Morbid Mixtures: hybridity, pain and transnational dying

Abstract

Three stories about diseased and dying migrants in the United Kingdom are at the heart of this paper. Working with these narratives, I investigate the neurobiological, subjective and sociocultural entanglements of disease, pain and dying and the challenges these hybridisations present for attempts to recognise and alleviate suffering. My aim is to show the differential workings of hybridising forces with regard to assumed correspondences and time, as well as the indeterminate and liminal states of subjective experience that disease can amplify. The paper engages with the growing literature on 'social pain' and suggests that social pain is the mortar rather than merely a reflection of the affects and neurology of transnational migrations, loss and social violation.

Keywords:

Bodies, care, ethics, migrants, neurology, temporality.

In the early stages of an on-going project, I sent out a call through palliative care networks in the UK, for stories about transnational dying and care. The first story that I received came from

Errol, a music therapist, who described his work with Tony, a Rastafarian and migrant from Jamaica. Tony was in his late sixties and was nearing the end of his life in an urban hospice (all names are pseudonyms). Errol explained how Tony 'on the basis of his beliefs, had refused conventional cancer treatment such as chemotherapy and radiotherapy' and 'was adamant that he did not wish any opiates or western medical painkillers'. When Errol met him for the first time - taking a tambourine, a guitar and a small hand drum to the single-bedded room - Tony was writhing in 'silent agony' in his bed. Errol continued

I immediately began playing the guitar trying to match the intensity of his movements and mood with the intention of providing a musical focus that called his attention to the music and away from the pain. Upon hearing this, Tony responded by indicating he wanted the hand drum. For the next hour the sound of improvised rhythmic grooves, Reggae rhythms and various Bob Marley songs could be heard to the delight of staff, floating down the ward as Tony, who proved to be a consummate drummer, played himself into a state of musical transcendence - music, used therapeutically had helped him tap into his own resources of pain management. The session ended and Tony asked for the drum to be left.

As I exited, promising to return the following day, he thanked me and smiled saying he felt better..."more like me old self".

There was a similar event of shared musical improvisation the next day with Tony's release from pain through music. Because it was a Friday, Errol left the instruments with Tony for the weekend. On his return to the hospice on Monday, a nurse told him that Tony had died on Sunday morning, peacefully and without pain. He had spent much of the previous day singing and playing the drums with his family and friends.

Errol's story opens up three crucial matters for my discussion of hybridity at the migrant deathbed in the UK. First, there is the underlying mixing that characterises transnational dying

and involves the crossing of two simultaneous thresholds, the movement across territories and the phenomenological transition from life to death (Gunaratnam 2012). Second, there is pain as a knot or 'hybrid object' (see Luckhurst 2002; 2010); an experience that in hospice care is known through the physiological and the psycho-social, and has been produced in its journeying across conceptual, diagnostic and disciplinary borders. As I will elaborate, the hospice and palliative care philosophy of 'total pain' is entirely entangled as an impure biopsycho-social mutant. It is open in its ontology to the disjunctures and transitions of experience that disease, pain and suffering can instigate and manifest; both a 'contradictory simultaneity' of subjectivity, to use Michelle Bastian's phrase (2011), and indeterminacy. Third, is the polyvalent nature and states of pain, and pain relief, in the story that bring out implicit assumptions about relations of correspondence (or homology, see the Introduction to this issue), transaction and intra-action (Barad 2007) between the bio and the socio-cultural that, as I discuss later, have been taken up in the neuroscience investigation of 'social pain'.

Taking into account these different forms and strata of mixing, I approach hybridity as an idea that names the trouble that is caused by the crossing of boundaries (Nederveen Pieterse 2001). I also make use of Homi Bhabha's work on the potential of hybridity to confect an indeterminate 'Third Space' of relating (2004; 1996; 1998). In Bhabha's Third Space, the discontinuous temporality and tension between the subject of a proposition and the subject of an enunciation, injects ambivalence into the translation and interpretation of meaning, so that 'The meaning of an utterance is quite literally neither the one or the other' (Bhabha 1994/2004, p.53). Rather than Bhabha's focus on the discursivity of the Third Space that can install opportunities for cultural symbols to be 'appropriated, translated, rehistoricized and read anew' (p.55), I am also interested in the material and affective states and events of pain and disease.

In bringing together anthropological and ontological approaches to liminality, Paul Stenner and Eduardo Moreno (2013) offer some possibilities for thinking about the creativity of such occasions. Stenner and Moreno's is an empirically driven account of decisions about organ donation at the chaotic times of sudden death and grief in Spain. These are marginal times and places, marked by a breakdown and crisis in the social; everything is up in the air, events unfurl unpredictably, moment-by-moment; decisions could go either way. Three crucial and intersecting layers of this rich analysis are relevant to hybridity at times of transnational and debilitated dying, when the borders between the socio-cultural, the body and affect, the present and the past can produce nested transitional states. First, there is the insistence from Stenner and Moreno of holding together event and structure. This accompanies a Whiteheadian reading of affect as liminality, described as 'threshold experiences of transition between states, structures and patterns' (p.10). Second, by resisting the structure/event separation - seen as characterising affect theory (for example Massumi 2002) - novel possibilities are opened up for affectivity that is not herded into corners by structure or is entirely feral and asubjective in its intensive flows. And third, the attention given to the socio-cultural infusing of life's transitional moments (van Gennep 1960) gives value, history and context to participant concerns. For Stenner and Moreno, giving simultaneous attention to event and structure makes room for an appreciation of concrete occasions of affect and the contradictory potential of liminal experiences to replenish and disrupt the social

A concept of liminality can ...help us to articulate a genuinely process oriented approach capable of integrating affect and discourse-oriented tendencies by addressing structure and event as analytically distinguishable but empirically always related aspects of process. (p.10-1)

What is intriguing, but less clear is the temporal dimensions of liminality. A superficial rendering of liminal states and terms such as 'transition' can imply a fleeting and progressive temporality to the in-betweenness of the liminal. Such a reading is not at odds with Van Gennep's (1960) rites of passage as constituted by the three phases of separation, transition and incorporation. The arrow of time flies forward, the flux of transition can be absorbed by social life. This tacit temporalisation is something that I want to investigate further both in

relation to disease and pain and the unidirectionality of linear time in the social science hybridity literature: phenomena and processes come together and blend in ways that cannot be undone or reversed. Through a discussion of two further stories that capture some of the relays between cultural inscriptions and the diseased body I want to consider the potential for a certain reversibility or folding back of the blended, through which biographical as well as neurological histories of slow violation (see Berlant 2007; Nixon 2011) can make an appearance. Might the reggae music and drumming alleviate Tony's pain because it corresponds to unfolding intersubjective and material experiencing and at the same time retains or makes resonant socioneural connections from a prior time and place, perhaps centuries old?

My discussion will draw upon examples from two main bodies of empirical work (i) an ongoing British Academy Fellowship project involving research in the Cicely Saunders Archive at King's College (London) on the development of total pain and the collection of stories and art related to transnational dying; (ii) narrative interviews with dying migrants and practitioners from my previous projects (see Author forthcoming for full methodological details). A common strand across these different endeavours has been my interest in narratives and stories in oral, written and artistic forms as performative 'processual, action based approaches to social reality' (Abbott 1992, p.430). Stories, for me, convey and produce experience; they are agentic in the sense that they disclose usually implicit thinking about how the world works (Greenhouse 1996).

Service provision, technology and migration patterns have changed over the nearly twenty years that I have been involved in palliative care. When I first began my research there were few racially minoritised professionals, such as Errol - a Black British Caribbean man - working in hospices; digital death, e-memory and inheritance were not end of life predicaments (Walter et al. 2011); and market-oriented health care reforms that the World Bank began promoting in 1993 were in their infancy (Lister 2013). These changing institutional, technological and global circumstances are significant in the ways that they manufacture varying channels and occasions for the rearranging of experience for dying people, their family and friends, and care practitioners. Despite these reconfigurations, the problem of understanding and responding to another's pain and symptoms remains an enduring challenge. Let me now return to that hospice bedroom to flesh out the matters of hybridisation that concern me.

Hybridity and total pain in palliative care

In addition to the cultural mixedness of reggae in Errol's story, where the music has been a

cipher for social discontents and suffering¹, there is the hybridity of pain that resists what David Morris (1993) calls the modern 'Myth of two pains'; the dividing of pain into the physical and the subjective, mirroring a Cartesian mind/body cleaving (see also Bendelow & Williams 1995a; 1995b). Pain in the account is physical, but is alleviated, or in Errol's words 'transcended', by the acoustic and kinetic energies of music working through the affective 'hinge' of the subjectivities and bodies of the two men (Csordas 2008). As soon as Errol enters Tony's room, he uses his guitar to mirror and join with the tempo of Tony's painful writhing. It is a rhythmic response, further augmented by Tony's drumming; drumming can be a

meditative/spiritual practice for some Rastafarians, transcending consciousness². These sensual rhythms and transfer seem to bring Tony some relief or distraction from pain, without pharmaceutical drugs, but in ways that remain empirically ambiguous (see Igawa-Silva et al. 2007).

It could be that Tony's pain is more than disease related, incorporating 'social pain', described in palliative care and in the neurosciences as pain caused by the loss of close relationships. Neuroscience research suggests that there is structural correspondence between physical and social pain in their sharing of the same somatosensory substrates (Eisenberger 2012; Eisenberger et al. 2003; Kross et al. 2011). The studies using neuroimaging technologies and

controlled experiments (most often with functional MRI) visualise brain activity in real time. They show that two regions of the brain - the dorsal anterior cingulate cortex and the anterior insula - are both involved in the experience of physical and social pain. The finding of a correspondence in the neurocircuitry of pain has been seen as having practical and ethical implications - should social pain at the end of life be relieved through medication, for example? Should patients with symptoms of physical pain also be given psychotherapeutic interventions? As yet, the research does not tell us about the meaning, events or history of pain in an individual's life. In other words, there are discussions to be had about the psycho-social impacts of pain and the neurological correspondences through which pain can appear (pain as an experience and pain as a sensation). It is one thing to recognise how the same part of the brain can light up in a fMRI scan when a person's thumb is held in a vice and when they are excluded in a computer simulated game of catch (Eisenberger et al. 2003). It is something quite different to exist in a situation of social marginalisation outside the laboratory and to live in an unpredictable relation with racism and the threat of other violations. This is not to suggest that neuronal pathways are socially illiterate (Wilson 1999), but that the alliances between the bio and socio-cultural have yet to deciphered.

If we move our focus from this intimate contact and towards the institutional setting of the hospice where music and art psychotherapy are a part of day-to-day care, we meet other fusions. As Nederveen Pieterse (2001) points out, cultural hybridity has a long history, with relatively less attention being given to hybridisation in the 'thematization of mixing as a discourse and perspective' (p.222), such as in the bringing together of ideas and literatures from different disciplines by psychoanalysis. Thematic hybridity is the hallmark of the contemporary hospice movement and its philosophy of 'total pain', developed by Cicely Saunders in the 1950s and 1960s, and owing much to Saunders' disciplinary border crossings: she was a Philosophy, Economics and Politics student at Oxford, turned nurse, social worker and then doctor in London. Saunders' success in inspiring the new specialty of palliative medicine owes much to her abilities in bringing together a wide range of interests and technologies that included theology, clinical pharmacology, *anaesthesiology*, survey and qualitative research, the new pain clinics, the Tavistock Institute's psychoanalytic work on loss,

and public concerns about end of life care in hospitals³.

Total pain unsettles the Cartesian mind/body divide in recognising pain as physical, spiritual, psychological and social (see Clark 2000). This holding together of multiple constituents and *loci* of pain characterised Cicely Saunders' research with dying patients, that began at St Joseph's hospice in the East End of London in the 1960s; a hospice that included Irish and Eastern European Jewish migrants (Winslow & Clark 2005). In addition to Saunders' extensive clinical trialling of pain relieving drugs, she was a doctor who carried a tape recorder. She used patient stories (as well as their artwork and poetry) to deepen her understanding of the subjective experience of disease, pain and dying and in her campaigning work to improve end of life care (Saunders & Clark 2006). The patient in Saunders' research and writing is a person with a social and emotional biography and relationships. She is also a flesh and blood body of skin, bones, blood, hormones and neuro-transmitters.

What is especially interesting about the total pain concept is that despite its name it is not really totalising. It does not assume either a 'flat ontology' (DeLanda 2002), where there is a givenness of democratic correspondence between entities, or unidirectional relationships between, for example, the neurochemical and the social, or the past and the present. What is more, total pain (ideally speaking) is open to the recessive qualities and differential and interbleeding temporalities and relationships between painful phenomena that can defy rationalist scientific knowledge and neurochemical management (see Author 2012). Recognition of a withdrawnness and/or indeterminacy to subjective and bodily experiencing means that a person's pain could well be categorised diagnostically and treated symptom by symptom so that pain relief is effective. But this intelligibility of pain is necessarily tenuous; there can

always be an excess to scupper or to slip unnoticed past bio-medical surveillance and management.

This openness to the ontology of pain and to the insufficiencies of scientific knowledge in total pain was supplemented by a commitment to the emotional accompaniment of patients - 'being there' as Saunders so often put it - especially when attempts at analgesic pain relief failed, as they still often do (see Moore et al. 2013). And although empathic and intersubjective connection was advocated as a goal of care, its achievement was by no means assumed. So a certain vulnerability and uncertainty was recognised as part of a caring response (see Saunders 1980, p.8). In such circumstances the work of *trying* to understand a patient's experience was advocated and valued, and the failures of care were acknowledged as part of a vigilant ethical care-taking. In an article first published in 1963 on 'The Treatment of Intractable Pain in Terminal Cancer', Saunders wrote

I once asked a patient who knew that he was dying what he wanted to see in the people who were looking after him. His answer, 'for someone to look as if they are trying to understand me'...It is indeed hard to understand another person but I always remember that he said 'trying'. He did not ask for success but only that someone should care to make the effort. (2006/1963, p.64)

If we draw our focus outwards yet again from Tony's bedside and the institutional environment, we encounter the material, cultural and spectral traces of transnational migration. The UK's post-war migrants are now ageing and dying in greater numbers (Lievesley 2010), so that their need for end-of-life care is increasing, leading to more discussions and initiatives on 'culturally competent' palliative care (see Evans et al. 2012). There is a tendency in cultural competence policy initiatives and training resources to see culturalist knowledge, either naturalised in shared ethnicity/faith or gained through training - as a means to the end of responsive, bespoke care (Author, 2008); a sort of intersubjective capital. This tendency is at odds with the day-to-day experience of caregivers that often attests to how the organic effects of disease and the trauma of past violation can intertwine and accrue in migrant and racially minoritised bodies, disrupting the typifications of culturalist schema that assume synchronous relationships between cultural typologies and behaviours (Author, forthcoming).

There are numerous examples in Saunders' research records that include references to how the trauma of war and concentration camps could return at the end of life. In an undated lecture entitled 'The Problem Patient' based upon hospice patients she had cared for between 1978-9, Saunders described a Polish patient, a Mrs P 'A patient with an extermination camp background who later developed severe depression with hallucinations, helped by E.C.T.' (*Electroconvulsive Therapy*). Saunders also observed that as some patients neared the end of their lives 'they sometimes had recurrent nightmares, reliving traumatic experiences of past lives such as war and internment'. Similar phenomena have been reported more recently by Swedish nurses caring for refugees and the survivors of concentration camps, where trauma has re-surfaced with the mundane practices and instruments of care, such as the administering of oxygen masks and injections, requiring increased sensitivity in physical care giving (see Ekblad et al. 2000)⁴.

The belatedness and the excessive haunting of past injustices as continually disturbing the synchrony of intersubjective relationships is a theme in the writing of postcolonial and feminist writers and scholars (Khanna 2003; Morrison 1992; Anim-Addo 2007; Cho 2008; de Alwis 2009; Karavanta 2013). It is a theme that I will pursue later in its interrelation with disease and tempos of violation that are relevant to thinking about what can characterise the hybridising and the indeterminacy of the co-implicatedness of the bio and the social at the end of a migrant's life. For the moment, using a case example of dementia, I want to further describe the hybridisations that can be instigated by disease, locating and highlighting the different elements within a 'psychosomatic economy' (Wilson 1999) that crosses continents and times.

'Her fingers still work the mala' : shifting times Harshini, an Indian migrant, who cares for her mother, At times there are great difficulties for us. Although she is here, in her mind she always thought that she was back home. She was always talking about India. She would wake up early in the morning and tell me "I'm going to the fields" and she would open the door and walk out and that was really scary. It happened a number of times that she had opened the door, walked out and got lost. On a

> couple of occasions we had to involve the police to find her. She had walked about two miles away from home. Then when I was away on holiday my brother took the decision to put her in to a care home... My mother, she was always a very religious person. Without fail she would go to the temple and would do the puja daily, and even today although she is not aware of what she is doing with her hands, without a mala her hands, her fingers are still working as if she is praying. And the other thing is that she was always very strict about food. Food was not allowed from outside, even bread. Now she doesn't know what she is fed on. She doesn't know what she is eating. She just eats whatever is given to her in the care home. She finds it hard to express herself and without the language she is totally in her own world, totally shut down. Day by day she is getting weaker.

Harshini's mother, a devout Hindu, has dementia - a non-specific syndrome with varying effects upon memory and sensory motor control, depending upon which part of the brain has been damaged. The disease has taken away her mother's memories, her awareness of the religious prescriptions that she lived by, and her self-consciousness. Harshini's mother can walk out of a house in Leicestershire to wander the fields surrounding a village in India that she left many years ago. Her fingers still work the mala 'as if she is praying'. The poet Novalis believed that prayer was 'to religion what thinking is to philosophy' (quoted in Heiler 1932, p.viii). Yet prayer in many traditions is the very emptying out of thought. It is a somatisation in and of itself, conveyed through the muscle memory of fingers, gestures, rhythms and comportment (see Hirschkind 2006). In Harshini's story, the affective and material traces of these other times, places and culturally honed sensorium intertwine with the changing

neurochemisty of the demented body, desiccating experience⁴.

As Rose and Abi-Rached (2013) argue, although increasing evidence suggests that neurological structures and processes are continually being altered by social and cultural contexts, we know little about this dynamic hybridising of biology and culture. What I find so provocative in thinking about the vital relationships between the bio and socio-cultural networks in Harshini's story is how the story touches upon usually implicit operations in the making and unmaking of correspondences (or homology) within mixing. Although there is mutual constitution, the spatio-temporal disruptions of migration within Harshini's mother's life, leaves traces of points of conjoining, perhaps even primacy, in the mishmash of psychobiology in dementia.

If we think about the homologous relations in Harshini's story, there is both distinctiveness and a blurring of varying states and processes of hybridisation. With eating within the institution of an English care home, the difference and boundaries between food that is religiously pure and that which is not, is a practice and a 'cultural time' (Edensor 2006) that is lost in the present for Harshini's mother. There are no boundaries one might say, with one type of food corresponding to and standing-in for another. With prayer, there is a continuum; the body seems to retain a cultural time and rhythm of the past in the compulsive passing of the (imagined) mala beads between the fingers, that perhaps was a practice that never relied upon rational/conscious thinking. And when Harshini's mother wanders out from her home in Leicestershire to enter the fields of her village in India there is a 1:1 correspondence in a spatiotemporal folding of a past into the present in her 'motility'; 'the way in which an individual appropriates what is possible in the domain of mobility and puts this potential to use for his or her activities' (Kaufmann 2000, p.37).

Multiple thresholds, rhythms and times are put into play simultaneously in real time, with Cartesian rifts opening up between the eloping mind and body, but where the body remains a

point of contact or metronome of variant bio-social rhythms (Lefebvre 2004)⁴. For Harshini's mother, cultural hybridisations seem to be selectively kindled, created and unzipped by disease, with continuums, some states and processes of mixture being created anew, whilst others are reversed or perhaps become cyclical⁵. And within these differential mixings and psychic disgorging are numerous liminalities, where Harshini's mother is not quite a Hindu, not quite in the present, not quite the mother that Harshini knew.

In the next case example I will continue to consider these coincidences between disease and embodied subjectivity, this time adding an analytic concern with gender and race violation. Through a brief consideration of ambiguous symptoms and aetiological uncertainty, I come back to another side of some the themes raised by Errol's story that surpass the immediate intersubjectivity of care-giving.

Slow pain: issues and tissues

Maxine had migrated to London from Jamaica in the 1960s, taking a series of low-paid, unskilled jobs; often shift work to fit around the care of her ten children. Her last job as a nursing auxiliary was the least precarious. What is important for this discussion is the ambivalence of Maxine's body throughout the story of her life. In our three interviews, she recalled several episodes of domestic and racist violence on the streets of South-East London, and talked about her intolerance of institutionalisation and the painful tests and procedures that she had to undergo during the diagnosis and treatment of her bladder cancer. When I visited Maxine, after she had been admitted into a hospice, she told me that she suspected that the nurses were racist. They did not seem to show her the same warmth and attention as the other five white British patients in her bay (at the time Maxine's hospice team was white, of varying ethnicities). Maxine did not tell the nurses about what she was feeling 'I never complain because I fed up you know, Dose girls no repec no black people. You have to fight for yourself.'

In the last two weeks of her life, Maxine's became more sensitized and unsettled. She was given new combinations and titrations of drugs to relieve her increasing pain and symptoms. Hypersensitivity, agitation and irascibility are not uncommon with advanced disease, when patients can have multiple physical and psychological symptoms and can be on a variety of drugs which carry the increased risk of adverse reactions (Chochinov & Brietbart 2009). Maxine became increasingly anxious when being touched and moved by her nurses. One day when she had been secured into a hoist that would elevate and then lower her into the warm soapy bubble bath that she loved, she refused to keep her hands tucked in as she had been instructed. The hoist, as it raised her off the ground, made her feel unsafe 'like a piece of meat.' Days after this incident, Maxine was refusing all hands-on care, despite personal hygiene and appearance being important to her. When she died she was unkempt and smelly.

Maxine's nurses were not unaware of her anxieties and had alerted their colleagues of the need to take greater care when lifting and moving her. There was a suggestion in her care team that she had 'paranoid ideas'. Paranoia is a clinical term in this context of use. It refers to agitation, mistrustfulness and irritability and can suggest possible underlying organic causes that require monitoring. As the psychiatrist and anti-colonial activist and scholar Franz Fanon (1986/1967) has recognised, living with any consciousness of racism is also to live in an uncertain and liminal state, a 'constellation of delirium, frequently bordering on the region of the pathological' (p.60).

Maxine had noticed some of the relationships between her body's intensifying sensitivities and her antipathy to the nurses 'It's worse...when I have very bad migraines' she told me after a story about how a nurse in the midst of responding to one of her questions had abandoned her abruptly when another patient had called out to her. Such interruptions are not uncommon in a busy ward and not by themselves evidence of racism. Nevertheless, how such events feel in the present, gather weight from their correspondence, resemblance and continuities with past experiences in the 'lifeworld' (Adam 2004). And with racism, as Sara Ahmed (2010) has insisted, there is always a certain amount of doubt about what you are sensing and feeling. Doubt is the seed of racism's paranoia and 'Our feelings become its truth' (p.84) Ahmed writes.

Racism's paranoia, socially produced and culturally variable, is not annexed from disease. Paranoia and anxiety at the end of life are part of a condition known as terminal restlessness. It can include *paranoid* psychosis or exacerbation of underlying and unrecognized confusion caused by medication (opioids, anti-seizure drugs, steroids and anxiolytics), decreased oxygen, dehydration or untreated physical pain (Dein 2003). The confluence between advancing disease, adverse reactions to psychotropic drugs and compromised renal and hepatic function can alter the biochemistry and neurology of the body in ways that are impossible to disentangle from past biographical experience and/or more habituated and evolving dispositions. And such dispositions are themselves enmeshed in neural pathways, giving empirical weight to the possibility that Elizabeth Wilson (1998) has raised that 'neurology may already enact and disseminate...malleability, politics, and difference...' (p.19). In other words, the care problematic includes responding to the neurological intimacy of racist and sexual violence and

trauma 6 within diseased somatosensory pathways.

When responding to the care needs of patients such as Maxine, practitioners must work with a succession of possible circuits of hybridisation and causes. Is that woman being difficult and pugnacious because of her disease? Is this how she normally is? Might her antipathy be a response to traumatic histories and events that have been overlooked? The critical problem in end of life care is how to make-sense when another's sensibility is corroding and in retreat. What are the varying tonalities and accords of biography, disease, medication, social violation and trauma?

The ontology of total pain recognises the complex mingling, indeterminacy and varying temporalities of such hypersensitivities, pain and distress. When a patient's life involves past violence and trauma, the goal of care is to explore, imagine and respond to such pain and not necessarily with language (see also Clough 2009). For example, massage is often used in palliative care to improve quality of life and to relieve pain and suffering (Wilkinson et al. 1999; Keir & Saling 2012). On-going multidisciplinary case review and 'Day After Death' meetings with relatives are also a part of most hospice care routines. The case reviews provide a forum for interrogating care practices as well as considering why a person's body might express itself in the way that it does. Doctors and nurses are usually the ones who take the lead in speculating about bio-medical conditions and aetiology. In matters of social differences it is social workers that are considered as having the greater expertise. In the following extract from a focus group, hospice social workers show how interpretations and care practices in cases similar to that of Maxine's, have to be created speculatively, moving backwards and forwards between the past and the present and quotidian institutional demands

Jo: I kind of wonder about black people who have been in this country for a while, who have experienced racism on and off throughout their lives, that it becomes a kind of automatic response to any situation where they're powerless, which you are if you're being lifted, um, it's very frightening because if your experience is that white people cannot be trusted with you when you're vulnerable (...) then I think, your levels of fear must be really quite high, and that maybe, one argument for that would be "Well then she's paranoid". Another argument would be "Well that means we have to be more careful". But we have to know that when, if we're a group of white people with a black person, that they might have a history about their relationship with white people, and we either acknowledge that or we deal with it in some way.

Jane: I think particularly when you're touching people, you know as nurses touch, and I think for black people who perhaps have never been touched by a white person, or only attacked, I think that must be particularly, particularly er, complex, you know, it really probably needs to be talked about really.

Jo: And I also think that if you work on a shift on a ward for thirty-five hours a week with these patients who are continually dying, that maybe all your top level of tolerance and patience, you know you're up to here with it (her hand goes to the top of her forehead) and then if you take a difficult patient on top-

Jane: Or somebody who lives too long-

Jo: Or somebody who lives too long, or somebody who nearly dies and then lives, and nearly dies, or something's the matter with them going home or not, or else a difficult family. I mean all that makes it difficult for them and which is also, you know, I think that maybe their tolerance levels can get quite low.

As the social workers suggest environment and temporal schema are very much a part of the 'problem' of the coextensiveness between biology and culture in care giving - in what are known as *co-morbid psychopathologies* - where bodily symptoms can carry and allude to traumatic histories that are latent, slow-moving and non-verbal. 'Even though pain is described by many as non-intentional, as not 'about' something' Sara Ahmed (2004) writes 'it is affected by objects of perception that gather as one's past bodily experience.' (p.25). At the same time this stirring of the past within the present can be differentially sedated, rearranged or rebounded into another orbit of abeyance by the evolving neurology of disease and its management - and all the time within the varying cultures, architectures and rhythms of care regimes and institutions. In Maxine's case, the latter also include the risk of 'diagnostic overshadowing', where symptoms are more likely to be misattributed if a patient is perceived as having mental health problems and/or is a black woman (Jones et al. 2008).

The undecidability of causes, events and affects in such occasions - that cannot be fully assimilated into culturalist schema, identity or diagnostic categories - brings out the variable temporal tapestry and pacing of pain throughout a body and a life. In Maxine's case, attunement to the extents of her suffering cannot rely upon the perceptible interactional hinge (Csordas 2008) that brought Tony some relief from his pain. The scattering of the affects/ effects of pain within institutions and across the bodies of different care professionals can be generative to the extent that it leaves behind affective residues (see Cho 2008) and interrupts routinised care practices. Yet, because embodied social suffering and its histories are often porous, unspoken and incoherent, the full extents and nature of pain can evade recognition or

be misrecognised⁶. Crucial matters here are how some expressions of pain become discernible and others do not; and what it means that social pain might go unrecognised, yet because of its intimacy with physiology, might be relieved (inadvertently) through biochemical interventions.

Diasporic neurologies

So far as the economy of the metropolitan country is concerned, migrant workers are immortal: immortal because continually interchangeable. They are not born: they are not brought up and they do not age: they do not get tired: they do not die. (Berger and Mohr 2010/1975, p.68) Debility, violence and a wearing away of all kinds, stand and lie at the meeting points between the mounting paradox of the global demand for healthy aspirational migrant workers and responsibilities for long term care and pain relief. John Berger has parodied capitalism's denial of the migrant worker's vulnerability and finitude. But as we know, migrants die. And our dying, I have suggested, can reveal the disjunctive temporalities and creative play of hybridisation that Homi Bhabha's 'Third Space' first elucidated. For the dying migrant, sociocultural and material forces are not only in constant relation, they can sometimes overwrite and variably loosen their hold over one another, producing novel effects and liminalities.

In effect, what I have been charting are intimate internal somatosensory migrations, mixings and re-arrangements - beneath the skin. These migrations reveal hidden border-crossings and the long-term, slow effects of the erosion and violation of migrant bodies that can be missed in the focus upon state borders (see Andrijasevic 2009). At the same time, there are the trails of the past in an indeterminate present - what George Herbert Mead has called 'the carrying on of relations' (1932, p.96) – that carry vital traces of the psycho-social history and the neurological 'writing' (Wilson 1999) of inequality and injustice into a body. In this regard, the dying diseased migrant is a figure that makes present past injustices. She undermines the 'happy hybridity' model of multicultural assimilation that treats hybridity as a commensurable and contemporaneous absorption of difference (Lo 2000). She would have us consider the creative and complicated ways in which diasporic forces are at work within and through the debilitated body.

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Notes

- The music that the men play is a blending of different traditions and historical resonances. Reggae as an expression of Rastafari, melds Jamaican folk, American R&B and jazz. It is a genre haunted by the violence and suffering of slavery (King et al. 2002), where music was both restorative and subversive in expressing pain, hope and defiance. Robert Hill (2010) writing about Bob Marley's 'Redemption Song' that weaves together the Atlantic slave trade with concerns about nuclear power and 'mental slavery'- suggests that the redemption that Marley commemorated is the 'work' of connectedness in the diaspora 'a product of dispersed networks of belonging that bind us as people.' (p.207).
- My hunch is that this was Niyabinghi drumming (played in 4/4 time on three drums) that is used to reach meditative states (see Davis & Simon 2003). For Deleuze (2003, p. 47) music is the spiritualization of the body.

When music sets up its sonorous systems and its polyvalent organ, the ear, it addresses itself to something very different from the material reality of bodies. It gives a disembodied and dematerialised body to the most spiritual of entities.

- Saunders' success in harnessing biomedical and public support for hospices can be understood through the five conditions that Bruno Latour (1986) has identified as being necessary for the translation of scientific concepts and findings: (i): 'mobilization of the world' where phenomena in the real world are translated into scientific discourse; (ii) autonomization, the professionalisation of a discipline with its own specialist knowledge base; (iii) alliances where external support is harnessed and enrolled; (iv) public representation that engages nonspecialist and lay audiences; and (v) the 'links and 'knots' of the scientific concept (total pain, for example) itself.
- Research in migration studies shows how time is rarely lived as sequential but can

encompass extremes, arriving in frenzied clusters, as discrete moments or can be stuck and drawn out, depending upon one's immigration status. Time for asylum seeks is often experienced as a limbo time (see Griffiths, Rogers and Anderson, 2012).

- Unlike those transitions that are accompanied by rites and rituals, the 'prolonged dwindling' (Lynn & Adamson 2003) that characterizes the trajectory of dementia infuses the event of the disease with a long-drawn out uncertainty for all those involved, including doctors. The slow progression of the disease elongates the transitions between health, illness, in/dependence and death, so that the affective state of living in uncertainty is one that does not seem as amenable to rites of passage.
- At the borders of the phenomenological, 'experiences of suffering are quasicontradictory experiences' Harrison writes 'in that they tend towards the limits of experience, towards the unexperienceable and irrecuperable.' (2007, p.595). Using trauma studies as her example, Claire Stocks has unearthed a cultural bias in the binary that is implicit in the ontology of the traumatised subject 'that juxtaposes the healthy, unified subject with a pathological, fractured self' (2007, pp.73–4). For Lauren Berlant (2001) trauma is ineloquence.

References

Abbott, A., 1992. From Causes to Events Notes on Narrative Positivism. *Sociological Methods & Research*, 20(4), pp.428–455.

Adam, B., 2004. Time, Cambridge: Polity.

Ahmed, S., 2004. The Cultural Politics of Emotion, Edinburgh University Press.

Ahmed, S., 2010. *The Promise of Happiness*, Durham and London: Duke University Press. De Alwis, M., 2009. "Disappearance" and "Displacement" in Sri Lanka. *Journal of Refugee Studies*, 22(3), pp.378–391.

Andrijasevic, R., 2009. Sex on the move: Gender, subjectivity and differential inclusion. *Subjectivity*, 29(1), pp.389–406.

Anim-Addo, J., 2007. *Touching the body: history, language and African-Caribbean women's writing*, London, UK: Mango Publishing.

Anon, 1980. Foreword. In *Care of the Dying*. London: Penguin Books Ltd, pp. 7–12. Barad, K.M., 2007. *Meeting the universe halfway: quantum physics and the entanglement of matter and meaning*, Durham, NC.: Duke University Press.

Bastian, M., 2011. the contradictory simultaneity of being with others: exploring concepts of time and community in the work of Gloria Anzaldúa. *Feminist Review*, 97(1), pp.151–167. Bendelow, G. & Williams, S., 1995. Pain and the Mind-Body Dualism: A Sociological Approach. *Body & Society*, 1(2), pp.83–103.

Bendelow, G.A. & Williams, S.J., 1995. Transcending the dualisms: towards a sociology of pain. *Sociology of Health & Illness*, 17(2), pp.139–165.

Berger, J. & Mohr, J., 2010. *A Seventh Man* 2nd ed., London and New York: Verso. Berlant, L., 2007. Slow Death (Sovereignty, Obesity, Lateral Agency). *Critical Inquiry*, 33(4), pp.754–780.

Berlant, L., 2001. Trauma and ineloquence. *Cultural Values*, 5(1), pp.41–58.

Bhabha, H.K., 1996. Culture's In-Between. In S. Hall & P. du Gay, eds. *Questions of Cultural Identity*. London: Sage Publications Ltd, pp. 53–60.

Bhabha, H.K., 1994. The Location of Culture, London and New York: Routledge.

Bhabha, H.K., 1998. The Third Space: Interview with Homi Bhabha. In J. Rutherford, ed. *Identity: community, culture, difference*. London: Lawrence & Wishart, pp. 207–221.

Cho, G.M., 2008. *Haunting the Korean Diaspora: Shame, Secrecy, and the Forgotten War*, Minneapolis, MN: University of Minnesota Press.

Chochinov, H.M. & Brietbart, W., 2009. *Handbook of Psychiatry in Palliative Medicine*. Second edition., Oxford and New York: Oxford University Press.

Clark, D., 2000. Total Pain: The Work of Cicely Saunders and the Hospice Movement.

American Pain Society Bulletin, 10(4). Available at: http://www.ampainsoc.org/library/bulletin/jul00/hist1.htm [Accessed July 21, 2011].

Clough, P.T., 2009. Reflections on sessions early in an analysis: Trauma, affect and "enactive

witnessing." *Women & Performance: a journal of feminist theory*, 19(2), pp.149–159. Csordas, T.J., 2008. Intersubjectivity and Intercorporeality. *Subjectivity*, 22(1), pp.110–121. Davis, S. & Simon, P., 2003. *Reggae Bloodlines: In Search of the Music and Culture of Jamaica*, New York: Da Capo Press.

Dein, S., 2003. Psychiatric liaison in palliative care. *Advances in Psychiatric Treatment*, 9(4), pp.241–248.

DeLanda, M., 2002. *Intensive science and virtual philosophy*, London and New York: Continuum International Publishing Group.

Deleuze, G., 2003. *Francis Bacon: The Logic of Sensation*, Minneapolis, MN: University of Minnesota Press.

Edensor, T., 2006. Reconsidering National Temporalities: institutional times, everyday routines, serial spaces and synchronicities. *European Journal of Social Theory*, 9, pp.525–545. Eisenberger, N.I., 2012. Broken Hearts and Broken Bones: A Neural Perspective on the Similarities Between Social and Physical Pain. *Current Directions in Psychological Science*, 21 (1), pp.42–47.

Eisenberger, N.I., Lieberman, M.D. & Williams, K.D., 2003. Does Rejection Hurt? An fMRI Study of Social Exclusion. *Science*, 302(5643), pp.290–292.

Ekblad, S., Marttila, A. & Emilsson, M., 2000. Cultural challenges in end-of-life care: reflections from focus groups' interviews with hospice staff in Stockholm. *Journal of Advanced Nursing*, 31(3), pp.623–630.

Evans, N. et al., 2012. Cultural Competence in End-of-Life Care: Terms, Definitions, and Conceptual Models from the British Literature. *Journal of Palliative Medicine*, 15(7), pp.812–820.

Fanon, F., 1986. *Black skin, white masks*. Second Edition., London: Pluto Press. Van Gennep, A., 1960. *The Rites of Passage*, Chicago: The University of Chicago Press. Greenhouse, C.J., 1996. *A Moment's Notice: Time Politics Across Cultures*, New York: Cornell University Press.

Gunaratnam, Y., 2012. Learning to be affected: social suffering and total pain at life's borders. *The Sociological Review*, 60, pp.108–123.

Harrison, P., 2007. "How shall I say it ...?" Relating the nonrelational. *Environment and Planning A*, 39(3), pp.590 – 608.

Heiler, F., 1932. *Prayer: a study in the history and psychology of religion*, London: Oxford University Press.

Hill, R.A., 2010. Redemption Works: From "African Redemption" to "Redemption Song." *Review: Literature and Arts of the Americas*, 43(2), pp.200–207.

Hirschkind, C., 2006. *The Ethical Soundscape: Cassette Sermons and Islamic Counterpublics*, Columbia University Press.

Igawa-Silva, W., Wu, S. & Harrigan, R., 2007. Music and cancer pain management. *Hawaii medical journal*, 66(11), pp.292–295.

Jones, S., Howard, L. & Thornicroft, G., 2008. "Diagnostic overshadowing": worse physical health care for people with mental illness. *Acta Psychiatrica Scandinavica*, 118(3), pp.169–171.

Karavanta, M., 2013. the injunctions of the spectre of slavery: affective memory and the counterwriting of community. *Feminist Review*, 104(1), pp.42–60.

Kaufmann, V., 2000. Modal Practices: From the rationales behind car and public transport use to coherent transport policies. *World Transport Policy and Practice*, 6(3), pp.8–17.

Keir, S.T. & Saling, J.R., 2012. Pilot study of the impact of massage therapy on sources and levels of distress in brain tumour patients. *BMJ Supportive & Palliative Care*. Available at: http://spcare.bmj.com/content/early/2012/09/27/bmjspcare-2012-000224 [Accessed August 15, 2013].

Khanna, R., 2003. *Dark Continents: Psychoanalysis and Colonialism*, Durham: Duke University Press.

King, S.A., Bays, B. & Foster, P.R., 2002. Reggae, Rastafari, and the rhetoric of social control [electronic resource], Jackson, MS: Univ. Press of Mississippi.

Kross, E. et al., 2011. Social rejection shares somatosensory representations with physical

pain. *Proceedings of the National Academy of Sciences*, 108(15), pp.6270–6275. Latour, B., 1986. *Laboratory Life: The Construction of Scientific Facts*, Princeton, N.J: Princeton University Press.

Lefebvre, H., 2004. *Rhythmanalysis: Space, Time and Everyday Life*, London: Continuum. Lievesley, N., 2010. *The future ageing of the ethnic minority population of England and Wales -Older BME People and Financial Inclusion Report*, London: Runnymede and Centre for Policy on Ageing.

Lister, J., 2013. *Health Policy Reform - Global Health versus Private Profit*, Enfield: Libri. Lo, J., 2000. Beyond Happy Hybridity: Performing Asian-Australian Identities. In I. Ang, S. Chalmers, & M. Thomas, eds. *Alter/Asians: Asian-Australian Identities in Art, Media and Popular Culture*. Annandale, NSW: Pluto Press, pp. 152–168.

Luckhurst, R., 2002. *The Invention of Telepathy: 1870-1901*, Oxford: Oxford University Press.

Lynn, J. & Adamson, D.M., 2003. Living Well at the End of Life. Available at: http://www.rand.org/pubs/white_papers/WP137.html [Accessed January 15, 2013].

Massumi, B., 2002. *Parables of the virtual: Movement, Affect, Sensation*, Durham, NC.: Duke University Press.

Mead, G.H., 1932. *The Philosophy of the Present*, London: The Open Court Company. Moore, A. et al., 2013. Expect analgesic failure; pursue analgesic success. *BMJ*, 346(may03 1), pp.f2690–f2690.

Morris, D.B., 1993. *The Culture of Pain* New Ed., Berkeley and Los Angeles: University of California Press.

Morrison, T., 1992. *Playing in the Dark: Whiteness and the Literary Imagination*, Harvard University Press.

Nixon, R., 2011. *Slow Violence*, Cambridge, Mass and London: Harvard University Press. Pieterse, J.N., 2001. Hybridity, So What? The Anti-Hybridity Backlash and the Riddles of Recognition. *Theory, Culture & Society*, 18(2-3), pp.219–245.

Rose, N. & Abi-Rached, J.M., 2013. *Neuro: The New Brain Sciences and the Management of the Mind*, Princeton University Press.

Saunders, C.M. & Clark, D., 2006. *Cicely Saunders: selected writings 1958-2004*, Oxford University Press.

Stocks, C., 2007. Trauma theory and the singular self: rethinking extreme experiences in the light of cross cultural identity. *Textual Practice*, 21(1), pp.71–92.

Walter, T. et al., 2011. Does the internet change how we die and mourn? Overview and analysis. *Omega (Westport)*, 64(4), p.275.

Wilkinson, S. et al., 1999. An evaluation of aromatherapy massage in palliative care. *Palliative medicine*, 13(5), pp.409–417.

Wilson, E.A., 1998. *Neural geographies: feminism and the microstructure of cognition*, New York and London: Routledge.

Wilson, E.A. (Elizabeth A., 1999. Melancholic Biology: Prozac, Freud, and Neurological Determinism. *Configurations*, 7(3), pp.403–419.

Winslow, M. & Clark, D., 2005. *St. Joseph's Hospice, Hackney: A Century of Caring in the East End of London*, Sheffiled: Observatory Publications.

Word count: 8138

References

Griffiths, M., Rogers, A., Anderson, B. (2013) Migration, Time and Temporalities: Review and Prospect. http://www.compas.ox.ac.uk/publications/research-resources/ (accessed April 2013)

Wilkinson S, Aldridge J, Salmon I, Cain E, Wilson B.

Subjectivity, 6(3) pp. 229–253