**Title**

The intimate uncertainties of kidney care: moral economy and treatment regimes in comparative perspective

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**Abstract**

Today the social and material situations of sick bodies are increasingly and *intimately* bound up with the variable moral economies of national healthcare systems in uncertain and contrastive ways. I approach these ‘intimate uncertainties’ comparatively and methodologically by drawing on ethnographic fieldwork on transplant medicine in Mexico in order to interrogate European healthcare, specifically the UK. The UK National Health Service is an exemplary site of moral economy, one which the Mexican case *appears* to stand in stark contrast to. However, as I show, the uncertainties we see at work in Mexico enable us to seek them out in the UK too, particularly those generated at the nexus of the state, failing organs and new strategies for healthcare rationing. The article traces the gendered and socio-economic inequalities, which follow from these shifts, while offering a cultural critique of analyses which take the European and North American experience as methodologically foundational.

**Keywords:** Moral economy, Biopolitics, Intimate uncertainties, Chronic Kidney Disease, Mexico, UK

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**Introduction**

This article takes, as its subject, transplant medicine and one of the conditions it seeks to alleviate, Chronic Kidney Disease (CKD). Both condition and treatment are intimately bound up with the variable biopolitics and moral economies of different national healthcare systems in uncertain and contrastive ways. Neither can be viewed as things in and of themselves with stable affects across different sites and settings, but are, instead, entangled with the social relations and material conditions within which they take form. Because of this, I will treat the exploration of the intimate uncertaintiesthat arise from these entanglements as a comparative project. As an example of what that comparative project might deliver, I draw into play ethnographic fieldwork on transplant medicine in Mexico in order to think about how we might begin to interrogate European healthcare, specifically the British National Health Service (NHS). The NHS, on one reading, appears to stand in stark contrast to the Mexican case. However, as I will show, the uncertainties we see at work in Mexico enable us to seek them out in the UK, bringing both situations into clearer focus.

Adopting a comparative perspective follows what I take to be one of anthropology’s central analytic frames, though one which has proved to be a persistent and vexing challenge for the discipline. Comparison, particularly in its more programmatic elements, fell from grace during the reflexive debates in the 1980s, suffering paralysis by its associations with grand theorising, objectivist frameworks, a reliance on bounded modes of cultural comparison and varied and variable links to the colonial project (Clifford and Marcus 1986). Recent years, however, have marked seen a resurgence of interest in comparison and its potential to provide new perspectives on older concerns. This has been driven, inter alia, by preoccupations with global connectedness, uncertainty and insecurity, radical assertions from the periphery and changing public responsibilities to discourses of human rights and resource entitlement (see Gingrich and Fox 2002; [Niewöhner](http://b-ok.xyz/g/Niew%C3%B6hner) and Scheffer 2010). As part of this reworking of the comparative project. [Niewöhner](http://b-ok.xyz/g/Niew%C3%B6hner) and Scheffer argue for a tentative and reflexive engagement, recognising its limits but also its capacity to open-up new dialogues, producing new insights as well as methodological innovation and experimentation.

And so, with access to biotechnical therapeutic regimes in mind, a comparative approach can work to denaturalise their stability and certainties, recognising that their take up and use across global sites and settings follows no uniform, predetermined path. Trying to establish what makes failing organs and the arrangements in place to deal with them specifically uncertain in any particular place will lead us in very different directions depending on where and with what we start. For heuristic rather than programmatic purposes, I start by focusing on those specific instances where we might begin to understand similarity and difference across settings, and in so doing counter the superficial better-or-worse distinctions that can emerge when cases in the global north are contrasted with cases from the global south. As Strathern suggests, to speak generally, can only be to speak through specifics, and that is what I intend to do here to work this comparison through (Strathern 2002)

The explicit employment of a comparative optic – one driven by seeking out uncertainty – provides an opening through which the changing arrangements and invisible infrastructures of the NHS, often considered an impenetrable state monolith, can be made visible, offering a respecification of its moral economy in the process. As with my use of a comparative perspective, my employment of ideas of moral economy in my analysis is also sensitive to his antecedents. With roots in the work of E.P. Thompson’s (1971) study of food riots in the eighteenth century and James Scott’s (1976) analysis of peasant movements, moral economy emerged as a way to understand state, capital and society relations through the complex and grounded motivations of the dispossessed to negotiate entitlement. Since the nineteen-seventies, the term has been put to all manner of ends and means to the extent that it has become trivialised (Fassin 2009) and muddled (Hann 2016). A recent review of the concept by Palomera and Vetta (2016) sees two particular strands to its deployments: one which scrutinises those systems of provisioning – i.e. altruism; systems of solidarity or moral obligations – that lie distinctly outside of formal economy and, as a consequence, mount a challenge to its logics (see Orlando 2010; Trip 2006) the other which marks an explicit move away from economy altogether, replacing, as they see it, a moral economy with an economy of morals (see Fassin 2012; Zigon 2007). Both approaches, Palomera and Vetta suggest, problematically obscure the material ground of class-capital relations and argue forcefully for its reengagement. One such reengagement lies in the work of Susan Narotzky (2015) on flexible capitalism by showing how class circumstance and inequality are concretely bound to or metabolised through the entangled practices of the state and capital accumulation. Perhaps to state another way, in bringing class-capital relations back in, moral economy requires an understanding of political economy as the conditions for its understanding. It is this orientation to moral economy which shapes the argument of this paper, one that sees the healthcare systems of both Mexico and the UK in the context of the social relations of welfare and capital and their capacity to configure the life chances and practices of the disenfranchised.

**A Methodological Orientation to Uncertainty**

The British NHS makes for a useful case-study because in so many respects it is still, despite criticism, regarded as an exemplary site of moral economy, one which produces particular regimes of care and particular forms of biopolitics[[1]](#endnote-1) (Fassin 2006; Foucault 1980). Unlike most of its European counterparts (e.g., health care systems in France, Holland and Germany), the NHS operates as a single unified ‘agent’, funded by proportionate taxation, administered centrally and free at the point of use without subscription to insurance – with fewer people in Britain encountering cost-related barriers than any other country, including Sweden (King’s Fund 2014). Often said to be the third biggest employer in the world after the Chinese Communist Party and the Indian Railways, with publicly-funded, universal coverage provided through a single overarching organisational framework, it is one of the cheaper healthcare systems in Europe (King’s Fund 2014).

Coming into operation in 1948 following the nationalisation of primary, secondary and tertiary healthcare services, the NHS was established as part of an explicit ‘Beveridgean/Keynesian’ political economic contract between the state, the market and the individual (Esping-Andersen 1990). It was designed to be universalistic in at least two senses: not only would all be entitled to access healthcare, no variations in access to treatment would be tolerated, something which has meant ‘private’ healthcare has played a relatively small role in the UK, being largely used to bypass waiting lists or access better ‘hotel’ services there, rather than better treatment. Social attitudes surveys consistently find that the NHS is both one of the most trusted institutions of government and the most loved. For all these reasons and more, the NHS can be said to project a distinctive moral economy. It is one that masks the material entanglements of state, capital and society – but could be read in Andrew Sayer’s terms, as that which “... embodies norms and sentiments regarding the responsibilities and rights of individuals and institutions with respect to others. These norms and sentiments go beyond matters of justice and equality to conceptions of the good” (Sayer 2000: 79). The NHS exemplifies the public good – at such a discursive level – and is one of the pillars upon which British social citizenship continues to rest (Marshall 1950), something powerfully re-articulated during a recent wave of strikes in which the question of who should defend that public good – the government or doctors – was the central focus of dispute (The Guardian Letters 2016).

Approached anthropologically, however, the place the NHS occupies within the public imaginary poses difficulties. The rhetorical even ritual invocation of its ‘cradle to grave’ regime of care suggests that the terms on which any citizen enters the system are *uniform*, with the connections between the causes and effects of sickness and the biomedical responses deployed to address them, unproblematic. The specificity of the operations and infrastructures which deliver that uniformity go undifferentiated, they are not explicitly marked but played down, treated as secondary and inconsequential.

Ultimately, therefore, we learn little about health or the practices of medicine in the UK from the standard picture sketched above. The taken-for-granted character of these arrangements and pathways to medical treatment makes it hard to grasp *in practice* the social relations (i.e. the interactions between healthcare professionals, medical infrastructures and bureaucracies, family relationships and so on) which underpin the role played by sick bodies in various medical fields. They make the practices of medicine and their differential grounds disappear. In this sense, the moral economy through which principles of universalism, entitlements and equity find expression prefigures and over-determines our engagements with it. This begs the question: how do we interrogate public goods like nationalised healthcare which have already been thoroughly moralised by others? Ways have to be found of stepping back in order to better see what is in front of us. And, as anthropology demonstrates, that can mean looking somewhere else first. More specifically, in the face of moral certainties that are seemingly institutionally and culturally hard-wired – producing too smooth a surface to gain analytical purchase on – attending to the production of uncertainties in the context of healthcare can be particularly helpful. The moral status of the citizen upon which the NHS is based is, after all, not a natural one and ‘the beneficence’ of the state in its guise as the NHS is not something that should be taken at face value. It is neither static nor discrete but rests on sets of arrangements and the articulation of moving parts.

The aim of this article is to use the trope of uncertainty to open-up the differentiated arrangements, relations and practices that the beneficence and moral economy of the British NHS rests upon. This is to be taken as an analytical policy for prospective ethnographic work on the NHS rather than a reflection of already completed research. As part of prospectively scoping these shifting fields, I focus specifically on the institutional pathways that failing kidneys traverse, i.e. how sick ‘renal’ bodies help us to see the arrangements of kidney care. In drawing on the comparative case of Mexico, where healthcare and its relationship to the Mexican state operates in very different ways, it might be tempting to draw a contrastive or naïve like-for-like comparison. That is not the purpose here. Instead of a ‘better or worse’ treatment, I suggest that what is happening in Mexico can help us approach the moral and biopolitical economy of the UK, and indeed other European societies, in a new light.

This article is organised into two sections. In part one, I detail the Mexican case based on my ongoing ethnographic research and the exemplar case of José Luis, a young CKD patient, who shows us that the Mexican (renal) body is a site where disease not only finds expression, but where self and world meet in variable and disruptive ways. These disruptive effects extend outwards to draw the bodies of others into direct relationship via the differentiated organisation of transplant medicine. I trace the intimate uncertainties that this gives rise to, uncertainties which bring into view a moral economy of care that is mediated through the efforts of Mexican families, particularly through the labour of women, as *they* knit together the biopolitical apparatus of state, economy, medicine and the sick body.

In part two, the Mexico case is used as a sensitising device to make visible the intimate uncertainties generated at the nexus of the state, failing organs and healthcare in the UK, a system increasingly characterised by austerity, new forms of public-private financing and hence profit-making activities. I discuss the socio-economic and gendered inequalities which follow from these shifts. In the concluding section of this article, I offer a cultural critique of analyses which take the European and North American experience as methodologically foundational. As I hope the article will demonstrate, Euro/American-centrism not only mischaracterises the experience elsewhere, it also fails to sufficiently problematise itself.

**Part One: Failing organs and the biopolitics of renal care**

Lying in his bed in a Mexican public hospital, José Luis, a young man in his early twenties, twisted and turned, as he struggled with leg cramps.[[2]](#endnote-2) His parents were sitting by his side. They had been with him in the hospital for three weeks, his mother sleeping at a nearby religious hostel, his father on the floor beside his son. Jose had been diagnosed with CKD at the age of 15. Up until then, he had been working as a farm labourer in ‘the berries’: North American agri-companies that cultivate and export berries, close to Lake Chapala, some 60km outside of the city of Guadalajara.

José’s family didn’t know why their son’s kidneys were failing, neither did his doctors. Like other young and poor kidney patients, José arrived at the public hospital with ‘riñones chiquitos’ – small kidneys, too small to biopsy to establish a cause. *Not-known,* an increasingly important category of reference for disease aetiology, is routinely referred to as the second largest cause of CKD after diabetes in Mexico[[3]](#endnote-3). José’s doctor explained that for people living and working around Chapala, there is increasing concern about the toxicity of the water and the agricultural land that families like José’s are reliant on. Whatever the causal factors, themselves disputed and politically controversial, the situation is one where kidneys fail unexpectedly – for no certain reason – in unexpected bodies, those where there has been no prior history or warning of kidney disease. As I will show, this inflects the pathways those bodies trace thereafter.

José was brought to the public hospital on the 19th May, 2011 and was being treated by diet, medication and intermittent dialysis, while his kidneys slowly moved to the end stages of functioning. Soon he would need routine dialysis, which would be in the form of peritoneal dialysis[[4]](#endnote-4) and out-sourced to the care of his family at great financial and emotional cost and for temporary effect. It would only be a matter of time before José would need an organ transplant to survive. Mexico relies on a system of living-related organ donation, one also dependent on the family, particularly women already culturalised as responsible for the ‘burden of caregiving’ (DiGirolama and Salgado de Snyder 2008). José’s donor would, in all likelihood, be a female relative.

Successfully obtaining a transplant would also depend on the efforts and financial support of José’s family and friends, not only to source the appropriate services from a myriad of private and public providers but to pay for each aspect of it in turn. On that, Jose’s mother explained:

“We have nothing. We have to ask lots of people for help to cover José’s medications, stays in the hospital and tests. Even the diet is too much - not just for him - but for the family, it is a total change and very expensive. What can we buy to eat? We can’t just eat beans and tortillas. This disease makes us work hard. We’re working hard and moving all the time, going here, going there. And when you don’t know anything you have to learn, by force.”

Being sick in Mexico necessities work and continual movement, as José’s mother states. Her family are poor and uninsured, a class of citizen comprising approximately 50% percent of the population all caught within the very same practical dilemmas posed by this moral economy of care. In the absence of social entitlements, families like Jose’s have to mobilise whatever resources they can to access Mexico’s fragmented healthcare system. Entitlements to support are highly differentiated, administered via a complex social welfare system, which is contingent on labour-market position (Kierans et al. 2013). This is a moral economy intimately bound to a political economy, one organised around one’s capacity to secure ‘good’ work, with all the insecurities and uncertainties that this implies. For José’s family, who struggle to secure ‘good’ work and hence lack formal social insurance entitlements, services have traditionally been provided at a subsidised rate by the clinics and hospitals of the Ministry of Health and Welfare, a limited, partially subsidised system of healthcare, run with no guaranteed package of services and heavily reliant on out-of-pocket payments at the point of use.

José’s case and the analytical concerns it gives rise to is supported by ethnographic fieldwork conducted during 2011 and 2012 which comprised 105 interviews, across 138 respondents, including 51 kidney patients, 34 caregivers donors and family members and 53 health and social care professionals, including medical suppliers and charitable organisations (see Kierans et al 2013, 2015). As I have described in relation to this data, Mexican renal patients embark upon their searches for care without a coherent logic of healthcare access. There is no clear pathway, and so they zig-zag between separate and distinct systems of renal care, from private laboratory testing to quasi-public infrastructures of organ transplantation. This complex of articulations or ‘apparatus’ as Gregory Feldman terms, refuses the idea of a specific ethnographic locale. Instead, it shows that sites of care are “composed of processes that link a multitude of locales” (Feldman 2011: 376). Negotiating this complex terrain of public and private healthcare providers, clinics and laboratories, families like Jose’s are required to pay for everything: “hospitalisation; surgical procedures; routine check-ups and tests; dialysis; pre-transplant protocols; biopsy needles; stitching for wounds; disinfectant and medications. This is in addition to travel costs, dietary costs, structural costs for home dialysis, informal care-giving and the loss of formal earnings” (Kierans 2015:18). The labour involved in doing so is carried out with no certainty of a positive health outcome. Many patients die during dialysis, due to peritonitis[[5]](#endnote-5), or do not survive for long with an organ transplant, should they be able to secure one, lacking the money needed to maintain the required levels of immunosuppression[[6]](#endnote-6) medication, a necessity for the long-term functioning of a transplanted organ. Most however, do not make it as far as therapy at all, with half of all ‘registered’ renal patients dying within six months of their initial diagnosis (Gutierrez-Padilla et al. 2010).

While the efforts to establish renal care may not always produce ‘health’, they are productive in other ways. The work Mexican families do to secure forms of care involves, among other things, lobbying healthcare professionals, politicians and local businesses, paying insurance premiums, appealing to networks of family and friends, selling land, property and inheritances, begging – all of which is channelled back into a healthcare infrastructure which requires that work in the first place. This work also generates capital for others, by pulling various public and private interests into play: pharmacompanies, medical suppliers, laboratories, pharmacies and medical staff. It is through the labour and movement of Mexican patients, and the uncertainties that this labour manifests, that we see a distinctive form of biopolitics at work, one very different to those grounded in predictable technologies of calculation and administration through which the state renders its population visible and knowable (Foucault 1980), something often assumed to be central to the functioning of European healthcare systems. In Mexico, uninsured kidney patients are only ever partial objects of knowledge and the state does not even pretend to have made them legible (Scott 1998). The country does not, for instance, have an integrated national kidney registry. Population data which is reported is acknowledged to be weakened by voluntary and inconsistent reporting (Cusumano et al. 2011). Not only does the Mexican state not know why people’s kidneys fail, it does not, therefore, definitively know whose kidneys have failed either. In what Brian Rappert (2012) refers to as the operational strategy of ‘states of ignorance’, unknowns don’t just proliferate, they are cultivated. Instead of legibility arrangements, what constitutes kidney patients as a population is the manner in which they are put on the move, creating regimes of care as they go. It is through such activity, I have argued, that regimes of power and government are stabilised (Kierans 2015). It is only by paying attention to the work undertaken by patients and their families as a consequence of the intimate uncertainties of care that we come face-to-face with the parasitic nature of transplant medicine in Mexico as part of those regimes – the fact that it thrives by debilitating those it is meant to ‘cure’.

When discussing the dysfunctions of Mexican healthcare with nephrology staff, they routinely invoked what they assumed to be smoother functioning and better funded healthcare systems elsewhere. This drawing of ‘better/worse’ distinctions, however, has the unfortunate effect of making invisible elsewhere or, indeed, in the UK what was dramatically in relief in Mexico. If we avoid such distinctions, a more productive question can be asked. That is, how can remaining alive to the distinctive features of the Mexican case sensitise us to aspects of the situation in the UK that might at first glance be considered in direct contrast? More pointedly, what are the states of uncertainty which attend failing organs as they make their way through regimes of care in the UK and how might we gain a better understanding of moral economy by attending to them?

What the Mexican case can help us to see is that a moral economy of care cannot be understood from the outside, but has to be seen at the intimate junctures, which shape where failing organs and arrangements of care meet and which are themselves a product of political economy (Palomera and Vetta 2016). The intimate uncertainties which in Mexico clearly structure the apparatus of care include: am I going to be able to access treatment?; is it going to work?; do I and those around me have sufficient resources to see this through?; am I going to die? Because Mexican patients are involved in establishing the care arrangements upon which they rely, their practical work provides a clear vantage point from which to understand the nexus of healthcare, the state and the market.

**Part Two: Following uncertainties in UK kidney care**

Unlike the haphazard routes to healthcare experienced by Mexican patients and their families, the publicly funded infrastructure of renal care in the UK, by comparison, *appears* to be clearly mapped out and organised. This infrastructure is dependent on an ‘opt-in’ system of deceased organ-donation, the principle mechanism, in the UK, for acquiring organs-for-transplant, and is underpinned by a nation-wide programme of haemodialysis, one with broad geographical reach across the British State.

The provision and articulation of renal services is bound to the Renal Transplantation Service Specification, a legal document defining relations between NHS England, 19 adult transplant centres and 52 specialist renal centres (NHS England 2013a).[[7]](#endnote-7) This document describes what each specialist renal centre *must* provide to every transplant patient and living donor. It states “a clear, unambiguous, evidence-based care pathway must be followed to ensure equity of access and high quality of care throughout” (NHS England 2013a). It also suggests, as aminimum, providers of kidney transplant services must ensure that there is “equity of access to transplantation, regardless of point of referral and location” (NHS England 2013b: 10). This legal framework is the organisational apparatus for the UK’s National Service Framework for Renal Services. It offers a formal system of sign-posting for both healthcare professionals and patients and underpins the entire patient pathway from diagnosis to end-of-life care.

As I have described elsewhere, the bureaucratic rendering of the patient pathway is one which is assumed to be predictable, routine and with explicit formalisations of responsibility and accountability. What is more, the distribution and spread of CKD in the UK is charted via the national Renal Registry. Functioning as an apparatus for ‘seeing’ CKD, its methods are coeval with the techniques available for treating the condition. As a site of knowledge production (Ruppert 2012), it systematically collects and analyses data from Renal Units on the incidence, management, and outcome of renal disease. This integrated approach to counting renal patients has produced a tightly governed population, with the incidence of and treatment for CKD comprehensively mapped alongside, as a function of the responsibilities of the British State” (Kierans 2017: 279).[[8]](#endnote-8)

However, as stated above, it is difficult to gain analytical purchase on the ‘actually existing’ practices of renal care when the terms of its operations are so explicitly mapped out in advance. That is, until we start to unpick the moral certainties at the heart of its claims: where do they find the organs upon which access to renal care and organ transplantation depends?; how are organs procured and allocated?; at what costs, and to whom, is care dependent on? These questions are much less easy to answer in advance, suggesting even in such an apparently prefigured system we cannot take the trajectories to renal care at face value. Once we begin to identify different states of uncertainty, it becomes possible to pursue a different kind of understanding of these arrangements.

For one, despite the moral rhetoric of universalised healthcare, no-one can ensure a system based on the gifting of deceased organs-for-transplant can ever meet demand. Organ transplantation is, by its own complex and controversial history, wrought with uncertainties as the anthropological record attests (Avera 2009; Hamdy 2010; Kierans 2015; Sharp 2006). CKD and its related treatments are, as a result, underpinned by challenges and inequalities all along the ‘standardised’ patient pathway. Moreover, these are said to disproportionally affect those from lower socio-economic groups and so-called Black and Minority Ethnic Groups (Udayaray et al. 2010)[[9]](#endnote-9). White socially deprived patients have reduced access to the transplant waiting list, an issue which also increases with age. Furthermore, they suffer an increased risk of death at 1 and 5 years post-transplant (Caskey 2013). Members of minority ethnic groups have a statistically greater need for a kidney transplant, yet are comparatively less likely to obtain one (Deedat et al. 2013). They also present later to nephrologists. These issues are made worse by regional variation. Clinical research via the ATTOM study, a study established to understand and improve equity, standardisation and transparency in organ transplantation, shows significant inter-centre variability in access to renal transplantation in the UK, an issue which the study team claim is not properly recognised (Oniscu et al. 2016).

Understanding inequalities, particularly in the context of universalised healthcare, is limited by the methodological approaches employed to do so. The literatures which predominate tend to reflect clinical, statistical and public health priorities and focus on renal care as set of fragmented or discrete stages, meaning we learn little about how different patients actually encounter healthcare beyond broad stroke references to demographics. We also learn little about the implications of the wider moral economy of care for families or, indeed, its gendered consequences. A persistent problem is a tendency to assume that the determinants of inequality lie outside clinical or institutional practices, often tied to abstract social, economic or political factors. This has produced a blindness to the particular ways in which the ordinary workings of healthcare infrastructures, bureaucracies, administrative routines and systems of accounting and rationing are bound up with uneven access to healthcare.

Take, for example, inequalities of access to transplantable kidneys for members of minority ethnic groups. This is a problem routinely treated as an outcome of low donation rates among these so-defined groups, and subsequently turned into a social or cultural problem, one lying firmly outside the operations of healthcare itself. This renders invisible the ways in which organ procurement and allocation practices are bound up with a nationally-devised body of clinical, scientific and laboratory practices, which designate who can be matched with who – practices which will never be encountered by the kidney patient and are rarely questioned in terms of their accountability (Kierans and Cooper 2011).

Under the current UK allocation scheme, kidneys are allocated according to an algorithm that takes account of variables such as length of time waiting for an organ, age, fitness for surgery and blood and tissue matching (or HLA Human Leukocyte Antigen matching). This algorithm produces a quantifiable forecast, in the form of Quality Adjusted Life Years (QALYs) – the number of ‘healthy’ years a transplant recipient (or any patient undergoing medical interventions) can expect to live following the intervention. These metrics determine the relationship of cost to benefit as part of the apparatus of rationing.

Decisions based on these practices are not easily captured or explained by the type of social contract imagined to hold between citizen and state that is enshrined in the moral project of the NHS. Instead, they depend on the complex associations between medical, corporate and governmental actors that shape the ways in which sick bodies encounter and move through the healthcare system. And while systems of rationing are central to a well-functioning healthcare system, in order to extend equality of opportunity and healthcare for all given available resources, the precise nature of this decision making process – the cost (human and economic) of working to its calculus of benefit and need – is itself uncertain because it lacks transparency. Because of this, it constitutes an ethical problem for ensuring equity in access to transplantation (Oniscu et al. 2016).

As an example, in a provocative article published in the Guardian Newspaper, Stacie Lewis, a writer and Leukaemia sufferer, described what she encountered when told she would need a second bone marrow transplant. Her doctors explained that while they were in unanimous agreement about her need for the surgery, the decision wasn’t up to them. It was up to NHS England, and to receive a decision they would have to fill out an Individual Funding Request (IFR) on her behalf. Finding a blank application form for an IFR on-line, the patient was confounded by the following questions:

*9b. If this treatment were to be funded for this patient on an individual basis, would the decision set a precedent for other requests?*

*11. What is the evidence base for the clinical and cost effectiveness/safety of this procedure/treatment?*

*17. What is the cost of the treatment/procedure and how does this compare with the cost of the standard therapy it replaces? Please ensure you include all attributable costs that are connected to providing the treatment/procedure e.g. drug/staff/follow-up/diagnostics etc.*

These questions prompted Lewis to ask: what is my life worth?; are decisions made within NHS England based on money or the best treatment to save my life? The cost of Stacie’s second transplant surgery was somewhere in the region of £100,000. With demand for organs outstripping supply, there are almost 10,000 people waiting for a transplant, with many dying before they get to the head of a very complex rationing system. The question of cost inevitably opens up a range of further questions: who exactly is paying?; what in effect are they paying for? what are the costs of the costs?; what worth is placed on sick bodies as they move through trajectories of healthcare? These uncertainties in care have been amplified by the erosion of the British welfare state since the 1980s (Pollack 2004) but also more recently in terms of a new political economy of austerity. These changing features of British healthcare, which I now proceed to discuss, help to bring lessons from Mexico even more firmly back to mind.

Austerity followed the 2008 banking crisis and was used as a justification to drive through a targeted set of ideological reforms by the governing British Conservative Party. The reforms were organised around the Health and Social Care Act, 2012, a piece of legislation designed to promote new efficiency measures and facilitate greater private sector involvement under the guise of enhancing ‘patient-choice’. Efficiency measures also included cuts to central government spending and with that a shift of powers to General Practitioners (GPs) via the establishment of General Practitioner Commissioning Groups, an arrangement which effectively placed the commissioning of frontline healthcare services in their hands (NHS White Paper, 2010). This would open up healthcare to aggressive lobbying by the private sector, but also raised the question as to whether General Practice was the appropriate sector to navigate and manage this shifting political economy of health, not to mention whether it was actually in the best interests of their patients for GPs to do so. The fact that resource-intensive medical technologies such as dialysis and transplantation were already experiencing cut-backs in funding to their services, meant that it would be difficult to block encroaching private sector interests. With price becoming the determining criterion upon which such commissioning decisions have to be made, this suggests a logic of integrated care (Mol 2008) is being progressively displaced by a logic of disintegrated profit.

In effect, the NHS with its enormous range of activities and multi-billion pound budgets provides new low risk, high turnover opportunities for the private sector, as well as the multiple contractors (builders, banks and consultancies) bound up with new Private Finance Initiatives (see below). According to Allyson Pollack (2004), after serving as a model for comprehensive and universal healthcare, the NHS has become a lab where market mechanisms are tested before being exported across Europe. This is a quickening process, she asserts, which has led to a dismantling of universal healthcare. The real costs to patients and the British tax paying citizenry remain largely hidden. At the same time, the rhetoric of standardisation persists via the NHS Plan and National Standards Frameworks their benchmarks for good practice and equity. The contradictions generated by commitments to nationalised, standardised care pursued through the incentivisation of localised, marketised provision produce remarkable ‘states of ignorance’ characterised by deep uncertainties around how British healthcare actually functions in terms of; what patients can expect; who pays; who benefits; and who is accountable to whom for what.

Many of the services upon which transplant medicine depends are vulnerable to the vagaries of this shifting political economy of health. Of the 82% of renal patients treated by In-Centre haemodialysis either in general or satellite units, 30% are treated by private healthcare providers (NHS England 2013). Relatedly, the blood services on which renal care depends have also undergone privatisation, creating new challenges for the timely supply of blood products. Moreover, the national tariffs for renal services (2015/16) also reflect a 13% cut in payments for hospital and satellite-delivered[[10]](#endnote-10) haemodialysis[[11]](#endnote-11) and the tariffs proposed for 2017-19 propose a reduction in payments for multi-professional outpatient follow-ups of 38% from 2016 (NHS 2015). These cuts not only affect the delivery of renal services but likely delays in transplant listing and worse patient outcomes.

An entire moral economy based on principles of universalism is imperilled when such regionalised, market-oriented variations start to show. If Mexico provides an example of a system which has progressively disembedded healthcare from the society it serves, then it is also a basis for assessing the form that process might take in other societies, such as the UK. Of course, the precise nature of the infrastructural privatisation we see in the UK is difficult to accurately detail from the trajectories of British patients and I have only begun to sketch this above. Unlike the Mexican patient who must physically go to a private laboratory, pay for, and take their analyses back to a nephrologist in a public hospital among many other things, in the UK it is much more difficult to get an understanding of who is doing what based on encounters with what appears, at least on the surface, to be a single, unified public entity. There is, as a result, much work to be done to ethnographically document the uncertain trajectories of healthcare in this context. Tracing those points at which patients encounter regimes of care and on what basis is one place to start but so too are the physical sites or infrastructures of renal care itself – the clinic and the hospital, settings to which I now turn. In these settings, we see the much broader consequences of a disembedding healthcare system, including the production of new moral economies of care with specifically gendered characteristics.

Rather than fund new medical infrastructures through direct government spending, they are delivered in the UK through a species of public-private partnership known as the Private Finance Initiative (PFI). Under PFI, a consortium of private sector banks and construction firms finance, build, own, operate and service essential health infrastructure, leasing it back to the UK government over a period of 30-35 years. As a result of PFI deals signed to date, UK taxpayers must make [£305 billion in PFI repayments across 700+ projects](http://www.theguardian.com/news/datablog/2012/jul/05/pfi-contracts-list).  PFI initiatives have been likened to paying for a hospital on your credit card (BBC Panorama), with the cost of borrowing at least two times higher than Government financed works according to a [2011 HM Treasury Report](http://www.parliament.uk/business/committees/committees-a-z/commons-select/treasury-committee/news/pfi-report/). What PFI has done, unknown to the patient who encounters healthcare, is reconstruct the relationship between the citizen and the state, so that public services, still free at the point of use, are no longer publicly provided (Mair and Jones 2005). Indeed, due to commercial confidentiality clauses, the public are not allowed to know the terms under which a PFI agreement has been made. 70% of new infrastructure in healthcare in the UK is now under PFI arrangements, representing one of the biggest redistributions of money from the public sector to the private sector in the history of the British state (Shaoul, 2011), an extraordinarily generous form of ‘corporate welfare’. This is bad for the service staff, who would once have enjoyed the benefits of public sector employment in the healthcare sector, bad for the taxpayer, but also bad for patients. It also has profound implications for women, particularly when viewed within the context of austerity.

Describing austerity as a feminist issue, British Labour MP Shami Chakrabarti points out that women depend more on state benefits, are more likely to be single parents, are more likely to be employed in the gig economy, and thus budget cuts affect them disproportionately. Although men, particularly poor men, are also profoundly affected, women represent the majority of the public-sector workforce. They are biggest users of public services and make up 77% of NHS staff. They also make up the bulk of low-paid home care and agency staff, as well as family carers for disabled children and elderly parents. When a council cuts a care package, it is largely wives, mothers, and daughters who undertake the unpaid labour to plug the gap (Ryan 2017). It is they who shoulder a much heavier burden when support and welfare responsibilities are returned to the family by a retreating welfare state, a shift which looks increasingly similar to the gendered structures of care-giving we see in the Mexican context. With less access to public support, it is women in the UK who also have to work to knit new regimes of care together.

Whether in Mexico or the UK, then, the new economic and technological arrangements that constitute the marketised welfare state intensify, through innumerable channels, the demands on women to sustain daily life for themselves and others and produce a feminisation of poverty embedded within a growing ‘homework economy’ in which the work once done by the state is realigned with that traditionally done by women (Gordon 1985; Haraway 1991). Haraway suggests that this process disassembles, reassembles and exploits women as a reserve labour force, less as workers, however, than as servers in, I would add, market-making projects led, financed and directed by the state.

Marxist feminists have written widely on this ontological re-structuring of the division of labour (Adkins 2002; Federici 2012; Skeggs 2003), and how it reconstitutes ideas of women and their roles in producing the social (Hartsock 1983; Harding 1986). This work critically collapses those public-private distinctions once ideologically imagined to characterise divides between factory and home or market and home. These dichotomies are reconstituting each other in practice, signalling moves away from old hierarchies to what Haraway has referred to as new ‘informatics of domination’ (Haraway 1991). In a situation of this kind, relations between home, workplace, market, public institutions and the body, particularly sick bodies but also those other bodies which support them, are reconfigured and given new kinds of work to do. Understanding how responsibility for care is being redistributed across those new relations is critically important for all the reasons outlined above.

**Conclusion**

Haraway’s contention that older hierarchical forms are succumbing to hybrid systems of domination provides an accurate summary of the changing bureaucratic infrastructures of the British NHS and their shifting moral-economic foundations. As with the situation in Mexico, it also highlights the increasing problems for ‘seeing like a state’ (Scott 1998) perspectives. Neither Mexico nor the UK are engaged in making healthcare more legible, it is instead becoming less transparent, more problematic and more intimately uncertain over time.

This again resonates with contemporary modes of organising, distributing and allocating healthcare in the UK. The role of PFI contracts and their capacity to redefine the terms under which sick bodies access care in the UK provides one example of how the state and its organisational infrastructures can serve new ends, shifting a responsive democracy of rationing to one fixed to the demands of new private healthcare markets and where the terms of PFI contracts are legally binding and hence immutable. With shrinking budgets, higher demand but more money proportionately going to service PFI contracts as a fixed item on those budgets, the size of healthcare rations decreases. That funds are increasingly being diverted in these ways is something few would regard as acceptable if it were pointed out to them, but the very complexity of infrastructural ‘innovations’ like PFI or commissioning mean their implications are rarely spelt out in public debate (see Mettler’s excellent 2011 study for the situation in the US). Put another way, if ‘western’ welfare states are moving away from knowledge-based visibilities to much higher states of ignorance and uncertainty, then the clear and stable relations between state, market and society that are the basis of the moral economy of entities like the NHS can no longer be assured. There are also epistemological consequences: most importantly, the Euro-American centric view that treats ‘our’ systems as the benchmark against which others are to be characterised and assessed is subject to a destabilising perspectival shift in which the differences between ‘our’ experiences and ‘theirs’ can no longer be assumed.

The ‘beneficent’ practices of valuation associated with an older political economy of state-led care based on the principles of universalism may not survive the translation to a new market-led one. The Mexican case, therefore, stands in close relation to the UK rather than a stark comparison. It is a sober forewarning of the catastrophic harm that results when public goods, like health, are not only transformed into commodities but are increasingly harnessed as material resources for generating capital.

We might suggest that the Mexican health system is one which foregrounds an existential uncertainty, where the UK emphasises an epistemic uncertainty, though both systems exhibit both features. Whereas in Mexico, people do not know whether they will be able to access care, in the UK, people do not know – are not allowed or encouraged to know – the terms upon which they access the care they do. This uncertainty is deep and invidious: the caring work of the state, carried out by private actors at public expense under the cloak of market rules but also by poor women in the context of work, family and community relations, hides its lack of care. By contrast, the Mexican system wears its dysfunction on its sleeve and, as a result, shows us logics whose operations we can follow through not just to understand Mexico better but also our own situations too. By way of a brief return to E.P. Thompson, his attempts to make visible the historical agency of ‘crowd’ teaches us something critical about attending to the practices, actions, regimes of value and uncertainties of ordinary citizens as they encounter and become concretely bound to a political economy of provisioning and resourcing. This not only shows the significant role moral economy plays in unpicking and making visible the workings of state-capital relations, but also as Palomera and Vetta (2016) keenly argue, that moral economy provides us with a uniquely anthropological approach to studying political economy and its attendant processes of social formation.

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1. Despite the fact that there has been sustained critique of the NHS over the past thirty years, particularly in the context of austerity and privatisation (see Pollack 2004), it is nevertheless important to note that the nature of this critique itself presupposes a moral economy, and therefore gains its critical traction by showing that is now falling short of its own ideals. [↑](#endnote-ref-1)
2. Muscle cramps are a common complication for patients on haemodialysis, the causes of which are not well-understood. [↑](#endnote-ref-2)
3. Mexico, like many countries in Central America, is facing a marked increase in CKD. Commonly known as Chronic Kidney Disease of Unknown Origin, the increase in this condition cannot be accounted for in ‘conventional’ etiological terms – i.e., attributed to increases in diabetes or hypertension. Instead, it has been linked to the wider structural consequences of global economic development: environmental toxicity, deregulation and precarious working conditions (Correa-Rotter et al. 2014). This, in turn, has affected particular constituencies of the population (young men predominantly); particular labour environments (the agri-industries, mining, fishing and tanneries); as well as sites of environmental toxicity and pollution. [↑](#endnote-ref-3)
4. Peritoneal dialysis, by far the most common modality of dialysis used in Mexico, works by using the lining of the stomach as an organic filtration system to remove waste products from the blood. [↑](#endnote-ref-4)
5. Peritonitisis an inflammation of the peritoneum, the thin layer of tissue that lines the inside of the abdomen. [↑](#endnote-ref-5)
6. Immunosuppression drugs suppress the body’s immune response in order to prevent a newly transplanted organ from being rejected. [↑](#endnote-ref-6)
7. Note, I am concentrating on England for the sake of simplicity here rather than including the other constituent nations of the UK too. Similar arrangements are in place across the other nations and NHS England deals with the vast majority of patients given England’s relative size. [↑](#endnote-ref-7)
8. This quote draws from a book chapter focusing on transplant medicine and the concept of value. It contains preliminary thinking on the mobilisation of a comparative optic when examining health systems and served to germinate the ideas which form the basis of my argument in this article. [↑](#endnote-ref-8)
9. Despite the moral project of NHS, universal healthcare, free at the point of access, this is nevertheless a rationed system, based on available resources. In the case of access to organ transplantation, rationing is contingent on the public’s willingness to donate deceased organs as well as on a strict set of criteria that match donor and recipient and which themselves generate inequalities (see Avera 2009; Kierans and Cooper 2011). [↑](#endnote-ref-9)
10. A satellite clinic or service is a facility owned by a hospital but operated at a distant site. [↑](#endnote-ref-10)
11. Hemodialysis, is a form of treatment for kidney disease, where blood is pumped out from the body through a tubing system into an artificial kidney machine, by virtue of a connection called a fistula usually placed in the wrist. It is then returned cleansed to the body via the same connection [↑](#endnote-ref-11)