

## Care, Kidneys and Clones: the distance of space, time and imagination

Sarah Atkinson

Department of Geography and the Centre for Medical Humanities, Durham University

‘We lived, as usual by ignoring. Ignoring isn't the same as ignorance, you have to work at it.’

(Margaret Atwood in *The Handmaid's Tale*)<sup>1</sup>

Care as a concept is central to any engagement with health, ill-health and the practices that aim to prevent, mitigate or cure, and the term itself is mobilised in a variety of different ways and at a variety of different scales. The vibrancy of the medical humanities as a relatively new field of enquiry has principally derived from the elaboration of experiential accounts of differential and dynamic conditions of health. Given this particular emphasis, attention to care and caring practices has predominantly concerned the nuanced and complex relations of care at an inter-personal and proximate scale. However, in contemporary landscapes of health care, given the resources for caring for ourselves or for those whom we cherish in our immediate environment are often scarce and demand greatly outstrips the supply available within a national system, increasingly health care resources are sourced globally: from the migrant care worker<sup>2</sup> through to the transplant tourist.<sup>3</sup> A major challenge, then, for an expanded and more critically directed field of medical humanities is to extend the geographical reach to renegotiate encounters with the central concepts of our field at different spatial and temporal scales. Several chapters in this Companion take up the challenge to develop medical humanities as globally situated and with critical attention to the uneven flows and distributions of resources, including those of power and care.<sup>4</sup>

This chapter explores the dilemmas, paradoxes and challenges in how we care at a global scale with reference to the unequal availability and accessibility of transplant technology. In the medical humanities, we often draw our insights from imaginative literature, a source which can be read in many different ways. As a social scientist examining the practices and tensions in care at different scales, my reading of imaginative fiction attends specifically to the issues, rhetoric and modes of argumentation mobilised or disclosed within different imagined scenarios. And unlike much of the emergent work on global medical humanities, my focus is not on the historical and post-colonial roots of current global inequity and treatment of differentiated bodies as the ways in which access to new technologies follows established inequalities is already well documented.<sup>5</sup> Instead, I attend to existing and possible future rhetorics of care in relation to the relatively recent technology of organ transplant. In particular, I draw out the tensions in deciding for whom we care, and for whom we do not care and argue that the privileging of some bodies over others requires explicit rhetorical, discursive and enacted strategies for both caring and not caring.

### **The case of the transplant tourist**

Autobiographical narratives offer nuanced accounts of the experiences of altered health and of the author's journey in seeking health care provision. Such accounts furnish mainstream medical humanities with a 'database' of experiential knowledge from which to redress the invisibility of those actually living with conditions of ill-health prevalent in traditional medical and educational accounts. However, first-hand accounts of the experiences of sourcing medical care through a global market are few. *Larry's Kidney*<sup>6</sup> is a rare autobiography of transplant tourism recounted by Daniel, who has been asked by his cousin Larry to accompany him in seeking a kidney illegally in China. The focus in this account primarily on the experiential aspects of their journey reveals how such accounts may occlude

ethical aspects. Daniel nods towards the ethical concerns of Larry's quest only twice in the account, making clear he has decided to shelve his reservations and respond to his cousin's request. It falls to an expatriate in China to voice objections, "I'm just against checkbook medical tourism," he declaims flatly. "There are two million people waiting for organs in China. It's repugnant for cowboys to come in and try to jump ahead of them."<sup>7</sup> In response, Daniel effectively asserts that any care related to unknown others is trumped by care related to those we know intimately, "All I'm saying is that under ordinary circumstances I might be tempted to be dogmatic too," I tell the man. "But when it's your own relative's life on the line, you tend to see a few more shades of grey." and, "Well, I'm suspending all ethical considerations because he's my cousin."<sup>8</sup> Despite Daniel's declaration that he's going to effectively shelve worrying about the wider ethical concerns in favour of the intimate care for his cousin, he also works at ignoring the issue through a justification grounded in different cultural ethics, "But here people don't have the same general attitude against it that there is in the West. It's not frowned upon ethically the way it is in much of your United States."<sup>9</sup>

### **Scales of Care**

These few quotations from *Larry's Kidney* indicate a tension between different scales and practices of care, but this is a tension explicitly ignored in preference for attention to practical and emotional experiences.<sup>10</sup> The emerging global pathways for sourcing caring resources, stretching beyond the reach of national regulatory agencies or locally shared values and sanctions, present new challenges for how we conceptualise care and for whom we care.

Different understandings and definitions of care draw on at least two etymological roots which together inflect the concept with an inherent tension. On the one hand, the Latin root '*cura*' relates the immediate and intimate emotional bonds of love or friendship as a care

directed to others that is characterised by both devotion and worry for their wellbeing. On the other hand, the Latin '*cogitare*' is commonly translated in terms of a distanced care of others manifest through contemplation, attention or interest but which still involves a commitment to the object's wellbeing.<sup>11</sup> Care is presented as a broad attitude and way of being in the world in which our focus is directed away from the self and towards relationalities with others; such relationalities are characterised on the one hand by affection and commitment and on the other by concern and responsibility.<sup>12</sup> These two etymological origins of care also inform contemporary feminist theorisations which commonly make a distinction between 'caring-for' known and proximate others and 'caring-about' issues and others beyond our immediate everyday lives.<sup>13</sup> This distinction extends beyond people to embrace other life forms, places and issues: 'caring-for' our pets, our gardens and our local, immediate political issues compared with 'caring-about' biodiversity, rain forests or poverty and global justice.

At the heart of this distinction is an engagement of different emotional intensities. We are emotionally invested in our immediate spaces of material place, persons and issues; 'caring-for' people and things close to us is treated as natural and unproblematic in its cultivation even whilst simultaneously treated as gendered, undervalued and largely invisible.<sup>14</sup> A failure to care for those whom society assumes you naturally should is met with an abhorrence and condemnation, the extremes of which are reserved for women in general and mothers in particular.<sup>15</sup> By contrast, the cultivation of 'caring-about' more distant others may be acknowledged as desirable, a wise collective investment in social coherence as well as personal insurance, but this requires the collective ratification of formalised structures to enable us to express such caring within certain limits. The collective agreement of how we care about others takes different form in different societies; in the United Kingdom, the NHS reflects a collective agreement to provide health care to all at the point of delivery and

through a progressive form of taxation; elsewhere, health systems funded through private insurance assert an individualised responsibility for health care but a collective care for regulating provision. ‘Caring-about’ is treated as a matter for an impartial, unemotional attention to social justice and egalitarian rights.<sup>16</sup> Although willingness for collective care about one another may evoke emotional intensity, this is an intensity of commitment invested into an idea, of justice, of solidarity or of morality, rather than an intensity of affective attachment to the specific other. Moreover, caring about unknown others, places or issues is not understood or treated as natural and self-evident; on the contrary, the implicit default position is that it is natural not to care about others and that to do so requires a rationale and some intentional effort.

These diverse modalities of caring collectively about others are shaped by complex interactions of vested interests and cultural currencies in terms of how we conceive of ourselves, our bodies, health and the possibilities for health care. These complex interactions have, to date, largely been confronted through formal structures within the bounds of the nation-state. Where caring about an issue or distant other can be assigned a monetary value, modalities for expressing such care are relatively easily mobilised. Thus, we collectively agree on how to fund public institutions of care; we collectively agree to government spending on international development. But where ‘caring-about’ depends on less well established or easily engaged routes for expression as when it is evoked through a rhetoric of advocacy, social justice or morality, the pathways for translating emotional care into a responsive practice are not obvious. An emphasis on this translation from intention to action challenges the primacy of ‘caring-about’ as an attitude; whilst care may indeed be usefully comprehended as first and foremost an attitude to our ways of being in the world and our

relationalities to others, if such an attitude of care is not also translated into a practice of care it signifies little more than token sentimentality.

There is, therefore, a potential inherent tension in how these differentiated trajectories of personal and abstract care may relate to one another. The relation may be complementary: a commitment, attitude and policy of caring about unknown others may be necessary to enable both the attitudes and opportunities to enact 'caring-for'; a capacity of caring for immediate others may constitute an affective attitude of compassion that extends into the expression of 'caring-about'.<sup>17</sup> However, if the resources and practices needed to fulfil 'caring-for' are in competition or conflict with those needed to fulfil 'caring-about', the tension of caring will be resolved through accommodations derived from both hidden, unspoken assumptions and the exercise of specific arguments. The emerging critical medical humanities are particularly well situated to disclose and interrogate the discourses and rhetoric that inform the accommodations made in specific case examples. The feminist ethic of care offers an important response to the tension between 'caring-for' and 'caring-about'.<sup>18</sup> The approach emphasises the certain interdependence of all humans over the life-course; at different points in our lives we are all likely both to receive care and provide care. As such, the desirable citizen is not autonomous and independent and that care, far from being a marginal activity, is in fact the central activity in human social life, 'care ethics raises caring, nurturing, and the maintenance of interpersonal relationships to the status of foundational moral importance'.<sup>19</sup> Understood this way, it follows that policy should position caring relations as its primary goal, 'In short, care is society's work in the sense that care is absolutely central to our individual and collective survival'.<sup>20</sup>

These various engagements with care all implicitly suggest that a lack of ‘caring-about’ is something of a default and passive position; we are without care, careless, inattentive or ignorant about the relations shaping the circumstances of others. As such, our lack of care, our care-lessness is an attitude or way of being in the world but one that does not entail any action, practice or doing, an attitude constituting a state of ‘uncare’.<sup>21</sup> The attention is given to the possible strategies we have to put in place to enable and facilitate an active state of ‘caring-about’: a political commitment to public provision, a monetarised on-line charitable consumer experience that benefits distant others or an overall ethic that makes care central to society’s norms. In contrast, I will argue in line with the chapter’s opening quotation from Margaret Atwood that we are not merely ignorant but actively ignoring and, as such, we engage in strategies through which we are enabled and enable ourselves to sustain the passive ignorance of ‘uncare’ and to practice an actively ignoring ‘not-care’. These strategies for ‘uncare’ and ‘not-care’ draw on the distances of space, time and imagination.

### **Imagining strategies of care and practice**

Rapid advances in biomedical technologies for reproduction, reconstruction and regeneration include the transplantation of organs from one body to another. Alongside such ‘miracles’ of modern medical practice, contemporary processes of globalisation have eased travel and trade to generate new spaces, markets, rhetoric and imaginaries for medical care at an international level. These new possibilities to reinvent and recycle ourselves are accompanied by new ethical challenges related to resource flows, inequalities of access and the nature of care at a global scale. Imaginative fiction offers medical humanities at least two entry points in developing a global and critical engagement with the practices of care. First, literature and film enable their audiences to encounter the issues, to confront their own reactions in relation to care and to reflect on the implications of the rhetoric for different practices of care. As

such, engagement with the creative imaginings of future or alternative dystopic societies and of relatively unfamiliar aspects of contemporary societies can illuminate the ways we do and might practice care, uncare and not-caring. Moreover, and secondly, as the conduit for our reflections on different practices, scales and tensions of care, these creative imaginings have their own agency as strategies themselves for care, uncare and not-caring. To effect a critical medical humanities, we need not only to examine the differentiated modes of argumentation for different practices of care that are conceived within creative worlds, but to engage critically how imaginary practices themselves inform our practices at local and global scales.

### **Imagining future dystopias**

Imagined future worlds free us to play with the potential limits of the logics of our own caring practices. Creative imaginings of future or alternative dystopic societies have positioned the population's wellbeing as maintained through the medical exploitation of a parallel sub-class.

In such imaginings, the moral position is always unequivocal: the uncaring practices are condemned and humanity is restored to exploited bodies. The insights for our own contemporary practices of care may be drawn from the various discourses that are used by the dominant population to justify treating and categorising their supplier population as non-human. In the *New Earth* of the year 5 billion and 23, imagined by the creators of the BBC's *Dr Who*<sup>22</sup>, the hospital run by the Sisters of Plenitude, cat-kind nuns, can cure all human ailments. However, it transpires that the nuns' healing expertise has been gained through macabre means. The sisters have accelerated their rate of knowledge acquisition by experimenting on thousands of human clones which they secretly grow in vaults and infect with diseases. The sisters suppress the clones' potential humanity through constant sedation

and kill any that display resistance to the drugs and signs of awareness and thought. The actions of the sisters are illegal in the society of New Earth but it seems no-one is looking too closely at the source of the evident gains. Similarly, in Michael Bay's film, *The Island*<sup>23</sup>, the use that is being made of technology to exploit a sub- or non-human class is not condoned; customers think they have purchased the growth of customised, matching organs. In this case, it is the scientist-businessman who has found it more convenient and successful - for which we understand profitable - to produce whole body clones. But again, we intuit a society happy not to ask too many questions about the procedures making good their investments. Indeed, when the non-clone customer confronts the reality of his cloned body double, acting in a caring and ethical manner proves too difficult in the face of his potential mortality.

The society of Kazuo Ishiguro's novel *Never Let Me Go*<sup>24</sup> has also invested in clone technology as a response to the growing medical demand for organ transplants in its population. However, by contrast to *New Earth* and *The Island*, in Ishiguro's world cloning for the purpose of increased and customised organ supply is expressly condoned by the society, that is, the exploitation of the clones is openly sanctioned and, as such, requires different and collective strategies to justify their subjugation to organ harvesting. Whilst the clones are well looked after, they must nevertheless still be categorised as sub-human, even by those most intimately involved with their childhoods. A woman who collects their art work displays her abhorrence; their head-teacher admits that she always had to steel herself to face them. Ishiguro makes more explicit the ways that discourse differentiates bodies and underpins the power relations that enable the sustainable exploitation of some bodies by others. However, unlike the discourses of racism and slavery, discrimination against the corporeal other is no longer grounded in assumed associations and disassociations of genetics and geographical origins; differentiation is not based on outward signs of potential group

otherness such as colour, dress or religion but by an inward or invisible otherness defined by their personal provenance. Where two bodies intentionally share the same genetic make-up, superiority and dominance are granted on the grounds of which body is authentically human (see a related discussion in Viney's chapter in this volume on twins in science). In turn, human authenticity becomes dependent on being begotten of two parents and on being the original first version; identical 'copies' derived through technology do not count as authentically human and, as such, have no claim to human rights.

These alternative societies warn of moral perils from medical technology, but their distance in time or imagination and the clear moral condemnation with which they are treated by their authors implies their scenarios are improbable. Collectively, as reader or viewer, we endorse the condemnation inherent in these explorations and we acknowledge the perils of new biotechnologies through enforcing strict regulation and ensuring regular public reflection and debate on that regulation. However, treating these scenarios as improbable cautionary tales may overstate both our condemnation and the power of regulation. Even in the setting in which the clones are most abused, the morality is tinged with a troubling ambiguity. The Sisters of Plenitude in *Dr. Who* do not act from self-interest; they act from a professional commitment, compassion even, to care both about and for their human patients and as such justify their actions by arguing that more humane methods of research would have been too slow. This form of argumentation, whilst supporting a horrendous practice, does nonetheless chime with contemporary exposures of health professionals acting illegally, but for the collective good, including through body mining.<sup>25</sup> In *Never Let Me Go*, Ishiguro cleverly complicates the distances of space and time by imagining a society that, apart from cloning, resonates in all respects with a British recent past. Indeed, he plays down the technology to

discomfort us in relation to caring, or to what I have called uncaring, about others across a range of contemporary issues.<sup>26</sup>

Ishiguro's novel is instructive in a further sense. The cloned young people that the novel follows through the account of Kathy largely accept their destiny as donors. There are perhaps only two moments in the book when the characters dream of by-passing their fate and at no time do they attempt to resist the path laid out for them. Thus, even those exploited by society's practices accept them, resonant with a Nietzschean concept of the slave morality. This theme is echoed in Ninni Holmqvist's *The Unit*<sup>27</sup> which imagines a most plausible future society, a near-future Sweden that has adapted its tradition of a strong collective commitment to the welfare state to encompass a collective response to the demand for scarce organs. At fifty, those persons categorised as non-essential must move to the closed 'Unit' of the title from where they will be involved in drug tests and make donations up to their death. The Unit is luxurious, the inhabitants well looked after in a similar way to Kathy and her friends in *Never Let Me Go*; the critical aspect here is who counts as essential and who does not. The Unit is thus populated by those without children, without established partners or not in a valued occupation; many of the population are artists. But child-care duties and natural parenthood is not quite enough, it transpires; when the main character falls in love and becomes pregnant, she cannot be reclassified and not because of bureaucracy. As an artist, as a late parent, she is already fatally designated as unsuitable to care for her child who will be adopted by a 'normalised' family. She escapes with help from sympathetic workers at the facility, but chooses to return, accepting her society's values and future pathways for both her and her child. In both Ishiguro and Holmqvist's novels, socialisation into a given set of values enables the exploitation of some by others in part because the exploited enact their own compliance with the system of collective care.

Atwood<sup>28</sup>, reflecting on Ishiguro, comments that the insight here may be how much we all have the capacity to accept the status quo and our embedding norms, an insight easily extended to practices of uncaring and not caring. Moreover, the assigned role for the designated donor ironically is a role of caring both about and directly for unknown others and the donors are, up to a point, themselves formally cared both about and for through the collectively supported institutions they inhabit. But both Holmqvist and Ishiguro indicate the fragility of the care offered to these donor bodies in their imagined societies, as explicitly stressed to Kathy in *Never Let Me Go*:

“When I watched you dancing that day, I saw something else. I saw a new world coming rapidly. More scientific, efficient, yes. More cures for the old sicknesses. Very good. But a harsh, cruel world. And I saw a little girl, her eyes tightly closed, holding to her breast the old kind world, one that she knew in her heart could not remain, and she was holding it and pleading, never to let her go.”<sup>29</sup>

Once bodies are cast as less valued, as amenable to exploitation to save more valued others, then they are already effectively categorised as lesser humans and the discourse supporting a limited caring about and for those bodies can be easily transformed into the very different justifications underpinning an attitude and practice of uncaring and not caring.

### **Imagining contemporary beneficence**

By contrast to the exploitative practice of organ transplants in these future or alternative imaginary worlds, fictions involving medical technology in real-world contemporary Western societies mostly explore personal beatific and emotional dimensions to donation. The sudden and unexpected loss of a child offers a narrative theme through which to explore journeys in managing grief by caring about others and to promote donation by relatives of those

deceased. Two novels exemplify this particular narrative<sup>30</sup>: Lauraine Snelling's *One Perfect Day* and Jill Wolfson's *Cold Hands, Warm Heart*. Both follow the emotional journeys of several characters closely connected to the child who has died and to the ill child who benefits from the donation. The focus on children underscores both the loss and the benefit by maximising the time lost and reclaimed and renders both loss and benefit wholly unambiguous. And the unambiguous benefit of donation to save the life of an ill child affords the relatives of the deceased a form of redemption from their suffering. In a similar vein, Manuela, the central character in Pedro Almodóvar's film *All About My Mother*<sup>31</sup>, finds meaning after the death of her son through a story that 'depends, as so many things do, on the kindness of strangers.'<sup>32</sup> Almodóvar, however, goes further by unrolling the notion of care as embracing difference, inclusion and acceptance. As well as the stranger who now carries Esteban's heart, Manuela encounters various others who transgress bodily norms, who 'improvise their way through their own lives' but who are always present for each other. Their enactment of care not only helps with practical matters but accepts and nourishes one another.<sup>33</sup>

These imaginings parallel and mirror the contemporary discourses of organ donation in affluent societies which predominantly celebrate an altruistic caring about unknown others through the metaphor of the gift.<sup>34</sup> Where live donation is possible, as for kidneys, the heroic and life-saving rhetoric is even stronger, yet strangely buoyed up further with commercial post-donation products such as t-shirts or jewellery, which serve both to advertise live donation and to bring the donor greater public acclaim. This shift in emphasis, from the private satisfaction of caring to public acclaim, intimates at subtle shifts in the dominant discourse of voluntary caring, shifts related to organ procurement that revolve around ownership and commoditisation of bodies. The most common organ procurement route is

through voluntary opt-in donation after death: those willing to donate sign up to a registry, carry a card or have their wishes recorded on their driving licence. However, as demand continues to out-pace supply, alternative strategies to increase donation are under debate. Several countries have already introduced the controversial opt-out system for posthumous donation, including Spain and Finland, in which donation is assumed unless the deceased has made express wishes to the contrary before death.<sup>35</sup> The issues embedding debates in favour and against an opt-out system for organ procurement in part turn on an associated debate on who owns the body after death. In an opt-out system, the body is effectively owned by the state to be used to care for others unless otherwise indicated by the deceased and, as such, the wishes of surviving relatives need no longer be sought and in theory would have no purchase over the uses made of cadaveric materials. The necessity of maintaining the viability of a healthy organ from posthumous organ donation has been accompanied by a redefinition of what constitutes death which in turn is associated with counter discourses and debates related to the possibilities of continued awareness and the practice of ventilation before donation.<sup>36</sup> Such expressions of disquiet may engage philosophical and ethical considerations of what constitutes life and death, but none of these discourses suggests any move towards justifying the exploitation evident in *New Earth* or *The Island*. Nonetheless, the inherent and growing gap between demand and supply informs the imaginary society to care about its non-cloned population through a justified not caring about its cloned bodies; this gap is a feature of the contemporary world, a gap that is rapidly increasing as technologies advance. Organ transplants, once miraculous, are increasingly normalised such that the only barrier to stepping past death may be seen as organ availability.

In new emerging discourses, some momentum towards the commoditisation of body parts is evident. The internet now furnishes registers through which to connect donors and patients,

an availability of contact which potentially transforms the traditional practice of donation. Patients can make their own personal and often highly emotive pleas for assistance. The conventional mode of caring about others by donating has been to donate to the medical system which determines who has the priority need, the recipient remaining an anonymous other, except in the case of family donations. Thus, the ethical principles established for both donating and receiving, mediated by the procedures and criteria of the medical system, are undermined. Those wary of this shift point out the perils of a market-based competition for a donated organ in which would-be recipients have to make a pitch to appeal to the caring sensibilities of potential donors who may privilege or discriminate against particular bodies in their criteria for deciding who to care about and favour with their body parts. Many of the positive literary and cinematic explorations of organ donation have centred on the loss or illness of a young person, a loss or need evoking an almost universal sympathy. For example, in Seattle in 2013 a father-of-two found a kidney donor by telling his story on Facebook – his donor came forward to care not for the ill adult man himself but on behalf of his children and their potential loss.<sup>37</sup> Underpinning this emergent practice is a reassertion that body parts belong to their original individual ‘owner’ who holds the right to decide which other bodies they care about and to determine with which other bodies their parts may be incorporated.

This reassertion of private ownership of body parts is implicit in Gabriele Muccino’s film *Seven Pounds*.<sup>38</sup> Ben seeks redemption following his negligent, careless driving which caused the death of seven people including his fiancée. He has identified seven people, all strangers, to benefit from what he has to offer, following his suicide, including body parts. The film provides two forms of contemporary discourse through which we might effect not caring about others. First, the film focuses predominantly on the love story between Ben and one of his designated beneficiaries, and in the absence of any other likely donor, he finally sacrifices

himself not for a distanced ‘caring-about’ redemption but an intimate ‘caring-for’ love. This motive for his suicide is clearly positioned as better than his guilt and search for redemption. With a modern focus on personal wellbeing, constructed as self-confidence and self-esteem<sup>39</sup>, guilt and redemption become pathological in contrast to the healthy pursuit of personal happiness. In this, ‘caring-for’ is clearly positioned as a superior motive than an abstract and guilt-ridden ‘caring-about’ which does not bode well for broader discussions of global interconnectedness, interdependence and mutual responsibilities through ‘caring-about’.

But first he wants to meet them, to make sure they are worthy of his gift. However, whilst a ploy to bring the two characters together, the process of evaluating whether the beneficiaries are deserving or not invokes a long tradition of judging who is deserving of charity and social care and, conversely, who is not. The opportunity afforded by social media to choose what categories of person we care about enough to offer a gift of donation opens up issues of how scarce resources are to be allocated, who should decide and on what criteria. There is here an intimation of a quasi-market in which, although the explicit exchange of money is prohibited, bids, bargaining and biases start to inform the flow of organs, albeit a supply still dependent on gifting.

### **Local beneficence and global markets**

From here it may be only a small step to a fully commoditised market. If we are deemed the owners of our original body parts, it should follow that we hold the right to sell them. The arguments against the commercialisation of body parts include the acknowledgement that markets are care-less of the large inequalities both within countries and between countries in access to transplant technology. The success of immunosuppressant drugs in transplant technology renders the acceptance of an organ possible from a far wider population pool than

was the case in the early years of donation. Whilst organs may not be sold in Western societies, it is difficult to detect if a donation by an apparently consenting and caring adult has, in reality, been bought. Regulation across borders is even more challenging. Moreover, new markets for transplant tourism amplify the general concerns of medical tourism, for not only are scarce resources of finance and expertise drawn into the private sector and away from public care for the local population, but the flow of the scarce resource of a donated organ from donor to recipient tracks and reproduces existing inequalities in flowing from underprivileged to privileged: from south to north; from poor bodies to rich bodies; from women to men; from black bodies to white bodies.<sup>5</sup>

Regulating organ transplantation shares challenges and responses with the governance of other global health concerns: global agreement has been drawn up through the 2008 Declaration of Istanbul informing the laws subsequently introduced in those countries endorsing the declaration.<sup>40</sup> But making guidelines effective also needs the support of resources and attitudes. The gap between demand and supply and inequalities in ability to pay has generated a well-documented illegal trade in the unregulated movement of organs. Direct coercion, as in the extraction of organs from executed prisoners without prior or family consent, has been condemned as an abuse of human rights, a practice that in China at least has been modified in response to international protest. Nonetheless, the treatment of prisoners' bodies as belonging to the state hints at how short the distance may be towards a discourse of practice resonant with those found in *New Earth*, *The Island* or *Never Let Me Go* which enables the recategorisation of criminals on death row as no longer full citizens entitled to human rights or practices of care (Lisa Guenther, in this Companion, also discusses the exercise of power and care over bodies on death row in the United States). Indirect coercion involves organ and kidney 'brokers' who encourage the sale of kidneys by

those in poverty and debt. Whereas the altruistic Facebook donor donated to a known other from 'care-about' that other's family, the indebted seller donates to an unknown other for money through which to 'care-for' his or her own family. The commoditisation of body parts has commonly been viewed as exploitative and abhorrent and the practice is illegal in many countries, although there are alternative viewpoints which point out that the informal organ trade can take many different forms, each bringing different sets of ethical dilemmas.<sup>41</sup> Furthermore, a new advocacy for a pro-market stance is now emerging. The arguments take at least two directions. First, if we are to 'care-about' meeting the current and future needs for organ transplant, then increasing organ supply through market processes justifies a pro-market policy.<sup>42</sup> The Economist calculated that current demand for organs in the United States could be met if just 0.06% of its population aged 19-65 years were to donate.<sup>43</sup> Secondly, methodological innovations that 'care-about' the voice of the poor themselves enable expression of a narrative of life-changing benefit for those selling their kidneys, 'Their reaction was: "Who are you to judge? Walk a mile in my shoes. You don't know what it's like to live in poverty." These men weren't bothered by their choice. Some of them changed their lives, others squandered the money. All of them say, "I made money, but I also saved a life."'44

This use of people's own voices to transform what has been viewed as exploitation into a form of liberation presents methodological, ethical and normative issues for a field like medical humanities that privileges experiential accounts. If a first-hand experiential account is taken uncritically at face-value, then various practices that in many ways seem far from caring become justified and normalised. On the other hand, if people's own accounts are dismissed as representing a false consciousness or an adaptive preference, then we return to privileging only the accounts of the few (see discussions elsewhere in medical humanities by

Parry<sup>45</sup> or Atkinson<sup>46</sup>). People's own narratives are not, of course, always supportive of the status quo or complicit in their own exploitation. French folklorist Veronique Campion-Vincent in 1997 first identified a genre of local story-telling that recounted tales of organ theft which she documented across different parts of the world. These narratives, she argued, 'express a unified set of beliefs in organized criminal groups of organ traffickers who use kidnapping and murder, often of children and infants, to procure human organs for a vast network of medical professionals engaged in covert transplants that yield huge sums of money both for the criminal traffickers and the medical professionals'.<sup>47</sup>

Campion-Vincent interprets these narratives as reflecting a world-wide malaise with the advances of medical technology, and especially organ-transplant technology which 'transgresses boundaries of life and death, self and other'.<sup>48</sup> Anthropologist and activist Nancy Scheper-Hughes argues for a different interpretation by emphasising the context of inequalities in which the poor are explicitly frightened about their potential, and in some proven cases actual, powerlessness in protecting their corporeal integrity.<sup>49</sup> This fear of explicit coercion informs a thriller or horror film genre in which the protagonists, again usually young, have to escape capture for the purposes of organ harvesting. The horror draws on middle-class anxieties of a criminal sub-section in society through which illegal trade occurs and enables its unequivocal condemnation. The additional anxiety drawn on in John Stockwell's film *Turistas*<sup>50</sup> concerns the moral ambiguity of global inequalities in access to medical care. The tourists of the title are young people from affluent nations which their abductors claim have been stealing organs from Brazil. The tourists will be forced to pay back the organ theft and their organs will be given to poor recipients in the favelas of Rio. Although recognising the inequalities fuelling an illegal organ trade, the film distorts caring about others into a gruesome and reprehensible global variant on progressive and

redistributive taxation which, in turn, feeds a moral xenophobia that displaces audience sympathies. There is then a dominant imaginary about organ trafficking and transplant tourism: it is to be universally condemned, dominated by criminal thugs, tends to occur ‘elsewhere’ from the perspective of a western movie-going audience, and indeed has been likened to genocide or even a form of ‘neo-cannibalism’.

## **Conclusions**

The creative works presented here together with emergent discourses, narratives and personal accounts expose complexities, paradoxes and challenges for collective caring about others and particularly across global scales. In a world characterised by inequality, will caring about all others always be an elusive goal or, as in the futuristic and alternative dystopias, do we already only care selectively about some whilst denying our uncaring about others through a set of distancing strategies? Part of how we effect our uncaring is through our depictions of who, how, where and when such uncaring occurs. In the context of high-income countries in which donation is still predominantly shaped by the metaphor of the altruistic gift, our imagining of an explicitly ‘not-caring’ exploitative trade is tightly circumscribed, our care about such risks displaced through at least three strategies involving the distances of imagination, time and space. First, we appreciate and acknowledge the potential risks of medical technologies spawning ‘not-caring’ practices, but distance our own caring about such risks by locating these into imaginary futures, futures that we will avoid becoming through existing and further regulation and public debate. Secondly, we know of examples when the use of medical technologies has resulted in ‘not-caring’ practices in contemporary medical settings but distance our own caring about such occurrences by locating these into the sphere

of a criminal under-class, unreservedly condemning malpractice and supporting legislative regulation. New regulatory practices also enable examples of malpractice to be consigned safely to a misguided past (see also Will Viney's discussion of the history of twin studies in this volume). Thirdly, our caring about exploitative and illegal malpractice is further distanced by locating such practices predominantly within the settings of lower income countries which are in need of support in policing and regulation.

The rhetoric of the altruistic gift may remain the dominant discourse both in popular and policy settings, but new arguments are emergent to justify compulsory donation, commoditisation and market-based systems and which reformulate the relations between 'caring-for' and 'caring-about'. Encounters with imaginary future and contemporary accounts of organ transplantation expose several axes around which current discourses of how we respond, practice and manage the procurement of scarce organs are in flux: ownership of our body and our body parts after we die; the right to use, sell and profit from our body parts; the claim on receiving and benefiting from our body parts; the possibilities for recategorising some bodies as less valuable than other bodies.

The chapter began with an example of the kind of autobiographical account that has informed mainstream medical humanities. The rest of the chapter complicates such accounts by demonstrating the need to position even intimate encounters within the broader relations of space, time and power. The imaginary future worlds demonstrate the work involved in justifying an exploitative and 'non-caring' practice, work which paradoxically draws on rhetorics of 'caring-for' and 'caring-about'. Fictional explorations of contemporary settings disclose the shifting interplay of 'caring-for' and 'caring-about' and the rhetorical work involved in privileging one over the other and some bodies over others. The chapter then

demonstrates the importance for those working within medical humanities to expand the scope of our research gaze to different scales of space and time. The chapter offers such an expansion through drawing out the forms of argumentation mobilised in a range of different fictional genres and thereby highlighting the complexities of the negotiations underpinning specific, individual choices narrated in first-hand accounts. A critical medical humanities then, in this chapter, is enacted through a close interrogation of emergent contemporary discourses located within different spatial and temporal scales which discloses the hidden but essential work that underpins strategies of ‘not-caring’ and through which we continue to effect the distancing strategies of ‘uncare’.

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