Acute pain is sexy and chronic pain is not: representations, language and transformation.

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Abstract

This chapter explores interdisciplinary thinking about pain and its relation to language as a complex, layered sociocultural and historically gendered communication. It argues that the relationship between pain and language is one that merits further work and offers potential therapeutic value for the field of pain studies. To do this, it uses an reflexive and creative feminist approach, a form of prospective *bricolage* or DIY, drawing on a range of interdisciplinary information. It considers broad contexts of the world-views or belief systems (ontology) within which ideas about pain are located in Western culture from patient and healthcare professionals perspectives. It discuses the physiology of how pain works and how pain relieving drugs function as well as how language works as pain experience communication. Exploring how the languages and images of pain are constructed, it comments on echoes and parallels with historical and traditional representations to conscious thought processes and individual identity. Thus, the section on the physiology of pain explores triggers and draws on mind-body connections indicating evidence of how changing brain patterns and thought processes can affect and might therefore also help modify pain for some people.

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Introduction:

I experience intermittent chronic pain and this has been the starting point for this chapter. A feminist academic with a background in Art History and French, I am a reader of visual and verbal languages; I work part time with Social Sciences (Education) and with Medical Humanities and I also work as a complementary therapist and medical herbalist, with patients and their narratives. Pain, like any object of scrutiny has a wider context, presented and influenced by environments intersected by time, place and culture. Acute and chronic pain, their physiology and representations are complex and layered. That is to say they are always expressed and listened to through particular frameworks, or ways of thinking about bodies, health and illness. Good health and care are a fundamental human rights and Western bio-medicine challenges indigenous or traditional methods economically and with the power of its promises.

In the UK the different genders, ethic identities and indeed languages of different patients requires a critical, personalised and self-referential approach for two main reasons. The first is that reflective self-critical examination offers a healthy political starting point for any consideration of something of which one is a part. The second is that both biomedicine and biomedical perspectives are themselves Western cultural products. My background presents a mixed interdisciplinary lens employing Western critical and cultural constructions. It does not assume to speak for other individuals, nor other cultures. That is not to say that some of this may not applicable in other cultures but it is to say that not all of it can be. Meaning-making and the representations of pain are different not only across different cultures but operate differently for different individuals within the broader environment of the dominant medical culture. Thus, the ways in which people talk about their pain and that of others is influenced by cultural contexts and beliefs about pain, its relationships to physiology and the role of traditional pain relieving medicines of the past. These roles and experiences intersect with patient and personal roles and identities through the national, individual, local and familial cultures of which these roles and identities are formed. I believe and hope positioning the approach employed here can facilitate some adaptable principles for working with pain where these resonate.

Questions emerging from starting to write and think about this chapter: *What is pain? Is it a thing, an experience or a communication? Is pain an 'it' when 'it' is experienced? What about agency? What changes the experience? Why does something like pain have such a different set of cultural references relating to whether it is acute or chronic? As an experience, why do we use one word for something that feels different for different people? Do different types of experiences correlate with different forms of illness? Can diagnosis differentiate? How can the experience be communicated?* As I began to collect my materials, I considered the contexts for them and the shape this chapter might take.

My immediate questions about the nature of pain indicate how easy it is to make 'a thing' out of pain rather than to consider the experience or the process of experience. Yet, any translation of sensation or experience into language is precisely that; a translation. Indeed, just as language and metaphors translate pain experiences into communications, none of these things are neutral or separable from the contexts that give rise to them. So this chapter explores these questions from linguistic perspectives, considering the ways in which meaning is made and how aspects of interpretation, translation, metaphor and intertextual communications operate as aspects of visual and verbal languages. This facilitates a discussion of how and why some patients make and use pain metaphors to describe how we feel and indeed, whether language might therefore carry the potential for changing experience. It aims to contribute in a small way to clinical skills for medical and nursing education that promises improved listening and linguistic capacity and offers a framework of underpinnings from language-based perspectives.

Contexts and methods

Pain is sexist, demonstrating a gender gap with more women than men experiencing chronic pain, research in which more studies are carried out on men than women, and treatment where pain in women is taken less seriously, involves longer waiting times and greater variability (Fenton 2016). Gender variations in treatment speak not only of societal and cultural attitudes but also its lack of correction in health and medical education (Bendelow, 2000). Such embedded bias drives the need for a creative feminist approach here, influenced in particular by the works of Luce Irigaray[1] and Julia Kristeva[2].

The title of this chapter refers to a substantive Western cultural history of sado-masochism that conflates images of sexual desire with acute pain, considering why it can be considered sexy, while images and discourses of chronic pain are largely hidden, rarely visible, ignored, causative of illness and disability, misunderstood, often shameful. The reference is deliberate because considering a complex multifaceted issue demands a complex multifaceted approach, with sustainable grounding in reviewing and recycling information. Employing a qualitative perspective reflects the tensions between the quantitative measures associated with medical sciences versus the lived lives of patients. Employing investigative humanities approaches with a nod to social sciences engages with the ontological processes of truth in relation to being and experience, evocative of cultural pain constructions[3]. That is to say, the chapter draws on a range of interdisciplinary information and lenses, discussing, abstracting, presenting and reworking arguments in its seeking and framing of questions and answers[4].

The lived lives and real-life identities, the inhabited spaces, scenes and situations and the role-based performances of various actors are social constructs[5]. They are widely variable with a wide range of socio-cultural (ethnicity, class, gender), personal and familial identity-based intersections. It is some time since the work of Michel Foucault (1963) illuminated the inherent institutional power dynamics of patient/professional/institutional relationships, and their impact on individuals and framing of health. These very different worlds meet and become entangled in complex, layered illness experiences. With a further nod to Claude Lévi-Strauss and Jacques Derrida, the individual, complex psychosocial and personalized nature of chronic pain is therefore reflected through the use of applied critical theory in the form of a creative and adapted feminist *bricolage*, a form of purposive DIY[6].

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[1] I am indebted to Irigaray in my thinking for ideas about objectification and mirroring from her PhD work through to those on difference, visibility and phenomenology in relation to othering, and those on shared breath in her later work.

[2] Amongst others, I am indebted to Kristeva's work on relationships in clinical encounters.

[3] Discussion draws on art history and language based critical theory.

[4] Pain as an experience is a phenomenon that presents existential questions. As a linguistic construction, methods from structuralism to post modernism including feminism can employ deconstruction and discourse analysis to demonstrate and challenge institutional practices and equity issues.

[5] The chapter also therefore draws pragmatically and more generally on social theory throughout although with the emphasis on a linguistic and humanities focus. It is also influenced by Bakhtin and dialogic feminism in its consideration of voice and language.

[6] See Levi Strauss for *bricolage* and Derrida's critique '*La structure, le signe et le jeu dans le discours des sciences humaines'* published in *L'écriture et la difference.* The same volume contains Derrida's critique of Foucault on the *cogito*.

All of this talk about pain takes place within the wider contexts of what we believe and think about our lives and our bodies. The underlying assumption that as human beings we all have bodies and bodies get ill and that particular illnesses requires treatment in much the same ways is a singular biological perspective that has successfully underpinned and driven Western medicine forwards for a hundred years or more. The dominance of the biomedical model of healthcare and illness sits behind huge population health and treatment improvements, especially from national perspectives (Wade and Halligan, 2004). This is the model whose 'seductive disruptive technologies' currently hold power in the relationship between professionals and patients (Greenhalgh, 2001, p. 39). Awareness of its limitations has been slowly growing especially with reference to the psychosocial and relational factors of illness, accepted for some time in health psychology and complementary therapies (Engel 1989; Sheridan and Radmacher 1992; Wade and Halligan 2004). Tensions of the shift from a singular biomedical worldview to pluralist biopsychosocial models of care align with patient demands and economics[7]. Economics and patient-centred approaches to healthcare in the current NHS form the framework for training interventions to improve communication problems between healthcare professionals focused on illness and disease management on the one hand and patients and their lives on the other (Dwamena, F. *et al*, 2012). Parallel systemic tensions between conflict and collaboration operate on the level of singular versus plural worldviews or belief systems between biomedicine on the one hand and disciplines within the humanities and social sciences including psychology on the other.

Experiences, sensations and consciousness

This section considers that if pain is a body experience in time, its persistence over time is both complex and multidimensional and culturally related to the ontological experience of being in a body.

Pain is a sensation that is translated, discussed and exhibited through methods of communication, in visual and verbal languages as well as in body expressions and postures with a good degree of recognizable specificity (Walsh, Eccleston, and Keogh, 2014). By its very nature, as Joanna Bourke (2014:17) has brilliantly argued, pain is not an independent agent nor an ontological entity and is better read as an event, being "chronologically flexibly and culturally complex". For Elaine Scarry (1995), it is ultimately inexpressible, something we communicate and also frequently interpreted as something that communicates to us. In discussion with my 13yr old son about the peculiarities of having a single word describing sensations that range from headaches to injuries, I asked him what he thought pain was. It's "a construct" is what he said and from every perspective but especially from a linguistic one, this is important. 'Pain' is an

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[7] Gradual recognition that Virchow's model of cellular abnormality does not underpin all models of illness led to the World Health Organization's (2001) biopsychosocial international reclassification of health and disability. While this embraces a model less pathology-led and less biologically reliant, from a sociocultural perspective, it still assumes an equality between what is experienced (subjective) and what is observed (physical and pathological). It does not consider cultural and gender characteristics that for pain, in particular, could from lay socio-cultural perspectives, be demonstrable as inequitable discriminatory practice.

undeniably broad term, a word for a sensation or experience with a periodicity that is individually and culturally constructed through communication into meaning, subject to a wide range of influences and linked in time and space to a body. Its meanings therefore are also communications (with a not inconsiderable power) that can in turn become themselves taken on, embodied, even affecting sensations.

Acute and chronic are standardized medical definitions, the former being usually sudden and always self-limiting, meaning it will resolve in time and the latter being persistent over time and longer term; three months or more. As a felt experience, pain can be viewed as a communication from another entity: the embodied mind. As a sensation pain has a seeming fluidity that suggests its more verbal nature yet it commonly masquerades as a noun, perhaps to ensure its cultural importance, or because of it (Bourke, 2014)[8]. Whether short or longer term, pain occurs as a result of something and as this sort of signifier it represents the past (whether finite or continuous) in the present. The appearance of pain has always been associated with imbalance or something wrong (although historically it has been reified and transformed into a spiritual gift, a promise of a better time in another world) and therefore a conundrum requiring detection, diagnosis and treatment, usually medical or spiritual.

Like other phantom sensations, pain can be experienced when part of the body, such as a limb, is missing. Conversely, it cannot exist without an act of thinking or cognition and arguably one of ‘re-cognition’ (a linguistic pun on ‘communicating-to-self’ that is important for physiological mechanisms discussed below). Whether pain exists in a body without a conscious mind is a contemporary debate that goes back to the philosophical divisions of mind and body derived from 16th Century Cartesian dualism[9]. Yet the deductive philosophical processes congruent with contemporary scientific and mathematic rationalism that form the basis Western thinking and biomedicine today, may be based upon misunderstandings or misreading of divisions of body and mind as separate (different) rather than as materially different entities[10].

The idea that pain is something that makes us human is commonly to be found through a UK internet search in a series 20th and 21st Century ‘feel-good’ inspirational quotes and on the Huffington Post Blog (Pandit Dasa 12/05/2011). Such references to particular sorts of pain and pain narratives raise questions of consciousness that are especially relevant at this current time. As new and applied technologies change the information and perspectives on debates about sentient animals, so we start to question what we know about communication, intelligence and consciousness. Technological advances have lead to changes in understanding embryotic development and therefore also our knowledge

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[8] For a discussion of the reification of pain, see Bourke’s introductory chapter.

[9] Descartes’ (1596-1650) *cogito* (‘I think, therefore I am’) answers the question of ‘how can I know that I exist’ and places knowledge and understanding of the world within a subjective independent mind.

[10] Descartes discusses the cogito and elaborates on understandings and misunderstandings in letters to Princess Elisabeth of Bohemia (see Shapiro, 2007).

about when a fetus feels pain. Thus, new technologies change both our knowledge and our thinking about consciousness and also what we believe about pain being felt.

Historical perceptions blend physical and psychological pain as concepts underpinned by common cultural metaphors resulting in a range of narratives. Broadly speaking pain is to be endured (stoicism); overcome or conquered (heroics); it destroys (victim) or it makes you grow and/or question life's purpose (transformation). The common inference that pain is punishment and that life is hard in the West, derives particularly from Christian ideologies, although pain and suffering are similarly constructed in many religions, sometimes with the idea that suffering is the cognitive recognition of pain (Bourke 2014; Dedeli and Kaptan 2013). For Aristotle in Classical Greece from which much Western cultural thought derives, pain was an emotion in opposition to pleasure; experienced in relation to living a moral ethics of behaviour. This position indicates a fusing of mind and body at odds with Cartesian mind/body dualism and the concept of a mechanistic body.

Yet, while pain may be a reminder of the vulnerability of the body for many (and sometimes of our separation from it), the idea of a humanizing or learning benefit to pain is also, rightly a romanticised and offensive concept. For example in her analysis of womens holocaust texts, Loew (2013) discusses how as a holocaust survivor, Beuber-Neumann would argue precisely the opposite and that in her experience of the camps an excess of pain removes individual and collective human rights. The context of persecution, war and genocide changes perception yet the cultural weight of the affluent contemporary Western world, is to turn pain into something else. So, while there is also nothing romantic about chronic pain, yet culturally the texts associated with pain, present out of body experiences as a means of escape or creativity, a point taken up below.

The arguments that I have made so far in support of altering perceptions of pain suggest that other management strategies will work for some people. This suggestion is strengthened by research in one field showing that for chronic pain patients, having a belief system or spirituality is both an important adaptive and also a negative cognitive and behavioural strategy for dealing with pain management (Dedeli and Kaptan 2013). Reviewing the literature, the same research highlights a number of pain and spirituality experiments including the positive influence of meditation practices and neurological processing differences in brain imagery when viewing religious images. It argues the need for healthcare professionals to incorporate understandings of patients' beliefs, attitudes and their spiritual identity or way of life for more effective healthcare and the importance of a biopsychosocial approach to pain.

Physiology

Broadly speaking when the body experiences pain it goes into fight or flight mode. This sympathetic nervous system (SNS) survival mechanism response is a body's 'something dangerous is happening' reaction, when the heart pumps faster, airways widen, muscles contract, ready to flee and everything unnecessary for surviving the immediate context shuts down. The adrenal medulla releases acetylcholine, activating and releasing the fast acting hormones adrenaline (epinephedrine) and noraderenaline and slower, longer acting glucocorticoids. This response to chemicals released in the body affects all organs, operating numerous changes at cellular and systemetic levels, for example as glucose for energy is released in response to particular stimuli.

The parasympathetic nervous system switches off the sympathetic allowing the body to "rest and digest" and return to normal balance (homeostasis)[11]. In long term or chronic circumstances such as stress, it simply doesn't switch off, or as recent anesthesia research has started to show, it doesn't all switch off (Neukirchen and Kienbaum 2008)[12]. Chronic or persistent release of slower-acting glucocorticoid stress hormones puts health at risk with multifaceted stress implications for auto-immune conditions (Stojanovich and Marisavljevich, 2008). Since fight or flight is designed to be a short-term solution to protect the body, prolonged episodes lead to symptoms ranging from sleep disorders, blood pressure and digestive problems with further serious health implications.

And yet, short-term bursts of adrenaline are actually extremely good for us, especially when we can switch off and relax afterwards. Adventure sports, positive emotions such as excitement, and orgasm all trigger similar chemical signaling (Komisaruk, Beyer-Flores and Whipple (2008). So, in fact the immediate physiology of acute pain (which self-resolves) is the same as that of orgasm but more importantly for a culture that is visually based[13], acute pain *looks* exactly like orgasm. Deadly nightshade (*Atropa belladonna*) is a medicinal herb traditionally used since ancient times for pain relief whose phytochemical constituents (scopolamines, atropine alkaloids) act on the central nervous system. It gets its name (*belladonna* or 'beautiful lady') from its use by women during the Renaissance to make their pupils widen attractively (as if in orgasm).

Sex, death, consciousness, knowledge and altered states of consciousness are inextricably connected in the cultural history of pain and pain relieving drugs and like the rest of Western culture the herbs traditionally employed are embedded with gender sterotypes, myths and stories (Carter, 1996). *Hyoscyamus niger* (henbane) also in the nightshade family (*Solanaceae*) is another poisonous plant traditionally associated with witches, flying and sexualised out of body experiences[14]. Most anaesthetics work to inhibit the messaging system of the sympathetic nervous system or on the cardio vascular system

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[11] The sympathetic nervous system (fight or flight) is part of the self balancing Autonomic nervous system that includes the parasympathetic nervous system (rest and digest) and the relatively recently discovered enteric nervous system (the 2-way communication system known as the brain gut).

[12] Some treatment for pain relief is similar if milder to anesthesia, brings about a loss of consciousness by depressing the central nervous system although exact mechanisms are theoretical (Lambert, 2011).

[13] The fact that "the way that we think in Western Culture is guided by a visual paradigm" has a consciously conceptual history and been recognized for some time (Jenks, 1995: 1). Work by John Berger and later by a range of feminists demonstrate the general non-neutrality of the eye, a further contributor to tensions between the rule of measure (as that which is perceptible by the senses) and the reality of lived lives.

[14] Other members of this family (tomatoes, strawberries, peppers, potatoes) are often implicated in allergic reactions.

(Neukirchen and Kienbaum 2008). Main biomedical and herbal pain relieving drugs (analgesics) act chemically either to inhibit or suppress the Sympathetic Nervous System or to excite and stimulate the Parasympathetic. Many of these were historically used in mainstream medicine as anaesthetics. Most are considered poisons, associated with loss of consciousness and causing death in large doses and some with spiritual and shamanic work or inspiring creativity in low doses[15]. The opium poppy used for pain relief by Ancient civilisations expanded as a vast market by the East India Company across continents. The use of laudanum[16], led to the creation of morphine, the strongest analgesic today and its derivative heroin. The dominance and spread of opium-based drugs has led to an individual cultural history associated with contemporary visual culture, while addiction is known to have a neurological basis in the brain conflated with medicinal applications (Hickman, 2010; Robinson and Berridge, 1993).

David, Jacques-Louis (1748-1825). *Death of Socrates (1787).* Metropolitan Museum of Art, New York. Catharine Lorillard Wolfe Collection, Wolfe Fund, 1931

The nervous system being part of the wider neuro-endocrine system hints at the inseparable relationship between chemical messaging and consciousness and between pain and perception as thought. The death of Socrates as recounted by Plato and subsequently represented by David and other artists, presents this correlation between nervous system paralysis, living consciousness and death[17]. Socrates choice of hemlock (*conium maculatum*), commensurate with his moral stance, enabled the philosopher to engage in a unique examination of the transition between life and death for the purpose of knowledge. Ironically, as health professionals will be well aware, SOCRATES (site, onset, character, radiating, alleviating, time, exacerbating, severity) is the mnemonic for the main pain assessment framework learned in case-taking skills[18].

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[15] In the EU and UK unsafe plants are subject to a range of prohibitions and restrictions, and like other pharmaceuticals available only through prescription by qualified practitioners and subject to maximum dosage regulation (https://www.gov.uk/government/publications/list-of-banned-or-restricted-herbal-ingredients-for-medicinal-use/banned-and-restricted-herbal-ingredients).

[16] Laudanum is tincture of opium. Authors and poets use is exoticised and associated with Thomas de Quincy and Samuel Taylor Coleridge amongst others.

[17] David's Neoclassical style, the composition and Socrates dramatic pose reference leadership in individual moral choices when the State is unjust, in pre-revolutionary France. Socrates upward pointing finger indicates his engagement with moral ethics and emphasises the action of the poison, from the legs upwards.

[18] https://www.medistudents.com/en/learning/osce-skills/other-skills/patient-history-taking/

The persistence of chronic pain causes a wide and variable range of health problems and pathology but individual responses and effects vary enormously in reaction to complex contributory stimuli or triggers: pain, fear, work-related stress and a wide range of psychological and emotional stressors through to physical ones such as lack of food, water or extreme temperature changes. The psychosocial nature of some of these triggers is backed up by evidence for the success of cognitive-behaviourally informed treatment (CBT) such as research confirming confidence in the positive effects of psychological interventions in chronic low back pain[19], as well as by practice-based evidence (Morley Williams and Hussain, 2008).

Similarly, research using a variety of methodologies has demonstrated the effective use of mindfulness as a chronic pain management strategy in different ages groups (Kabat-Zinn 1982; Kabat-Zinn, Lipworth and Burney 1985; Morone, Greco and Weiner 2008; Zeidan, Gordon, Merchant and Goolkasian 2010). These practices demonstrate that changing thought patterns and changing thinking have positive outcomes for pain. Changing the story is another way if changing thinking.

Languages of Pain: narrative

We make sense of our world by telling stories about it constructed through visual and verbal languages. Narratives, elements of the form (shape) and content of language all offer diagnostic and transformative potential; the potential for changing the whole system that is an individual, their pain, illness, experience, identity and lived life.

From his experience as a doctor and then as a patient, Arthur Frank (1995: 1) discusses the ways in which illness interrupts an individual's life story, constituting not only "a loss of destination and map" but also a change of identity, of potential alienation, and the necessity of generating a new narrative as a way of "thinking differently". Frank's work identifies four broad types of story: restitution, chaos, quest narratives and testimony[20].

Restitution refers to the belief in bodies as mechanisms that can be fixed, repaired or cured. Required by the biomedical disease model of medicine (the system central to today's marketization of healthcare) it forms the main narrative and is promoted through images of cured, happy and clean patients. It organizes compliance. The promise of restitution sits behind the social control model of institutional healthcare offering cure, sometimes in relation to affordability. However, while it manufactures a performance of 'being ill' that works for some or may function for a while, it does not represent the experience of being ill. Instead it mythologizes illness as a temporary blip in the project of restoration to a previously healthy state. A lack of patient agency is required by a system that projects expertise and responsibility for one person's body onto an other (as

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[19] See Hoffman, Papas, Chatkoff and Kerns's (2007) meta-analysis of randomized controlled trials (RCTs) on this subject.

[20] Biomedical and legal institutions and cultures identifying positive masculine traits embed patriarchal and paternalist language frameworks and values.

though an individual has already left it). The patients reality is distanced through an objectification of the sick body by the medical gaze or increasingly today, by the alienating technological gaze of internal diagnoses (Foucault cited in Greenhalgh, 2001). The model generates a split from self and current experience that mirrors the narrative disassociation in the patient's body and mind, depending on an imaginary future located in previously embodied knowledge. Frank discusses its power (many patients become better, many healthcare professionals and patients are heroic) and limitations (when its viability runs out there is nothing to fall back on; commodification and affordability; increasing desperation and continuing search for cure when there is none). In terms of life experience and timelines, its dependence on projecting the past into the future future means that living in the moment as a conscious act cedes place and there is a potential void, since when restitution is no longer viable, everyday life is fiction.

The chaos narrative is presented as a metaphor of a hole that cannot be sutured, where the body is in decline and cannot be repaired, the point where narrative does not flow, becoming anti-narrative without sequence or conscious reflective grasp that enables the telling. This is a space where the tidy timeline proposed by the restitution narrative is no longer valid, where telling, listening and hearing become difficult. There is a loss of time, of control, of life and of the making sense of life with knock on effects such as financial and other difficulties.

I am struck by the difference between two close friends who have been unexpectedly diagnosed with cancer this year, attending the same hospital. One whose cancer has been removed sees her successful treatment as a positive experience. Treatment was very structured, extremely painful, with everyone being very helpful (a restitution narrative). The other friend has struggled with appalling experiences (a litany of chaos) with each diagnosis being worse than could ever be expected. Notes and appointments were missing from the computer. The cancer grew during chemotherapy, treatment plans had to be abandoned, reinvented. Trying to make sense of the colliding worlds is hugely difficult, indeed surreal. She is not in pain. Her specialist nurse didn't compute that her illness is terminal, has never accompanied her and cannot seem to talk to her. It would be easy to say this was down to individual characters. However, from non-scientific observations while attending clinics with both friends, I believe this is about communication and relational challenges with one presenting a high potential for cure and a rapid terminal diagnosis, and the other where the mainstream sympathy model simply doesn't fit – what is there to say.

Perhaps unsurprisingly given the cultural contexts discussed earlier in the chapter, conscious knowledge in the form of gaining or learning from the experience rather than recovery sits at the heart of the quest narrative[21]. For Frank, this is represented by the story of Neitzche's "dog", the invented name for his pain, which created a new relational understanding. For me the typology of quest sits at odds and from a feminist standpoint Franks narrative typologies of quest, heroic and testament (a word that literally references the history of women's exclusion from legal status as swearing by the testes) are

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[21] See Death of Socrates (above).

problematic here and require revision, especially on account of the patient/healthcare professional power dynamics already in play[22]. Journey narratives are not always quests, a notion that is philosophically and culturally loaded (Patterson, 1993).

For Frank, testimony frames a different set of roles and responsibilities. Still related to narrative, he defines it as a pedagogy of suffering taught through illness stories to healthcare students, related to medical ethics and clinical relationship education. Stories of embodied being simply are. Bearing living witness as a communicative body also offers value to caregivers and as guides to others in overwhelm. Framing it as a narrative ethics in relation to the effect of stories on our lives, it is also a social ethic in response to illness that foregrounds vulnerability and pain. Indeed, citing Charon it is one that has much to teach about the coherence, conflict and complexity of difficult moral and ethical decisions.

Such narrative typologies are given further sociological context in Deborah Lupton's (2012) work, which considers realities from lay perspectives of collapsing social worlds, physical changes from medical treatments such as radical surgery, the messiness of decaying and dying bodies, sexual challenges in disruptive disabilities, and the labour of maintaining daily life engagement amid embodied cancer crises. Meanwhile from the professional perspective, bringing illness events together to form a coherent narrative in the patient's lifeworld (a sociological concept) is also form of labour, a cultural brokerage undertaken by healthcare professionals. Lupton cites Reeve *et al*'s 2010 research establishing the centrality of emotional and embodied contexts for the formation of narrative and articulation of illness experience (Lupton 2012, p. 90). These are the links that create cohesion in maintaining, recreating and reforming patients identities.

In language terms there is a chicken and egg question about whether the thought or the language comes first. This is a useful starting point for thinking about pain sensations, identities and various experiments that have been done on pain's social aspect – whether it exists if it has never been felt - that leads at one extreme into the theoretical/practical impasse of the possible non-existence of pain. Pain is, of course just a name and a 'catch all' one at that, since it describes sensations with physical, emotional or spiritual origins and visible and invisible sources. The etymology of the word 'pain' from the old French *peine* – or suffering, identifies it as something thought of as part of the human condition that was abstracted for religious purposes and that therefore retains an enormous cultural history of religious and moral overtones[23]. Bourke (2014) discusses representations including pain personified, where images depict small demons inflicting pain. The loss of agency accompanying such narratives on pain as being something that is done to someone, imply the patient's helplessness or loss of agency. Since chronic pain, like

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[22] See Brownmiller, Susan (1975). Against Our Will: Men, Women and Rape. New York: Simon and Schuster

[23] In French, one is in pain, or can cause pain, which can also read as distress. Being in pain is a state that can be physical, emotional, spiritual, diffuse (suffering, distress, annoyance) or specific (also *mal*, sore, hurt).

illness disrupts an individual’s life narrative, this loss of agency is mirrored by the loss of agency in taking on the role of a patient, within the power dynamic of the clinic.

Thus we create narratives that frame our identities and consciousness about ourselves and the world in which we live (the chicken and egg relationship). We also recreate them and use language to do this but we can employ more conscious and creative ways of doing this.

On health and discussing body mind and soul relationships, Descartes letters to Elisabeth of Bohemia suggest that family difficulties may have affected her health (these included Charles 1st as her uncle, financial crises and more immediate sibling and familial problems). Her reply looks to the wider issues of her place in the world; it is more likely to be her emotional susceptibility being female (a gender issue) which she employs as a way of exploring rational embodied differences (Shapiro, 1999). Frank’s narratives group recognizable internalised patterns in relation to institutional, individual, and patient roles (stoic, pessimistic and optimistic; compliant, abandoned, taking control) but also it seems to me, represent stages of illness experiences and relationships, being as much typologies as chronologies, defining and creating stories and identities bound by illness. Sensitive storying the narrative of illness is therefore one way of considering wider challenges, of grieving, letting go and of changing what we think and know about situations. Art therapy, drama therapy, psychotherapy, creative collage, creative writing and guided meditation, for example, offer patients ways of creating new and changing worlds. Such narratives creatively encourage other realities supporting changes in identity constructs.

Languages of Pain, Form: communication, intertexts and agency

We do not tell stories in a vacuum, we do it to communicate.

Patient research necessarily places the patient first, a wholly appropriate and institutionalised form of ethics. Yet the language that the patient speaks is completely subordinate to and changed by the clinical setting. A communication is one thing when written as spoken, but a case history recorded, is already an interpreted text. Utterances can take the form of narratives, verbalized and non-verbalized responses to questions, prompts, silences and reactions to clinical examination. The clinician who is usually not themselves in pain and represents answers and solutions to the pain experienced, has particular frameworks for categorizing pain, a range of other diagnostic possibilities (including technological versions of a patient’s body unreadable to themself) and therefore power over what is examined, asked, spoken and elicited. Thus the consultation or clinic inscribes a context where what is said is interpreted under time constraints by someone with incredible power. Thus critically, the way a patient describes their pain may in fact say more about the context or their experience than it does about pain but how that is understood says more about the person listening and their breadth of reference.

Since patients describe pain (both differently and similarly) through language and metaphors, it is both useful and appropriate to value and develop the use of critical art and literature-based disciplines more in health and particularly in health research. Such disciplines have developed a range of expert theoretical perspectives and understandings of the ways in which words and images function and the networked plurality of meanings produced by reading. They offer broad and complex micro- and macro-level readings of historical and cultural linguistic entanglement, and, embedded as they are with Western Culture, such readings open space for other readings and cultures.

Thus communications in a clinical context can be seen not only as a performance of roles but also as a process of bringing things together to fit by the reader of the text, a system of defining and refining. Julia Kristeva (1969), the French language theorist has called this plurality of cross-referencing “intertexuality”. Her work is particularly useful and relevant for pain narratives as she is a psychoanalyst, primarily referring therefore to communication between analyst and analysand, a positioning that parallels the different therapeutic context of patient and clinician. It is, of course not so simple as this. The lineage of intertexual process of interaction and meaning-making recognized (if not by the same name) and charged with dynamic power relations from Plato’s (*Ion*) onwards, referring to the interdependence of imitation onwards is more fully discussed in Worton and Still’s introduction to *Intertexuality*.

It is in its detailed forensic work on narrative form that Rita Charon’s (2006) Narrative medicine comes into its own. Her work honours patients and their stories in a way that is very different to institutional or consumer-led management of patient experience. It is her own experience in general medical practice and the importance of narrative that sits behind her innovative work in the US and that of Brian Hurwitz and Trish Greenhalgh in the UK (1998). My experience of attending her teaching seminars is above all one of attention to detail that sparks multiple outcomes, all driven by improving care for patients in ways that matter to them and to healthcare professionals as people. Aimed to improve the close listening skills of healthcare and medical professionals, narrative-based analyses (across multiple media) highlight language and narrative patterns; turning points, changes in structure, shape, meter and direction.

Close listening educates the listener to hear better, to gain nuanced understanding of a case, to find out what matters to a patient and to better support and honour what they are going through. Patterns, emphasis and turning points in patient narratives present what they believe about their illness, what is entangled with it and sometimes what they feel has or will help effect change. Since the patient is the embodied expert, noticing and exploring such beliefs not only honours this expertise but also brings the patient’s conscious attention to what they are saying and this can often effect a transformative experience. Most importantly it repositions the healthcare professional in respect of the patients life, rather than their illness. As stories are individual, this form of healing demands a different approach to care, one taught through narrative (Charon, 2006).

Detailed listening practices in small groups also enabled safe spaces for professional and personal reflection, nurturing resilience by supporting an interface that is often ignored. Healthcare professionals talked through resonances and reverberations from stories and poems of critical incidents, personal feelings, aspects of their own illnesses and those of loved ones; things they had not had time to fully process and that fed professional practice. Supporting the intersection of professional and personal identities involves opening the heart and this enables working with compassion towards self and others.

Understandings of how text and language work as underpinned by the philosophical and psycho-critical French linguistic critical traditions offer further depth in reading the processes of communication, interpretation and diagnostic narrative.

The aim of communication is to share or tell someone something. But if pain is a communication, then who is talking and to whom? Consider for the moment that the sensory experience of pain is a communication from the body. Just as there is an aspect of communication, there also is one of translation, and of form, in the speaking and voicing of pain. This is even more so when it comes to detailing what this sensation is or ‘feels like’. The ‘is’ of pain is therefore an embodied communication, an individual’s conscious recognition of the sensation, as it were, indivisible from an existential process, event and from its being-in-time. Much of my work as a therapist involves a process of decoding what my patients are telling me. A large percentage ‘know’ in the telling of pain or illness what they are saying but have not brought it into conscious awareness and processed whatever needs to be done so as to change the story or the metaphor. Working in this way is highly individual.

Some years ago a young female patient came to see me for complementary therapy. She was undergoing cancer treatment at a local hospital. Her narrative was fragmented and emerged over time. She had difficult feelings towards her young son. She was frightened and felt guilty that she didn’t or couldn’t love him. Elements of her story included passions and uncertainty in her married life, financial worries, a change of identity and career that had come too soon, fear of not being a good mother and complete terror about her illness and how to cope. She was very young. Her son was under school age and she didn’t have much support. Her illness had meant she was easily tired, emotionally out of sorts and could not do all the things she wanted to do. She felt she was a terrible mother. She was terrified and very unhappy; enormous feelings of guilt created a block that left her unable to digest and make sense of all of her other emotions. She felt she no longer knew who she was. Her dreams were full of disembodiment, unhappiness, absence and drifting. Gradually adding these into a detailed timeline alongside the case history of symptoms and diagnoses revealed that her cancer had probably developed during pregnancy, something that is not uncommon. Seeing the guilt block in the context of the illness timeline made sense of her emotions and this started a process of talking and changing things. The process was interrupted when she had to move but she found an excellent psychotherapist and was able to work through and recover her identity. Not all stories resolve so clearly but today, she is happy in her family life, loves her son and is fully recovered from cancer.

I have chosen this example of working with communication because it takes different forms and although it is about an illness, it involved chronic pain. The patient intuitively knew (as many patients do) what was happening in her life. The elements of the narrative involved short stories about everyday and wider life events (social, personal, familial, professional), updates and processing of this over time; symptoms of pain and aspects of her illness, diagnosis and treatment; sensations and emotions; metaphors and dream stories, as well as my observations of gaps, silences, emphases, descriptions, linguistic parallels and questions checking I understood or eliciting more. She needed space to be heard and help in making sense of everything, in seeing patterns, a process of listening and reflecting. Above all, she did not need interpretation, which would have further removed agency over her narrative and caused potential damage. Her emotions held the key and what she couldn't say came through in dreams. Regaining agency over her story and attending to the emotions was necessary for full recovery to take place.

Languages of Pain, Content: codes, images and metaphors

As a sensed experience pain verbalises a wide range of sensations that can have physical, emotional or even spiritual origins. One means of communicating a felt sensation is to translate it into something meaningful or recognisable to others using a culturally shared or meaningful image. In this process it may be personified so that it is given agency, it becomes that which actively produces the sensation or it may be represented as a causative agency outside of the body (such as the small torturing devils historically associated with Western Religious pain Culture, Bourke 2014) or given specific meaning by being allied to another sensation or all of these.

Neitzche's transformation of his pain into a dog is creative and transformative in that it changes the shape of pain (a reification!). However, Neitsche is looking for something to vent his mood and this pain accompanies him everywhere (it literally and figuratively dogs his steps), as does his mood. This strategy enables him to use communication to change the relationship and gain embodied understanding but because he makes the pain into a dog, it has a certain will of its own too, appearing as and when it wishes. Making communication possible enables a generation of agency that is more complex that it would seem since it works both for the pain and for Neitzche. It is not by chance that Frank cites Neitzche, since his more modern ideas on emotions, pain and cognitive states are in dialogue with Classical Greek philosophy and Socratic concepts of pain as an emotive state within a moral ethics of consciousness.

Serendipitously in the summer, a Greek taxi driver taking me to the airport was a qualified teacher of Classical Greek and Latin who was unable in the current economic climate to find a teaching position. He confirmed the pragmatic etymology of the word '*metaphor*' as a very literal form of 'trans-fer' or carrying across of something. Thus he moved a cigarette package across the dashboard to demonstrate how he was literally taking me from one place to another (meta-phor). In language the use of metaphor is a particular effect. In language it is a way of taking something from one place to another to better express, define or communicate what is meant by something else. But language is not neutral. So, the meaning that is carried across is of course, environmentally (culturally, socially, geographically etc) mediated as a linguistic or visual language and potentially within an embodied experience. So language often functions as a signpost indicating something that cannot be fully expressed. In the example of my patient above, the content and sensations in her dreams combined in retelling with her feelings, to give clues to terrifying emotions she could not speak about, let alone feel. She was a shadow, a pale outline, wandering through empty houses. She was grieving, she was terrified and above all her ghostly image represented how frightened she was of dying.

Dr Arthur Kleinman (1988) is a psychiatrist and anthropologist who reads illness and pain within wider social and cultural contexts of promises, expectations and operational realities. Since "several"…of the stories and experiences of chronic pain patients he has had are "so similar" he creates the fictional case of Antigone Paget, an amalgam of patients, as an exemplar of wider frustrations of life lived within cultural and traditional social expectations (pp.88-99). Through this case and others he describes patterns of illness in relation to realities of life and lack of agency and choice with particular sensitivity to class and gender intersections.

Antigone Paget's chronic pain is "sharp, hot, aching, tight, nagging, punishing", the result of a car accident, is located in a "large lump of muscles, nerves and tendons bunched together" that goes into excruciating spasm (Kleinman 1988: pp.89;90). Self-descriptions of obedience, being stiff necked, crucified relate this pain in her back to an inner pain, a buried hurt related to the frustration of desire in the absence of a fulfilling life. Leaving her family, she is stuck in an impasse mediated by pain, familial and economic conflict. Like all cases, the detail of the language and the events in this semi-invented narrative are too complex to reproduce, interrogate and elaborate on here; they are more rich and complex than writing can present but the narrative work lies in listening through the patterns of entanglement and a negated possibility of opening up, to a painful choice that the patient is ultimately unable to resolve. Kleinman uses the story to indicate the need for a doctor's work to include bearing witness, to argue for treatment of physical and emotional pain, for emotional therapeutic work of grieving and remoralisation. Thus for Antigone Paget, this is a struggle for freedom, self-actualisation and fulfillment literally tied up (bunched) by gender-based obligations and personal and professional frustration in the face of societal expectations. Indeed, the particular values of sociology as a means of exploring sexism inherent in chronic pain and gender intersections is given further weight in Bendelow's (2000) empirical research. Kleinman moves with compassion and empathy between close detailed listening and empathetic broad societal understandings in which to locate and work with embodied narratives, especially those that relate to chronicity.

Becoming a knowledgeable listener requires compassionate listening, practice, patience and observation. Words embedded in the content of a story hold clues and aspects of something that needs to be decoded but it is decoding their relevance for the teller that is important, of sitting and sharing breath as human beings in the consultation.

Such clues to embodied emotions are often different in different cultures and pertain to different parts of the body – indigestion is, in French, a liver crisis whose pains can be burning or sharp, for example. Some cultures have words and phrases that describe mental/emotional experiences as physical harm to the body. An extreme example of this is someone who is 'heart broken' or who describes feeling 'a knife turning in my heart'; while stomach ache can be 'gut rot', or an unpleasant experience something that 'turned my stomach' or left a 'sour taste'. We can also be sick and tired of everything, 'fit for the knackers yard' or feel we have 'a burden to bear". IN each case it is the meaning these hold for the patient that is key. A number of metaphors commonly describe pain sensations and these are enormously important to patients but less so to doctors as they not specific enough to correlate diagnostically and may even be referred to a different part of the body. Pins, needles, knives and blades are sharp, slice, stick and prick. Pain eats, bores gnaws. Other more individual images and metaphors hold clues for patient emotions, so clearly they are medically important in a wider embodied world view than the narrow traditional biomedical paradigm with which this chapter began.

Indeed, Candace Pert's (1997) cutting edge 'pyschoneuroimmunbiological' research on mind-body cellular communication has demonstrated that the emotions communicate with the immune system via neuropeptides (known to mediate behavior and mood) and their receptors. Like drugs, emotions generate ligands attaching to receptors that act to shape our memories and thinking; they simultaneously activate circuits creating a "constellation of body changes that occurs with each shift of subjective feeling" (Pert, 1997, p.145). This changed her thinking as a scientist and has a range of implications that run countercurrent to the biomedical paradigm. She indicates that we must take responsibility for how we feel, for our food and physical exercise and be proactive in our healthy habits. Living by what we believe is an ethical habit, typified by Socrates.

Thus, incredibly, modern scientific knowledge is starting to confirm some general Ancient Classical and also Eastern understandings of what we call embodiment. Current research into pain and emotions sits at the intersection of modern and ancient knowledge and consciousness of what embodied understandings of being human means, pain and its treatment in Western healthcare provision and other treatments that offer relief. With a caveat from the socio-cultural mainstream that removing pain is "often unattainable…[and that] it is important to realize that not all 'pain treatments' are equally efficacious, and that questions must be asked regarding specificity—'which therapies, for which patients, and for what purposes?' (Tunks, Bellissimo and Roy, 1990), there is much that can be achieved through narrative diagnosis and medicine to support people with chronic pain.

Conclusion - diaries are written to be read…

A word, an image, a piece of written or spoken text is a communication in a visual or verbal language. Narrative comes from the Latin, *narrare* to tell, while the text, *texere* to weave, is the result or product of the telling that emerges from processes of meaning making. It has arguably no meaning without someone producing it and someone else or even the same person enacting, looking, reading or listening to it. Relationally dependent, it also has a special relationship with time and with philosophy and specifically, as its reality depends on its being experienced, with an existential view of reality (within a time and experience-based ideology of worldviews), thus with perception and beliefs about the world. The success of CBT and mindfulness therapies in the management of chronic pain indicates the potential that changing thought processes has for changing pain experiences. Since experiences are communicated through language, it follows that changing language has the potential for changing the experience.

Meaning exists during reading on a range of levels in different times and places, through the way that words and images work. It is at once individual and communal and never neutral. Each person engaged in the process of meaning-making employs culturally mediated conscious and unconscious references. Questions around whether meaning or language came first, or whether thinking can happen without language, lead back to centuries of discussion. Language offers the potential for transforming chronic pain in individually different and complex ways working together with patients and stories that necessitate care-ful attention, detailed listening, attention to patterns of form, metaphor, symbols and emotions; and wider understandings of the attitudes, limits and restrictions of the society in which we live.

> *A sharp agonizing burst of pain on the right and my leg, paralysed, gave way. Bewildered, I simply didn't know what was going on. I assumed it was temporary and indeed it was. Yet while temporary and at first occasional, it gradually became more frequent. I saw the GP and would try and describe how my leg gave way because of the pain; already I felt it was in charge of me, dictating what I could and couldn't do. This pain is different from a deeper ache in my hips that comes sometimes at night, waking me from sleep. That pain gives me time to think, to meditate, consider my path. I have learned quite a bit about how my body has been changing. I have learned with my head about gender gaps and silences and I have learned by listening to my body what makes this pain better and worse, when it is likely to happen and how I can work with it. I focus on joy. I avoid tiredness. I am at a crossroads and I have time to think. As I listen and begin to work with my body, both kinds of pain come less often; or as communication increases, 'complaints' lessen. X-rays show arthritis and osteoporosis.*

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