could evoke phantom sensations by going deep into herself. She said subsequently that although these sensations are always there, they become worse if you would focus on them:

*If you focus on that... you make it more worse than it is... there are people who are in pain constantly... I attribute that... to the fact that people are (too) occupied with it... with their own body image [lichaamsbeeld]... that they don’t have anymore... and that they couldn’t cope with that... and in that way they evoke pain themselves... that the sensation phantom [sensatie-fantoom] is subject to this... I think that when people have not coped with the acceptance (of the amputation)... therefore, they react very powerfully on this pain...*
From the preceding statement it seems that acceptance of the amputation and a changed body image could influence the experience of phantom sensations. The feeling of these sensations and at the same time coping with a changed body image would focus someone too much on the body. According to this informant, continuous felt phantom sensations in this way could mean that they turn out to be experienced as phantom pain. Thus a connection is made between how one sees one's body and the experience of phantoms. And this could be influenced by the way people accept their amputation and as a consequence, their changed body image. In the next account an informant (49) explains that doctors said to him that he had not accepted his leg, because he began to reject it. He did not feel he had a leg until his groin:

*I rejected my leg... I didn't know how to accept it, according to doctors... in a sense that was true because my leg became thinner and thinner... and it [bleef eraan hangen]... but I walked with my prosthesis... I was very quick to walk again after the operation... and then people said: "You haven't had the time to cope... to start the grieving process [rouwproces]... because you started walking straight away... [*]"

This informants' story is, it seems, a search for the truth in the phrase 'you haven't accepted the amputation'. In the next statement he again explains that they may have been right. Maybe he didn't accept his amputation:

*I mean... you're damaged [gehavend]... I mean... I have a mirror in my bedroom... when I undress... then I would see myself every moment of the evening... but I wont do that... I turn away from the mirror... and then I undress myself... I switch the light off and I go into bed... I never look... when I am swimming I don't look... I never look down there... Thus, seeing it from this angle... it could be true... But, it's just what you accept isn't it?... I function... I do everything outside the things I've never done... According to my opinion acceptance had got nothing to do with phantoms...

It seems that in the end he did have his doubts about the importance of the acceptance of the amputation (which others continuously emphasized) in relation to how one sees one's body and the experience of phantoms.

There are other things that could influence or evoke phantom sensations. In the next statement an informant (55) lost her upper leg almost 8 years ago, after a bus accident. The left side of her body is very sensitive in evoking phantom feeling, especially when someone strokes her there.
But it's not only the skin which is very sensitive in her case, but also when someone touches her on her 'prosthesis leg' [prothese been] severe [prikkelingen] could emerge:

Yes, I find it very annoying when someone says for example: '[Hé joh]... and taps on my prosthesis leg [prothese been]... then I always call out: '[Daar heb ik niets aan]'... it's hostile... I know that... but when someone taps you on your leg, then I think noooo... it's because you slap on it... you stimulate [prikkelt] the edge of the stump... and then you feel this terrible [prikkeling] in your foot or if someone kicks against your (prosthesis) foot, then it comes again... then you activate it... because someone touches your body... but I say... everything is closed up [opgesloten] in your body... and I find that really strange... that your mind [geest] can be so occupied with that...

This informant seems to explain that things could be 'closed' in the body as a recollection point [herinneringspunt]. She illustrated this point with an example:

I shall give you an example: our cat died some time ago... then I know that he always kept nuzzling up [kopjes geven] here... and the cat is here (points to a place on her leg) and there are more things that you store up in your body, like a recollection point [herinneringspunt].

It seems that when someone would touch her on her prosthesis leg, or would kick against her prosthesis leg it would still give her the reaction of pain, because that particular touch had been stored in her body. The things that have been 'stored' in her leg have not been lost since her limb has been amputated; they are still there in the phantom limb.

One informant (38, who had a left lower leg amputation one year ago) said that he had heard about biomedical explanations of the phantom sensations he experienced. He explained what he had heard like this:

I hear... these medical explanations... that nerves have been cut... at the end of these nerves are receptors, which transmit certain signals... up... (to the brain)... that could be an explanation... but I did notice that when I had these [tintelingen]... these very specific ones... pain which I used to have returned... that is suggestive of the fact that it hasn't only got to do with nerves... nut also with what is stored in your head and comes up again...
There are striking similarities between the previous two statements. Things (pain, points/touches of contact) can be stored in the body. Only in the former statement the informant explained that these things have been laid down in her body: in her leg, thus in her phantom leg. The latter statement is about pain memories, which are stored in the brain and could later surface while experiencing phantoms.

This informant (44), had an accident with her motorcycle when she was 16 years old. Her leg was shattered as a consequence. After that she had 20 operations to save her leg. Then she developed clubfeet and couldn’t move her toes. She explained to me that she had experienced infections, deformed growth, everything that could go wrong, went wrong. Thirteen years later the situation was unbearable, the damage to her foot so considerable, that she and her husband decided to ask for an amputation. Although she experienced phantom feeling shortly after the amputation, she first had phantom pain months after the operation.

When she talked about her experiences of phantom pain, she said:

Yes... well... my foot was really damaged... there was one particular spot which was very painful... I mean... before the amputation... and now I do experience that it’s that same spot... exactly the same feeling... after thirteen years... I had a clubfoot... I couldn’t move my foot... and when you don’t have any movement in your foot for years... [...] But I don’t know were it really comes from... you can only guess a few things...

It seems that this informant’s phantom pain resembles pre amputation pain. However it remains difficult for her to really understand were phantom pain exactly comes from. From my informants’ stories it seems that they all have had to deal with the fact that phantom pain is ungraspable and difficult for others to understand. In the case of the next informant (49) it seems that especially doctors didn’t accept phantom pain. When he had told them about his experiences they had said that ‘it’s all in the head’ [tussen de oren]:

In the medical world they don’t acknowledge it... I can feel something for that... because it could partly be ‘in your head’... pains which return... are the pains that were released when the machine was lifted from my leg... if its reality or not... I do feel it... if it’s all in my head or if they are real pains at that moment, I don’t know... but doctors say... they aren’t real pains... they are phantoms: literally meaning: ghosts [spook]... yes phantom is like a spectre [schrikbeeld]... but you can’t function when you have phantom pains... if it’s true that it is ‘all in the head’, then phantom pain would fade in time... but it returns when the weather changes...
When this informant was told that phantom pain was ‘all it his head’, doctors had used the literal meaning of the word to ‘demonstrate’ that phantom pain didn’t exist in their eyes. It could well be that people with phantom pain could have difficulties with the word phantom, which, when you look it up in the dictionary means ‘ghost’. But for them it’s real pain, which the informant in the previous statement described so well. But from his account it seems that he still has his doubts about the ‘reality’ of his pain, because pre amputation pains had returned in the form of amputation pain. And that is something, which, according to him, happens in his head. But he said that his pain is felt as real pain.

Apart from this there is also a secondary meaning to the phrase ‘it’s all in your head’ [het zit tussen je oren]. When someone would say this to you it could mean that the other is implying that you are imagining things. From some of my informants’ stories is seemed that they were aware of this and that this secondary meaning is nonsense in the case of phantom pain. As will be shown in the subsequent statement.

The next informant (52, who lost her left lower leg 40 years ago) said that talking about phantom pain had to do with it or it could influence it. But this did not indicate that phantom pain is all in the head:

Talking about it... certainly influences phantom pain... but don’t let them say that ‘it’s all in the head’ [dat het tussen je oren zit], because all over the world there are people who experience it... and we really didn’t tell each other about it...

In former days... it wasn’t really accepted... it wasn’t taken seriously... and I think there’s a difference compared with how things are developing now... now it is accepted... of course you used to talk about it... but they never paid any attention to it... you were not educated by doctors or nurses or by other kinds of people that had something to do with it... you did speak about it... but they never reacted...

The informant in the latter statement seems to imply that the period in which you were amputated was important in the extent to which doctors and nurses would have paid any attention to what amputees were saying about phantom pain. The next informant (49, who lost his leg after an industrial accident 20 years ago) also said something in this direction:

A lot of people who were amputated in the forties and fifties... don’t have much phantom pain... there was really no attention for phantom pain... they just had to accept that they were amputated and that they had to go on like that... and now... there is a lot of attention... from all sides... especially when you compare this with the people who were amputated in the forties and fifties... and if this is really the case, then maybe it is true there is a part that’s in the head [dat het voor een gedeelte tussen je oren zit]
This informant agreed with the fact that there used to be very little or no attention for phantom pain experiences and that this has changed recently. He seemed to imply that it could well be true that people who did not have had any attention for their phantom pain also used not to experience further phantom pain (because they just had to go on) and that people who did get all the attention experience more phantom pain. He seemed to propose that this could be 'evidence' for the suggestion that maybe phantom pain could partly be 'in the head' [tussen de oren].

A physiotherapist (who's leg was amputated while he was 18 years old), attached another meaning to the attention issue. He said that when he asks amputees in his practice about phantom pain, he wonders if it's really phantom pain:

> There is now a lot of attention for phantom pain... but sometimes I have the idea that people with phantom pain... sometimes confuse phantom feeling (with phantom pain)... when you talk about... is it actual pain... and you ask people... and then they say... 'it's kind of itching'... well, can you consider itching as phantom pain?

In this statement the informant seems to imply that there now is so much attention for phantom pain, that people who are having phantom feelings could sometimes believe that they are having phantom pain, which is not always the case according to this informant.

Not all the informants I spoke with agree with the suggestion that there is more awareness for phantom pain.

This informant (55, who lost both her legs and a part of her hand during a car accident 18 years ago) would like to see people to be more prepared, by doctors or nurses for example, before the operation. She would like people to know what to expect, for example what is involved in phantom pain:

> And then I think... at least prepare people... then you could at least take something into account, especially when you have to decide for yourself if your leg has to be taken off...

When the physiotherapist I interviewed talked about what, according to him, is phantom pain, he said that when you talk about ('real') phantom pain it means that there is no apparent factor present which is causing these pains or sensations.
In this statement he talked about a case in which it is clear that there is an apparent reason why someone can have phantom sensations:

When I am looking at the liner [a kind of holding mechanism for the prosthesis, which is pulled over the stump] and I pull it tightly over the stump... then you experience these sensations... but then I say with great emphasis... can you call that phantom pain...

In the case described in the previous statement there is, according to the informant, an apparent cause for phantom pain. And then it could also be possible to do something about it, like adapting the prosthesis. According to the same informant, the issue of: is there a cause for phantom pain or no cause at all, is what makes phantom pain ghostly [spookachtig]:

Phantom pain is a little bit ghostly, in the sense of... 'I have this pain and there isn't a clear cause'... what it is that it comes into existence... and when you do have a apparent cause you could, so to say... eliminate the problem... pain is there for... to indicate that there is damage, when there is no damage or your leg or tooth isn't there anymore... then... and I cannot explain how it comes into being... that's phantom pain...

The next informant (44) lost her lower leg almost 13 years ago. She also emphasized that if there is an understandable reason for phantom pain to occur, you then might understand were it comes from and subsequently find a solution for it. Comparing her phantom pain with other pains, she called it nerve pain [zenuwpijn], because it's stabbing [stekend], like a needle has been stuck in. It is like a root canal treatment at her dentist's. Because there could be a reason for her phantom pain in some situations, she has had doubts about really experiencing ‘nerve pain’ [zenuwpijn] or not:

I've been to the theatre some time ago... we were sitting on the balcony and there was very little legroom... my knee was locked in [beklemd gezeten] for a couple of hours... I think it has to do with that... that the circulation one way or another had been jammed too long... but that's not always the case (or cause)... but I do think it really has got something to do with that... but then it's not really nerve pain [zenuwpijn]... if you now how it came about [als je weet waar het door komt]... then maybe you know the solution...

From the latter account it seems that in some situations the informant might have known what caused phantom pain to emerge, but in other situations she apparently did not.
From what I have heard my informants say, there are situations where phantom pain emerges unexpectedly and I assume that this makes phantom pain intangible and difficult to explain. However, some informants could see a pattern in their (episodes of) phantom pain, when they discovered that there was an identifiable influencing factor. That is why some informants expressed their doubts about the unexpectedness of the emergence of phantom pain. And as a consequence, these identifiable factors could contradict with other possible explanations of phantom pain, as is explained by an informant in the subsequent statement.

Influencing factors of phantom pain that were discussed above, for example a bad fitted prosthesis, are more or less controllable. Someone could adapt his prosthesis and try to find a solution. But the factors discussed in the following section would be impossible to control by informants.

In this account, the informant (55, both upper legs had to be amputated after a car accident 18 years ago), said that phantom pain could have something to do with the nerve system but has her doubt about this, since she experiences phantom pain while air pressure changes:

*Maybe it has got something to do with your nerves... but that couldn't be it... because, the moment you think about... when do I have this pain... then you hear on television... that a high pressure area is arriving... and then it's very clear... then phantom pain could not emerge unexpectedly.*

One informant (52, who's leg was amputated from the pelvis 23 years ago) illustrated this by saying that in the case of what influences phantom pain there is no single guideline. It means that very different factors are playing a role in phantom pain. She said that doctors also didn't clarify things for her:

*When you are going to discuss it... one doctor says: 'you will never get rid of it (phantom pain)';... and the other says: 'you are imagining things, you feel it because you are thinking about it';... so there's not one absolute guideline... it's cold... it's differences in warmth [warmteverschill]... yesterday I stepped in the swimming pool and then you can feel that they did not close the covers of the pool... as a result... the swimming pool didn't cool down as much...*
In the previous account the informant said that she could sense the slight variations in the water temperature in the swimming pool. In the subsequent statement she is talking about how she discovered in hospital (after the operation) that the warm water was good for her phantom pain, but the moment the water became too cold, she had to leave the water:

Then the physiotherapist was swimming with other patients... and I asked if I could go... I didn't manage to get in of course, but luckily a nurse was there and she helped me to get in... and it really went very well... but it was wonderful (remedy) for my phantom pain... I became aware of that pretty soon... the warm water... but the moment it became colder I had to get out... That cold on the wound... You can't bear it... it causes phantom pain immediately...
I did everything... every time I went swimming... and then every afternoon I felt total loss from swimming and would fall asleep... before that I couldn't... because of the phantom pain...

In the previous statement she is explaining that temperature changes could affect her phantom pain. Hot – cold temperature changes, but also weather changes, air pressure alterations were common influencing factors on phantom pain for most informants. However, not one story was identical, as all my informants’ experiences of phantom pain are quite dissimilar.

The same informant (52) who talked about hot – cold changes in water temperature, said that weather circumstances could also have an impact on phantom pain:

When there are snow showers... hail storms... or rain showers... I once said... I could better work for television as a weather woman than Krol...
[dus dat je het meer bij het rechte eind hebt]

In this informant’s (53, lost her leg almost 40 years ago) case, phantom pain is something which occurs especially in the winter:

The weather certainly has an impact... In the summer... you're not bothered by it as much... but in the winter... snow and hail... then it just becomes stronger...
The following informant (55, who lost both her legs 18 years ago), has got a husband who also misses two legs. They both experience that air pressure changes are of influence on their phantom pain. It seems that in this case, phantom pain is almost a collective experience, because the same factor plays a role:

*But, we are with the two of us of course, so we can look back at it [pain] when it occurs... often it goes like this; I will say to my husband: 'o, my hand hurts' and then my leg begins to hurt. And then my husband often says to me the next day or evening: 'now I start to have it'... In most cases, when the air pressure changes, it happens. Either the pressure changes from a lower to higher pressure or the other way around.*

The informant's father had also lost his leg due to a vascular disease. He had the same experience as she and her husband. And other amputees she had spoken about it experience phantom pain when air pressure changes:

(...) My father for example, has lost his leg due to a vascular disease and he said: 'I have the feeling the pain is always there', I said: 'You must write it down when you really feel it' and the remarkable thing is that he is experiencing it at the same moment we do. When you start thinking back you notice that the air pressure has changed. The people with whom I spoke about it and who are troubled with it do experience it at those moments when air pressure changes.

Another informant (23) had an accident with his bike almost 10 years ago, he came under the back wheel of a truck. Doctors tried to save his leg for three weeks. But he felt so bad, had a fever, that they had decided to amputate. The muscles and tendons from his leg were destroyed during the accident. After the operation he felt better, the infections disappeared. At the time of the interview he told me that he was now going true a period in which he would think back at what happened 10 years ago; he had never taken the time before. He fist experienced phantom pain at the time he started walking with his prosthesis. However, his prosthesis did not have anything to do with phantom pain. It mostly depends on the weather, he said:

*It's mostly during summer... then I have phantom pain...*

It depends on the whole situation he told me. It also occurs more often when he has been tired:

*I have it... When I am very tired... when I've walked all day...*
From the stories my informants have told me it appears that weather conditions are important factors influencing phantom pain. But as is shown in the previous statements there is no single principle which all the informants adhere to. Next to conditions of the weather, an informant in the previous statement revealed another factor which could be influencing phantom pain. In contrary to weather conditions, these factors are more or less controllable.

This informant (49), is having cramping and shooting phantom pains, but sometimes he experiences the same pains which were released when the machine was lifted from his leg. He explained that phantom pain is not something, which is completely 'in your head' [tussen de oren], because then it would fade away in time:

\[\text{If it would be something which is 'all in the head'... then it would fade... but it returns in particular situations... when there are weather changes... stress situations... when there are problems at work or at home... then the phantoms come up more intense [dan komen de fantomen veel erger]}\]

His 'cramping' phantoms had (indirectly) something to do with his muscles being cut off:

\[\text{Because, you do feel it... the muscles... of course... have been cut... and cauterized... then you get a tendency to convulse [krampneigingen] these muscles... what could turn out to be a phantom...}\]

Some informants described that too much stress and tiredness could influence phantom pain. The next informant (52 lost her left leg from the pelvis, due to a tumor) had said that hot-cold differences in water temperature could be of influence in her case, but there are other factors, which play a role. During the interview she spoke about a journey she once made with a ship from the Red Cross. Swimming is very important for her, she had told me. It gives her freedom and she wished she could do everything swimming.

One time she had asked the nurses if it would be possible to leave the ship and swim for a while. They agreed and together they swum around the ship. She told about this experience:

\[\text{And then... the phantom pain again shoots up in your body [dan schiet de fantoompijn weer in je lijf]... not because of the water... but when you see the head of the ship... with that huge red cross... you think of it as mighty or powerful or something... thus... all the emotions... act on [werken in op] that leg... happiness, sorrow, fear... everything actually...}\]

With this statement she seems to express that emotions could affect phantom pain. And that emotions act on the phantom limb and evoke phantom pain or feeling.
This had happened in a particular situation, but in more daily situations she is also confronted with emotions that could influence phantom pain. She explains it in this way:

_When you are very concerned with something... then I intensify it... something threatens to fall... it shoots up [schiët] in my leg... my husband threatens to bump his car... he needs to slam on the brakes... a child that wants to cross the street walking behind a ball... that could mean that I still have this strong phantom feeling three ours afterwards..._

Next to explanations of weather changes, stress, fatigue and emotions that were described by the informants, the majority also explained that phantom pain also had something to do with the nervous system. I have tried to show before that nervous system explanations could contradict other explanations (like changes in air pressure). But most informants talked about several explanations which could coincide or could occur at the same time. Explanations of nerves (or signals) are differently interpreted by informants as will be shown in the next statements.

One informant (23) said that phantom pain is something psychological and that signals are passed on to the muscles:

_It think it's just psychological... that there still is a signal which is passed on to the muscles... which aren't there anymore... but sometimes still think that they are..._

This informant lost both her legs during a car accident 18 years ago, she also experiences phantoms in her right hand; she lost her little finger. She explained that phantom pains start in her little finger:

_It always starts in my hand, or to be precise, in my little finger, which I also lost. I have the idea that it's closer to my brain and that is why it brings about such strong phantom pains. I have the feeling that it is connected to the brain, also your nerve bundles of course... at the moment something happens there... you register it at the top... yes, that is a strong feeling I have, that it comes out the nervous system._

When the next informant experiences phantom pain, she can't see anything or hear anything. It is a very intense, fierce pain from which she is suddenly taken back. The only thing she could do is taking care that the pain recedes from her body, she had told me during the interview.
When she explained what is involved in phantom pain, she talked about what happens when a limb is instantly taken off. Information coming from the missing limb is stopped after amputation:

They had to saw it off acutely... and cut it away... thus there isn't coming any information from that area... thus also from the nerves... so... I could imagine that the transmissions, which actually have to take place there, they keep on floating there [die blijven daar zweven]... But why I experience these pains once and awhile... I sometimes think to myself... could something nice or unpleasant have happened during that time? No... I can't put a finger behind it [ik kan er geen vinger achter krijgen]... it just happens... (...) It is just part of me now... gradually it integrates...

Although this informant explained that the nerve system is involved, she is still guessing at what causes phantom pain to emerge at a certain moment. Phantom pain became part of her; she couldn't fight it because she could not think of other factors that she could influence (for example fatigue or (emotional) stress) herself. I have tried to show that other informants had, apart from 'nerve' explanations, other factors playing a role like stress, fatigue, changing weather conditions and emotions. These explanations would in some cases stand opposite each other or contradict each other, but at least these informants could fall back on these explanations to make phantom pain more or less comprehensible and less ungraspable.

The neuroscientist I interviewed also had his views about what happens when phantom pain occurs. He explained that it (among other things) has to do with the neuromatrix (which I also tried to explain in the first chapter), which is derived from the gate-control theory of pain by Melzack and Wall.

He explained it in the following way:

The neuromatrix is like a curtain of neurons [which contains: the cortex, thalamus, brainstem and the spinal cord, see p. 330 Melzack and Wall: The challenge of Pain, 1982]... normally there is input (from the nerves), but what a lot of people don't know is that when there is a lot of input... there's an inhibition effect [inhiberend effect]... when a limb is lost... the inhibition ceases... it's called deafferentation... it means... when input is omitted... someone will get positive feelings... and those feelings are projected on a particular spot (the limb)... but projection is one of the major problems in the neurosciences...
I interviewed one informant (36) who had said that he had experienced phantom pain a few times in the period of one and a half years after his amputation. After that period he started walking with his prosthesis. He did and still does experience pain, which comes from a nerve in his stump.

He explains why he never experienced phantom pain afterwards:

> It could be that I have imposed it... when I have pain, it has to be there... because there's noting down there... maybe this thought has been so dominant... that it took the place of another experience... you direct your attention to the stump... you've reinstalled it, as it were [opnieuw geïnstalleerd]... for me pain is pain in the stump... the nerve bundles which give off signals...

There was one informant (53) who believed that modern techniques of amputation could have caused less phantom pain to occur. She told that the scare is on the base of her stump and that doctors now place the scar on the backside of the stump.

> Well, it's very visible that my scar is on the bottom... but now they place the scar on the backside hé... to prevent problems... and that scar... you walk on it... and if the scar is on the backside... then it's free [dan zit het vrij]... I think that a very good improvement... I think it (phantom pain) has got to do with the old techniques of amputation.

In the previous statement this informant seems to imply that pressure on the scar evokes phantom pain.

The acupuncturist I have interviewed also said something about scar tissue that could have an impact on phantom pain:

> With an amputation... there's a lot of scar tissue... that could give a disturbance in the meridian circulation. In Chinese medicine there are disturbances on organ level (which don't have anything to do with Western organs, for example the Chinese liver has to do with muscles) and on meridian level... through that the energy flows from one place to another... and treatment is... to restore the energy flow... you influence the Chinese organ system... by [aanprikken] of the meridians...
I have begun this subparagraph by indicating the mechanisms, which underlie phantom sensations. Just like certain bodily processes like urinating could evoke phantom feeling, these processes could also evoke phantom sensations.

Concentrating on and talking about these sensations could also induce phantom sensations. Focusing on them would even make them worse and could eventually lead to phantom pain. According to one informant one reason for this could be that people are confronted with a new body image after the amputation and could have difficulties coping with this. Here a connection is made between how one sees one’s body and phantom sensations (which could be converted into phantom pain).

Another informant wondered if acceptance or coping with the amputation did have anything to do with how he experienced phantom sensations (and pain), because he functioned the same way before the operation.

One informant told about a different (body) mechanism, which could influence phantom sensations. Certain areas of her skin were very sensitive and if someone would stroke these areas she would immediately experience severe phantom sensations. And when someone would kick against or tap on her prosthesis leg, this would still result in (phantom) pain, because she had stored certain touches in her body (and thus also in the phantom limb), as a memory. Another informant experienced pains, which he had before the amputation, in the form of phantom sensations. These pre-amputation pains have been stored in the brain and could be experienced in the amputated limb.

From almost all my informants' stories it seems that they have had to deal with the fact that phantom pain is ungraspable and difficult for others to understand. In the case of one informant doctors had said to him that the pain he experienced 'was all in his head'. It seemed that these doctors held on to the literal meaning of the word phantom ('ghost'). Some informants were aware of the secondary meaning of 'it's all in your head', which could mean: 'your are imagining things'. They spoke out against this presupposition; one informant said that phantom pain is real pain and that amputees all over the world experience it. According to some informants, phantom pain was not accepted in former days. One informant said that it might be true that in times when there was less attention for phantom pain, people experienced it much less compared to nowadays. Today there is much more attention for phantom pain and maybe this could affect peoples' experiences, according to this informant. Another informant said that people could mix up phantom feeling with phantom pain because of today's attention for this subject.
Some informants further discussed the issue of what makes phantom pain 'real' phantom pain. Some informants said that when there is an apparent cause for phantom pain to emerge (like a bad fitted prosthesis), could it then still be called phantom pain? Because then there might be a solution, such as adapting the prosthesis. But, according to the majority of the informants, in most cases there is no apparent cause that could be easily fixed. Although there were circumstances which could influence phantom pain, such as weather conditions, hot-cold temperature, and changing air pressure. There is no single guideline however. Different influences could play a role and coincide at the same time, for example stress, fatigue, emotions and explanations about the nervous system. In some cases these different explanations (such as weather conditions and 'nerves') could contradict each other.

One informant said that amputation techniques could be of influence in the incidence of phantom pain. This had to do with the fact that surgeons now place the scar on the stump on the backside instead of on the base of the stump. The acupuncturist said that scar tissue could be of influence on phantom pain, because scar tissue could disturbance the energy flow.

In the last paragraph of this chapter I will try to describe what my informants have done about and cope with phantom pain.
3.3. What people do about phantoms

As I have described in the first chapter, there have been many attempts by doctors to 'treat' phantoms. Not many of those have done people any good, and some treatments have caused severe damage. Before I started fieldwork I wondered what kind of treatments people have tried, if there were any. And if they had any experiences with treatment failures. I wondered if they had gone to doctors, or talked about phantom pain with (other) health care workers. During interviewing I discovered that most of them had talked about it with their doctors on some occasions, for example before or some time after the amputation. A few informants received medications and others tried and still use a device for electro stimulation (TENS: Transcutaneous Electrical Nerve Stimulation), which could give relief. There are also informants who have tried 'alternative' treatments, which sometimes worked very well and sometimes not. And some informants had to accept that nothing could really help to relief phantom pain. What seemed very eminent in their stories was that they had developed their own ways of coping with phantom pain. Most of the informants had to find out these strategies themselves. It seemed that while people were talking about coping with phantom pain, they also talked about what their handicap of missing a limb meant to them and how they have dealt with that. Next to this, they also spoke about how they have coped or dealt with experiencing phantom pain in social situations (for example during a meeting while talking to other people).

3.3.1. The possibilities of finding relief for phantom pain

From the stories my informants told me it seems that they all had different strategies when they tried to find relief for phantom pain. Some informants tried to look for possible relief trough things which were 'external' to their bodies - for example trough hot/ cold water, electrical stimulation, medication, massage and exerting pressure to the stump - to have affect in the body (in the phantom limb). Others have tried to find relief trough mechanisms within their body, for example concentration and the moving of muscles. But it remained very difficult for them to actually influence phantom pain, especially because of the unexpectedness of it. The problem here was that they could not prevent an episode or they could not prepare themselves for phantom pain. I suppose that is why people have talked about accepting phantom pain; that 'you just have to learn to live with it'.

Amsterdam Master's in Medical Anthropology, Experiences of Phantoms, by Krista Coppoolse
Let me first start with the 'external' things people have tried to use to find some release from phantom pain. This informant (55) experiences very sharp, flash-like phantom pains. It starts in her hand, from which she has lost the little finger, and shoots down to her phantom limb. She told me that she couldn't influence phantom pain (unlike phantom sensations), the moment it occurs. She and her husband, who also has got phantom pain, have tried a lot of different things to find relief.

She told me about what kind of things they have tried:

And you've tried it once and a while with warm water... if that helps... cold water... but that was getting you nowhere [dat zet geen zoden aan de dijk]... the only thing that helps me sometimes... when it's really terrible... if it's really worse I'll do it, because it's real rubbish to take... [Diclofenac]... a painkiller... then you're muscles are totally relaxed... then I have the feeling that it decreases a little bit... we have also used TENS... but it's five minutes... it diminishes... and then it returns two times as hard... with great intensity...

Thus, this couple has been trying different methods, which did not help much. In some cases she had tried to take a painkiller, but hesitantly, because of possible side effects. And when she used TENS it even had the opposite effect. She explained that through the years she has experienced phantom pain as something, which is 'part of the game' [het hoort erbij]:

Yes... I mean... we still do everything... you try to do the same things you used to do... but if someone would say: 'you've really coped with it'... I don't think that's true... In most cases these pains do not occur for a long time... then you are able to overcome it... but if it persists... when you have it the whole evening and night... yes... then it's very annoying... but it's not like... now I can't go on anymore... you can live with it, but it still is annoying...

Although this informant explained that she could live with these pains, they could still be very aggravating.

The following informant (38) experienced very severe phantom sensations. Now he has got more global phantoms that float across his phantom limb. But when he suffered from these severe phantom sensations he started to use anti-epileptic medication. It was described in a much smaller dose, then is described in the case of epilepsy, but did have an affect on pain signals in the brain. He explained how he sees his use of medication:

I now use these pills... [rivotril®]... it works on the signals arriving in the brain...
His general practitioner recommended him to go to an acupuncturist. After a couple of treatments it had effect, and the very specific [tintelingen] which he had, disappeared. But he said that he had wondered about what is most effective; the medications or acupuncture:

*I am very curious about what would happen if I wouldn't do anything... how sure are you that certain things work or not?... These pills... that's easy to determine... I have stopped a few times... but then the [tintelingen] returned... that's a clear indication that it works... and concerning acupuncture... first it was more general acupuncture and after that the very specific locations were I had these sensations were treated... that was the right method... then I could see which method worked or not...*

He had tried to stop with his medication, but the phantom sensations returned. Now he is trying to cut down on his medication instead. He said that some people suffer from phantom pain all their life. But he explained that his personality is such that he is able to reconcile himself with the situation:

*I can pretty much reconcile myself with the situation... I am pretty rational... I could imagine that a lot of people are more bothered by it... but I am not so occupied with it... it is annoying... once and a while I was fed up with the fact that I had these pain in the phantom... but... it's part of the game [het hoort erbij].*

Although the two latter informants still had to deal with phantoms and with medication use, they said that they are not too preoccupied with it. They explained that they had to live with it and ['het hoort erbij'].

In the subsequent statement this informant (52) illustrated how she had tried to use electrical stimulation, whereby one needs to place electrodes on the stump area. The electrodes give off impulses and cause [prikkelingen] in the stump:

*I've read about what other people use... they have a [kastje]... I've had him here... it activates and causes [prikkeljes]... it's a stimulator... then it decreases phantom pain... but it didn't work... I had more pain, thus I stopped with that... at the moment there is no remedy.*

The acupuncturist I interviewed explained that TENS and acupuncture have more or less the same underlying mechanisms. But there is an important difference between the two. She first explained how she has treated phantom pain. Together with the patient she localizes the pain site.
The acupuncturist could not apply the needle on the amputated limb, so she starts from the leg that is not amputated. At the level of the spinal cord the sensory nerves come together and they cross, so one could influence one side of the body through the other side. She went on to say:

Nerve cells also converge in the spinal cord... that means that nerves from a particular skin area, from the muscles or from the bones, but also from the organs arrive at the spinal cord on the same level... and that is what you do with acupuncture... you apply a needle in the skin... and you could for example apply extra information to the nerves which are coming from (muscles in the leg)... I always compare these needle techniques with... like you are causing a traffic jam... a kind of overkill of information... a pain signal coming from a muscle gets blocked... The difference between TENS and acupuncture is that TENS stimulates non-specific sites... you just apply (electric) power near the pain site... and acupuncture is applied on very specific pain sites and on certain meridians.

The informant who had acupuncture therapy said that the acupuncturist applied the needles in the corresponding pain sites on his non-amputated foot. It was effective because he could very specifically point out where he experienced phantom sensations on his phantom foot. He subsequently could identify these points by using the non-affected foot.

There were several informants who did find TENS to be effective. The next informant (49) explained that there are only a few things that have helped him to find relief for his often very painful phantoms:

I massage... I knead... I really knead the muscles very hard... I have a nerve stimulator... I can put on... which stimulates the bundles [banen]... there isn’t much what I could do...

He also told about what had happened during a really severe episode of phantom pain. He compared it with the situation we all have once in a while. When you are wearing shoes and your foot would get in a cramp, you immediately try to stand up, but there’s nothing much you could do. But he explained that he is not able to do that while having phantom pain. When he was amputated 20 years ago they had told him to exert a lot of pressure to his stump to ‘release’ the phantoms:

When these cramps come up... you can’t do anything about them... you’re not able to stand up... they really could turn out to be real nightmares... that you really don’t know what to do anymore... and that your hammering [hammeren] with your stump on the coffee table... what you also had to do in former days... when we were just amputated... we had to hammer with the stump... with that ‘fresh’ stump we had to kick out that leg... if you could...
He said that hammering his stump on the table really was the last thing he turned to, when everything else had failed:

> When you're having phantom pain... you've been kneading... hot water, cold water, shock baths [schrikbaden]... putting ice water on it... it didn't help anything and it doesn't work... I am actually very glad that we have a heavy oak table... you're having scars from hitting (against the table)... But this happens only once a year... that it is so bad you can't do anything about it... And further... I take care that my prosthesis is fitted really tight... sometimes I put on extra stockings, that it's really tight... then it diminishes somewhat.

In the preceding statements informants have explained that they have to learn to live with it, although they often have these severe pains. The informant of the last statement also said that he has learnt to cope with it, although the phantoms still remain. He explained that he can only really talk about it with others who also had to miss a leg and would understand how it feels like:

> You could only explain this to others who also had to miss a limb... Sometimes, I have the idea... when you have lost loved ones... that... that also evokes a kind of phantom... But the moment you get these phantoms... you learn to live with them... it fades... but it stays... the moments you think back at it... it's also painful...

For this informant, thinking back at what had happened is also be painful; the accident, losing his leg etc. He compared it with losing a loved one; that could also evoke pain. It seems that these painful memories could make it hard for him to deal with phantoms also because they sometimes could resemble pains he had whilst the machine was lifted from his leg. But he said that he had learnt to deal with this over the years.

In a previous statement the same informant said that while he experienced phantom pain he could not manage to stand up; this also happens when he is wearing his prosthesis. The next informant (52) told me that phantom pains may come up very unexpectedly, for instance while she is eating or while she is visiting someone. It is a kind of stab [scheut], for which she can't prepare herself.

She also has learnt to live with phantoms but this is very difficult because sometimes she is not able to bend her leg when experiencing phantoms:

> You learn to live with it... I mean... I never make a fuss about these phantom pains... but sometimes when you're having it... you can't sit down... then you are wearing your prosthesis... and then I have these phantom pains... then I am not able to bend my leg... it's not because my prosthesis is locked [geblokkeerd], but I just can't sit down...
In the following account she describes that she could not explain why she is not able to bend her leg while having phantom pain:

[wat dat dan is]... I can't explain it... it's very strange... [...] but I've always thought about the handicapped people I have worked with... 'I didn't do it to myself... I have to make the best of it [je moet er van maken wat er van te maken is]

These informants have said that phantom pain could become more difficult to handle because in some cases they are not able to move their leg (because of these phantoms) and carry out activities as normal. What have people done to deal with these cramps? The latter informant said that when someone would have a cramp in a foot, then the ‘general wisdom’ is to counterpoise:

And when you're having cramp in your foot... when you swim for example... they say: 'you have to counterpoise' [tegendruk geven]... but I can't do that... I can't rub against anything...

From this statement it seems that it is virtually impossible to do the same things which one normally would do in case of cramps. It seems that this is why all the problems people have described here, to find relief for phantom pain, is directed towards the stump. The following informant (53) explained what she has been doing to find relief. She has experienced phantom pain and feeling since the (lower leg) amputation 40 years ago. But she said that it is almost 'part' of her now [het hoort bij haar]; she has accepted it.

She went on to explain:

I slap myself on my upper leg... I slap myself rock-hard [keihard] on my leg... I am not doing anything else about it... and then it's over... it could repeat itself... in one hour it could return 10 or 20 times... these stabs (of knives) [messteken]... but I slap myself on my upper leg... on the outside... well... I can't explain it to you... why I do this... but it does have an effect because it diminishes or it stops... but you feel it as very painful... it's terribly painful... and now the problem for me is... it is part of me now... I don't want to do anything about it... once I heard a woman say 'I think it's (phantom feeling) a nice feeling'... but phantom pain isn't, it's really awful...

Although her own way of finding a remedy for phantom pain is directed towards the stump, it does have an effect on the feeling of pain in the phantom limb. She could not explain why this is her method to find relief for phantom pain.
There are also informants who have tried to find relief for phantom pain by mechanisms within the body. It seems that they could direct their attention to the phantom limb and could exercise influence there. But they had found their own ways in trying to accomplish this. One informant (40) said that she directed her thoughts to her pain. She explained that she is able to more or less control phantom pain and that it is something, which is part of an amputation. She spoke about what she has done to control phantom pain:

Yes... I direct my attention to the pain... and then I tighten all the muscles... which are still there... it is difficult... but I can tighten them... if I really try... this happens in the stump of course... but I feel my toes... if I do that... most of the time it will go away...

She talked about the fact that all the muscles, which used to go to her leg, are still there in her stump although they have been cut. But when she is tightening these muscles she is able to move (the muscles in) her phantom limb. Another informant (22) has also been trying to move his phantom limb, but it had scared him a little bit:

I am trying to... finding out for myself to... move it... so that psychologically... you feel that your moving it... but that you also know that it (the leg) is not there anymore, but I am a little bit scared for that... that there is still something in my leg that moves, which is not there...

It seems that trying to move the phantom limb could result in a dual feeling; one perfectly knows that the limb is not there anymore, but one is able to move something in the phantom limb. The ability to move a phantom limb could be very useful in therapy. This is very important according to the neuroscientist. He explained it in the following way:

With phantom pain... something is spontaneously activated in the brain... and that is what you try to influence... there are people who try to influence their phantom... people who are able to actively move their phantom... but that is something different compared to a phantom which is fixed (in one position)... and that means that you can try, within physiotherapy, to look for motor – programs in which you could try to get a limb out of it’s cramping (state)... you could do that...
The physiotherapist (41) said that if there is the possibility of evoking phantoms (by concentration for example), there is also the possibility of diverting someone's attention from phantoms. The method then is not to direct someone's attention to the phantom limb but to be working on the stump (for example through massage):

What I do when people with phantom pain come to my practice... if they are able to evoke these phantoms... you could say... you could divert someone from this pain... by working on the stump through massage for example... then the signals will be passed on to the brain... a habituation process of... there the stump ends... the body schema...

It seems that the neuroscientist found it important to direct attention to the moving of the phantom limb to get it out of the cramping state, but the physiotherapist' therapy is directed towards the stump. But both views depart from the theory of the body schema in the brain, which they both want to influence in some way. With this view one ultimately implies that phantom pain is something, which happens in the brain. But from what I have tried to show through my informants' stories it seems that it is something, which is lived and experienced in the body. Although for some informants this could be very difficult to deal with. The next informant (55) has told me about experiences of severe phantom pain. She spoke about how she stores memories in her body. And that phantom pain is something that happened in her body and that she had to do something about it, because it was so comprehensive. Noises would escape from her throat, everybody in her proximity would look at her: what is this? She had to give the phantom pain a place. She went on by saying:

Then I thought... I leave it there... in that leg... what isn't there anymore... because... if I would store it in my real body... then I could experience pain there... I've left it there... and if it happens there... and it ought to be happening there... that is my formula for dealing with it...

In this subparagraph I have tried to describe my informants practices in finding relief for phantom pain. They have tried to look for possible remedies by using things 'external' to their bodies, such as warm water, cold water, 'shock-baths', medication and the exerting of pressure to the stump (slapping on the stump or hammering) and TENS. Although phantom pains could be very aggravating for my informants, almost all of them said that they (had to) learn to live with it. One informant had explained that by now these pains were part of her. All these (possible) remedies were directed towards the stump and had an effect on the phantom limb.
The (alternative) treatment of acupuncture I have discussed more or less makes use of the same principle as TENS (which was used by more then half of my informants, with varying success). It has to do with signals being sent to the spinal cord via the non affected limb, in such a way that signals from the affected limb are left out because of an overkill of information.

Some informants have tried to find relief for phantom pain by mechanisms within the body. One of these is moving the muscles within the stump; these muscles used to lead to the amputated limb. And by actively moving these muscles some informants could move their phantom foot, this could relief them from (cramping) phantom pain. But this had not been an easy thing to do, according to one informant. I assumed that this is because one would perfectly know that the limb is not there anymore, but it could be hard for the person to understand that it could still move. This mechanism could, according to a neuroscientist, be very important for developing therapy programs. The physiotherapist has laid the emphasis on the stump in his therapy. According to this informant, signals are passed on to the brain; 'here the stump ends', and this could influence (but slowly) the body schema or the image of our body in the brain. Both the neuroscientist' and physiotherapist' explanations start from the idea that phantom pain is something caused in the brain, my informants focus their explanations of phantom pain in their body. One informant said it was difficult to accept that phantom pain was part of her 'real' body because she feared this would hurt more. In the last subparagraph of this chapter I will describe how the informants spoke about coping with phantom pain in social situations.

3.3.2. Coping with phantom pain in social situations

In this subparagraph I will illustrate how informants have talked about what they do in social situations whilst experiencing phantom pain and how this affects their relationships with others. From what they told me this has something to do with the emergence of phantom pain and to which extent this was accompanied by certain (noticeable) bodily signs, such as gasping breathing sounds. Some informants told me that while they were experiencing a (sudden) flash or stab of phantom pain, they couldn't really say anything for a moment. This is what the next informant (55) had experienced. She is feeling phantom sensations all day, but phantom pain emerges very unexpectedly, like a stab. She told me not being able to speak for a while, when these stabs emerge:

*Phantom pain... that's the real pain... it takes about thirty seconds, but it's very painful, then you really can't say anything for a while... if you not already uttered a sound*
She explained what happens when she is somewhere else:

Yes, that happens sometimes... if you're somewhere else... then I always go somewhere... then I start to wince... then I really need to be on my own for a while... but it could also happen... when you're in an audience somewhere... that you're not always able to go away... that's really annoying...

This informant explained that she sometimes needed to be alone for a while, when she is having severe phantom pains.

The subsequent informant (55) said that when someone would stoke the left side of her body, severe phantom feelings emerged; this had been a great disturbance in the relationship with her husband.

Phantom feeling... yes... it is more intense... when I touch myself... then noting is going on... but when someone else touches me... then something gets activated in one way or another... now I know what happens, but in the beginning, when I wasn't at home (in the rehabilitation clinic) I didn't know... then you're in bed together and you cuddle... and then you think: see, that is also not going to work... and then you get aggressive... and then you don't want anything to do with your husband... until you realize what is going on in your body... then you give it a place... but it's not gone after a couple of years.

The next informant (52) told me that she experiences phantom pain when loud music causes the floor and the seat to vibrate; these vibrations are taken up by her prosthesis and phantom pain emerges. She said that when she is somewhere where there is (loud) music, she needed to go home. It seems that this restricts her social live.

Loud music... when you go too churches... a concert where... the floor and the seats vibrate... from the music... phantom pain... then I'd better go home... Tomorrow evening there's a party... from the volunteer organisation I work with... now I am already afraid for the music... and that can't be good... I mostly drive the car and I take four other people along with me... if they weren't there... then I might have gone home midway because I wouldn't enjoy it...

From the previous statements it seems that the informants experience phantom pain in totally different ways (other factors are influencing their pain) and that is why it also affects their relationships with others in very different ways.
The latter informant said that if her husband had not supported her so much as he has done, then the difficulties she had with dealing with the amputation and with phantom pain, would be much worse:

*When you have a husband like me... when you don't... when the people dear to you don't accept you as you are... then you're nowhere... then you can read books, do all kinds of studies, courses... but you really need that other person next to you.*

The next informant (46) is experiencing these stabs of phantom pain every six seconds, while she is having an episode. She told me that she has not been experiencing these severe episodes very much, but when she does, she is feeling total loss and she is has not been able to sleep. She explained that she used to make sharp gasping breathing sounds, but that has changed she told me:

*And when I have it now... I don't do that anymore... other persons became anxious, because I made that sound... then I would say... 'O, I have phantom pain'... well... then they accepted it... and now they can't see when I am having phantom pain... Maybe it's my pain threshold is bigger... maybe the intensity of phantom pain decreases... I don't know that...*

Although others have said that they accepted her having phantom pain, she explained that other people are not able to really understand what it is like to have phantom pain. That is because phantom pain is ghostly, that you cannot 'grab it':

*They don't really understand... how can you feel your toes when they're not there?... that is of course a phantom... it is ghostly [spookachtig]... and it is... it's ungraspable... you can't rub... nothing...*

In the previous subparagraph there was one informant (53) who had her own way of finding a remedy for phantom pain. She would slap on her stump. Now she explained what she would do in the company of others:

*I just keep standing... because it's there... and I am not ashamed... and the shame... it's very huge among people who have a prosthesis hè... I just slap myself... I can't walk away from it... this method helps me... and I do it... a la minute... it can't wait... it's so terribly painful... it really is...*
In the previous subparagraph this informant (55) said that noises would escape from her throat, everybody in her proximity would look at her: what is this? As a consequence, she tried to suppress it, but that is not always possible. Sometimes she would wince with pain:

Well, nobody understands it fully... they see you contracted from pain... and crying and they think... what have you got... yes phantom pain... during that moment you really can't say that anyway... I then I thought what if this happens in a concert hall or in the car... or wherever... then you'll make it very difficult for yourself... but I also disturb others with it... so I try to suppress it, but I can't do that always...

The following informant (40) said that she doesn't mind when she is having phantom pain among people with whom she is familiar. But this is different in situations were she does not know the people very well. Then she finds it difficult to say something about it:

Most of the times... when my husband is with me... he often says... 'Yes, she's got phantom pain'... because then I am really out of it... I don't really mind when I am in the company of people who I know well... then I also say it... but when I am in the middle of a conversation and I am alone... then I try to say nothing... I find it very difficult to say something about it... especially when you don't know people very well... then I really [stokte]... but then I try to go on... but that's very difficult... because then the pain remains... then you notice that people find it really strange when you say something about it... they look as if... what is that?... how can you feel something which isn't there anymore?... They're still very unfamiliar with it...

In this account she explained that she had tried not to show any signs of phantom pain while in the company of strangers. She had noticed that other people would look strangely at her, when she tried to explain it. But this had affected her experience of phantom pain, because holding back meant that the pain would stay longer in her body.

Another informant (23) said that when he explained to others what phantom pain is, they accepted it but said that it is still rather strange:

I say that you have pain in your leg... or that itching feeling... then I say... that it's a kind of ghost pain... to translate... there isn't anything there, but you still feel it... most of the time they do get that... however, then they say... 'strange'... but I know best... what it's like... people can't really understand what it is...
In the subsequent statement this informant (49) explained that if he would ask his wife: ‘what is phantom pain’, she would not know what it is except from the fact that he is having phantom pain and that a bath (warm or cold) helps him to relief phantom pain:

She knows that I am having phantom pains... I say to her that it’s really painful and that I am taking a bath... but then... that’s it... and that is were the ideas of stabs of knives [messteken] come from... you have to make clear to people... what that feeling could be like... Everybody uses a Stanley – knife... it’s the same thing with a piece of paper... when you get a pile of paper... and one paper sticks out... that’s what you feel... these stabs (of knives)... but then ten times more awful... and that’s what you try to make clear to your environment... that it could feel like that... I have not find out what it is... how then could you expect from your environment what phantom pain is...

Thus according to this informant, the comparisons people have used to clarify what they mean or what they have felt, is also done to let others know what phantom pain could feel like. But this in not an easy task, he explained. That is because he did not know himself what phantom pain is and how it is caused and were it is influenced by.

The next informant (23) lost his leg when he was 12 years old. He told me that he found it difficult to talk with his parents about what had happened 10 years ago. He said that his parents have been through a lot after the accident and that he did not want to trouble his parents with his problems:

I don't talk about it much with my parents... I just can’t talk about it easily... However... I can talk about it with my brother... only when something really serious is going on... then I can talk, but apart from that... no... I used to go downstairs when I had taken off my prosthesis... but I don’t do that anymore... my parents find it strange too see that leg... therefore, I always wear my prosthesis... only when I am upstairs in my room... in the evening... but actually, I am hardly ever at home... I just can't stay at home and be relaxed...

In the previous statements informants have said that talking about phantoms, in order to explain what they are experiencing, can be very difficult. Not only because it can be difficult for them to exactly find the right words, but also because what others have said or the way others have looked at them.
Talking about phantom pain can also be difficult for another reason, according to the next informant (55) who has talked to a lot of fellow – sufferers:

The home situation would be able to... would want to... and would know how to, and the first half year his environment would also want to (talk about it)... but often... it comes after that... after a year... two years... and then they still want to talk about it... it's like that with a lot more subjects... and then you have fellow – sufferers... they have a shoulder to lean on [een luisterend oor]... they know what you're talking about... phantom feeling and phantom pain... you're the one that understands... and not the doctor or the nurse... with two sound legs...

In the last subparagraph of this chapter I have reflected on what informants have done in situations where they experienced phantom pain. One informant needed to retrieve herself while experiencing phantom pain in the company of (unfamiliar) others. Another informant experienced phantom pain when her husband stroked her; this had an impact on their relationship. There was one informant who experienced phantom pain in situations when there is loud music; this has restricted her in going to these social gatherings. Another informant said that she slapped herself on her leg and that she was not ashamed doing so. Because if she would postpone (the slapping on her leg) the phantom pain she experienced would not go away. There was an informant who suppressed bodily signs of phantom pain (such as gasping sounds); she did not want others to notice, with the consequence that it remained in her body.

Most informants have said that it is difficult to explain, and difficult for others to understand, what phantom pain actually is. This affects their relationships with others. Some informants have said that others would look strangely at them, if they did try to explain. One informant implied that this is why people with phantom pain are using words such as stabs (of knives) and other comparisons, to clarify to others what phantom pain feels like. According to another informant, talking about phantom pain can also be difficult because amputees still feel the need to talk about it one or two years after the amputation. Phantom pain sometimes starts one or two years after the amputation, which is not always understood by the person's environment. She said that talking about phantom pain and other subjects with fellow sufferers could then give support.

In the following chapter I will describe the conclusions of my research according to the research questions I have depicted in chapter one. Then I will try to relate my research findings to the literature (review), described in chapter one.
4. Conclusion and Discussion

In this chapter I will answer the research questions stated in the third paragraph of the first chapter. These questions are derived from the general objective of this study. The aim of the study is to explore and describe the informants' own experiences and explanations of phantom feeling, sensation and pain in relation to their body and how these explanations fit in with biomedical theories of phantom pain. I will give an interpretation of the experiences of my informants, without undermining the infinite nuances in their stories. I will also try to link my informants experiences with the theoretical viewpoints described in the literature review of chapter one.

- *Experiences of phantom feeling, sensations and pain and the body*

Almost all informants make distinctions between phantom feeling, phantom sensations and phantom pain. Most of them talk about the feeling of the phantom limb. It is almost always described as non-painful. However, first experiences of phantom feeling can be very confusing for some informants. Informants develop a kind of phantom feeling in the sense that they are able to move, feel and exactly locate the phantom toes and feet, ankle and sometimes the knee.

Ramachandran has developed the mirror box experiment; he described that in one case he might have succeeded in the first 'amputation' of a phantom limb (Ramachandran & Blakeslee, 1998: 49). I presume that the amputation of phantom limbs is not always useful since phantom feeling can be functional in some cases. According to some informants, a phantom limb that coincides with the prostheses is a very comfortable feeling and is useful in being able to walk better. According to the physiotherapist and the neuroscientist a phantom limb which is integrated in a prosthesis could be functional because in this way body schemas in the brain can be adjusted and new ones build up. Some informants do not have a phantom limb which coincides with their prosthesis and this can be an annoying experience.

The informants in my study clearly distinguish between phantom feeling and the 'awareness of having two legs', they can understand this awareness because the brain had been programmed on having two legs for so long. Phantom feeling is, according to the informants a kind of sensation of mostly the phantom foot, although one knows this foot is not there anymore. Having the 'awareness of two legs' implies that one really must have thought for a moment to have two legs; this is the basic body schema in the brain and this is what the plasticity theories I described in the first chapter are all about.
According to these theories the mind is the center where we get a sense of our body. Apparently, these brain processes can be activated without input from the body. Ramachandran went as far as to say that our own body is a phantom (Ramachandran & Blakeslee, 1998:58). However, when informants talk about phantom feeling, severe phantom sensations and phantom pain, they do not believe that these phantoms 'happen' in the brain but they experience these phantoms in their body. Only when they talk about the 'awareness of two legs', which does not occur very often, they mention that the body schema in the brain is involved. The 'awareness of two legs' has to do with build-in patterns in the brain of 'having two legs', which in a sense resembles the body schema theories the physiotherapist and neuroscientist mention.

Although phantom feeling is non-painful, phantom sensations and phantom pains are almost always painful. Nearly half of my respondents experience phantom sensations, mostly described as [zware tintelingen]. These sensations are characterized by their continuous presence and exact locations. According to Jackson (1994:206) we try to objectify pain in order to understand and control the difference between painful and painless states. Some informants in this study also try to objectify phantom pain by saying that although phantom sensations are felt continuously, they are clearly not as painful as phantom pain. This distinction is important because they differentiate between painless states (the experience of 'mere' sensations or 'chilblains'; these could be evoked by informants) and painful states (phantom pain). I presume that this is because if one would consider phantom sensations to be painful, one would be in pain unremittingly and even 'become one with the pain (Jackson, 1994:206).'

Jackson (p.207) states that 'as members of present-day Western culture, most of us tend to think of pain as something physical: since we experience pain in the body, in so far as we see our bodies as physical objects, so will we also see pain as physical.' Pain is sometimes conceptualised in terms of the presence of a physical object inside oneself. Pain exists and is real. But because phantom pain is felt in a limb which is not there anymore, it seems that people need to stress that their pain is real even more, compared to other pain syndromes where there is something physically wrong which causes the pain to emerge in a particular localized pain site. Phantom pain also emerges in very specific localised pain sites. Some informants state that they can feel more of the phantom limb during an 'episode' of phantom pain. When the informants talk about phantom pain experiences they emphasize the physical presence of the phantom limb. Phantom pain can be felt in the different parts from which a leg is build up (nerve, muscle, blood and bone). The words used to describe phantom pain stand for more or less physical or tangible objects, which are felt in the phantom limb.
Terms to describe shooting or stabbing pain, which is associated with the nerve system, are: 'stabbing of knitting needles', 'toothache in the leg' and 'trust of a knife'. With these terms the informants also want to emphasise the unexpectedness of phantom pain compared to phantoms sensations, which are mostly continuous. According to one informant, this characteristic of phantom pain is what makes it ghostly [spookachtig]. Cramping pains are associated with muscles and compared with 'labour pains'. According to the neuroscientist all kinds of neurological disorders, such as extreme positions of the limb and joints (spastic pareses) can also exist in the phantom limb. Phantom pains can also resemble pre-amputation pains or they can be similar to the pains which were felt during the accident. For some informants experiences of phantom pain can bring back memories and emotions related to the accident, because again the same pain is felt. One informant however, wonders if her phantom pain resembles the pain she felt during the accident. Because she cannot remember the accident it is very difficult for her to retrieve memories which are related to the accident.

- **Etiologies of phantom feeling, sensations and pain and the body**

Because of the unexpectedness of phantom pain people have been wondering what causes phantom pain to emerge or what influences phantom pain. People develop their own patterns of 'phantom' experiences. But the problem is that this is only possible in retrospect. Informants also discuss the kind of factors which have an effect on an intensification of phantom feeling. Phantom feeling can be evoked for example by contracting muscles in the stump, by thinking of the phantom limb but also by talking about it. Especially talking about the phantom limb is according to almost all informants a factor which intensifies phantom feeling. One informant says that mere talking about phantoms can evoke them; this could be a reason why people who are coping with their amputation avoid the subject. Bodily processes like urinating, defecating and menstruation also evoke intensified phantom feeling according to some informants. The neuroscientist states that people have been afraid to talk about these phenomena, in fear of being called insane. There are also other bodily processes which can evoke phantom feeling. One informant says that when parts of her body are stroked, intense phantom feeling emerges. Also phantom sensations can be evoked through bodily processes. Focussing on these sensations can even make them worse and can lead to phantom pain. A reason for this could be, according to an informant, that feeling these sensations and at the same time coping with a changed body image after an amputation, would focus someone too much on the body. This suggests a connection between how one sees one's body and the experience of phantom pain. It also suggests that 'pain is by definition simultaneously bodily experience and mental- emotional experience
Some informants say that certain touches or pre-amputation pain can be stored in the body and later emerge as phantom pains. One informant says that she still feels certain touches or 'recollection points' in her phantom limb; these could still give a reaction of pain. Another informant says that certain pain memories are stored in the brain and sometimes surface.

Most of my informants say that they have to deal with the fact that phantom pain is ungraspable and difficult for others to understand. Some informants say that doctors had told them that 'it's all in the head' or that they had been imagining things. It seems these doctors want to 'subjectify' their patients' pain, in order to make it 'a figment of the imagination' (Jackson, 1994: 203). Some informants were simply advised by their doctors to not think about phantom pain, since thinking about phantom pain could evoke these pains. One informant says that in his case a doctor had used the literal meaning of the word phantom pain (ghost pain) when he talked with him about his experiences. Jackson stated (p.204) that in her study among patients of a chronic pain treatment center, some patients welcomed this kind of subjective pain because, even though 'all in my head pain' is stigmatized pain, subjectifying the pain by accepting 'it doesn't exist' should make it less horrible. Some informants in my study are aware of the secondary meaning of 'it's all in your head', which could mean: 'your are imagining things' and most of them (strongly) object to this presupposition. In former days there was not much attention for phantom pain, according to several informants. One informant even assumes that this could be the reason that people who were for example amputated fifty years ago, experience less phantom pain compared to nowadays. In earlier days people just had to go on after the amputation. If this is an accurate assumption, then maybe phantom pain is something which is, to a degree, 'all in the head', according to this informant. Another informant says that because now there is more attention for phantom pain (with which not all informants agree), people confuse phantom feeling with phantom pain.

A few informants wondered if the pain they are having is 'real' phantom pain when there is an apparent cause for it to emerge, such as a bad fitted prosthesis, which could be fixed. Although other informants agree that there could be an evident factor which is causing phantom pain to emerge; for them it is real pain. Phantom pain can be influenced by several factors. The majority of the informants state that weather conditions, changing air pressure and hot-cold temperature changes influence phantom pain. However, there is no single guideline; most informants say that other influences such as stress, fatigue and emotions also influence phantom pain. Although some informants attribute the onset of their pain to (emotional) stress or fatigue they still see their pain as mostly physical; nearly all informants explain that phantom pain has got something to do with the nervous system. Jackson also
Some informants try to look for possible relief through things which are 'external' to their bodies, such as warm water, cold water, 'shock baths', medication, the exerting of pressure to the stump (slapping or hammering) and TENS (used by nearly half of the informants, with varying success). Most informants say that these methods may work in some situations and in others they will not. Almost all informants say they have to learn to live with it and try not to focus on it too much. Another informant says that phantom pain is now part of her and that she does not want to do anything else about it and that slapping on her upper leg is effective. I have stated before that it seems that most informants, when they try to make sense of their pain, move towards 'objectification' of their pain. But when they talk about coping with their pain, they subjectify their pain by saying that they have accepted it and that phantom pain is now part of them. In this way pain patients 'attempt to decrease the power of their pain (....) by accepting it and even identifying with it, then paradoxically, one better controls it (Jackson, 1994:204).’ Not all informants however are able to merge the pain more with their selves or with their identity. One informant says that her way of dealing with phantom pain is to ‘leave phantom pain in the phantom limb’, because if she would store phantom pain in her ‘real’ body, it would hurt more.

Remedies such as TENS and acupuncture, shock-baths and slapping and hammering are all remedies which add stimuli to the stump, which could sound contradictory when finding relief for phantom pain is the aim. Especially when some of these remedies (like temperature changes to the stump) can also evoke phantom pain. The acupuncturist gives an explanation for this: through the generation of so many impulses in the stump, the (pain) signals from the amputated limb do not reach the spinal cord (because of an overkill of information they are left out).

Other informants try to look for possible relief for phantom pain through mechanisms within the body. Several informants say that they can evoke phantom feeling by contracting muscles in the stump; some of them make use of this by moving the phantom foot to relief phantom pain. But this could be very complicated. I presume this is because trying to move the phantom limb could result in a dual feeling; one perfectly knows that the limb is not there anymore, but one is able to move the phantom limb. According to the neuroscientist moving the phantom is an important mechanism which could be used in therapy to relax cramping phantoms. The physiotherapist gives therapy (massage etc.) which is directed to the stump; in that way signals are passed on to the brain: 'here the stump ends'. Both these methods however aim at influencing (but slowly) the body schema or the image of our body in the brain, albeit in very different ways.
Informants also talk about how they have coped with phantom pain in social situations and how this affected their relationships with others. One informant experiences phantom pain when her husband strokes her; this disturbed her relationship with her husband. Some informants need to retrieve while experiencing phantom pain. Others try to suppress bodily signs of phantom pain; because of the way others look at them or because of the way others react to the fact that they are having pain in a limb which is not there anymore. Suppressing bodily signs of phantom pain could result in the pain to remain in the body. Explaining to others what phantom pain feels like is very difficult and that is why, according to an informant, words like stabs (of a Stanley knife) and other comparisons are used. However, these terms are not sufficient enough to explain its impact; they are almost always followed by: 'but then ten times as bad' or 'but then more awful'. One informant has used the literal meaning of the word phantom [spookpijn] to clarify to outsiders what phantom pain is. Some informants say that when they tried to explain to others what phantom pain feels like; they would look in disbelief at them. Informants in this study emphasized that it is difficult for laypersons to know what phantom pain is and that only other members of the fellow sufferers group understand what it is they are feeling. Jackson (1994: 213) states that pain sufferers often report that only other pain sufferers understand their pre-objective experiences of pain, but not through the normal medium of communication – everyday-world language. According to Jackson, pain patients claim that other forms of communication, intuitive and involving a kind of communitas, facilitate mutual understanding.
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Sherman R.A. and D.E. Casey Jones

states that the patients she observed in the treatment center, see their pain as ‘primarily ‘real pain’ – physical, body pain (p.208).’ She also says that ‘people in chronic pain struggle with its meaning partly because they have been socialized to see pain as a sensation, as basically a physical feeling (…) the mind-body distinction requires that pain be spoken as only sensation – albeit with overlays of meaning (p.211).’ The informants in this study say that some signals are still passed on to the brain, although the limb is not there anymore. It also has got to do with nerves and muscles being (instantly) cut off. Although the nerves and muscles have been cut, several informants say that the rest is still there so that the feeling of sensations or pain in the phantom limb is still possible. The neuroscientist explains that when nerve cells get (normal) input there is an inhibition effect. When a limb is taken away these cells lose their input and become activated; someone will get ‘positive sensations’ when inhibition ceases. And those feelings are projected on the limb, from which there still exists a representation in the neuromatrix or body schema in the brain. According to another informant the transmissions that actually have to take place there keep on floating since there is no information coming from the amputated limb. This informant cannot explain why phantom pain tends to emerge at certain moments. She says that it just happens. In contrary to other informants she can’t find any other explanation (such as weather conditions, stress, fatigue, emotion), therefore phantom pain just became part of her. It seems that this informant ‘merges the pain more with her self (Jackson, 1994:204).’ By doing this, one does not fight it and in this way better controls it (p.204). I assume that informants who have several explanations for their phantom pain to emerge tend to ‘move towards greater objectification of their pain.’ It is not that these informants try to ‘fight’ their pain, but they can fall back on these explanations to make sense of phantom pain and to make it less ungraspable.

Techniques of amputation could also be of influence according to a few informants. One informant says that currently, the scar is placed on the backside of the stump. This could cause less phantom pain to occur. Scar tissue itself could also be of influence on phantom pain according to the acupuncturist, because scar tissue could disturb the energy flow in the stump.

- **Peoples’ practises to deal with, find relief and cope with phantom pain.**

Although it is not easy for informants to explain what is involved in phantom pain, they did try to find relief for phantom pain. What seemed very eminent in their stories was that they had developed their own ways of coping with phantom pain. Most of the informants had to find out these strategies themselves.
Annex I

From: Grégoire, 1990, p.29

From: R.A. Sherman and D.E. Casey Jones 1997, p.199

Figure 3. How pain can be felt in a part of the body different from where the pain “signal” started. When your finger is touched (lightning bolt), a signal travels along nerves past your elbow, through your spine, to your brain. The signal goes to a part of your brain (the homunculus) corresponding to your finger. You can send a signal to the same part of your brain by bumping your elbow (hammer) because the brain can’t tell where it began. This is why your fingers tingle when you bump your “funny bone.” The nerves and brain don’t change much after an amputation, so you still feel your hand when you start a signal in the stamp.
Figure 1. Typical descriptions of phantom limb pain (from Sherman, Sherman, & Grana, 1989).

Annex II

Interview guide

Topics and probing questions (sequence not rigid)

For interview with sufferer of phantom pain and/or phantom sensations:

- Experiences and descriptions of phantom feeling
  - What kind of feeling do you have in your phantom?

- Experiences and descriptions of the feeling of phantom sensations and phantom pain
  - What kind of pain do you experience? How often? In what kind of situations?
  - How would you contrast phantom pain with other kinds of pain?

- Thoughts and descriptions about causation of phantom pain (and/or sensations)
  - What do you think is involved in phantom sensations and/or pain?

- Thoughts, descriptions and feelings about the influence of the reason and the circumstances of the amputation
  - How did you experience the amputation? How long ago was it? When did you first experience phantom pain? How did former experiences influence your pain?

- Experiences and descriptions about other kinds of pain that have/had to do with the amputation
  - How did you experience these pains? How often? How did it influence phantom pain/sensations? Which pain dominated (e.g. amputation pain or phantom pain) and when?

- Experiences and descriptions about coping in daily life
  - How do you explain to other people how you experience your pain? How do you feel when people do not understand? What do you do? How do you experience the fellow-sufferers contact? What kind of other support do you experience in coping with your pain/sensations?

- Experiences, descriptions and opinions and about former, current and alternative treatment of phantom pain (and/or sensations)
  - How were (are) you treated for phantom pain? By whom? How often? What did your doctor(s) say about the treatment? What kinds of other treatments have you tried? How did you experience these treatments in comparison with medical treatments?
• Experiences and descriptions about factors influencing phantom pain (and/or sensations)
  - What kind of things makes your pain worse or better? In what kind of situations?
    How can you influence that? What kinds of other pains (e.g. back pain, headache etc.) influences phantom pain? How do you experience that? What do you do in situations when you are in the company of other people when you have pain? How do you cope with that?

For interview with provider of biomedical treatment of phantom pain and/or phantom sensations:

• Descriptions of different categories of 'phantoms' (feeling, sensation, pain)
  - How do you explain the different categories of 'phantoms'?

• Thoughts and descriptions about causation of phantom feeling, phantom sensations and phantom pain
  - What do you think is involved in these different categories of 'phantoms'? What kind of etiologies lie behind these different 'phantoms'? How do you explain the different qualities of phantom pain ('itching, warmth, twisting, cramp etc.)?

• Thoughts and descriptions about former and current treatment of phantom pain (and/or sensations) in general
  - What is your opinion about former treatment practices? What are the current treatments? How do they differ from former treatments? What kind of theories lie behind the different treatments? How did they change in time?

• Thoughts about own way of treating phantom pain and/or sensations
  - What kind of treatments did you give to people with phantom pain? What treatments do you consider to be the most effective? What do you think that people can do themselves to influence their pain?

• Thoughts and opinions about alternative treatments
  - What kind of alternative treatments have you heard of? What do you think of them? How do you think of referring patients to alternative healers?

For interview with provider of alternative treatment of phantom pain and/or sensations:

• Descriptions of different kind of 'phantoms' (feeling, sensation, pain)
  - How do you explain the different categories of 'phantoms'?

• Thoughts and descriptions about causation of phantom feeling, sensations and pain
  - What do you think is involved in these different categories of 'phantoms'
• Thoughts about alternative treatment of phantom pain
  - How do you treat phantom pain? What is your theory behind it? How do you treat the different qualities of phantom pain?

• Opinion about biomedical treatment of phantom pain (and in general)
  - What do you think of the biomedical treatment of phantom pain? What do you think of biomedical treatment in general?

• Thoughts about the difference between alternative and biomedical treatment of phantom pain (and in general)
  - What do you think of the different way phantom pain is treated in biomedicine and your way of healing? What do you think of the difference in general? How is your way of treatment effective?