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Death and the Migrant – An Introduction



Figure 1.1 Grandmother.

Courtesy: Nela Milic

Feng Dai sits facing his doctor in a clinic at a London teaching hospital. Mr Dai has been told with great care that his cancer is no longer treatable. He seems to take the news with equanimity. His wife is a calm presence beside him. No, he does not have any questions at the moment. There is nothing more that he wants to talk about. Before he gets up to leave, Mr Dai asks for a pen and writes a single

word on a small scrap of paper. He tells the doctor that he will look the word up in his dictionary later at home. The word? *Terminal*.

Along with the capacity for mobility, reinvention and resilience required of migrants, there is another side to our world on the move that deserves greater recognition and understanding. Attending to the situation of the migrant at times of illness and death is to open ourselves to the coming together of two of the most radical thresholds of bodily estrangement and vulnerability: the movement across territories and from life to death.

Frank, *A first journey*

Originally, I'm from St Lucia. Why did I come? Well, according to the word of God, he say man shall travel to and fro and knowledge shall be increased and shall travel for betterment. Mind you, when I was back home I was my own boss. I had a mini-cab. When I first came here I work in a hotel. Well, I couldn't get a job which I knew about, motor mechanical, and it was cold, very cold, and I said I couldn't do an outside job. I wanted an inside job and I was lucky I had a friend who was working there and he get the job for me, and I was just washing glasses, that's all.

Harshini, *The last migration*

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 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,



Figure 1.2 Hands.

Courtesy: Nadia Bettega

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.

Despite the dissimulating of state borders by globalization and digital capitalism – e-commerce, telecommunications, biotechnology and the like – the problem of the border most often comes to mind as a problem of spatial movement. Where are you going? Where have you come from? Who belongs? Who can or cannot cross this threshold? In transnational dying, questions of territorial mobility fold into matters of time – into life as a province.¹

This unique time that is *my* life, that is *your* life, is a *terra infirma*, neither flat nor secure underfoot. It is continually broken up and fissured by events that send the present and the imagined future spiralling off in unforeseen directions. The lives of my mother, brother and I changed on a February morning in 1985 when my father suffered brain damage during coronary artery by-pass surgery. James' life was transformed on a Sunday afternoon with a thrush infection in his mouth (see Dissimulation). Mr Balani's descent into dementia unfurled over a period of years (see Slowly, Slowly in Chapter 11). And June's turning point came on a bus journey to work when her leg suddenly collapsed under her (see Moving On). For the psychoanalyst Christopher Bollas the existential dispossessions of life are even more fundamental than this. 'Moving from the maternal order to the paternal order, from the image-sense world of the infantile place to the symbolic order of language, may be our first taste of exile' Bollas suggests.²

When borders are reimagined as a temporality, dying people, wherever they have come from, are already foreigners of a sort, unmoored from everyday worlds and all that is familiar, by the vicissitudes of the body. Who are you when you are leaving your life? Where are you? Who is that strange person that you see as you pass a window or a mirror? 'Well, I was sad because of my shape, I have a horrible shape now' says June Alexander, who has multiple myeloma. 'No waist, an my bottom gone in an everything. If you see me naked you would be surprised. It takes a while to get used to it. I mean, I'm still learning'. As the geographers Dikeç, Clark and Barnett explain,

amidst all the attention to the negotiation of territorial boundaries which Kant put centre stage and which intensifying globalization has kept on the agenda, 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. . . .

Illness, destitution, death of loved ones, unexpected pregnancy, love or desire beyond the bounds of communal acceptability, these are all predicaments that 'befall us', exceeding our knowledge and preparedness, carrying with them the risk of a radical de-worlding.³

In the debility and the dying of migrants we encounter this shared human susceptibility and also the particular 'de-worldings' that come with the increasing movement across geo-social frontiers that are transforming our thinking and experience of any sense of a bounded national culture or tradition. Claus Leggiwe,

transmigrants live long term in two or more places, constantly speak two or more languages, possess *en masse* two or more passports, and pass continually in both directions through makeshift households, networks of relationships and spaces of communication.⁴

It would be wrong to think about the coincidence of the multifarious border-crossings in transnational dying in terms of matters of scale or of type alone. Mediated by the body and by heightened emotions, the flows between place, economy and culture, are as unruly and paradoxical as they are creative and surprising. Fantasized 'roots' meet up with cosmopolitan 'routes' so that hospice and hospital wards have that similar feel of the airline transit lounge, characterized by long chains of cultural interconnectedness and intergenerational migration.⁵ But with illness and disease the interconnections proliferate. Hallucinations, paranoia and hypersensitivities can cohabit with and jostle among prayers, promises, plans, rituals and life-long habituations, pulling the body and self down familiar and new paths (see *Dirt* in Chapter 4).

'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' says Harshini. Harshini's mother, a devout Hindu, has dementia. The disease is taking away her mother's memories, her awareness of the religious beliefs that she has lived by and her self-consciousness. At the same time she 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'.⁶ He was mistaken. Prayer in some of our traditions is the very emptying out of thought. It is a somatization in and of itself, conveyed in the muscle memory of fingers, the voice, the ears, the rhythmic movements, gestures and comportment of the body.⁷

As migrant bodies deplete and unravel with illness, the traces of these other times, places and culturally honed sensorium intermingle with the day-to-day unfolding of diasporic life, post-migration settlements and care in institutions and in homes. The finding of one's ground amid such shifting circumstances is a place-making that even at the end of life spawns practices that are continually produced and discovered. 'You need to be creative and adaptable' says Alex who looked after her mother Olga, who had Alzheimer's disease. 'We got some woollen leggings for her a while back to help her to go to the commode more often. They allowed her to pee without having to pull her trousers down.'

Nadia Bettega, a photographer and researcher, began to photograph Olga over ten years ago – when she was in the early stages of Alzheimer's – until her death in November 2012 at the age of 99. 'My mother is not a vegetable wasting away in bed' Alex says. 'She is an animated lady wishing to communicate with anyone who has the interest, the time, to visit and reach out to her. Looking at her I know that here is a human soul with attitude struggling to live and enjoy life.' Bettega had wanted to tell the story of Olga's incredible life through the objects that surrounded her and that came to take care of her, and Alex too. 'Her whole life was condensed into one room, invisible to the outside world' Bettega explains.

Alex: My mother loved literature and poetry and could recite it for hours on end. She loved music. She liked to dress well and she liked to eat well. I remember with pleasure her reading of *Le lac* by Alphonse de Lamartine, but above everything she loved people. She loved conversation.

A carer is a someone who provides unpaid care for a person who is sick, disabled or frail.

The number of carers increased from 5.2 million to 5.8 million in England and Wales between 2001 and 2011.

The greatest rise has been among those providing over 20 hours care – the point at which caring starts to have adverse affects on the health of the carer and their ability to hold down paid employment.⁸

With her mother, younger brother and a pig, Olga was among the two million people who fled from the violence that had erupted during the Russian Revolution and Civil War in 1917. During their escape they were forced to scavenge for food

'stealing the odd potato, or two, or more' Alex says. 'This was about survival and a complex set of rules emerged from this life of chaos. They travelled by train when someone was willing to help them, but most of all they walked.' The troika travelled 1,400 miles to Belgium via Lithuania. In Belgium, Olga and her brother were delivered into the care of Catholic institutions, while Olga's mother carried on her journey to England. The children subsequently joined her and were sent to boarding schools in Scarborough.

As Olga's short-term memory began to deteriorate, Alex found that she would journey into the past, recalling happy times and using objects to bridge worlds. A ring passed across and between Olga's fingers could return her brother to her once more. The convent in Belgium came to life when she held her rosary.

For the sociologist Pierre Bourdieu, our everyday worlds are a mosaic of these small 'practices'. Practice, as Bourdieu imagined it, is an improvised, bodily know-how, a sensual capacity to 'habilement' – to skilfully and adroitly navigate through the challenges of daily life.⁹ With disability and disease the habitual skill of mundane practice comes under increasing duress from the biochemistry of the body. My feeling is that the practices of living with dying are more analogous to the art forms of music and dance than the rationalities of conscious thought. The philosopher Gilles Deleuze believed that the individuality of the body is



Figure 1.3 Olga and rosary.

Courtesy: Nadia Bettega

ultimately defined by delicate *musical* relationships between inertia, rest, slowness and speed. ‘It is not just a matter of music but of how to live’ Deleuze asserts,

it is by speed and slowness that one slips in among things, that one connects with something else. One never commences; one never has a *tabula rasa*; one slips in, enters in the middle; one takes up or lays down rhythms.¹⁰

The film *Aaj Kaal*¹¹ – translated as yesterday, today and tomorrow – made in 1990 by Avtar Brah, Jasbir Panesar and Vipin Kumar in collaboration with Punjabi elders in West London, is a beautifully rendered evocation of some of the musical embodied place-making practices that I am talking about. The film was part of a participative project at the Milap Day Centre for older people in Southall. By coincidence Milap was also a place where I did my first interviews for a project to produce information for South Asian carers of older people at the same time that *Aaj Kaal* was being made.¹² The film, in Punjabi with English subtitles, is a heady mix of poetry, song and dance and footage from the life of the day centre, including trips to the seaside and interviews between the elders.

Nirmal Puwar has excavated the little known film in commemorating the work of Avtar Brah and the passing of this first generation of Punjabi migrants. Commenting on the closing scene of the film that features a *gidda*, ‘an expressive dance formation that has enabled Punjabi women to air their joys, frustrations and sorrows’,¹³ Puwar describes how,

For earlier generations . . . the *gidda* sessions were central to how they settled and made Britain a home for themselves, in an admixture of pleasure, performance and gendered territory. It is in these zones that they made their public lives together. These modes of coming together provide one layer, so far largely unregistered, of migration and settlement in the making of the post-war British front room.¹⁴

The coda to Puwar’s article turns to her 91-year-old mother’s sustenance at an Asian day centre in Coventry (subsequently closed due to funding cuts) and recalls her Mother’s *gidda* dancing with a zimmer frame at her ninetieth birthday party in the public spaces of a hall. Puwar’s coda seems to sing and dance back to those very different earlier histories recorded by *Aaj Kaal*, gesturing to the new debilitated spaces of the Punjabi front room. Here I catch a glimpse of the *gidda* entwining with and being extended by the prosthetics of disability and disease, rearranging the furnishings of diasporic and post-migration socialities once more. All of which is to say that *what* and *how* it is for migrants to be deworled by disability, old age, disease and death is a zone of vitality that even as it depletes cannot be assumed.

And so, as strange as it might seem, *Death and the Migrant* is not primarily a book about loss. My hope is that the stories will show the vitality and musicality of human experiencing right up to the point of death. And sometimes beyond.

Diasporic dying

In the United Kingdom the nature and extents of the overlapping estrangements of migration, disease and dying are in some ways becoming less tenebrous as the cohort of our first generation of post-war migrants are reaching old age and are dying in increasing numbers. Generation Exodus – the nurses, doctors, cleaners, cooks, bus drivers, construction workers and soldiers – leave behind them psycho-geographic trails that began for many with the lure of economic betterment, Empire and personal ambition and which can end in a doctor's surgery, Accident and Emergency cubicle or care home, tinkling with a morbid poetry of words such as *malignant*, *metastases* and *palliative care*.

History, geo-politics, cultural and religious prescription hover around the migrant's deathbed to pay their last respects, but they do so in strange and uneven ways. There are migrants who because of their marginalization, whether related to their disease, citizenship status or because they queer normative expectations, occupy ambivalent, tenuous positions in the lexicon of transnational life and what Bridget Anderson has called *communities of value*.¹⁵ Struggles over cultural authenticity, who speaks for whom, who can and cannot belong and who is deserving of care continue into illness and death and can even extend into post-mortem 'life' (see Dissimulation).

In following the smaller affects of estrangement that gather weight and grain from the most mundane of circumstances, I hope to derail dominant ideas and narratives about migrants by showing something of our singular differences and our humanity.

I take my cue on this point from vibrant discussions and writing in feminist and queer migration studies.¹⁶ If brutalizing exclusions and contestations take place at state borders, more recent work is also drawing attention to how emotional investments, memory, fantasy and imagination shape the 'multiple and potentially contradictory positions that migrant subjects occupy'.¹⁷

Ricardo is a recent Portuguese migrant from Brazil. He was diagnosed with advanced cancer about a year after he had settled in London. His is one of many stories that I have heard that express the contrary dispositions of migrants beset by illness. Through an interpreter Ricardo tells me that in Brazil he would have

had to sell his house to pay for the cancer treatment he is now receiving from the British National Health Service (NHS). He wants to make it clear that he is a good and responsible patient. Despite the aggressiveness of his disease, he has defied medical expectations. Unlike some others he can think of, he has led a healthy life. He does not drink or smoke. He complies with all the medical advice and guidance that he is given.

Ricardo's repeated affirmations of his responsible determination relegate the inexorable facts of his loneliness and impending death to *crac allure*. Amid talk of seeming banalities – the manioc that he spotted with delight and nostalgia in a local market, his granddaughter in Brazil asking him on Skype when he is going to take to her to McDonalds again – he erupts repeatedly into paroxysms of sobbing. The interpreter and I struggle with our own tears. It is in his account of hospitalization that Ricardo's most immediate and prosaic challenges arc into bigger geometries of his hopeful bargaining of compliance for life.

Sometimes when I was in hospital I had cheese, but I don't like cheese, and with the language barrier I did not know how to say it. I had to eat it, because if I did not eat I would lose much more weight than I already did, and I think we have to have the will and be stronger when we are in a hospital. Eat your meal and do the right thing, accept the advice, do everything right, and if you do it this way it helps a lot.

For those who die, and for those of us who are left behind, we cannot but pass through the weft between the large and the small in our journeys towards the ends of life. The borders, turning points and transitions in transnational dying feature a familiar human terrain: love, revelation, family feuds, reparation, disappointment, legacy, inheritance and imperfect endings. The relationships recovered miraculously at the death-bed. Those torn apart at the last moment by confessions and confrontations, petty arguments and resentments over who gets grandma's ring, who can come to the funeral or the *proper* spelling of a name.

There is also a layered novelty in transnational dying and bereavement that through the evocation of 'home', tradition or citizenship rights gives some form and musculature to what has been taken-for-granted or never seemed to matter before. Fears of cultural dilution or amnesia can loom large, even for the ethnically agnostic, hopelessly mixed or many times diasporised. The search for meaning so often induced by frailty and dying can take a more down-to-earth turn. There are worries about remittances, repatriation and reputations; the lives and souls of loved ones; the loss of a language or religion, unmoisturized bodies.

The bereaved too can be fearful of the severing of the threads that connected them to other times, peoples and places. Recipes get written down for the first time. Photograph albums are devoured. Oral history is sought out and recorded on mobile phones and webcams. Sometimes a careless utterance cast out from the internal free-wheeling of a morphine haze, where the words *passports* and *tickets* are just decipherable, can turn from metaphor into Mission Impossible.

Dead bodies and plastic hermetically sealed caskets of ashes are flown across the globe in a rewriting of the Homeric script of return. Emptied of any triumph for some, but a homecoming nonetheless. The flabby idiosyncratic bureaucracy of embassies and airlines will be negotiated to get a near-comatose patient onto an arduous flight to a distant homeland. Shafina says it is much easier that way in the long run. When she heard that her father had a week or so to live, they flew with him from East London to Pakistan. He died at eight o'clock in the morning. By three that afternoon they were at his funeral. Nurses and social workers are usually the ones who spend hours on the phone trying to make it all happen, emotionally committed but often mystified by the indomitable compulsions behind these last journeys.

We once had a patient who had lived in a remote part of Sudan. The professionals that were involved felt her needs were such that she wasn't actually going to make the journey. She was very, very symptomatic. She had a lot of pain. She was virtually constantly vomiting. The family then agreed, perhaps under a bit of pressure, that they would just take her to their home in Tooting and that's where she would die. They'd have twenty-four-hour care, so a lot of time and money was invested in setting all of that up. The family organised their own transport, they organised a private ambulance and instead of taking her home they took her to the airport.

The hospital Macmillan nurse shudders as she tells this story. She does not know how or where the fatal odyssey ended. But she has gone through the various possibilities and outcomes. She imagines a Land Rover waiting at a Sudanese airport to take the family to the far-flung village where the mother was born. She worries that they did not have enough pain control and anti-emetics, that the patient may have died en-route. She re-settles herself and reasons it out. 'It's cheaper to take someone home alive, than to fly a coffin home, which can cost five to ten thousand pounds to fly someone home when they're dead.'

Five thousand pounds is the figure that Brian gives when he talks about flying Aliz home to Hungary to die with her family. Brian, a hospital social worker in central London, has noticed that his younger, East European patients can be resistant to palliative care, clinging to the remotest of hopes alluded to in active

treatment or in the abstract odds ratios of survival rates. Brian speaks of the loneliness of facing death away from family and friends, of the heavy burden that can fall onto the most flimsy of contacts, transformed overnight into next-of-kin and who become responsible for momentous decisions and breaking bad news long-distance to strangers.

Aliz chose to die at home in Hungary in the very last stages of her life, resulting in the need for a business class flight and an accompanying doctor. The doctor's fees came close to 2,500 pounds. Surprisingly for Brian, some of the money for Aliz's home death came from a generous donation from a global chain of continental bakeries where she had worked in London for just nine months.

For the Jarrant family, there was no kindly benefactor on hand to help, when 91-year-old (Curt) Willi Jarrant died. Willi's wife and daughter were arrested at Liverpool's John Lennon Airport in April 2010, accused of trying to smuggle Willi onto an EasyJet flight to his native Berlin.¹⁸ They had dressed Willi in a big coat and sunglasses, strapped him into a wheelchair, and told airport personnel that he was sleeping. Both women continued to insist that they did not know that Willi was dead, that he must have died at the airport. Willi's stepdaughter Anke told reporters that Willi had Alzheimer's disease and had not been in good health. He had wanted to go back to Germany to die. The repatriation costs of flying a dead body to Germany at the time were about £3,000.

To be impoverished of life chances, and to feel the pull of a distant home at the end of life, is not the same vulnerability that we all face of not knowing what the future holds. What is distinctive about the stories of transnational dying that I offer in this book is that they move between and reveal these different registers of estrangement. They complicate what we think of as migration, globalization and care.

'To outline the experience of the migrant worker and to relate this to what surrounds him – both physically and historically' John Berger insists, 'is to grasp more surely the political reality of the world at this moment'.¹⁹ The 'this moment' that Berger is referring to was 1970s Europe. At that time migration was largely the province of men. It is a trend that is now reversing with the increasing feminization of transnational migration due to the rising demand for care workers in the global North.²⁰ Parodying the myth of infinite substitution and the denial of the male migrant worker's susceptibility and finitude in global capitalism, Berger wrote,

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.²¹

Migrants die. And the increasing prevalence of their debility and dying brings us to a neglected plane and temporality in migration trajectories. This is a zone in which the very conditions of migration – movement, improvisation and uncertainty – meet the demands of one last journey into the unknown.

Hospice-tality and the geo-social

One in 33 people in the world today is a transnational migrant²² and the number of working-age people in the United Kingdom who were born overseas increased from 2.9 million in 1993 to nearly six million in 2011.²³

I could have chosen to investigate diasporic dying in a number of settings. The predicament of dying in a strange place is not only about those who are ill and impoverished. It is the stuff of Greek tragedies; philosophy; imperilled border crossings; violence and forced labour; immigration detention centres and refugee camps. It has, and will, continue to befall cosmopolitan entrepreneurs and elites, adventurers, soldiers, criminals, tourists and those who fell in love or just wanted a change of climate. As well as the personal reasons that brought me to end-of-life care, modern hospice and palliative care, as I discuss in *Eros*, has been most explicitly oriented to matters of hospitality and estrangement. The *question of the foreigner*,²⁴ as the philosopher Jacques Derrida has phrased it, is most acute at times of debility and death, summoning up the borders and meanings of community and hospitality. With the idea of community in mind, the philosopher Alphonso Lingis puts it this way,

Community forms when one exposes oneself to the naked one, the destitute one, the outcast, the dying one. One enters into community not by affirming oneself and one's forces but by exposing oneself to expenditure at a loss, to sacrifice. Community forms in a movement by which one exposes oneself to the other, to forces and powers outside oneself, to death and to others who die.²⁵

Lingis's proposition is counter-intuitive. A community is made not by commonality, invulnerability and enclave but through its responsiveness to catastrophe, exile and loss – a theme and existential metaphor that recurs throughout the Abrahamic religions. These are not abstract matters for philosophers and social

scientists. They come into play in how we think about the extents of transnational hospitality, human rights and our interdependence.

In January 2008, Ama Sumani, a Ghanaian migrant with malignant myeloma was taken by immigration officers from her hospital bed in Cardiff in Wales to Gatwick airport and deported. Ama had violated the terms of her visa by failing to maintain contact with immigration officials and to update her details when she had moved home. The prestigious medical journal *The Lancet* described the deportation as ‘atrocious barbarism.’²⁶ There was also the chuntering of disgruntled citizen commentators in the blogosphere and on the airwaves who supported Ama’s deportation amid fears of treatment tourism and an already over-stretched NHS.

The BBC’s East Africa correspondent, Will Ross, had met Ama shortly after she had arrived in Accra, where she had stayed briefly in a hotel with two British immigration officers. The officers had tried unsuccessfully to pay for Ama’s first dialysis sessions at Accra’s main hospital. Ross describes how both officers looked distressed. One had given Ama a pair of her own silver earrings. They left without saying goodbye to a bemused Ama who tried repeatedly to call them on their mobile phones.

Ama died three months after her deportation. In that time over £70,000 had been raised by supporters and friends in the United Kingdom for her treatment and drugs. Speaking to the controversy and resentments surrounding Ama’s case, Will Ross offered an alternative set of moral coordinates for thinking about British hospitality. Excavating the global transfusions that the NHS is built upon, Ross observed ‘Turn up at a British hospital and do not be too surprised if the nurse or doctor who treats you is Ghanaian. With the drain of this exodus on the Ghanaian health service, some here suggest the UK might owe Ghana a favour or two.’²⁷

A 2011 study of nine sub-Saharan countries:

The countries lost an equivalent of \$2bn through the doctors that had left to work overseas.

The UK benefited by the equivalent of \$2.7bn.

The USA benefited by \$846m.²⁸

Médecins du monde: ‘Deportation to a country where access to adequate healthcare is impossible leads to the serious deterioration of health and sometimes death and goes against the European Convention on Human Rights “No one shall be subjected to torture or to inhuman or degrading treatment or punishment.”’²⁹

There is no escape from these global circuits in contemporary care-giving. Dorothy Ngoma, head of the main nursing union in Malawi, believes that the 200-odd Malawian doctors in Manchester outnumber those in the whole of Malawi, a brain drain that Ngoma feels is the cause of the high rates of maternal deaths in her country.³⁰ For at least four decades, some quarter to a third of all doctors working in the NHS have qualified overseas. And the NHS is the largest employer of racially minoritized workers in Europe.³¹ It is more than likely that whenever we have been in need of care, or will require it in the future, it will be provided in some part by migrant and minoritized workers. These caregivers deliver our children, tend to our parents and grandparents, cook our food, clean our hospitals and bear witness to our naked emotional distress.

Others and planetary inequalities are already under our skin, a part of the very bodies we have become rather than something that we can easily isolate and expel.

Neither reducible to, nor separate from these paradoxes and injustices, the dying migrant who wheezes and coughs, walks, limps and wheels herself with me through these pages, is one whose susceptibility I do not want to tether to cultural difference, to a disease or to an overarching sociological category. Nevertheless, her frailty plays out in a world where bodily vulnerability is unevenly fabricated, distributed and defended against, forcing us to think twice about 'the seamless production of abled-bodies' in the global North.³² Palliative care is increasingly being recognized as a human right, yet at a global level 'A significant number of countries still have no hospice-palliative care provision'³³

To consider the stories in *Death and the Migrant* with the geo-social in mind is to encounter an interconnected world riven with strange temporalities and *eschatological extremities*.³⁴

In the Anglo-American worlds biomedical innovation – screening programmes, DNA testing, prognostication – is creating a foreshadowing of death. Taking cancer as her example, Sarah Lochlan Jain believes that we are 'living in prognosis'.³⁵ Prognostic time anticipates the future. But it does so through levels of abstraction and chance that simultaneously bring death close and make it impossible to grasp in the day-to-day unique living of a life. As Jain sees it,

Statistics seem to present us with a certainty, such as '1 in 207 women who are 35 years old will be diagnosed with Stage III breast cancer'. But it says nothing about who will represent the one, so it also carries the counterfactual hint that it might be somebody else ('why me?') . . . Like car-crash deaths or suicides,

the individuated counternarrative folds into the magical inexorability of the aggregate.³⁶

The strange logics of living in prognosis time take on another significance in the context of global health. In middle- and low-income nations, cancer can be lived as belatedness. In Julie Livingston's ethnography of an oncology ward in Botswana, the consequences and debris of belatedness are everywhere.³⁷ We find it in the failure of an international public health agenda to tackle the 'circuits of toxicity' (from food to nuclear waste) that are correlated with carcinogenesis. It is there in the atrophying of African cancer research. It bulges out from the crammed spaces of the oncology ward and its clinic, in the hours and hours and hours that people travel and spend waiting to see the doctor. It is thrown up in the restricted access to analgesics and symptom control – there is a lot of nausea, retching and vomiting in the ward because of the relatively high costs of anti-emetics.

And throughout all of this there is the business of care as improvisation and a deep sociality – care practitioners, patients and their loved ones, tinkering away, trying to bridge the incommensurables, offering each other sustenance, humour and hope at times of great precarity. Livingston is painfully aware of the paradox of how biomedicine can both alleviate and exacerbate health inequalities. 'And yet' she argues 'biomedicine functions as a necessary, vital, palliative institution in a historically unjust world.'³⁸

The World Health Organization estimates that every year 5.5 million terminal cancer patients suffer moderate-to-severe pain.³⁹

A survey of 76 countries between 2010–12, found that few countries provided all seven of the opioid medications that are considered essential for the relief of cancer pain.⁴⁰

Ninety per cent of the world's morphine is consumed by 10 percent of us.⁴¹



Figure 1.4 Opioids.

Courtesy: Nadia Bettega

In similar ways to Livingston, I am constantly reminded of the global value, histories and the vitality of biomedicine and social care. I have experienced and been affected by good and scandalously bad, inhuman care. The effects of both can spread out far beyond a death and into the lives of a person's loved ones and a community. In *Death and the Migrant*, I am interested in what good care is and in what it might be. And so I work from within the existing terms and philosophies of palliative care and its utopian philosophy of 'total pain' that recognizes pain as being physical, psychological, social and spiritual. Within the domains of total pain the bodily suffering caused by a tumour pressing on the spinal cord and the emotional loss of legs that can no longer dance a *gidda*, are (ideally) both recognized as pain and are administered to. Total pain also gives recognition to pain that gathers over a lifetime.

In 2011 in the UK there were:

220 hospice and palliative care inpatient units

3,175 hospice and palliative care beds

288 home care services

127 Hospice at Home services

272 day care centres

343 hospital support services.⁴²

The World Health Organization:

Palliative care improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support, from diagnosis to the end-of-life and bereavement.⁴³

I have come to think of total pain as being a care practice that tries to simultaneously discover, recognize and become receptive to manifold and unacknowledged situations *as* pain (see Pain). As I go on to explain, the thinking and aspirations of palliative care and total pain have shaped and inspired the methods, writing and stories in *Death and the Migrant*.

Mortal chorographies

Two central themes that recur throughout the book are those of sensuality and space-time, where I see diasporic forces at work in the scattering and redistribution of the senses. I am drawing upon and adapting the insights of the philosopher

Jacques Rancière⁴⁴ on political aesthetics here. Rancière believes that the value of artistic practices lies in their potential to intervene in and question existing ways of apprehending and partitioning the world. So in Rancière's notion of politics, life that has previously been 'invisible' or is just 'noise', is given form. At the same time the carving up and ordering of space is questioned as it is rearranged. This giving of shape to what previously was unacknowledged does more than expand the spectrum of everyday sensual life. It interrupts and dissents from what is 'naturally' given.

My approach in *Death and the Migrant* is somewhat different from Rancière's and is two-fold. First, I suggest that the rearranging of sensibility in diasporic dying and care involves exploratory place-making activities that create novel potentials for transnational and multicultural hospitality. Picture a small hospice ward of about 20 beds (see Music). Suddenly, the ululating of an African mother bursts through the ordered quietness. The nurse manager of the ward is in an impossible situation. She tries to work out a just and caring way to respond to and accommodate the acoustic torrent of grief as it bounces and rolls around her. She must also consider her other patients, some of whom are dying and can be hypersensitive to sound. Because she does not know how to respond on this occasion, the ululating continues, filling up the ward. Her disturbance, conflicting fidelities and shock get under her skin. She grasps for the first time the tacit cultural codes of the hospice. She finds herself thinking more deeply about care and the regulation of acoustic space in the ward. The thinking and uncertainty, the holding of unresolved beliefs and sonic impressions, the abeyance of action in relation to this particular family, are all a response.

Whether the hospitality of the ward is permanently extended or not is in many ways beside the point. The reassembling of acoustic space is a disturbance through which a new space is intuited and travels into the future, not only because the issue came up at the ward's next team meeting, moving up from there to the Senior Management Team, but also because the event birthed a new sense of the ward/world.

My second and related point is about method and representation, of how to allude to and trace what can have effects but is non-manifest. The stories that you will read have been produced through an evolving mixed-method approach – mainly narrative interviews, observation and participation – and activism and teaching in palliative care. The research ideas and plans that I started off with in projects have invariably been transformed and recreated out of the in situ encounters and demands of these different settings. There are experiences that I have missed, not only because of carelessness but also because life goes on

beneath the world of sensual surfaces and appearance. ‘Chorography’ is the best term that I have found to describe this ongoing creating and finding of method (and life) by working between the sensible and an orientation to what can defy sensual impressions and rational knowledge.

A quick google search will tell you that chora is an antiquated, now rarely used term. It was first used by the philosopher Plato to connote a divine spirited sense of space and place. Not so much a material place/space (a ‘topos’), but a sort of ephemeral milieu that delivers being and is resistant to definition. Julia Kristeva, a feminist psychoanalyst and philosopher, has described chora as being ‘analogous only to vocal or kinetic rhythm’.⁴⁵

Chorography then, is an artful practice⁴⁶ and as Gregory Ulmer suggests ‘has to be approached indirectly, by extended analogies.’⁴⁷ The space of chora is evocative. Like the small fish that I played with as a child in Sri Lanka, it slips through the analytic fingers. But the ‘problem’ of the existential dark matter of chora is very much practical.

To borrow and adapt a question from Ulmer: What might care or research/writing be when it does not rely upon what can be represented?

I already have some ideas about the chorography of end-of-life care. It is music thanatology and the sonorous embrace of a dying person by live song and harp playing at the bedside (see Music). It is the magical properties of a pressure-relieving mattress for a double bed that brings a couple some last weeks of sleeping together, a time that is unquantifiable (see A Cough).

So my approach differs from Rancière’s work on sensibility in the ethical possibilities that I give to choric spaces and to what is sometimes withdrawn from sensibility and superficial appearances. In *Death and the Migrant* you will also come across this withdrawnness with regard to time and the semiotic (how things are symbolized and named by signs/language).

At the time of writing, my thinking is that the withdrawn are realms of existence that are not only elusive⁴⁸ but can also never be fully recuperated by careful thinking, a new aesthetic or by a shuffling around of space. I discuss withdrawnness most explicitly in the chapter on researching pain. The point that is relevant to my argument here – and which I also owe to the palliative care philosophy and practical implementation of the total pain approach – is how what is withheld can incite the inventive bridging work of care as a chorographic practice that has to work with intuitive knowledge. This is a labouring that is distributed across all of those who participate in caring relationships – patients, carers and care professionals, spaces and objects such as rings, rosaries or mattresses.

The following story is Eileen's, a cancer Clinical Nurse Specialist. Eileen wrote the story during one of the sessions that I teach on narrative on a postgraduate course in palliative care. With clarity and economy, the story articulates the everyday demands of the withdrawn in caring for others. It was written as part of an exercise that I have been developing called 'A Patient who Made Me'. In this exercise I ask practitioners to write about a care experience that has affected how they care. Eileen's story is about a woman whose pain and short life she had found especially difficult to face. Eileen was organizing the woman's discharge from hospital and she had become preoccupied with the complicated discharge arrangements. She felt that she had been distancing herself from her patient, using the discharge plans as distraction and protection.

I went to visit a patient on the ward to plan with her her discharge home. She was 31 years of age and had advanced lung cancer with a prognosis of weeks. I remember feeling particularly nervous and sad when talking to her about the practicalities of her discharge.

Suddenly she touched my arm and said 'I have had a life you know Eileen'. I was taken aback as I suddenly realized that I had never discussed her life before her illness. I said to her through my embarrassment 'Tell me about it.' She recounted the most wonderful stories of her travels abroad.

The experience reminded me that people have had lives before illness. There is a whole other person/experience rather than just the illness.

I have had a life you know Eileen is one way of speaking about what is latent, but can sometimes be alluded to. The allusion in Eileen's story might intrude upon the present of her relationship with her patient but it is ultimately inaccessible, a lost place/time not only for Eileen but also for the dying woman herself. How does one ever fully apprehend let alone convey the life that you have had? This is the unknowable otherness within all of us that always has the potential to shock or to surprise ('Where *did* that come from?'). In a way the withdrawn are not unlike vegetative existential metaphors with unpredictable qualities, traits and capacities. And because the withdrawn do not lend themselves to representation or to definition, a rift between lived existence and knowledge or an evidence base opens up. Care as much as research and writing must proceed through inference and extrapolation.

These are complicated matters to think about in the abstract. They recur in different ways throughout the stories in *Death and the Migrant*, where they do not require theoretical thinking.

The book

In bringing together stories informed by my involvement in two decades of transnational dying in the United Kingdom, I am also bringing into the open the taking of time to live with stories and their affects. This is an ethical as much as a methodological stance and context is important. Methodological details and thoughts for those who are interested are in the Appendix.

There have been changes in end-of-life care, demography and social life since I began my research in the mid-1990s that have had impacts for dying people and care professionals. In order to convey something of these developments I have ordered the stories into a loose chronology. The chapters at the beginning of the book provide a context to the development of hospice care and palliative care in the United Kingdom and to the challenges that transnational dying can pose to care regimes. These stories are generally taken from the 1990s when migrants' palliative care needs and service use in the United Kingdom was becoming more widely recognized. It was a time when discussions about hospices as 'white, middle-class and Christian'⁴⁹ and the need to 'widen access' to palliative care were also gathering impetus.⁵⁰ The chapters towards the end of the book are from more recent projects and draw from my on-going involvement in palliative care education.

There are four relevant changes that I have witnessed in the intervening years, aside from the increased numbers of migrants and racially minoritized people who are in need of palliative care. First is a growing diversity of palliative care staff and hospice volunteers (in the past, the latter were often referred to as 'formidable ladies'). The second has been in the expansion of provision of palliative care by generalists and its extension to those with non-malignant conditions such as dementia, cardiovascular diseases and respiratory disorders. Third is the use of polymedia such as smart phones, instant messaging and social networking sites by patients and carers that is transforming transnational living and dying.⁵¹ And the fourth is in care in the home.

With new opportunities opening up in care markets for 'culturally sensitive' care provision, novel segmentations of care industries along the lines of ethnicity, language, faith and gender are taking place, fortified in the United Kingdom by a social policy agenda of personalization and devolved 'direct payment' care funding schemes. Those in need of social and personal care now have some choice over how to spend their personal care budgets – if they are fortunate enough to have them. Migrants are being employed by migrants and also their long established

kin, with the former often living between two countries, producing a convoluted economics in the giving and receiving of care and resulting in care deficits in low- and middle-income nations.⁵² Despite care being big business globally it is low-paid, low-status and vulnerable work,⁵³ especially when it involves hands-on care or what is called ‘body work’⁵⁴ (see Home). It remains an ephemeral presence in economic and development policies and in the cultural psyche.

More palliative care services are also now employing interpreters, advocates or *cultural liaison* workers to support care to those who do not speak English. And *health promoting* palliative care is using new public health approaches to work with and learn about death from communities.⁵⁵ These approaches are subverting the conventional flow of good practice models from high-income nations to those in low-resource countries. For example, the Neighbourhood Network in Palliative Care is a community-led initiative, providing home-based palliative care in Kerala, South India. The service sees over 2,500 patients per week, covering over 60 per cent of people in many areas.⁵⁶ It has a simple aim: no one should die alone.⁵⁷ A report by the independent think-tank Demos has recommended that a similar scheme is adopted in the United Kingdom so that more people can die at or close to home.⁵⁸ Despite such developments, those who work in specialist palliative care are still overwhelmingly white, particularly outside of cities and in senior management. Often in meetings, I am still the only person of colour in the room.

Not so long ago, a hospice in the north of England was planning to relocate its in-patient accommodation and headquarters closer to the city centre. The Medical Director tells me that for all of their service innovations and campaigns, the relocation has had the single most beneficial impact in widening access to hospice care to people from different cultural backgrounds. Before the relocation, she had sent out questionnaires to General Practitioners and district nurses to garner their views and opinions on the potential move. One questionnaire returned by a district nurse was against the plans. It came back with a question of its own ‘Who wants to die amidst syringes and mosques?’ So please do not take my ordering of the chapters as a smooth narrative of progress.

Body and community’ Zygmunt Bauman writes ‘are the last defensive outposts on the increasingly deserted battlefield on which the war for certainty, security and safety is waged daily.’⁵⁹ Despite social and technological changes, I cannot imagine that the cultural significance of the body will change dramatically. Corporeality may be dispersible and subjectivity immortalized by the click of a finger, so that digital death, bereavement, inheritance⁶⁰ and hoarding⁶¹ are now end-of-life predicaments in the global North, but we cannot get around the

materiality and symbolic value of the body, even when it is fading. As Margrit Shildrick and Janet Price argue 'Embodiment finds new forms, but it does not disappear'.⁶²

I have written *Death and the Migrant* with the hope that it can allow you to read, use and move through the text and images in different ways. You can approach the book as a compilation of short stories about migrant lives and end-of-life care where there is an interweaving of oral history and contextual detail. Some of the stories might resonate with your own experiences or at least stir points of contrast and dialogue. You can also read the book as a fleshy account of geo-social politics from below. A different way of approaching scholarly concerns and debates about the body, transnational lives and multicultural hospitality. The chapters towards the end of the book on pain and the Epilogue are the most sociological. If you are a care practitioner I hope that the book will have relevance to your everyday work and dilemmas, adding other perspectives to policy, pedagogic and clinical initiatives that aim to improve care.