Transformation between Electronic Arts and Chronic Pain: Long-term Body Activity Data Visualisation and Pain Animation Expression

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For many digital artists, art is a critical technical practice, a means of critiquing the assumption that technology is a tool to be applied to all social problems. Aesthetic and affective approaches to visualisation by artists and scientists who comprise the Pain Studies Lab are integrated with tools created for patients who live with long-term chronic pain, and for their health professionals. Although this work is not the kind of personal expression of pain that artists like Frida Kahlo practiced, it is intended to provide users with an experience even as it conveys information.

Chronic pain. Transformation. Data visualisation. Electronic arts.

1. INTRODUCTION

The relationship between art and pain has long historical roots; in contemporary times, it has also been recognized, discussed and researched by artists and scientists. Art that is created in response to pain resonates not only with patients, but bear expressive and aesthetic dimensions that can move data into more expressive and familiar realms (Knill *et al.* 2005). When art taps into this reality, it can become transformative. Transforming invisible physical index data that represents chronic pain as art can provide patients with an overall visual feedback of their pain experience and how it changes over time. Also, the feelings conveyed by artworks can make the chronic pain experience available to other people, which may break down barriers among patients, doctors, families and caregivers to bring them closer together.

Artwork like graphics and animations are potentially more effective at communicating a pain experience than words, especially because pain—arguably more than any other experience—resists textual language (Scarry 1987). The transformation of pain can be achieved in more diversified and poetic ways through multiple techniques of expression using the diverse forms of electronic art, such as graphics and animations. More importantly, with the development of technologies like physical computing and biosensors, pain-related art and art therapy are no longer confined to traditional forms and allow us the opportunity to look at alternative

methods to represent bodily activities and embodied experiences.

Graphs are the main resource for patients to formalize their understanding of the way their condition is progressing, based on data from biosensors, and coupled with qualitative information. Information visualisation graphics, such as pie charts, bar graphs or line graphs, have normally been used as a representational approach to illustrate data (Meirelles 2013) including inferences of pain data. However, it is difficult to fully demonstrate periodical or longitudinal data in order to show the continuous timescale as time goes by with these representational approaches. Therefore, a circular structure, which was originally utilized in Nightingale's Rose Chart, was adapted in our work to display patients' long-term bodily activity data. An aesthetic approach to incorporating data in the circular graphic allows users to not only appreciate the aesthetic aspects of the graphic form and its possible and multiple symbolic allusions, but simultaneously also empowers them by enabling them to understand and compare the carefully encoded quantitative data.

Furthermore, we propose that the animated approach may also serve as a tool for expressing patients' pain in a manner believed to be therapeutic. There are several pain assessment tools developed for patients to report the severity and degree of their pain using numerical scales and verbal descriptions, such as the widely used

McGill Pain Questionnaire (MPQ) (Melzack 1975). The static quality of this tool, however, renders it complex and limited to what patients can indicate on an approximately two- to three-inch outline of a male or female body (Elton *et al.* 1979).

In this paper, we provide an overview of the relationship between art and pain, especially electronic arts and chronic pain, from both historical and realistic points of view. Next, two examples of the transformational processes of art and pain are discussed. In the first visualisation, we transformed patients' long-term pain data into a visual graphic with a temporal time dimension. In the second example, an animation and artistic visualisation, we presented different pain types and scales from an abstraction of pain, using the movement of jellyfish to articulate patients' pain to other people in a way that removes it from literal references to the human body for two reasons. Firstly, it is thought that ancient Greeks used intentional jellyfish stings to treat people who had long-term pain. Secondly, our anecdotal experience from working with chronic pain patients suggests that using a human reference often complicates patients' ability to articulate aspects of pain, which is an already difficult challenge. Therefore we presented pain data in a novel way in both cases, and consigned invisible pain a specific object – a circular pattern and the abstracted movements of a jellyfish. In our future work, we plan to conduct a study to evaluate the effectiveness of our visualisation methods to gain formalized feedback that may guide refinements of these approaches.

2. ELECTRONIC ARTS AND CHRONIC PAIN

Pain itself is an important aspect of life, one that alerts us to impending injury or disease. In contrast, chronic or neuropathic pain is thought to be a malfunction and hypersensitivity of the pain response system. Chronic pain then is a systemic malfunction, and a condition that operates as a disease. However, the processes that comprise chronic pain were only recognized at the end of World War II; thus, it is a fairly new but rapidly growing disease that currently has no known cause or cure (Gatchell *et al.*, 2007). Chronic pain is defined as pain that persists for more than six months, and often longer, and is a phenomenological experience resulting from biological, psychological, and social interactions (Kelly & Field 1996) concerning this long-term pain. Consequently, treatment of this complex, degenerative and debilitating health phenomenon is often approached from multidisciplinary and biopsychosocial perspectives. In other words, chronic pain is often conceived in ways that attempt to overcome strict distinctions between mind and body. The most common consequences of chronic

pain cited in research studies and other scholarly literature includes increased reports of depression, anxiety, and anger in relation to increased and unrelenting pain (Gatchell *et al.*, 2007). Over time, patients may also lose mobility and become socially isolated. Among all the approaches to articulating and expressing pain, art is an effective means of communicating or evoking this experience, in part because of the highly individual and qualitative nature of pain. In addition, since pain is nearly universal, the ability of art to break down or transcend barriers also renders it an apt approach. Moreover, visualizing and communicating a painful experience is a well-known form of catharsis, which is particularly important for people who live with chronic pain, since this disease resists linguistic articulation and because it is widely misunderstood and stigmatized. Therefore, visualizing one's pain may additionally act as a form of validation of what is otherwise an invisible and devastating experience.

The arts have been shown to improve and promote health (Stickley & Duncan 2007). Arts-based programs and activities, along with creative art therapy have been used as tools for improving and promoting health for more than a century in North America and many European countries (Sonke *et al.* 2009). Contrary to the treatment of acute pain—which requires rest to allow the body time to heal, and which is expected to dissipate—chronic pain management requires patients to remain active. Mind-body interventions specifically assist patients in understanding how psychological and physical symptoms are intertwined, paralleling the biopsychosocial approach of pain experts in healthcare. Thus, art therapy, as a form of psychotherapy that includes bodily awareness, may also play a significant role in promoting self-exploration and understanding by combining visual art-making (as well as music or performance) with psychotherapy (Clift 2012).

In the United Kingdom, the arts have been employed in healthcare for many decades, demonstrating real and measurable benefits. Growing research and experience in other countries, and more recently in Canada, demonstrate that participation in arts activities has significant benefits for medical treatment and sustainability of health care systems (Clift 2012). We contend that the practice of art therapy is a potentially important aspect of pain self-management. However, we also believe that lessons learned in both art therapy practice and from interactive arts more generally offer opportunities that are just beginning to be explored in long-term pain self-management strategies.

2.1 Electronic arts and chronic pain

Along with the development of digital media and interactive art are new opportunities for both chronic pain professionals and patients to design novel approaches to present, articulate and express pain. Pain Exhibit (*PainExhibit.org*), for example, is an online website exhibiting visual and electronic artwork from artists who live with chronic pain. It provides a platform for these artists to express facets of their pain experience. Others who live with chronic pain resonate with and find encouragement from this visual feedback, and many have been inspired to also produce visual pieces to express their own pain experience. Artistic venues also accept spiritual aspects of experience, and therefore can address or enhance a pain sufferer's quality of life beyond clinical medicine.

2.2 Employing electronic arts to represent chronic pain data and express abstract pain

Transforming intangible physical and psychological pain via electronic art allows a visually modelling of the pain's progression. For example, it can indicate what this invisible pain feels like to patients, and how this feeling of pain evolved over diverse periods of time. For instance, the bodily areas of a pain experience may expand to other parts of the body, a painful area can shrink and grow larger over time, or the stabbing characteristic of pain can "swallow" the head when it is at its worst intensity to indicate the kind of short-term cognitive impairment that arises during high intensity phases of pain.

Electronic art may also provide an approach to assisting patients with obtaining visual feedback of their pain condition, with more comprehensive understanding of patterns their pain may take, or how their pain may correlate to their regular activities. Here, the visuals could function as a form of tracking, indicating a patient's changing bodily situation through a continuously updated, longitudinal visualisation. The visualisation might then help motivate patients to trace their data for purposes like better managing their daily activities and patterns of activity. Patients may also share the updated visualisation information to health care professionals on a monthly scale that is compared to prior months to better communicate temporal aspects of their pain. The illumination of the unknown but nevertheless felt experiences of those suffering from pain, as demonstrated by electronic art, may therefore help patients in monitoring and managing their conditions. Simultaneously, those visual expressions and transformations may also evoke health care professionals' resonance or

empathy, and may offer a clearer understanding of the varying aspects of their pain.

3. TRANSFORMATION: FROM PAIN DATA VISUALISATION TO ELECTRONIC ARTS

3.1 Motivation for creating the visualisation

The visualisation in figure 3.2 is an example of an emerging computational area of personal data analytics, or what can be understood as the other side of the Big Data. Through this visualisation, patients can become aware and keep track of their long-term activity levels, and especially the changes that occur over specific periods of time. It was created for chronic pain patients because many of them also suffer from kinesiophobia, a fear or reluctance to move and remain active. Therefore, these patients may be interested in comparing their activity levels with their pain levels to determine if greater activity increases, decreases or otherwise affects their pain over time. For example, when patients increase their activity levels, they may find that it correlates with increased pain levels initially, but that their pain levels may ultimately decrease over the initial pain spike. Or, patients may find that their pain levels actually become lower if they maintain activity over longer periods of time.

The need for a new approach to show individual data and its analysis within particular time period comes along with an increasing interest in health-related monitoring devices that have been developed for sports conditioning and weight management areas, both in research and industry, such as the *FitBit* and the *Nike FuelBand*. They collect and track data like activity levels, sleeping patterns, stairs climbed, distances walked and so on. The original data visualisation of these monitoring devices is basically presented in a linear time sequence with bar graphs or pie charts. Although such visualisations could provide users with a fundamental understanding about actual daily data/body condition and tendencies during certain time periods, it still lacks the presentation of an overview of regular daily patterns, long-term comparisons or impressive recognition or representations of individual health profiles. Nonetheless, we believe that users could be better motivated to work on their activity levels and chronic pain management if such devices were adapted for specific issues that affect pain patients. Similarly, from the perspective of healthcare professionals, the oscillations and changes that occur between activity levels and pain levels during specific periods of time could be made legible in more specific and meaningful ways. Finally, devices of this nature, while widespread, are better at distinguishing between gross changes in activity,

and much less so in terms of the more modest changes in activity and sleep that are more appropriate for pain patients.

3.2 Design method and metaphor

Since we need to represent pain within time scales—an abstract concept that is not inherently visual—we adopted a temporal structure to represent flows and to trace and track variable processes of activity data (Figure 3.1). The visual aspect of this transformation of numerical to pictorial information makes the information easier to understand and remember, especially over discrete periods of time. Moreover, presenting long-term pain data as a visual graphic may make it much easier for doctors to interpret clinical quantitative and quantified data and communicate it to patients and their caregivers, and to better monitor the health condition of the patients in order to provide them with timely treatment.

This kind of monitoring newly fills a gap: people who live with chronic conditions generally require more frequent visits to health professionals than the regular kind of episodic visits that health professionals typically schedule. Visualisations, of course, cannot stand in for frequent visits to health professionals, but they can serve as valuable information about a patient's experience between visits. Moreover, while tracking data related to chronic pain on a daily basis may draw attention to the condition, externalizing the experience of pain has been shown to have therapeutic value. In addition, the correlations that patients may discover that relate to their pain, may also provide them with a greater sense of agency and potentially less hopelessness.

Significantly, an artistic approach to the graphics such as the one articulated here may evoke affective senses that numerical representations do not, yet the graphic *simultaneously* maintains the comparability of time and the integrity of the data set. Similarly, the abstract nature of the graphic is open to symbolic interpretation—as a life cycle or as an iris of the eye, for two possible examples—even though each data point can be 'read' with some degree of comparative precision. Moreover, transforming numerical data into aesthetically interesting graphics may move the information from its overt scientific allusions to more accessible and potentially personal ones. In this way, an artistic approach of this kind can be said to lie squarely in the realm of patient-centred design.

3.3 Operation and data abstraction

3.3.1. Representation

The power of activity data as represented in information visualisation stems, to a considerable

degree, from the ability to take raw data from the *FitBit* in the form of numbers, and present it visually in a graphic again—that is, represent it—in a different way, with the aim of informing patients with more desirable, intuitively comprehensible information, omitting a potentially unnecessary 'reading' process required of numerical data.

The data we want to present concerns activity levels collected from the *FitBit*, which are numerical integers starting from 0 and given out according to the users' activity level. The complexity of the data is in two dimensions, composed of both the log data attributes and the time being recorded. We encoded the quantitative values in a color transparency. We also established a mapping route of position and time in this circular graphic, expressing the activity level using color.

3.3.2. Presentation

In terms of how the presentation could be displayed, we initially offered the method as shown in Figure 3.1. However, it was clear that this arrangement of data would be unwieldy after one week. Therefore, we tried another approach, as seen in Figure 3.2. Here, a month of data containing physical activity data from a *FitBit* was analysed and arranged in this graphic. We used *Processing* (programming software) to process the raw data from the *FitBit*. We then filtered the data by extracting the activity data every five minutes, created a timing arrangement rule in the algorithm and finally generated the graphic in Figure 3.2.

In figure 3.2, each ring represents a day, and starts on the top at 12:00am. The time is arranged clockwise and like a clock, covers a whole day. The ring is divided into equal slots of 5 minutes. We mapped the activity level with the brightness of the colour in each slots, the brighter the slot, the more the person was active. As one would expect, the time between 12:00am and roughly 9:00am—typical time for sleep—is less bright. Most of us move during sleep, but the data represented here suggests that 'quality sleep' inferred by the *FitBit* data only occurs from about 1:00am to 4:00am for most of the month. A strong sleep disturbance consistently appears at 6:00am.

By referring to this graphic, patients can trace their activity levels and compare fluctuations during a specific time period. Moreover, they can discover aspects of their activity pattern by comparing different time slots in the same graphic. They could also have the opportunity to focus more on how to change their schedules to achieve more positive ways to better control their pain. The aesthetic value of the Life Cycle is that it transforms data related to pain and activity, implying that their painful experiences may be potentially more

manageable and a possible source for an increased sense of agency and motivation.

Figure 3.1: Sketch map of pain data circular flow graph

Figure 3.2: The Life Cycle: Visualisation of physical activity data over a month long period of time

3.3.3. Interaction

To further assist patients in developing a greater understanding of their bodily conditions, patients may hover the mouse or cursor over particular area, then zoom in or zoom out to see specific information on certain dates. In the zoomed-in display, the graphic will show detailed physical activity information in response to the mouse movement in a rollover window. In this case, the original data is preserved and the interactive display makes an abstract graphic more readable at overall and detailed levels.

4. TRANSFORMATION: FROM ELECTRONIC ARTS TO PAIN EXPRESSIONS

Having an outlet for expression that is not based on text can be therapeutic, as suggested by art therapy methods for treating chronic pain, along with similar methods developed by pain physicians (Gardner-Nix 2009). With this in mind, we visualized standardized pain characteristics using

animations of an abstracted jellyfish. We plan to integrate physiological data that correlates to affect, as gathered from biosensors, to make these visual animations more interactive in a physiological sense.

4.1 Motivation for use of visualisation

Unlike a broken arm, chronic pain cannot be seen or easily detected, as it often lacks easily recognisable physical indicators or measurable biomarkers. In addition, few people are aware of this newly identified disease. Therefore, many patients are misunderstood, not believed, or even unwittingly stigmatized by their family doctors, colleagues, friends and/or family (Gatchel *et al.* 2007).

Although several pain assessment tools have been developed and implemented, they require patients to rate their pain numerically, such as the Brief Pain Inventory (BPI), or to adopt specified verbal descriptors of pain, such as the MPQ. For instance, in healthcare contexts in North America, patients usually use the MPQ and the short form MPQ (SF-MPQ) to indicate where their pain is located; they also circle 'pain descriptors' – words about the quality and intensity of pain. The SF-MPQ consists of 11 sensory terms (sharp, shooting, and so on), and four affective, verbal descriptors (sickening, fearful, and so on). The patient is also usually asked to rate the intensity of pain related to each descriptor on a scale from 0 (none) to 3 (severe).

4.2 Design method and metaphor

To represent the various qualities of pain using animation, the morphological behaviours of an abstracted jellyfish were chosen. Ancient Greeks used jellyfish as a pain metaphor; physicians also had jellyfish sting patients who had persistent pain in an attempt to raise their pain tolerance. The abstracted jellyfish can convey different pain attributes through colour, movements and behaviour. In the animation (Figure 4.1), six of the most standard pain descriptors from the MPQ were chosen: throbbing, shooting, stabbing, burning, itching and aching. These six types were selected because they provide a basis for visualizing pain sensations, and thereby expressing invisible pain through animation, and because the six types were the terms most frequently used by patients.

4.3 Operation and data abstraction

4.3.1. Representation

Movements of the abstracted jellyfish from its top, side and bottom views are used to convey six characteristics of pain. These animations do not include representations of a human body or even common iconic drawings of a face, as it may be easier for patients to tease out the characteristics

of the pain they experience from other aspects, such as where the pain seems to be located (a complicated proposition since pain is often 'referred' or felt elsewhere), how the pain varies over time, or what positions or movements exacerbate their pain. The abstract jellyfish's movement and distinctions of colour and size form a composite—an abstract visualisation that helps patients to articulate the character of their pain to others. This specificity is often important for diagnostic and pain management purposes. As well, it may be useful for professionals who work with chronic pain patients to have a deeper understanding of a patient's experience through comparatively quicker means than the descriptors alone.

The data we present relates to various aspects of chronic pain that are provided by patients and categorized by the MSQ. Although these descriptors have proven to be useful and well-understood by healthcare workers (and less so by patients), we plan to test the effectiveness of our animations to see if they augment the textual descriptors or provide richer aspects of pain. We encoded the differing characteristics of pain into color, movement, point of view and size, as well as the speed of the animation.

4.3.2. Presentation

We incorporate the visual behaviours of the abstracted jellyfish movement to evoke specific characteristics of pain. Transforming the attributes of pain into an animation was accomplished, in part, from interviews with patients. Patients could describe the character of their pain to others by referring to certain movements of a jellyfish. Since the development, evolution and progress of pain, as well as its character, are communicated to health care professionals and other people, the animation may help patients to better express and share what is otherwise invisible—their experience of relentless pain. Thus, by demonstrating certain aspects of pain through the animation, including its aesthetics, greater voice may be available to the many patients who suffer in silence, and thereby transforming pain, if only to a modest degree.

4.3.3. Interaction

Biosensors build the connection between patients and the movement of the abstract jellyfish. Biosensors also offer a method to quantify or 'color' certain kinds of qualitative and verbal reporting data. Patients can first identify their physical sensation from the pain descriptor classifications, and then observe and change the animation to mirror their pain as closely as possible. Patients then further contribute to what the abstracted jellyfish looks like and how it moves by manipulating their own biopsychosocial state, as captured by biosensors. Current work focuses on

refining the kind of affective information that various kinds of biosensors can reliably provide beyond the current GSR (galvanic skin response) and HRV (heart rate variability) sensors.

Figure 4.1: Jellyfish Chronic Pain Metaphors: expressions of differing qualities of pain

5. CONCLUSION

The two visualisations convey the transformation idea between electronic art and pain. We highlight the potential of abstract visualisations to make available what is otherwise an invisible experience that is often discounted by uninformed others—persistent and chronic pain. Two cases are explored: (1) transformation of pain data via electronic art that enables patients to gain both general and specific feedback of their physical activity levels over discrete and longitudinal periods of time, and a way for patients to find potential correlations between their pain levels and activity patterns; and (2) transformation from electronic art to pain expressions provide patients, health care professionals and the public with potentially greater access to the biopsychosocial dimensions of chronic pain.

As we envisioned, drawing on approaches from electronic art and visualisation enables patients to better understand and express themselves. Tools designed with this approach may enhance the efficacy of communication among health care professionals and patients who live with chronic pain.

The visualisations of long-term activity data and pain expression have the potential to be generalized and utilized in daily life as well as in managing chronic pain. These visualisations may ease tension and fear if they are used to inform patients before challenging medical procedures or treatment with individual generated graphics. Most importantly, they may help to manage persistent pain and other chronic health conditions with visual feedback. The visualisations may also improve communication among medical staff, family, and perhaps the public with chronic pain patients.

However, the effectiveness of our visualisations and animations for chronic pain patients' specific health outcomes requires ongoing evaluation. In our future work, we plan to conduct user studies with relatively large numbers of chronic pain patients: to see if the life cycle visualisation can help motivate greater activity and to determine if patients indeed find useful correlations between their pain levels and activity patterns, and the jellyfish animations to determine how useful this graphic will be in helping patients specify pain attributes, and to what extent. After gaining insight of their feedback, we will then implement several iterations if appropriate, and subsequently test and refine the design of those transformations. More far-ranging studies of interest include asking patients and healthcare professionals to compare the more standard, numerical kinds of representations of information that relates to pain with the aesthetically attentive approach typified in the work described in this paper.

Given that pain is notoriously difficult to communicate and represent, the qualitative and individual nature of suffering from pain, the sheer numbers of people who increasingly live with chronic pain, the need to address ways of managing chronic pain, and that chronic pain is widely studied in biopsychosocial terms, we believe that the arts have a promising role to play for those who treat chronic pain patients and for those who live in pain.

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