

# Learning to be affected: social suffering and total pain at life's borders

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**Abstract:** The practice of 'live sociology' in situations of pain and suffering is the focus of this article. An outline of the challenges of understanding pain is followed by a discussion of Bourdieu's 'social suffering' (1999) and the palliative care philosophy of 'total pain'. Using examples from qualitative research on disadvantaged dying migrants in the UK, attention is given to the methods that are improvised by dying people and care practitioners in attempts to bridge intersubjective divides, where the causes and routes of pain can be ontologically and temporally indeterminate and/or withdrawn. The paper contends that these latter phenomena are the incitement for the inventive bridging and performative work of care and live sociological methods, both of which are concerned with opposing suffering. Drawing from the ontology of total pain, I highlight the importance of (1) an engagement with a range of materials out of which attempts at intersubjective bridging can be produced, and which exceed the social, the material, and the temporally linear; and (2) an empirical sensibility that is hospitable to the inaccessible and non-relational.

philosophy

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My 'live sociology' takes its vital inspiration from death.

For the past 15 years or so, pushed and pulled by biographical events, I have been researching migrants, illness, death and dying.<sup>1</sup> There is an existential and carnal density to this world of life at its limits that makes tangible a central sociological problematic – that of intersubjective communication and understanding. In Les Back's preliminary sketching of 'live sociology', understanding the experiences of others is an abiding methodological concern and one which carries an ethical charge: sociologists have a responsibility to seek out and bring to publicity 'the fragments, the voices and stories that are otherwise passed over or ignored' (2007: 1). Here, through a discussion of pain and disadvantaged dying migrants, I show how following idiosyncratic fragments and the fleeting can bring us not only to the larger and longer lasting, but also to the recessive, indeterminate and discontinuous qualities of life.

What is sociologically interesting and distinctive about transnational dying is that it is a situation constituted by two radical and simultaneous registers and

thresholds of estrangement: the spatio-temporal and the phenomenological. There is a dramatic ethico-political significance to such borders Derrida (1993: 3) tells us, making explicit the edges of belonging, language and territorialization and where 'borders of property' are not only grounded but also carry a metaphysical resonance connoting 'the right of property to our own life' (1993: 5). The idea of life as 'property' is a complicated one, evoking life as a province – a territory that is as much temporal as it is spatial – marked by borders to the unknown,<sup>2</sup> rendering it discontinuous and choppy, never at one with itself. And because all human life is characterized by thresholds and 'a common ontological condition as vulnerable' (Turner, 2006: 9) there are wider inferences to be made from the worlds of dislocated dying. Despite the ever-increasing contests over territorial boundaries, as Dikeç *et al.* remind us 'what is also always with us are the borders, thresholds, and turning points of ordinary, embodied existence. And these are no less significant than the more concrete figures of mobility and transition' (2009: 11).

Here, through a focus on pain, I will explicate something of what I have learned about methodology and ontology from the improvisations of dying migrants and care professionals at life's thresholds. There are two main things that I want to do. First, I suggest the value of multiple and interconnected analytic registers by bringing into conversation sociological accounts of 'social suffering' (Bourdieu, 1999) with what in palliative care is called 'total pain'. Total pain interpolates, and at times creolizes, physical, social, psychological and spiritual pain (Saunders, 1964). It also gives recognition to pain that is accrued over a lifetime.

Total pain is a multimodal method of auscultation and care as much as it is a philosophy. It seeks to invent and legitimize ways of reading and becoming receptive to multifarious situations *as* pain. In this regard, it is a performative method and care practice that both describes and helps to bring to symbolization the phenomena it tries to apprehend and get close to. A distinctive value of the inventiveness of total pain is how it provides for the assembling of heterogeneous phenomena within the domains of pain. However, unlike a flat ontology (DeLanda, 2002), it avoids a 'smear of equivalence' between entities (Lorimer, 2005: 88) by not presupposing that phenomena have an analogous status and by allowing for that which is ontologically and temporally insecure and/or withdrawn. The latter entities are not fully accessible in the here and now. They can lack a referent and/or inherent, stable qualities (see also Barad, 2007). I will argue that it is the excessive haunting of the withdrawn that incites the experimental bridging work of care, where improvised attempts to alleviate suffering cannot always rely upon an evidence base in sensual knowledge. In this regard, responsibility for – and accountability to – what is withdrawn constitutes a space of ethics (Levinas, 1994). And sometimes of politics.

Second, and relatedly, I examine the effects of these complex interfaces between entities and the work that they inspire, in relation to my knowledge exchange practices and the movements between circuits of 'learning to be affected' (Latour, 2004) by a diversity of realities and perspectives, and being

affected and provoked to learn. This is an interdisciplinarity where the limitations of existing knowledge can produce transformations in a given 'logic of ontology' of pain (Barry *et al.*, 2008). But more of this later. Let me first contextualize some more by describing the challenges of accounting for painful experiences.

## Pain

Physical pain does not simply resist language but destroys it, bringing about an immediate reversion to a state anterior to language, to the sounds and cries a human being makes before language is learned. (Scarry, 1987: 4)

At the heart of attempts to apprehend human pain and suffering is an implicit falling short of methodology and analysis (Bourdieu, 1999; Harrison, 2007). These experiential states, however loud and flailing, are deemed to mark a certain aporetic; a detachment and retreat from word and world. As Harrison puts it 'experiences of suffering are quasicontradictory experiences in that they tend towards the limits of experience, towards the unexperienceable and irrecoverable' (2007: 595). This falling back of the self into a depth of experiencing disturbs long-standing philosophical injunctions from Descartes' *cogito* to Nietzschean vitalism. It is also problematic for Anglophone interpretative social science and the pervading legacy of Verstehende approaches where a defining claim is that 'subjective understanding is the specific characteristic of sociological knowledge' (Weber, 1947: 104).

Yet even in the most radical accounts of pain as a destroyer of language, recognition is given to the role of pain translation and advocacy and to those such as physicians, where the success of the medical practitioner is dependent upon 'the acuity with which he or she can hear the fragmentary language of pain, coax it into clarity, and interpret it' (Scarry, 1987: 6). The role of pain translation and advocacy also exists in the social sciences where the demands that pain, trauma, vulnerability and suffering make upon social analysis have been given sustained attention (Bar-On, 1999; Harrison, 2007; Frost and Hoggett, 2008; Waddell, 1989; Warin and Dennis, 2008).

What characterizes these social science discussions is the recognition that pain and distress can be produced by the social: by inequality, marginalization, injustice, powerlessness and persecution. It is perhaps not surprising that such forms of suffering can manifest at the end of life for socially disadvantaged migrants, where lives are looked back on, regret and losses can (re)surface, and selves and bodies can become both more salient and more vulnerable as illness progresses and also at different stages of the care pathway that involve varying degrees and rhythms of exposure (Gunaratnam, 2008b). In a Swedish study, nurses reported that caring for refugees and for survivors of the Nazi concentration camps often demanded greater attention to the routines and technical procedures of bodily care. One nurse described how 'we had a patient who had been in a concentration camp... it was awful of course... talking about

gas . . . she had great difficulty in breathing and it was extremely hard and there were so many memories involved in it all . . . ' (Ekblad *et al.*, 2000: 628).

I have also found that at diagnosis, particularly if it is perceived to be problematic, commonly expressed questions of 'why?' (Saunders, 2006) and 'why me?' (Stanworth, 2004) can, for dying migrants, take on a twist of 'is it me?' A story recounted in a focus group interview by Mita, a Cancer Nurse Specialist, speaks of how the felt injustices of diagnostic care can resonate with the injuries of racism, producing a layered distress. Mita's story concerned an Indian Hindu patient with terminal cancer. The man's cancer had been repeatedly misdiagnosed leaving him feeling angry and distressed. The patient had been a teacher in India and on settlement in the UK could not get a teaching job, ~~and~~ so had worked in factories and as a bus driver. In Mita's words:

I think it (his feelings of being excluded from professional employment) had an impact on how he dealt with his condition, because unfortunately his diagnosis had been quite delayed. For a year he'd been going backwards and forwards to the GP, telling him all the classic symptoms of what he'd got . . . he still had this idea and he said 'I know I'm educated and I know I'm completely in the wrong box. I think they haven't treated me properly because I am who I am, because saying I was only good enough for bus driving, not for teaching and for the same reason they didn't think I was important enough to be diagnosed early enough to be treated in the right way.' And I found that very hard. That was really difficult, that was hard for me to take. I mean what can you say? . . . What can I actually say to him that's actually going to make a difference to him? And I found that really difficult. (Gunaratnam, 2008a: 35)

For Mita, the intractable problem is how to respond to and alleviate the patient's anguish at the multiple injustices he feels. In the study *The Weight of the World* (1999), first published in French in 1993, Pierre Bourdieu uses the term 'social suffering' to recognize such experiences and to examine the relationships between *la grande misère* (material inequality) and *la petite misère* or the 'ordinary suffering' of living with inequality and injustice. The *Weight of the World* combines ethnographic and interview methods to produce a series of pen portraits of ordinary suffering across and within different social strata. In the study there is a continuous overlapping between the social, the somatic and the 'spiritual' as Bourdieu calls it.

## The weight of the world

Because of the difficulties in expressing social suffering, sociological attentiveness to it has to be cultivated Bourdieu argues, through 'active and methodological listening' (1999: 609). In the project, interviewers often had a long-standing connection to, and embodied familiarity with the research sites and the participants, a practice developed by the research team to reduce social asymmetries and the risks of symbolic violence. In some respects and despite claims to the contrary, the methodological disposition that Bourdieu and his collaborators sought to develop – 'to situate oneself in the place the interviewees occupy in

the social space in order to understand them as necessarily *what they are . . .*' (1999: 613, author's emphasis) – appears close to an affective empathetic version of Weber's *Verstehen*. However, for Bourdieu, the aim was to confect an extraordinary attentiveness and proximity in the interviews in order to cut through the 'we've already seen and heard it all' (1999: 614) cynicism of the researcher, and to reach a practical understanding of how social structures and histories can be *felt* in each research participant's 'idiosyncrasy'.

Angela McRobbie (2002) has criticized Bourdieu's study for its sentimentality, lack of thick description and methodological rigour. The careful documenting and exposition of the negotiation between subjectivity and objectivity and theoretical and practical knowledge that usually characterize Bourdieu's empirical research, although present, are certainly more muted in this project. Instead, the pain translation and advocacy role of the sociologist is emphasized and situated in her ability to give time, space and self to the interviewee and 'like a mid-wife' (1999: 621) to bring deep buried suffering and discontent into the world of expression and understanding. This is not the 'communication as communion' (Shields, 1996: 276) model of *Verstehen* that Rob Shields has critiqued so vigorously. 'Against the old distinction made by Wilhem Dilthey', Bourdieu contends 'we must posit that *understanding and explaining are one*' (Bourdieu, 1999: 613, author's emphasis). In such qualifications and differentiations, Bourdieu appears acutely aware of the normative and controversial nature of his empirical approach to suffering:

at the risk of shocking both the rigorous methodologist and the inspired hermeneutic scholar, I would say that the interview can be considered a sort of *spiritual exercise* that . . . aims at a *true conversion of the way we look at other people* in the ordinary circumstances of life. The welcoming disposition, which leads one to make the respondent's problems one's own, the capacity to take that person and understand them just as they are in their distinctive necessity, is a sort of *intellectual love* . . . (1999: 614, emphasis in original)

The words 'spiritual'<sup>3</sup> and 'love' emphasized so provocatively by Bourdieu point to the limits of the 'scientific intent' (1999: 621) of social research. In its place Bourdieu institutes sociology as a 'craft', entailing improvisation and intersubjective and intercorporeal bridging work between the interviewer and research participant 'so as to help respondents deliver up their truth, or, rather, to be delivered of it' (1999: 621).

## Social suffering and the more-than-social

Mindful of McRobbie's critique of *The Weight of the World*, I am interested in what Bourdieu and his colleagues were trying to get at with their flagrant, if ambivalent, detours outside of methodological orthodoxy and into the more-than-social. In many respects their stubborn allegiance to the specific social constitution of suffering is very much in evidence throughout the project, ensuring that 'ordinary suffering' remains within sociological reach: it can be com-

prehended, thematized and explained empirically. But there is also a more intermittent acknowledgement of how attention to the 'idiosyncrasy' of suffering can necessitate a move outside of disciplinary traditions, so that analysis and methodology overflow into such matters as spirit and love that breach and offend scientific enterprise, categories and language. In this respect, and taking into account the long history of forensic attention to methodological practice that marks Bourdieu's research, there seems to be something more profound and artful going on than the 'sociological opportunism' that Angela McRobbie has read into the researchers' empirical rule-breaking (2002: 134). In the context of my research experiences, I want to suggest that Bourdieu's forays into the more-than-social can be read as a contact with the vitality and anti-thematizing qualities of suffering and the impossibility of limiting the affects and effects of the painful to one sphere of life and being.

The unruliness of pain, and the coincidence of the thresholds of the geo-social and the phenomenological, can be found in the situation of Ibrahim, a 46-year-old Ghanaian refugee with kidney cancer. Ibrahim had migrated to the UK in the 1980s as a part of a cohort of Ghanaians escaping political persecution. I interviewed him in his hospice bed, ten days before he died. Ibrahim's physical pain percolated into the form and content of our interview. He alternated between sitting up and lying down to relieve his pain. Spasms of pain were perceptible in his intonation and in the recuperative pauses and breaths that he took when speaking, leaving the transcript punctured by ellipses. My concerns about Ibrahim meant that I ended the interview prematurely and we made plans to resume our conversation a couple of days later. By that time Ibrahim was slipping into unconsciousness and I did not talk to him again.

The one interview that I had with Ibrahim was taken up by stories of his illness, diagnosis, and migration to the UK: '*I knew if I didn't move out of the country I would either lose my, my peace or my life altogether*'. He talked at length about his economic concerns: the financial future of his partner and 16-month-old baby in the UK, and how his extended family and two children in Ghana would survive without his regular remittances. Ibrahim worried aloud about the cultural identity of his baby son. At the time when we met, hospice doctors were overhauling Ibrahim's drugs to better control his pain and hospice social workers had secured a small grant to ease the family's financial burdens. Ibrahim had come up with his own solution to the problem he saw facing his baby. He wanted to be buried in Ghana:

I want my son to (. . .) one day not just melt away into this society, but think of a place where he comes from and one day, or once in a while go back there, and when he goes there and then there's this grave stone standing there and say 'Oh that's your Dad lying down there' just gives him some kind of attachment to a place which I will cherish (. . .) yeah, but if he stays here, just melts away into society and that's the end (. . .).

The constituency of Ibrahim's situation and the materials that he talked of using to bridge the thresholds of life and death, and here and there, bring into



view the affective, physical and metaphysical dimensions of the geo-social. We can understand something of Ibrahim's improvisations socially with regard to his citizenship status, cultural and masculinist concerns of inheritance, wider transnational networks and repatriation death rituals amongst Ghanaian migrants (see Krause, 2008). All of these phenomena provide insight into the movements of material and semiotic resources in Ibrahim's life. Nevertheless, to reduce these diverse matters to the social would be to abolish the many novel coordinates of Ibrahim's predicament. In a Northern European context, Ibrahim's desire for a post-death connection with his son is an anti-rational temporization, which, following Lisa Adkins (2009a), we might call 'event time'. For Adkins, event time marks a departure from the normative dominance of mechanical clock time that characterized industrial capitalism. In contrast, event time signifies a temporality that 'no longer stands outside phenomena . . . but unfolds *with* phenomena' (Adkins, 2009b: 336, original emphasis). Event time is thought to be a product of contemporary transformations in the social field from a territory to a contingent circulation.

The problem of how to ensure a child known in the present connects with a country he may have no experience of in the future, and where in the past his father was endangered, is a new affective and spatio-temporal drama and source of distress for Ibrahim. It is a predicament where questions of territory and circulation are coincident in the production of time. In these complicated circumstances, the attempt to forge an attachment, or to perhaps make a claim upon his son's future identity, is made by casting a lifeline<sup>4</sup> from a speech act requiring social (understanding of intention) and material (repatriation, burial, Ghanaian soil) uptake.

In this ethnographic study, I was able to follow what happened to Ibrahim after his death: his family in the UK could not afford to bury him in Ghana. The social *a priori* in such circumstance is imposing and seemingly determining, inhibiting the actualization of Ibrahim's desire for a post-mortem agency, and pointing to the force of broader socio-economic patterns. Valuable as ethnographic methods are in following the movement of practices and affects (Mol, 2006), they have their limits in tracking the contingencies, non-linearities and metaphysics of uptake and actualization; the ways in which Ibrahim's desire for a lifeline to his son might end with his burial in the UK, or might yet unfurl through unpredictable, and for me unknowable and untraceable, future events.

If Ibrahim's story brings into view the multiple layers of the geo-social, it also pushes attentiveness to improvisation outside of the social – to such matters as flesh, soil and spirit, and to the weird temporalities and idiosyncrasies of event time. However, Ibrahim's bridging work is more of a once-in-a-life-time method (a technique) than a developing methodology (a systematic theoretical and philosophical framework). It is in the work of care practitioners, who are involved in the daily work of attempting to bridge intersubjective divides that I have been able to better understand the value of the ontology of total pain and how it is relevant to the practising of live sociology.

### Total pain: 'all of me is wrong'

I remember one patient who said, when asked to describe her pain: 'Well, doctor, it began in my back but now it seems that all of me is wrong,' and she then described her other symptoms. She went on . . . 'I could have cried for the pills and injections but knew that I must not. My husband and son were wonderful but they were having to stay off work and lose their money.' She was suffering a 'total pain'. . . . It is, in a way, somewhat artificial thus to divide a whole experience but it may give an internal checklist on meeting a new patient. (Saunders, 1988: 171–172)

The biopsychosocial challenges of alleviating the chronic pain that characterizes terminal disease preoccupied Cicely Saunders, a philosophy student, turned nurse, social worker and then physician.<sup>5</sup> Saunders collected over 1,000 patient narratives, and used them, together with patient drawings, writing and poetry, to develop her ideas on end-of-life care and total pain. Saunders approached chronic pain as a 'situation' rather than an event (Saunders, 1970), requiring practitioners to be 'attentive to the body, to the family and to [the] patient's inner life' (2006: 217).

Taking her inspiration from patient narratives, Saunders argued that the constituency and temporality of pain had to be approached as a complex heterogeneity that included not only the physiological but also the social, economic and existential, so that focus shifted from the genre of disease, and from biochemistry and drugs, to treating the many symptoms of a terminal condition. In the domains of total pain, the plural constituents of pain are allowed a mysterious ecology, sometimes intra-relating and sometimes distinguishable, both substantial and withdrawn, requiring multidisciplinary, but also inventive care. And whilst recognition of total pain does not by itself ensure effective pain relief, the effort of *trying* to understand an-other's needs for care, even when one fails, remained practically and ethically significant for the content and quality of care practices (see also Mol, 2008).

In similar ways to Bourdieu's *The Weight of the World*, Saunders' work with pain often strayed into matters of the immaterial and unquantifiable: 'The spirit is more than the body which contains it' (Saunders, 1961: 396). Unlike Bourdieu, Cicely Saunders' work with death entailed recognizing irredeemable loss and the limitations of the bridging work of care in responding to different integrities, genealogies, temporalities and scales of pain. For every success story in Saunders' writing – a patient whose emotional pain is relieved by the right choice and dose of a tranquillizer – there is also often a reminder that some forms of pain cannot be explained or eased, so that in the case of emotional distress she writes 'a good deal of suffering has to be lived through' (2006: 219). The role of the care practitioner in such circumstances is marked by a quintessential passivity, and where attentiveness is not necessarily a bridge to the other 'We are not there to take away or explain, or even to understand but simply to "Watch with me". . . .' (Saunders, 2006: 219). Here, responsiveness to pain and to its enigmas transfigures into a non-acting serving and standing-by of others (Waddell, 1989).



In working between the quantitative empiricism of medicine – observing, measuring, indexing, calculating, trialling – and what Alain Badiou (2002) would call a fidelity to the unknown, Saunders' work questions disciplinary boundaries. It also reinstates care as a part of human adventuring (see Greco, 2009) requiring technical skills and expertise and 'negative capability'. 'Negative capability' is the term that the poet Keats (1958 [1817]) has used to denote the capacity to tolerate incomplete understanding and mystery. Whilst not forgetting that the 'total' of total pain raises matters of a non-innocent inscription and expanded surveillance (Clark, 1999), its domains and claims are not as totalizing as its nomenclature suggests. Rather than signifying a closed system, total pain seems to point to the infinite, acknowledging that even with its openness to diverse registers of pain, painful entities can elude understanding and control. In this non-relational ontology, recognition of the puncta produced by the cryptic and withdrawn qualities of painful things suggest that phenomena can always be more (or less) than the sum of their relations.

It is difficult to find concise examples from my research that demonstrate total pain as an inventive care practice, but an event that comes close, was described by a community-based nurse Rachel (see Gunaratnam, 2008b). Shortly before I interviewed Rachel, she had spent most of the afternoon on the telephone trying to find a specialist pressure-relieving mattress for a double bed (they are most commonly available to the National Health Service for single beds). The mattress was for a couple, originally from Jamaica. The husband, in his mid-seventies, had prostate cancer that had spread throughout his body and was unable to sleep at night because of a cough. In Rachel's opinion 'The cough is his way of trying to keep himself awake because he's afraid he'll die in his sleep.' The couple were finding it difficult to talk to each other and to professionals about the progressing cancer and the husband's impending death. In the interview Rachel told me:

My staff nurse had seen him first and had ordered a highfaluting pressure mattress. So I went to see them and said 'My colleague has ordered this for you, where do you normally sleep?' And the wife said 'Well, we've slept in the same bed for 43 years'. And I said 'Well how will you manage if we put your husband in a single bed?' 'Oh I'll sleep in a camp bed next to him.' I said 'Well at the moment things seem to be OK. If I get a double mattress would that be more preferable?' And that was what she wanted and that's what we've done. I think we will probably need to get a hospital bed and a super-duper mattress another two weeks down the line, but we've given them another 3 or 4 weeks of sleeping next to each other in bed, which I think is much more important for the moment while they build up their trust of us and cope with the loss of each other.

The three to four extra weeks of sleeping together that Rachel's act of poetic realism brought to this couple are significant both with regard to the increased valuing and pertinence of mechanical clock time for those who are dying, and in relation to an event time of togetherness that is unquantifiable. In the ontology of total pain the qualities of the mattress can be thought of as a psychic

and material bridge and a substrate that can continue to connect and support the couple in Rachel's absence. As an affective underpinning, the significance of the mattress and its potential to relieve suffering is indivisible from its materiality; the extent to which its form and sensual qualities are themselves 'actants' in the Latourian sense, impressed by two variously suffering bodies, a cough, the physiology and metaphysics of sleep for a dying man, and suspicion of professionals.

Tracing and speculating about the overlapping layers of pain and palliation involved in Rachel's improvised use of the mattress as a care practice would be theoretically and methodologically productive (see Harman, 2009 for a lively discussion of these matters). However, radical relationality with its emphasis on the ubiquity of relations is not necessarily sensitive to the ethical imperatives of total pain or to its recognition of the withdrawn, where the sources, substance and genealogy of painful entities can be mysterious and disjunctive, whilst fracturing the present. For this reason I want to draw attention to the ways in which the mattress as a performative act of attentiveness and care is characterized by an inventive use of available resources *and* negative capability. Rachel cannot verify the sources or different knots of pain that are involved in her patient's situation. She does not know that the mattress will alleviate pain and convey her recognition of the slow losses and fears that she feels this couple are living through. There are no clinical trials or evidence base that she can draw upon. Rather, Rachel's version of total pain is created and emerges from her relationship to the couple, and out of some regard for materials and affects in their everyday lives. Such palliative care-giving works off implicated interconnections between signs and the real, it seems cognizant of how emotions can materialize by 'sticking' to certain objects (Ahmed, 2004), but it also allows painful entities a non-presentness or 'dark diachronicity' as Wyschogrod might call it (1990: 108).

In this necessarily abbreviated account are the basic tenets of total pain that at first glance seems to operate much like a flat ontology, one in which tumours as much as mattresses and coughs are recognized as contiguous, intra-acting components of pain. Yet total pain also leaves spaces for the effects of undisclosed and unfathomable entities that can defy the most bespoke titration of drugs or care-full listening, so that the 'total' of total pain operates more as a provocation for care and as a tentative placeholder for a pluralized known and unknown.

## **Learning to be affected**

The philosophy of total pain revitalizes social science discussions of the limits of understanding pain and suffering. It also raises questions of what might be at stake in the revisions and extensions to the empirical that I have suggested that total pain implies. These questions become less abstract when applied to

my ongoing teaching and collaboration with palliative care professionals. Consider what can happen in teaching when I use case stories generated from my empirical research.

The case story of Maxine describes the end-of-life care of a 63-year-old hospice patient, a retired hospital domestic who lived alone in a council house (see Gunaratnam, 2004). Maxine had talked to me in some detail, and over a period of months, about her life with her violent ex-husband. She also recounted, with incongruous wit, several incidents of racist violence on the streets of South London in the 1960s, relatively soon after she had migrated to the UK from Jamaica. In the narrating of each account Maxine was more of a heroine than a victim. In one story of a racist attack when she was seven months pregnant, Maxine described giving chase to the young perpetrators who were forced to hide in a local shop, adding *'Every time I pass that shop . . . I stand up and give a little laugh, 'cause I remember that's where they run.'*

When Maxine was admitted into the hospice for terminal care, she grew increasingly agitated. She said that she felt anxious when being lifted and touched. Some of her nurses were overly loud, and she suspected, racist: *'those girls no respect no black people'*. Maxine's nurses were not unaware of some of these anxieties and team members discussed the need to show sensitivity to Maxine's fears and 'paranoia'. In the last days of her life Maxine began to resist all routine care practices, so that her death was 'dirty' (Lawton, 2000).

In multidisciplinary teaching sessions we discuss what might be involved in Maxine's situation. If it has not been raised, and drawing from the insights of feminist and psychoanalytic scholarship, I suggest how histories of gendered and racialized violence can be implicated in Maxine's anxieties about her bodily care. In making sense of the care problematic a doctor might layer the suggestions into what she has learned from 20 years of clinical practice and from evidence-based research: paranoia, agitation and hyper-sensitivity to touch and to noise can be the consequence of drugs, biopathology, and of dying itself. A social worker may draw upon pedagogies of anti-oppressive practice (Dominelli, 2002) and diversity training, relating the case story to his experiences of counselling survivors of war and women who have been raped, for whom physical care can be traumatic.

A crucial point is that the generation of these possibilities does not simply take place through a semiotic expansion – a piling up of new symbolic categories onto existing experiential and disciplinary knowledge in order to signify with greater accuracy, a previously unthought, but ultimately generalizable real. Neither is the aim to retrieve or recover to the present a lost (explanatory) object of pain in Maxine's past. Rather, these interdisciplinary exchanges become highly focused contextualizing and specifying practices through which we can become variously sensitized (depending upon the nature of different sites of care-giving) to more qualities and registers of Maxine's pain, including those that elude us. In this process, it is attentiveness to the singularities of Maxine's situation that can produce shifts in ~~the~~ ontology of pain, so that the content of the experienced world expands. This process is broadly akin to what the actor

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network theorist Bruno Latour calls 'articulation', a bodily practice of 'learning to be affected by differences' (2004: 210). It is a process that does not rely upon an object/subject, nature/culture split or upon common, uncontested epistemologies. For Latour, 'The more you articulate controversies, the wider the world becomes' (2004: 211).

## **Being affected to learn**

Latour's 'learning to be affected', although firmly defined as an embodied awareness, is relevant to thinking about methodology, ethics and the role of live sociological research: how might the attentiveness of live sociology be articulated? There is a supplement that I would add to the consideration of this question. In my teaching and learning with care professionals it is apparent that we are already affected by our encounters with pain, suffering and vulnerability. At the same time there are aspects of entities and others that cannot be fully recuperated into a taught, interdisciplinary or sensual affectedness. No matter how many different perspectives, experiences and levels of analysis are brought to the interpretation of Maxine's case-studied life, no matter how questions of disciplinary knowledge production are kept in sight, there are always aspects of her experience that are singularly untranslatable. So whilst the content of our worlds have expanded through our encounters with Maxine and with each other, we cannot claim to fully understand the sources, routes, levels, temporality and meanings of Maxine's pain.

And so, within learning to be affected there is also the unintelligible and the undecidable. It is this unintelligibility – an empirical counterpart of the withdrawn in philosophies of total pain – that can become an inspiration or interpellation to the bridging work of sociological attentiveness and the improvisations of methodology. In other words there are circuits or relays of inter-dependency between learning to be affected and being affected to learn which gain traction and impetus from the things we cannot resolve, recover or connect, but which nevertheless have a status as a response (Harrison, 2007).

'Incomprehensibility', Derrida writes '... is not the beginning of irrationalism but the wound or inspiration which opens speech and then makes possible every logos or every rationalism' (1978: 98). There are two notions of fidelity at work here: remaining faithful to the idiom and the milieu of what is unknowable, whilst also searching for, and using every possible means by which to know it differently. I am thinking here about the commonplace but often under-described 'wounding' inspirations of empirical research: Bourdieu's (1999: 622) struggles with the 'infidelities' of transcribing interviews; his admission that it took him over a decade (with repeated listening to an interview recording) to better appreciate the depth of the precarious existence of two farmers whom he had known personally for a long time; and my own turn to poetry and creative writing to evoke and convey non-linearities and enigma (Gunaratnam, 2007<sup>6</sup>). As Graham and Thrift (2007) have also recognized despite its origins in failure

and fault, in improvisation there is always the hope of a provisional responsiveness and learning:

Improvisation allows the work of maintenance and repair to go on when things may seem bleak and it takes in a whole series of responses, from simple repetition (such as trying it again) through to attempts to improve communication so as to be clear exactly what the problem is, through disagreement over causes, through to complex theorizing, responses which are often the result of long and complex apprenticeships and other means of teaching . . . (2007: 4)

Of course we need to be careful about valorizing or embracing too readily, the unintelligible. The unknown as beyond question always risks becoming complicit with the mystifications of social and political abjection (Spivak, 1988; Butler, 2004), or of neglecting the more mundane ways in which empirical inquiry can be ‘dumb’, stifled by a ‘dramatically poor repertoire of sympathies and antipathies’ (Latour, 2004: 219). Thinking about the status of what is inaccessible, mysterious or unlocatable is to think about differential histories and scales of existence and how these histories and scales are rendered and approached – and always *in media res* – from different, and sometimes antagonistic, disciplinary perspectives. But, it is also to return to basics; to recognize that critical methodologies, as much as care, are driven by a desire (and, for some, a responsibility) to oppose unnecessary suffering ‘it is precisely the radical destructibility of life that makes it a matter of care’ (Hagglund, 2011: 124). The unintelligible in this regard is not so much a bounded territory or domain, an empirical no-go zone. Rather, it signifies and problematizes the underlying drive of the attentiveness of live sociology as an imperative to uncover and to do something about unnecessary suffering.

Learning from the improvisations of dying migrants and care practitioners, I am suggesting that the unintelligible in the practice of live sociology involves something more than being the opposite or absence of intelligibility. Carrying the capacity to put into motion, touch, interrupt and halt it is the very condition of future ‘live’ empirical activity; a site of problem-making and accounting for that is simultaneously an opening to the generation of different methodological practices, knowledge, and ways of thinking about the usefulness of what we do (see Fraser, 2009) and also what is ‘sociologically unspeakable’ (Gordon, 2008: 178). By way of conclusion there are two methodological points that are important to me to highlight: (1) attentiveness to a range of different materials out of which attempts at intersubjective bridging and communication can be produced, and which exceed the social, the material and the temporally linear; and (2) the cultivating of an empirical sensibility that is hospitable to the inaccessible and the non-relational.

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## Notes

- 1 The events and accounts in this paper come from two separate research projects (for methodological details see Gunaratnam, 2001 and 2008b). The first, an ethnography of a London Hospice (1995–1999), generated Ibrahim's and Maxine's interviews; and the second, a study of older people from racialized minorities produced Mita and Rachel's narratives (2003–2007).
- 2 For Derrida, thresholds always involve the unknown, and in the case of death 'a certain *pas* [step/not]' (*Il y va d'un certain pas*) (1993: 6). The plurality of meaning in the French word *pas* as 'step' and 'not' is taken to 'mark the impossibility or impermissibility of such a step (one cannot or ought not cross)' (Calarco, 2002: 19), but it is an impossibility that also serves as an incitement to cross the impossible/impassable.
- 3 In Couze Venn's (2010: 148) discussion of the temporality and affective economy of narratives of spirituality, one aspect of spirituality is seen as involving 'recognition of insufficiency or incompleteness' and a waiting for unknown becomings.
- 4 As Sara Ahmed (2005) tells us, a lifeline involves affective and spatio-temporal orientations and investments, as well as being an expression of something that can save us. She notes that as much as a lifeline is something that is intended to save us 'we don't know what happens when we reach such a line and let ourselves live by holding on . . . We don't know what it means to follow the gift of the unexpected line that gives us the chance for new direction . . .' (2005: 18).
- 5 Alongside those such as Nelson Mandela, Martin Luther King Jr and Aung San Suu Kyi, Cicely Saunders was the subject of a book on courage by the former British Prime Minister Gordon Brown (2007). Of Saunders, Brown wrote ' . . . in her life she did more than anyone to come to terms with the greatest mystery of all: death' (2007: 6).
- 6 My ongoing work with knowledge exchange has included the transformation of data into artistic forms, the collaborative development of information materials for dying people, involvement in palliative care policy development; and educational initiatives for care professionals (for examples see Gunaratnam, 2007).

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