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Failing, Falling

About ten or so years ago, Denise Brady, the librarian at St Christopher's Hospice, showed me an extraordinary article. The paper, by Margaret Clarke, Illora Finlay and Ian Campbell, published in 1991 in the journal *Palliative Medicine*, is a compelling, short account of the end-of-life care of a recent migrant to Wales. The article opens with a salutary warning, insinuating discomfort in the palliative care reader from the offset 'It is easy to develop a complacent smugness about our caring' the authors write; the implication being that the acute vulnerability of dying can render patients and their loved ones overly grateful and uncritical.¹ For these wounded healers, it is the failures of care that are the most instructive.

The story, told in just three pages, is about a Korean family that spoke some English and where the mother, who was the patient, spoke none at all. She had undergone a mastectomy in Korea four years previously, but there was no paperwork from her doctors so it had not been possible to establish what the mastectomy had been for. The woman had had one dose of chemotherapy in the United Kingdom, which was presumed to be for a recurrence of breast cancer. She appeared to have refused further treatment or follow-up care.

When the hospice consultant visited the family, on the request of the patient's General Practitioner, the woman 'was lying flat on a board on the base of a single bed. She looked frightened and had obvious pain on movement'. Her husband did not believe in Western medicine and had been administering faith healing. This had included the whole family fasting over the preceding three months. They ate fresh fruit, no animal products or vegetable carbohydrates. The three children aged five, 11 and 13 had been allowed bread and boiled vegetables. The husband consented to a hospice admission on the condition that the fast continued and that his wife would not be given any drugs.

An image of the woman's chest X-ray on admission to the hospice is included in the article. It is described as showing 'multiple cavitating lesions with apical scarring consistent with advanced pulmonary tuberculosis'.² Analysis of the mother's sputum was negative for acid-fast bacilli and for malignant cells. 'Her country of origin, the lack of documented histology of the mastectomy and her clinical state suggested a possible diagnosis of TB', the authors tell us. During the early days of her hospice stay, the husband had continued to refuse analgesia on his wife's behalf. He subsequently agreed to one mg diamorphine intravenously every four to six hours and to liquid vegetarian dietary supplements. Communication with the family was impeded by language differences, further compounded by tensions with local interpreters whose help they had rejected on previous occasions.

The woman was given antituberculous therapy and improved during the first four days of treatment. She collapsed suddenly on the sixth day 'becoming rapidly shocked, clinically comparable with a Herxheimer reaction' (where a body eliminates toxins at a fast rate). In the last hours of her life the family sang hymns. When close to death they tried to revive her 'by rubbing her arms, hands and legs and shaking her body vigorously'.

The doctor and duty nurse remained with the family as much as possible during these last hours of her life. Both were weeping silently. When this was noticed by the eldest daughter a few minutes after the mother's death, she ceased screaming, allowed the doctor to hold her hand and the three children and father together with the doctor and nurse sank slowly to sit on the floor around the dead woman's bed.³

A post-mortem examination showed extensive cancer in the woman's lungs. There was no evidence of tuberculosis.

Confusion and chaotic distress saturate the account of this death as the authors retrace and question their clinical decisions and actions and the effects of differences in culture and language. It is in this episodic reliving of the technicality and phenomenology of care that cultural difference takes shape. It gathers form in the clinical investigations undertaken, in the diagnosis making, the negotiations about pain-relief and nutrition. It emerges in beliefs about health, medicine and pain, food, family relationships and death rituals. And it is there at the time of death, when words and professional protocols fail, drawing together in distress the family and the care professionals.

As the opening of the article forewarns, the storying of this death speaks to the very meaning and purpose of palliative care. Departing from the standard

structure of academic journal articles, the paper ends with a 'Comment' rather than a 'Conclusion' section suggesting that this experience could not be neatly rounded off or assimilated. The inclusion of the woman's chest X-ray was perhaps a way of supporting and evidencing the team's preliminary diagnosis of tuberculosis to the wider palliative care audience. But with the accompanying narrative, the image is more poignant than technical, bearing witness to a life, suggesting layers of submerged meaning.

Inklings

Radical doubt and uncertainty are not unique to cross-cultural palliative care. They can surface in situations where routines of care become ineffective, where trust and communication breaks down and professionals have to work out and improvise not just what to do, but also what kind of care they want to create and be a part of.

Feelings of jeopardy and failure in transcultural care – especially when there are cultural and language differences – can produce corrosive insecurities. These insecurities do not seem to have changed in the years since Clarke, Finlay and Campbell first publicized their experiences. How to judge the appropriateness of your care? What changes should you make to care protocols to accommodate different beliefs and values? Should care augment men's authority in the name of cultural sensitivity? How do you know whether your care is oppressive or violating?

There are objective measures and care plans against which professionals can begin to judge the quality of the clinical aspects of their care. Pain and symptom alleviation, for example, or improvements in breathing, movement, bowel function or appetite can tell you if you are on the right track. With culturally responsive care, judgements become more subjective, sometimes visceral. 'How do you know when you are providing good care?' I sometimes asked care professionals in the *Stories That Matter* project.

'It's very intuitive.'

'You kind of try and tune into what's going on.'

'You might have had an inkling.'

In one multidisciplinary group interview in a hospice there was laughter and nods of recognition to the phrase 'We're in' from a social worker describing moments of connection with his patients. 'I think sometimes we come out of,

say a first visit and say “We’re in” . . . and whether it’s body language, I don’t know what we’re picking up’.

And of course when you do not know what you are picking up on there is uncertainty. Professionals are able to tolerate and explore the unknown of intercultural care giving. Sometimes they need more. Joyce, a white British nurse in a community palliative care team, believes that good care can be better achieved with patients who are ‘open and honest with us about their culture’. Joyce made her point with a story about an Indian, Hindu grandmother who was dying at home. For some Hindus, lying on the floor to be closer to the earth is a part of death rituals.⁴ It was a practice that Joyce was unaware of at the time.

. . . when she [the patient] was very poorly, the nursing profession wanted to get her into a bed, but she insisted on sleeping on the sofa and the background to that actually was that the sofa was very much nearer the floor than her bed would have been, which is where she needed to be, but none of us knew that and that caused horrendous frustrations and difficulty. If we knew that from the beginning, we could work with her.

Yasmin: How did you find out about that?

I think it was the district nurses that established that in the end. But who told them or how they got it out of the family, I don’t know. It was probably the granddaughter who’s actually involved in the care as well and who was very Westernized, so she might have, I don’t know.

Nursing With Dignity,⁵

(an online training unit produced by the Nursing Times)

Hindu religious belief begins with the assumption that all living things have a soul, which passes through successive cycles of birth and rebirth

A dying person is placed on the floor on a clean sheet or mat, symbolising closeness to Mother Earth, freedom from physical constraints and the easing of the soul’s departure.

Cultural difference in Joyce’s story is animated through the practical activities and demands of home care, where space is restricted and interpreters are not always available. You come into a house and you see a dying person on a sofa and not on a bed for the first time in your nursing career. How do you respond using your personal and professional knowledge while remaining open to other perspectives and values? How do you communicate with a patient and their carers, about the conditions that you feel are most amenable for the setting

up and maintaining of syringe drivers and catheters that can help to alleviate symptoms, while not imposing these conditions upon them? What happens to the partnership and 'working with' aspirations of contemporary care that aim to promote enlightened patient choice?

There is a moral high ground in Joyce's story. Dying on a sofa designates this body as different. The difference is charged. It becomes an obstacle to care routines and expectations. Having a body at a more elevated height, with face, arms and legs accessible and not burrowed into crevices and corners, facilitates but certainly does not preclude pain and symptom control. Joyce's third-person distancing (*the nursing profession wanted to get her into a bed*) authorizes a technical rather than an arbitrary rationale behind the expectation of where patients should do their dying. It is a rationale that for Joyce includes the logic of the nurses needing to have knowledge of different cultural beliefs and practices in order to provide culturally sensitive and competent care.

But what if the patient or their carers do not know what you need to know? Or they do not know what you do not know? The answer for Joyce is 'horrendous frustration' turned against the family as the keepers of the Holy Grail of cultural knowledge that she thinks she must have in order to provide good care.

The high wire

That an ill person and her carers should be *open and honest* about their culture/ religion in order to receive good care is another way of saying that some people are to blame for bad care.

Joyce is not alone in her belief that cultural knowledge leads to good intercultural care. This is a pervasive logic that informs policy recommendations and training resources on 'cultural competence' where professionals are encouraged to increase their awareness of different cultures and faiths. Although there is little agreement as to what culturally competent care is,⁶ a common theme in the literature, debates and training resources is the need for practitioners to have some knowledge of the beliefs, traditions and practices of different cultural groups. 'I think we do need more information about cultures', a hospice nurse says, 'so that we can relate to people even more than we're doing at the moment, so we are really trying.'

This confidence in group typifications as a way of understanding the individual characterizes modern knowledge systems that operate through categories, codes and statistical probabilities. It is an approach that informs the science of epidemiology and public health, risk assessment and the prognostications that are made about our lives and deaths. In increasingly sophisticated and digitally augmented forms, the coding of human life into bio and geodemographic data is proliferating under information capitalism. Data from surveys and commercial sources are routinely used to get a sense of the *kinds* of people that we are⁷ – perhaps at risk of diabetes or breast cancer, or more banally ‘Affluent Greys’, ‘Aspiring Singles’ or ‘Struggling Families’ with certain consumer and lifestyle habits.

Typifications generated by different software are already prevalent within medicine and are stalking intercultural care. There is now a tool used in the commercial sector called *CultureGPS* – a menacing but ironic homonym. The tool claims to help users ‘to analyze visible behavior differences in intercultural encounters and to predict to a certain degree, which interactions evolve when people from different nationalities meet’⁸. The app does not actually use GPS technology (Global Positioning System). Its five-dimensional model of national cultures is based upon survey research and not satellite navigation technology. But how much the naming of this little app says about how cultural difference as distance and as an unknowable, dangerous terrain is imagined and sometimes felt.

Over the years I have become accustomed to hearing a recurring metaphor of intercultural care as what I can best describe as intuitive, precarious footwork.⁹ ‘We’re walking on a bit of tightrope’ a hospital-based social worker says. For a specialist palliative care nurse working in the community it is the walking of ‘a fine line’ between knowledge and nescience. As he sees it,

you don’t want to offend, but you don’t want to appear ignorant either. So it’s a fine line you walk actually and sometimes it’s just a gut instinct that you’re in there and sometimes you get a window opening of something and you just go with it . . .

And if something does not *open* up for you, there is the immobilization of fear to wrestle with. A hospice social worker says that not making assumptions about cultural beliefs and practices and asking questions ‘just frees up the whole thing, there’s less of a sense [of] . . . treading so warily that I’ll jam-up completely’.

Intercultural care as tightrope walking.

A sensual moment-by-moment balancing of

	uncertainty	faith
knowledge	risk	skill
	intuition	

An insecure unfolding of care as a ‘thinking on one’s feet’,¹⁰ and all the time underwritten by the risk of absolute

and spectacular failure

that can come with a

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As reassurance, hope, a balance pole or a safety net, cultural competence has the qualities – with an anthropological and postcolonial twist – that the sociologist Anthony Giddens has described as an ‘abstract system’.¹¹ Abstract systems, for Giddens, are a consequence of modernity’s drive for control amid accelerated social and technological change. They offer a quixotic fantasy of dominance over the unceasing churn of social life by promoting routinized practices. Abstract systems are a ‘protective cocoon’ excluding, deferring or dissolving difficult moral and existential questions.¹² Do not use up your energy thinking, questioning, fretting and worrying; just follow the protocol or tick the boxes. Giddens calls this giving away of moral responsibility the ‘sequestration of experience’.

Not-knowing

In the rationale of cultural competence, situations such as those described by Clarke, Finlay and Campbell could be avoided or at least could be less devastating if practitioners had knowledge – or now more likely profiling information – about Korean cultures. But what useful information or aggregate statistical probabilities, however meticulously gathered and assembled, could practitioners receive from books, pamphlets or their smart phones that could have enhanced the care of this family?

As Clarke, Finlay and Campbell suggest although cultural identity and practices are often approached as a constant – assumed to be continuous across

time and space, shared by groups and by families – as experiential knowledge and day-to-day living, culture is more disjunctive, pragmatic and feral. In relation with disease, the process that is lived culture not only resists, but can escape from the indexical clutches of culturalist knowledge. And no more so than at times of fast-moving crisis. Over the course of caring for the mother, the practitioners' understanding of what was happening, what was causing what, unfolded recursively. The effects of cultural and language differences became shifting simultaneities alongside the advancing disease, clinical practices and palliative care beliefs about what constitutes good care and a good death. And so in their commitment to learn something from the family and the temporary collapse of professional expertise and authority, they end up with more questions than answers.

... was it right to admit her to the hospice rather than obtain a domiciliary chest X-ray at home in an attempt to clarify the diagnosis? If this had been done would it have altered our action? Should we have attempted to contact Korea ... to obtain details of her histology? Can the hospice team insist on trying to provide analgesia against the family's wishes when the patient cannot express her own wishes? How can we prepare the family better for the death without language or similar culture? Knowledge of a country may not represent the subculture and religious denomination from which a patient comes.¹³

Care practitioners, educators and policy makers are not dupes. They know about the dangers of reductive thinking, of seeing complicated effects as the result of a single cause, or of taking culture at face value. They often talk about the importance of taking time to get to know each patient and their carers, of being open to the idiosyncrasies, cultural hybridities and the paradoxes of the living out of culture and faith. A doctor says that he tries to put himself in the position of his patients when it comes to intercultural care.

I think most of us choose to step out of our cultural context. I do ... I deviate wildly and if I was in a country or I didn't speak the language and somebody from my culture came along and said ... 'this is how we do things in our culture' that may be very, very different to how I would have chosen in that situation and I think we need to assume that other people in cultures with which I'm not familiar may choose to do the same thing ... I don't want to work in a way that doesn't allow them to make that choice.

'I think we need to guard against "I've read the Ladybird book of religion and therefore I know what Muslims want"' says a hospice social worker, parodying

transcultural training resources as the books that introduce children to reading. She continues ‘Everyone lives out their faith differently anyway, so in some ways it was better not to read the book at all and say “How do you want this done for you?”’

Asking a sick person and their carers ‘How do you want this done for you?’ as I understand what this social worker was saying in the context of the wider conversation, is the beginning of a process and not what the Dutch philosopher AnneMarie Mol has dubbed a ‘logic of choice.’¹⁴ The logic of choice is ubiquitous in contemporary care systems in the global North where patients have been reimagined as customers and consumers. The neoliberal logic of choice does not recognize how disease, depletion, fear and anxiety can make it difficult to choose or to be an active partner in care. Which is why palliative care doctors are not so easily unsettled by the injunction ‘You decide, doctor’.

‘Choice’ Mol insists ‘comes with many hierarchical dichotomies that are foreign to care: active versus passive; health versus disease; thinking versus action; will versus fate; mind versus body.’¹⁵ The trouble with dichotomies is that some people will always end up on the wrong side. In contrast, the logic of care, Mol tells us, arises from responsiveness to the ongoing practical activities and constantly changing demands of living with disease and caring for diseased bodies.

A clear message from Mol’s research is that good and responsive care involves the public telling of rich stories about care, including stories about mistakes and catastrophes. It also demands the creating and nurturing of spaces where bespoke care approaches are allowed to emerge and critical thinking and resilience can be supported when care fails – as it inevitably must.

improvement begins with the recognition that something needs to be improved. That not everything is as it should be. It fits with the logic of care to attend to frictions and problems. To acknowledge that some things do not work well, no matter how well intended they may be. This suggests an entirely different accountability practice.¹⁶

We failed this patient and her family Clarke, Finlay and Campbell say to the palliative care community. We do not fully understand what went wrong. We do have all the answers. But we will keep trying to understand. And so must you.

The accountability practice that begins to figure in the story of this case partially inverts the rationale of cultural competence. But it does not decentre the cultural values of palliative care. Cultural difference is produced as a strain and stress, an undermining of seemingly universal ideals of good care. When ‘ideal

standards cannot be attained because they do not correspond with the wishes of the patients and family' Clarke and colleagues write 'respecting the patient's autonomy puts a greater emotional stress on all members of the team'.¹⁷

Such a stance is truthful in its ambivalence. It is also silent with regard to its normalizing: how the privileging of autonomy is itself a cultural value as indeed are ideas of a good death as being pain-free, if sometimes insensible. It says little about how care can become complicit with myriad oppressions within families, or of how competent care might sometimes entail intervening in a status quo. At the same time there is a tentative questioning of care as an active doing and fixing¹⁸ and a pointing to the singularity of the situation that demanded a responsiveness that the practitioners felt unable (perhaps, 'incompetent') to provide, rendering them in many respects passive.

Sayantani DasGupta, a physician in the Program in Narrative Medicine at Columbia University, has named this vulnerability to the singular demands of patients as 'narrative humility'. For DasGupta, narrative humility is antithetical to cultural competence approaches that can become 'a sort of cultural mastery of marginalized communities'.¹⁹ In contrast, a disposition of narrative humility, for DasGupta, can help a practitioner 'to place herself in a position of receptivity, where she does not merely act upon others, but is in turn acted upon'.²⁰

The psychoanalyst and social work educator Margot Waddell has thought of the negotiation between activity and passivity in care as a difference between 'servicing' and 'serving'. Waddell believes that the ability to offer a receptive presence to evacuations of distress, anger and pain requires the negative capability of 'serving' rather than the frenetic activities of 'servicing'.

'Servicing' urges itself as a substitute for 'serving' because the not-acting of serving brings us in contact with feelings: feelings which are very hard to bear – the conscious phenomena of unconscious psychic pain . . . It may be more comfortable to be doing something, whether it is writing a prescription, making an interpretation, arranging a visit, than not doing so – although *not doing anything* does not constitute *doing nothing*.²¹

In the writing of the philosopher Emmanuel Levinas, passivity in encounters with the Other is an ethical relation in which Otherness always exceeds total knowledge and understanding. In a reversal of the logic of cultural competence, a vital feature of the ethics of the self-Other relation for Levinas is that it is not dependent upon understanding or shared experience as the foundation for responsibility. Passivity in a Levinasian schema involves something more than simply being the opposite or absence of activity. As the capacity to be moved,

touched and affected by the predicament of an Other, it becomes an opening to new ways of being with/for Others – without which it might be said there would be no desire or impetus for new forms of practice or indeed the pursuit of ‘competence’.

Approaching caregiving with humility has repercussions for technical knowledge as much as for interpersonal relationships between clinicians and patients. As Julie Livingston’s ethnography of an emerging cancer epidemic in Botswana has shown, what cancer is crystallizes between clinical interventions, resources and practices, the patients’ own bodily experiences and beliefs about disease and pain, and public discourses about the disease.²² The molecular, cultural and emotional event of one person’s cancer is not the same as another’s. Each will require a different care.

Recognizing the vitality of disease and of patient experiencing, reinstates care as an adventuring, my colleague, Monica Greco, argues. It includes holding the tension between knowing and not-knowing, or more accurately as Greco describes it ‘knowing that you *can* give, without knowing the positive content of the aim of that giving’.²³

In the skin of a lion

Matters of cultural difference in care are difficult to raise in the manner that Clarke, Finlay and Campbell have articulated them. It is even more difficult to talk about racism. Racism is the monster in the room in British palliative care teams and institutions.²⁴ Racism is an ‘unhappy’ signifier for the feminist theorist Sara Ahmed. It is a toxic, miserable little word that threatens to undermine the good feeling within institutions. It is far easier, much nicer, to talk about ‘diversity’ and ‘good practice’. ‘But what if the good – good feeling, good practice, positive stories – is what keeps our attention away from the bad’ Ahmed asks, ‘from what hurts, from what gets under the skin . . .’²⁵ For Ahmed, it is the black woman who voices her anger at racism who is the iconic killjoy, contaminating teams and organizations with bad feelings.

In palliative care it is social workers that are the killjoys. They most often interrupt the ‘complacent smugness’ that Clarke, Finlay and Campbell describe so aptly, that can run through palliative care cultures. Professional training in Anti-Oppressive Practice²⁶ means that social workers can be more cognizant of social inequalities and of how histories of racism and other injustices can affect care. They talk about racism more. And they talk about their feelings

about racism more, making explicit the feeling work or emotional labour of multicultural caring. When they are white and Anglo it can be this acute awareness of racism that can impede good care. 'I feel so ashamed and guilty', they say. Or 'I fear triggering rage and fury about white people's history of treatment of black people'.²⁷

Racism and cultural insensitivity as bad, sub-optimal care can be stark. More often than not it is blended into other deficiencies in organizational resources, disciplinary cultures or care protocols, so that it is felt in the mortar as much as in the architectures of care. Care practices may not look so different, but they *feel* different; the connective tissues can be weaker or more electrifying. Care is still administered, practitioners say, but it is more pared down, less holistic. If you are anxious or fearful you become less daring, less willing to take risks in case you get things very wrong and fall off that tightrope. 'I was thinking of a black family and the mother who's ill and she's very closed down' says a hospice social worker.

I don't think that I challenged that in her. I couldn't take the risk. I feel very aware around black, Afro Caribbean culture, around respect being very, very important as well as not being clear about the rules and boundaries and the cultural etiquettes around that. But I wonder if that's also me being frightened of actually saying 'Look you're very phlegmatic. You're very philosophical, but I actually don't believe that you aren't sad about the prospect that you are going to die and you're not worried about your son'. So I do wonder if I would have been different with a white person.

Even when ethnicity and language is shared other differences can adversely affect caregiving. 'I wouldn't even dream of asking a question about sexual intimacy' a bilingual health advocate reveals to the surprise of her colleagues, 'that would be one of the disadvantages (of shared ethnicity) . . . going to see an elderly Asian patient with prostate cancer. If you had a particular list of questions you're supposed to ask, I couldn't ask the question about his sex life.'

High-quality and innovative care involves risk-taking; trying something new and different; challenging patients, carers, colleagues and one's self; following intuitive hunches, wandering/wondering outside of established pathways and routines. Palliative care is a specialty that seems most hospitable to creative and quirky risk-taking, and professionals are not averse to making public their experiments. A French psychologist writes of playing Schubert's *Ave Maria* sung by Jesse Norman for a patient during a painful procedure.²⁸ A Japanese doctor shares his not uncommon practice of writing personalized traditional Japanese

poems (tanka) for his patients.²⁹ A British palliative care social worker who after years of trying very hard to acquire expertise through established protocols, is open about relaxing her desire for structure and certainty. 'I am now comfortable to work with mystery, to wait for the unspoken to emerge, to work with image and metaphor.'³⁰

One of the ways in which I think racism operates in palliative care is through a constriction of these adventurous spaces of caregiving. It is not just that migrants and racialized others can receive the worst forms of care, although I have little doubt that this can happen. It is also that some of the most vulnerable and the most 'different' of patients – recent migrants, those with limited English or without a family advocate³¹ – can be the least likely to benefit from practitioners tightrope walking their way into innovation and risk-taking. This can happen without consciousness. And it can happen through a twisting of very different ideas about unbridgeable differences. In what has been described as the 'new', 'cultural' or 'second degree' racisms, a fundamental incommensurability of lifestyles and experience that closes down the possibilities of relating to others.³² In the ethical philosophy of Emmanuel Levinas, it is the desire to bridge what is incommensurable that is the opening up of an ethical relationship and a new undetermined future. Dikeç, Clark and Barnett elaborate,

What Levinas reclaims and makes central then, is the very receptiveness of one person to an Other, that capacity an embodied self has to take its inspiration from what it perceives as the needs of an other self, an other body. His hospitality, we might say, proceeds from that *vertiginous moment* when one feels *bound to the other* – the moment that makes possible that ever risky tipping together of unfamiliar lives.³³

This is another perspective and recasting of the fibres and textures of the tightrope of intercultural care.

Elspeth, a hospice social worker, has a story about this sort of tightrope walking. 'I feel my knowledge is not as good as it could be' she began, prefacing her story of an Afghani patient who had told her 'terrible things' about his life and flight from Afghanistan. He had talked about himself as a lion, responsible for protecting his family from danger. At the same time he had felt guilty about surviving and leaving Afghanistan to come to the United Kingdom as an asylum seeker. Talking about all of this with Elspeth had been distressing.

Later, Elspeth was confronted by the patient's angry son 'You don't understand our culture. You mustn't talk about these things', he told her. 'You brought up things which should never be brought up.' Elspeth tried to reassure the son that

she had not been the one to bring things up. 'But he was very angry' Elspeth said, 'although interestingly, he then asked me if he could come to counselling, feeling that it would be more helpful to him, but his father shouldn't speak.' Elspeth felt so bad after this encounter that she did not return to see the father who was deteriorating and died shortly afterwards.

Elspeth's two social work colleagues responded to the story at this point. One spoke of the complicated family relationships that are involved in such cases and the difficulties of working across generations with different views and values – which also happens with white British families, she reminded them all. Using sexuality as an example, Elspeth's other colleague acknowledged how working with threatening topics and offering opportunities to talk can be particularly difficult at the end of life when sensitivities are heightened. So difficult, she suggested, that 'it can sometimes make you scared to offer those choices. Is that going to be imposing?' This conversational and imaginative pacing backwards and forwards between the familiar and the strange, the comparing and the contrasting, the recognizing of how fear and anxiety can affect all care encounters, shifted something in the conversation. When Elspeth next spoke she was more able to articulate some underlying fears.

I think we have all been trained . . . to ask questions [but] . . . there's still the sense that we are white and British and that . . . can take away our voice . . . because . . . we're holding guilt that we have abused people in the past. I mean racism. I mean . . . when you are sensitive to other cultures, it can actually have the opposite effect of making you so sensitive that you have no voice anymore. And I think there's something about having to take risks, both being curious about what's going on for that person and asking the questions, but being careful as you do it.

That awareness of history, of social differences and of racism should derail care in this way is a tyrannical underside to some transcultural care pedagogies, where a lack of knowledge and awareness is what is thought to stand in the way of responsive care (as it sometimes does). Elspeth seemed to be getting at and demonstrating something more: how in social work the capacity to be undone by the weight of postcolonial guilt and related feelings of fear, shame, anger and inadequacy – the capacity to be rendered incompetent as it were by a heightened political sensorium – can become an emblem or perhaps a side-effect of a certain racialised professional integrity.

Such twists and turns in the emotional life of racism have been themes in black feminist scholarship and activism where guilt and unexpressed anger are recognized as the stuff of deflection and defensiveness, impairing the creation of

a meeting point across differences. 'Guilt and defensiveness are bricks in a wall against which we all flounder' Audre Lorde wrote in her pioneering essay *The Uses of Anger*.³⁴ For Lorde, it is anger that is transformative, an affective terrain that 'implies peers meeting upon a common basis to examine difference, and to alter those distortions which history has created around our difference'.³⁵

Care is a face-to-face, body-to-body encounter. It is without doubt supported and enhanced by science and rational knowledge. The trouble with care is that it is also stubbornly non-rational. Emotions, feelings and sensibilities for all involved can ruffle the surfaces of an interaction, resisting, betraying, inflating, colliding with and burrowing under everything that has been learned in a training room or from reading.

I often find myself thinking about the emotional costs of the patriarch as lion for both the father and the son in Elspeth's story. How both men seemed to express the pain and pressures of breaking from the constraints of this version of invulnerable masculinity in the last days of their lives together. Their desolation and loss, their different ways of trying to bring some order to tragedy, were possibilities crowded out in Elspeth's narrative by her guilt and feelings of inadequacy. She did not seem to consider that it might have been the very differences of age, gender and culture that brought the father to this thoughtful and sensitive young woman, and that helped him to prise open the 'things that mustn't be talked about'.

That evening after the interview, I received an email from Elspeth. She says that her head has been full. It was good to talk and to listen; they do not often get that opportunity. The issues are so complicated. She knows there are no short cuts, that failure, mistakes and difficulties must be faced, not run away from. She wants to learn more about racism and about her own feelings and responses to racism as a white woman.

The fragile missive suggests other textures and worlds in walking a high wire.
Jeanette Winterson

I live in the space between chaos and shape. I walk the line that continually threatens to lose its tautness under me, dropping me into the dark pit where there is no meaning. At other times the line is so wired that it lights up the soles of my feet, gradually my whole body . . . and I see then the beauty of newly created worlds, a form that is not random. A new beginning.³⁶