

# EXAMINING ISSUES OF BODY IMAGE AND COMPLEX REGIONAL PAIN SYNDROME WITHIN THE DIGITAL

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Drawing upon the creation of a digital tool to replace self portrait sketches in the diagnosis of Complex Regional Pain Syndrome we will examine the body's depiction in the digital, drawing upon patient interviews to explore how the digital can help us understand our body image. In so doing it will challenge phenomenological accounts of the body and seek critique the structures that often assert the digital as an incorporeal space.

## Introduction

Body image can be altered by pain, 'peripheral' injuries such as amputations, or insults to the central nervous system. These conditions have also formed the basis of Merleau-Ponty's philosophical enquiry into how we might understand embodiment. Within clinical practice attempts are made to 'repair' patients' body image through rehabilitative techniques however the means of assessing these changes has been that of self-portrait sketches.

The use of self portraits has been problematic in that it has often been limited by the abilities of the patient and, not without irony, the additional limitations that the condition itself can place upon them. Alexa Wright's work on the Sci-Art funded *After Image* project (1997) investigated the phenomena of phantom limbs however the techniques involved in creating these images were not ones that could be easily utilised by patients within a clinical setting. As a result of this research was instigated that examined the possibilities of the manipulation of an avatar for suffers from Complex Regional Pain Syndrome (CRPS) within the Digital to communicate their experience of their body image. This was instigated by allowing patients to remove, scale, displace and render the body in a variety a ways.

This paper will examine issues concerning the perception and depiction of the body within the digital. It will draw upon research interviews with users of the system to explore how the digital, rather than promoting notions of 'virtual' self can help us understand our experiences of the physical. In so doing it will draw upon a phenomenological understanding of embodiment and seek to critique the structures that often assert the digital as an incorporeal space.

Complex Regional Pain Syndrome (CRPS) was first identified during the American civil war when it was named *Causalgia* derived from the Greek words for pain and heat which are symptoms typical of the syndrome. CRPS is associated with the body's extremities and can affect whole limbs. It is defined by two forms, Type 1 (CRPS1) and Type 2 (CRPS2), but the nature of the pain of this is common to both forms. In CRPS 2 the pain can (albeit disproportionately) be associated with identifiable nerve lesions or tissue damage however in CRPS1 there is no identifiable injury that can be associated with the pain that is suffered.

Our understanding of CRPS is still in development and there are still different sets of criteria for its diagnosis; a situation most likely exacerbated by the fact that many of its symptoms are not identifiable through the use of objective tests. As we have noted a common factor is chronic pain associated with heat; this is accompanied by extreme sensitivity and painful reactions to everyday sensations such as the touch of clothing. Along with this there are a range of other symptoms that may be experienced that can include the perceived (and sometimes actual) swelling of limbs and the sense that the affected region does not belong to the patient; in some cases this can lead to a desire to have the limb amputated. Perhaps one of the most perplexing aspects of these symptoms for patients and clinicians is that they can vary greatly through the course of a day.

As a result of these factors there has been a tendency to believe that there is a psychological basis to CRPS. However a systematic review<sup>[1]</sup> of research concerning this relationship has suggested that there was 'no relationships between psychological factors and CRPS1'. In fact the frustration of trying to understand and convey these symptoms can be more of an issue, in fact one patient involved with our study noted that 'I really thought I was losing it.'

If the range of experiences described are not the result of the patient's psychological makeup how might we begin to understand these symptoms?

## Body Image

Although body image is susceptible to distortion through psychological factors (as seen in conditions such as anorexia nervosa) neurological studies have shown that other factors play into its creation.

Work by Ehrsson, Holmes and Passingham's has sort to investigate this through an investigation of the "rubber-hand illusion". The illusion concerns the perception that a rubber hand was a part of a subject's body; this was generated by providing sight of a rubber hand being brushed whilst simultaneously brushing the subject's hidden hand. Ehrsson et al sought to establish whether the illusion was more than simply a result of the visual representation of the hand being brushed. This was tested by blindfolding their participants and moving the subjects hand to touch the rubber hand whilst simultaneously touching the participants hand in the 'same' place.

The results demonstrated that the illusion could be generated though synchronous touching without the need for a visual representation. Further tests also asked subjects to locate the index finger on the hand subject to the illusion. This revealed an error in locating the finger that appeared to be dependent upon the veracity of the illusion. Given this it appears that the illusion's power was such that it remapped the perception of where the participant's hand was in space.

## The Role of the Somatosensory System

The Somatosensory system incorporates the receptors and processing that provide our sense of touch, temperature, body position (proprioception) and pain (nociception). McCabe, Cohen, Hall, Lewis, Rodham and Harris have proposed that disruptions within the somatosensory system can begin to account for the symptoms described within CRPS [2]. They note how our body image is formed through the

...integration and processing of multimodal sensory percepts that involve the peripheral nervous system and central nervous system (CNS)... This is not a unidirectional system, whereby the CNS simply responds to a peripheral stimulation, but is a bidirectional process in which CNS activity may induce consequences.

This has some reaching consequences for our understanding of what we might understand body image to be. We often assume that our bodies are a given around which our perceptions are formed. The phenomenologist Edmund Husserl notes that

The Body is in the first place the medium of all perception...the zero point of orientation... each thing that appears has eo ipso and orientating relation to the body. (Edmund Husserl, *Ideas II* trans. Rojcewicz & Schuwer, Kluwer, 1989 p 61)

This is perhaps most clearly expressed in the phenomenology of Maurice Merleau-Ponty.

If my arm is resting on the table I should never think of saying that it is beside the ash-tray in the way the ash-tray is beside the telephone. The outline of my body is a frontier across which ordinary spatial relations do not cross. This is because its parts are interrelated in a peculiar way: they are not spread out side by side, but envelope each other. (Maurice Merleau-Ponty, *The Phenomenology of Perception*, trans. Colin Smith, Routledge, 1962 p98)

Phenomenology quite literally places the body centre stage and one might even claim that Merleau-Ponty's philosophy is based around an a-priori status for the body. In contrast to Merleau-Ponty's assertion, within CRPS we discover patients who can experience a limb to be foreign to their body and who possess 'a poor awareness of its location in space'.

In fact when asked to move an affected limb suffers of CRPS often do not move the limb itself but move from the unaffected part of their body as if the limb were an *object* within their peripersonal space (and therefore affectively 'besides') their body. In this regard we discover circumstances within which ordinary spatial relationships *have* entered the body.

Rather than possessing the body as a 'given' to which sensation 'adheres' it appears that body image emerges from the relationship between sensation and the CNS. Given this the 'enveloping' to which Merleau-Ponty refers effectively occurs prior to the body image. If sensation is not something appended to the body 'External' sensation and proprioceptive perception by necessity will envelope each other as they are processed by the CNS generating our body image and sense of space.

## Changes in Body Image

Our somatosensory system is known to be involved in more than just the perception of what we might consider to be our own sensations. When viewing the experience of others and imagining activities of various sorts the somatosensory and premotor cortices becomes active. Antonio Damasio describes the empathetic sensation of pain that we can experience as the “as-if-body-loop” mechanism.

It involves an internal brain simulation that consists of a rapid modification of ongoing body maps. (Antonio Damasio, *Looking for Spinoza*, Heinemann p 115)

However the notion of a body map is in itself problematic as Damasio points out

The result of the direct simulation of body states in body-sensing regions is no different from that of filtering of signals hailing from the body.... What one feels then is based on “false” construction, not on the “real” body state. (Ibid)

Damasio’s use of scare quotes is appropriate because the sensation is real, what differs is that in that empathising with somebody who has grazed their knees although we’ve physically not gone through that event we experience it in another way. Similarly the experience of CRPS patients is real even though they apparently possess a ‘normal’ limb.

A condition that has similarities with CRPS is Fibromyalgia (FMS). The symptoms of FMS include widespread pain, hypersensitivity to sensory stimuli, phantom swelling of limbs and reduced sensitivity to the position of limbs and motor abnormalities such as tremors or slowness in movement.

In order to examine whether a dysfunction in the interaction between motor and sensory systems might be involved in symptoms experienced in FMS McCabe et al conducted a series of tests using a mirror/whiteboard that created varying degrees of sensory conflict during congruent/incongruent limb movements. The results of this were that 89.7% (26 out of 29) of patients with FMS involved in the tests reported changes in perception compared with 48% of a healthy control group. The sensations experienced included...

...disorientation, pain, perceived changes in temperature, limb weight or body image. Subjects described how these symptoms were similar to those they experienced in a “flare” of their FMS. This led us to conclude that some sensory disturbances in FMS may be perpetuated by a mismatch between motor output and sensory feedback.

Whilst it appears that this mismatch plays a role within FMS it was also the case that the healthy participants also reported (albeit at a lower incidence) changes in perception. Rather than being a phenomena exclusively linked to the pathology of FMS the results of these tests point towards what appears to be the emergent nature of body image as an a priori condition of perception. The anomalies that appear to exist within FMS therefore appear to make those who suffer from the condition all the more vulnerable to new anomalies. Given this it would appear that within CRPS such disturbances are exacerbated.

Given the close integration between (the enveloping) of body image and spatial perception it appears that conflicting sensation, proprioception and visual perception or faulty sensory integration might explain the experience of CRPS patients who have difficulty in locating their limbs or who feel that they are not a part of their body.

### Communicating Painful Contradictions

The right side of my whole body actually feels quite normal, there no problem with that I don't have any difference in perception to what I see with that...

Because of the fact that CRPS is not well known diagnosis can often take some time. As was noted by one patient in our study

The thing I found difficult was getting this far, my GP knew nothing, so the diagnosis took forever...

During this period patients suffering from CRPS often doubt themselves because of the contradictory nature of their experiences.

A method currently used in assessing CRPS is the use of self portrait sketches or drawings made by clinicians; these have a number of limitations such as the ability of patients or staff to render these sensations. These are often revealing for those suffering from CRPS because it can often be the case that patients have not fully considered the nature of their sensation. It appears that they have often been trying to deal with the contradictions rather than 'inhabit' the sensations resulting from CRPS. One patient noted that

...its quite new to me because I hadn't really thought about this until I came in here.

This could be due to the nature of the sensations encountered...

I know there are fingers there and I even move them, I can't see fingers when I try closing my eyes to see it, I don't see anything, I just see a big blob

Inspiration for the development of a tool that would assist patients in communicating their symptoms came from Alexa Wright's *After Image* project which dealt with the experience of amputees and phantom limbs. Whilst Wright's work used Photoshop to manipulate photographic images of amputees this wasn't appropriate for the creation of a tool that could be easily used within a clinical setting. The spatial anomalies experienced CRPS patients also suggested that the development of a 3D tool would be more appropriate.

As a result of this a prototype tool was created that allowed the positioning, scaling and colouring of body parts to see whether this would aid patients in their description of their experiences. This was tested with patients suffering from CRPS who attending the Royal National Hospital for Rheumatic Diseases (RNHRD) in Bath.

Ethical clearance for the tests was of course required. One of our concerns was that in discussing their condition the level of pain experienced by patients often increases, as a result there were concerns that

use of the tool might negatively affect patients and so measures were put into place so that this could be addressed if it were to occur.

The tool was well received and considered to be a valuable improvement over established methods. What was interesting was that within the interviews that we conducted patients were asked if the experience of the tool was distressing for them in any way. In a number of instances increased pain was experienced but other benefits were expressed.

No, I don't think I've got a bad feeling from doing this, it's not a bad feeling it's just to me looking at that .... puts it into perspective what I've got its just I don't know how to explain it, it looks in human form exactly how I feel and I've never had that...

It was also the case that appeared that even if it hurt the process might have helped reconcile some of the contradictory sensations experienced by patients.

Patient: Seeing something and knowing that it's *your hand* is erm how can I put that into words, its erm, I don't know it I suppose accepting now that it's there, it's happened, I've got it..

Interviewer: Does this help you accept it?

Patient: *Yeah*, because you can see it...

Although the it was not something we sought to address through the use of the tool it is interesting to note that it may have benefits in the acceptance of the condition.

It wasn't that I disliked using it, it's just... for me as I say to visualise that how I feel I felt a bit emotional, but the more I'm looking at it, it's only because I'm sitting here thinking that is exactly how in my mind's eye what I look like so it was a bit of a shock I suppose.

## The Nature of Pain

You can't see pain

By its very nature the tool tended to focus upon the perception of the scale, position and possession of limbs. However the depiction of the quality of pain and the degree of contradiction often experienced within that pain was something that required further development.

My hand feels as if it's absolutely on fire and then if somebody touches it, it feels cold, and this pins and needles and I don't know how to represent that...

In fact these contradictions appear to be central to the nature of the pain experienced by many with CRPS.

These fingers here are numb, I suppose in a way they should be transparent really shouldn't they... 'cause these three fingers here are numb, I feel I could just stab them, but it's still got that hypersensitivity in it.

As a result of this we have now embarked upon the development of techniques that allow patients to approach a visual description of these sensations. However the sensation of 'pins and needles' described by one patient was, to varying degrees also reported by others.

Ok so the skin surface doesn't feel any different here, but when I've got my eyes closed it's very, it almost feels as if it's... if I say it's not there you know when you've sat on your foot and its gone to sleep, its that sort of feeling so you sort of know its there but if somebody said where is it its quite difficult to say it's just there...

In itself this provokes interesting questions concerning the issue of ownership of affected body parts... what if the pain is associated with a lack of sensation?

This opens up upon one of the therapies being used to minimise the pain suffered by those with CRPS. One of the emergent techniques used in treating CRPS concerns the sensory mapping of the affected region. It has been found that sensory retraining of the limb can reverse cortical changes and reduce pain.[3][4] Staff involved with the development of the Body Image tool are involved with the development of an Electrical Sensory Discrimination Therapy device (ESDT) that can improve sensory discrimination in the limb of healthy subjects and those with CRPS (funded by the NIHR[5]).

## Conclusion

What does all of this mean for the electronic arts? For many years there has been a tendency to view the data of electronic systems as being akin to the idealism of Plato. The evidence of neuroplasticity and devices developed by scientists such as Bach-y-Rita has been used to support such claims. However as we have seen vision also plays a part in the somatosensory system; it may be the case that devices such as the BrainPort naturally play into this.

However as we have seen through our discussion of CRPS perception appears to be far more complex than a simple case of sensory input and neurological output. What we need to do is to begin to develop an understanding of the ways in which the somatosensory system works and the ways in which it participates in the generation of our body image. If we were to buy into the rhetoric of a digital realm of the ideal, any attempt to achieve the production of a body image in any other world seems fraught with potential problems. However it also the case that the digital can be used to realise images that reflect the realities of that system for those who suffer from conditions such as CRPS.

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