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Situated compassion: affect, discretion and policy

Vicky Singleton and Steve Mee

Abstract

Care has become a focus of debate in feminist technoscience studies, with a recent call for researchers to be care-full about the politics of research and theorising and also to challenge ‘care’ as a taken-for-granted good (Martin et al., 2015). Care is a current focus of concern in Britain, where a crisis has been declared in national health and social care, and where previous policy has focused on quantity at the expense of quality (Keogh, 2013). The influential, government-commissioned Francis Report documents ‘appalling and unnecessary patient suffering’ and calls for action to put ‘compassion at the heart of healthcare’ (DOH, 2013a, p. 3–4). The report’s conclusions are widely supported, and there are new policy interventions to promote compassionate care (DOH, 2013b, 2013c, 2013d, 2013g; DOH, 2014). However, policy/care tensions exist; for example, the legislative responses are critiqued as meaningless to the realities of practice and as attempting to control rather than to support practitioners. In order to explore how compassion is being done differently in diverse instantiations and enactments, we juxtapose feminist technoscience studies on the politics of care with an analysis of health policy and with vignettes of located practices. The vignettes articulate affects, materials and relations of compassion in locations of practice and explore not only the good of what is considered compassion, but also possible harms, contestation and vulnerabilities. Thereby, the analytical approach aligns with Martin et al.’s (2015, p. 627) call for ‘critical care’ research that understands care as an ‘affectively charged and selective mode of attention’ and that exposes the dark side of care. The analysis also reflects on possibilities for formulating policy as a form of care that attends to situatedness and to affective and discretionary aspects of compassion as ethical relating.

Keywords

Critical care, policy, health, compassion, feminist technoscience studies, vignettes
Introduction: Capturing compassion

Compassion has become a central focus of British health care policy, and there is widespread agreement that it is essential to good care. However, the meaning of compassion is debated, its practice is poorly understood and its capture in policy is contested. The Oxford English Dictionary (2016) defines compassion in three senses. First, it can denote a feeling between equals or fellow sufferers when one ‘[suffers] together with another’. Second, it can indicate a feeling experienced by one who is free from suffering for another who suffers and therefore is not equal (‘the feeling or emotion when a person is moved by the suffering or distress of another, and by the desire to relieve it: pity that inclines one to spare or succor’). Third, it can imply an action (‘to have compassion on or to pity’) (www.oed.com, accessed 7.6.16). Compassion, far from being politically neutral, reflects and distributes relations of in/equality and difference. Moreover, it is an elusive and multiple entity. It names an affect and is a response to the suffering of another – or it is suffering with another. It therefore comes as no surprise that national policy, which requires ‘clear statements and principles for action that aim to change a situation’, should find it difficult to capture compassion. Yet, new British health policies are attempting to do just that. This paper juxtaposes analysis of current policy with vignettes about compassion in located care practices as a way of exploring the problems and possibilities that may arise when policy attempts to apprehend compassion.

Certain new formulations of health policy attend to previously undervalued, seemingly mundane aspects of care, such as compassion. This development (in itself a welcome one) has tended to carry assumptions and enact distributions that bear interrogation. In particular, policy documents and interventions typically seek to codify and quantify compassion, a process that inevitably masks crucial aspects of compassion as practitioners feel themselves under surveillance. These circumstances tend to interfere with our understanding of compassion and thus can negatively impact care. Recent work in Science and Technology Studies has figured care as collaborative practices of tinkering (Mol, 2008; Mol et al., 2010) and as ethical relating (Haraway, 2008). Bearing these views in mind, we locate our analysis of compassion as an aspect of policy within specific instances of health care practice. Through vignettes, we attend to affects, relations, materials and unsettling constituents of compassion that are often hidden, neglected or marginalised (Martin et al., 2015). Hence, following Murphy (2015), we caution against equating compassion with positive feelings and relief from suffering. We argue for exploration, through methodologies such as vignettes, of how affective and discretionary aspects of caring could be care-fully apprehended in debates about policy-care relations.

Vignettes as an intervention

Attending to patient care stories in debates about health policy and in the training and evaluation of practitioners is seen as crucial to providing good care in Western societies. Indeed, listening to patients and carers is one of the recommendations of The Francis Report (DOH, 2013a), the basis of which was an inquiry that collated stories from hundreds of patients, families and staff. Typically, health care delivery has focused on patients’ symptoms, with management plans designed to resolve and treat the corresponding medical problems. However, guidelines for good practice are increasingly recognising that good care requires acknowledgement of the dominant voice of the patient’s story, which arises from personal encounters with health and social care. Seeing the value
of stories of practice in improving health care is not a new idea; indeed, Snowden (1999) has suggested that the use of patient narratives describing direct experience can change a listener’s understanding of the patient experience and resonate with the practitioner’s own experience, thus offering incentive for practice development (see also Mee, 2012). Medical sociology has long urged a move away from a diagnostic stance, which defines illness simply by disease presentation, towards practices that understand that a person’s experience of disease within the context of the individual’s ‘lifeworld’, which can be influenced by social, cultural and political issues.

One challenge to incorporating patient narratives within health care is the fact that the practice of using stories conflicts with the training of most professional practitioners. Historically, nursing and medicine in general have tended to champion objectivity and evidence-based practices (EBP), along with quantitative research. Webb (2001) has argued that the preference for quantitative research derived mainly from medical science and is based in the scientific/positivist paradigm. The main concern is for replicability, reliability and generalisability. The ‘gold standard’ of research, and therefore evidence, is the randomised controlled trial (Dougherty and Lister, 2004; Parahoo, 2014). We might therefore ask what sort of knowledge and ‘evidence’ stories have to offer. Tevendale and Armstrong (2015) describe some of the benefits of using patient narrative in treatment: enhanced understanding of issues, improved problem solving and the ability to narrow the gap between experience and theory. All of these are critical issues; however, we would argue that these concerns fit an EBP professional narrative which reproduces a top-down version of good care as rational and detached. This orthodoxy ignores that stories offer the potential for reflexivity at a deep and nuanced level, in part because they invite an emotional response. Patient stories tend to narrativise patient experience in ways that differ from dominant professional and policy narratives.

Patient narratives about their experiences have become a powerful resource for patient activist groups. The narratives provide ‘evidence-based activism’ that facilitates patient participation in knowledge production and policy development (Rabeharisoa et al., 2014). At the same time, individual stories are often aggregated in the processes of policy development to reproduce hegemonies rather than articulate patient needs as specific, individual and context dependent. Brit Winthereick and Helen Verran (2012), in their paper ‘Ethnographic Stories as Generalizations That Intervene’, explore the risks of telling stories in academic work (e.g. the possibility of perpetuating hegemony). They suggest that the ethnographic stories researchers tell should encourage readers to critically and reflexively engage with the stories’ subjects, objects and tellers. For example, Winthereick and Verran suggest that stories incorporate disconcerting moments that serve to remind readers that that any story is only one of many possible narratives. Disconcerting moments are elements of a story that are unsettling and aim to promote affective engagement. For Winthereick and Verran, the aim is to prevent ‘hardening of the categories of the everyday’ and to challenge normative distributions, such as determinations of who is an expert, who/what is marginalised, or who/what is an object versus a subject. At the same time, Winthereick and Verran argue that ethnographic stories will only resonate with and speak to individuals (i.e. act in a potentially transformative way) if they are specific and faithful to lived experience.

In place of patient data obtained expressly for this study, we include here indicative vignettes chosen from academic research that we have carried out in the health and social care fields (Mee, 2012; Buckley, Corless and Mee, 2016; Singleton, 2005, 2010, 2012, 2015). The vignettes explore practices, affects, relations and materials of compassion that are often hidden and go unarticulated.
They include anger, distress, non-coherence, ambivalence and non-response. They aim to be generative rather than purely descriptive in that they articulate the complexity of doing compassion and thereby unsettle generalisations (Law, 2004). Hence, each vignette is specific but, as Mol has stated regarding patients’ stories, ‘That does not mean that their significance is local…. Not despite, but thanks to their specificity, these stories are strong enough to get across the importance of “good care”’ (2008, p. 2). We deliberately avoid framing each vignette with an analytical introduction because, following Winthereick and Verran (2012), our approach is one of ‘affectively charged engagement’ rather than an attempt at objective analysis.2 The first vignette illustrates our approach. The vignette is Mee’s account of an affective and transformative research encounter during which he was filming a man who had been cared for in a large Victorian mental health institution telling his care stories (Buckely et al., 2016, p23). This was part of a research project about articulating and valuing the experiences of people with learning disability (Mee, 2012). Mee was supporting the man’s efforts to tell stories about his life in the institution. The man described the abuse he saw meted out to people with a greater degree of learning disability than himself.

The man described how he used to get thumped and he didn't know why. He acted out a thump. He described how other learning disabled men were dragged. He acted out a dragging motion. I thought I had heard most of the stories before but I had never heard about 'Dragging'. I felt a wave of anger and lost focus on the filming.

I had a disturbing mental image of a person being dragged. I remembered a scene from a TV play, 'The Monacled Mutineer', in which a deserter was being dragged to the firing squad. He was screaming and being pulled along the floor. I also recalled a scene from a war documentary in which a Burmese 'comfort woman' was being dragged along the floor into a nissan hut by a Japanese officer. The woman had obviously been beaten but appeared resigned to her fate. The mental image of being 'thumped' allows for the person to 'thump back'. That would be a fight and might go either way. Being dragged on the floor is an image of total domination, there is no fighting back.

This vignette clearly exemplifies terrible care. For Mee it was as if he had never previously 'got' the nature of lives being dominated in an institution. He was haunted by the image. The vignette exposes ways in which hidden and silent practices can manifest inequalities and violence. The thumping and particularly the dragging mentioned in the vignette clearly leave Mee distressed as he associates these unsettling stories with his own recalled images of injustice and powerlessness. In particular, the haunting image of ‘dragging’ led to affecting and transformative reflection. Mee went on to reflect on the nature of power and the experience of being overpowered and draws on this story in a series of articles published in the professional journal, Nursing Times, about using patient stories to reflect on and improve all aspects of nursing (Buckley, et al., 2016). This vignette demonstrates that liveable worlds require us to care for one another and suggests that affective stories can promote compassion and understanding of how to do that.

**British health care policy: Compassion is a core value**

In February 2010 reports of widespread failures of care and higher than expected mortality rates at a hospital run by Mid Staffordshire NHS Foundation Trust led to a public inquiry. The final report of the
inquiry, The Francis Report (DOH, 2013a), received widespread media coverage and marks a watershed in health care policy in Britain. The inquiry documented ‘a story of appalling and unnecessary suffering of hundreds of people’ and a ‘lack of care, compassion, humanity and leadership’ (4). The Chair of the Inquiry, Robert Francis, argued that there were numerous causes of this ‘disaster in care’. The report runs to several volumes and makes 290 recommendations; however, the central problems are diagnosed as failure of the hospital management board, collective disengagement from responsibilities and lack of accountability, and lack of compassion. Subsequently, the government identified ‘compassion and care’ as the first of five key policy recommendations (DOH, 2013d; DOH, 2014). This followed the publication of a revised NHS constitution defining compassion as one of a set of six common values to underpin the NHS:

We ensure that compassion is central to the care we provide and respond with humanity and kindness to each person’s pain, distress, anxiety or need. We search for the things we can do, however small, to give comfort and relieve suffering. We find time for patients, their families and carers, as well as those we work alongside. We do not wait to be asked, because we care. (DOH, 2013c, p. 5)\(^4\)

NHS England, the public body of the DOH and NHS Commissioning Board that oversees budget, planning, delivery and day to day operation of the NHS in England, also emphasises and attempts to define compassion in their vision and strategy for nursing, midwifery and care staff titled *Compassion in Practice* (2012). The ‘6Cs strategy’ (compassion being one of the ‘Cs’) provides guidelines for practice and for training and evaluation of practitioners. Further, compassion is a central component in the development of ‘The Culture of Care Barometer’, which is a tool developed by NHS England to measure care culture in organisations. These attempts to codify and quantify compassion are supported by recommendation number 194 of the Francis Report, implemented in 2016, that nurses should evidence ‘commitment, compassion and caring for patients’ as part of their annual professional revalidation to practice (DOH, 2013a, p. 1696).

Note that the government acknowledges that the reach of policy is limited: ‘we know that publishing a national document is not going to change cultures in wards and teams across the country. What matters is whether teams are inspired to own and live the values set out in the constitution’ (2013c, p. 6). This suggests that the success of policy depends on whether care teams embody and practice it. The upshot is that the State is disengaged from responsibility for the quality of care received by patients, and policy is figured as distant from, and guiding, practice. The focus of policy is to change practitioners’ behaviour. Compassion is enacted as primarily a characteristic of the individual practitioner and as an effect of the decisions he or she makes. The aim of the policy is to ensure that compassion is adopted as a core value that is shared alike by all practitioners across locations of practice. Practitioners are responsibilised within a context of surveillance, threat of failure and loss of their professional status. It is in these ways that, even though limited and vulnerable, the policy generates relations of harm and lack of care. It couples compassion with calculation in problematic ways.

**Coupling compassion and quantification**
The following vignette is taken from Singleton’s field notes, written following a public event in Lancaster City titled ‘Caring with Compassion’ (5 March 2015). The event was very successful in terms of the number and diversity of visitors and also in terms of the wide range of practices and materials they identified as relating to compassion and care. Many participants spoke about when compassion had been lacking in their experiences of receiving or giving care. The vignette below recalls an account from a woman who was caring for her mother. The woman was visibly upset that her attempts to provide care were being compromised because access to oxygen had been codified according to funding boundaries. She said that she hoped her story would be told to those responsible for the policy.

The daughter explains that she has been caring for her mother who is very independent and has her own home. Her mother has a chronic heart condition and lives in Derby, 150 miles away. She said that for 2 years her mother has been travelling between her own home in Derby and her home in Lancaster. Her mother’s illness has good and bad spells. She needs a more or less continuous supply of oxygen. When she is very unwell her daughter drives to collect her and brings her to stay until she feels well and wants to return to her own home. The oxygen travels with her mother, between the two homes. The daughter said it has been difficult for her, partly because she is also trying to care for her children. She then became angry. She said the central problem she has had is access to oxygen. On one of the previous stays with her, her mother’s oxygen ran out. The daughter describes how she tried desperately to obtain some oxygen. She was repeatedly told that she could not have any because it is for her mother whose care is funded through a different health authority. She says that she was advised to take her mother to the Accident and Emergency Department at the local hospital, Lancaster. That’s what she did, reluctantly. Her mother was given oxygen and felt better. However, the staff said that regrettably she must obtain a home supply from her Mother’s own health authority. This has happened more than once. The nurses were very apologetic and said that it is, regrettably, how the system works. The daughter was very upset by this. In particular she said that she felt that attempts to care with compassion by her and by the local practitioners had been thwarted due to funding and institutional boundaries that did not acknowledge that compassion exceeds geographical and institutional boundaries (Fieldnote, Ms. B, 5 March 2015, p3).

Another woman spoke about caring for her daughter who had been dying from cancer. She didn’t talk explicitly about compassion. Rather she described things she and others had done that had helped her daughter and family. They included professionals calling her daughter by her first name during hospital visits and help for her daughter with activities such as ironing, dusting and shopping. She finally said ‘I didn’t know what it (compassion) was until I did it’ (Fieldnote, Mrs. C, 5 March 2015, p4).

The availability of oxygen as described by the carer is an effect of quantification and codification of care within geographically and economically defined institutional locations, rather than according to patient and carer need. The vignette suggests that compassion cannot easily be codified and quantified and yet is crucial to caring well for others. The emphasis on compassion in new formulations of health care policy suggests a welcome shift of focus towards ethics and quality of care and away from quantifiable outcomes and targets. However, policy debates suggest that qualitative and quantitative aspects of care are being coupled in ways that codify and seek to
measure compassion; such efforts thereby present an impoverished, if not meaningless, version of compassionate care. The new formulations of policy have been developed rapidly, in large part in response to the government inquiries that have linked a quantitative framing of care to patient harm, neglect and abuse (DOH, 2013e; DOH, 2013f). So, for example, the Francis Report argues that the failures of care are systemic and an effect of the political and economic framing of health care: ‘failure was in part the consequence of allowing a focus on reaching national access targets, achieving financial balance and seeking foundation trust status to be at the cost of delivering acceptable standards of care’ (Francis, 2013, p. 3; see also DOH, 2013a). Further, the Keogh Review of acute hospital care concluded that failures were a consequence of caring for outcome indicators and must now focus on the ‘quality agenda’ (2013e, p. 5).

Other important aspects of the context within which current policy is developing are debates in the popular media and activism by practitioner and patient organisations. The media have been full of distressing stories in which distraught and angry relatives and patients have spoken about deprivation of basic needs such as water, food and toileting. Newspaper headlines have presented the beloved icon of British values, the NHS, as causing, rather than preventing or relieving, suffering.7 Intensified activism has sought to increase compassion in locations of practice. For example, the Patient Association, an influential national UK charity representing patients, recently issued a call to action (2015) for all NHS, government and health care staff to clarify how the common values in the revised constitution, including compassion, will be enforced. The hugely successful ‘Hello my name is’ social media campaign, started in 2013 by terminally ill doctor Kate Granger following her experience of hospital care, urges all health care professionals to introduce themselves to every patient they meet because, she says, this is the first rung on the ladder to providing compassionate care. The then British Prime Minister, David Cameron, plus numerous celebrities, publically signed up to the campaign. The campaign has also been adopted by over one hundred Health Care Trusts across the UK, and in 2014 NHS England began the Kate Granger Award for Compassionate Care, an annual set of awards for individuals, teams and organisations who demonstrate outstanding care for their patients (NHS England, 2016).

Policy analysts note that a commitment to compassion is not new. For example, Smith (2008) states that compassion has long been at the heart of the philosophy of the NHS, and Lord Darzi’s 2008 review of the NHS demanded that health care be delivered compassionately. The King’s Fund (Firth-Cozens and Cornwell, 2009) and the British Medical Association (2011) have long promoted compassion in health care, and the Nursing and Midwifery Council have repeatedly committed to compassionate care (e.g. 2007). It seems that compassionate care has remained elusive in practice despite the long-standing and widespread commitment to the concept in health care policy. Consequently, one growing body of research has explored whether compassion can be fostered in locations of practice through training practitioners. Some of this work attempts to model compassionate care so that it can be taught, measured and evaluated. For example, Crawford et al. (2014) seek to ‘design’ compassionate care by identifying a set of rules of compassion (Crawford et al., 2014b; see also Cole-King and Gilbert, 2011).8 In doing so, Crawford et al. (2014) draw attention to the dearth of knowledge about the complexities of practising compassion (e.g. how organisational structures and processes affect compassion). Similarly, research in psychology and medical ethics suggests the value of compassion to both receiving and giving care while noting that compassion takes many forms (e.g. Gilbert, 2011; de Zulueta, 2013) and hence that there is no panacea when it comes to training (Gallagher, 2013).
Social scientists and health activists argue that the long-standing difficulty of ensuring compassion in practice is a consequence of social and economic factors that have impacted the capacity to provide care and have been effaced in policy (e.g. in relation to mental health policies; see Spandler and Stickler, 2011). So, critics have pointed out that the ways in which compassion is included in policy render it meaningless. In particular, some have claimed that the concept has been inserted into current policy in an abstract way that bears little relation to the reality of care practices; others have voiced concern that the idea of compassion is even emerging as a mechanism of control and surveillance of practitioners’ practices rather than a means of facilitating care. For example, Penny Campling, a practitioner and clinical director (2013), writes: ‘the concept of compassionate care is being bandied around in an evangelical fashion and squeezed into every document possible. But frankly there is an Orwellian touch to the way the word is being used and a real danger that the concept will be rendered trite and meaningless.’ Further, Bill Mumford (2013), practitioner and health activist, argues that compassion is essential to care practice but has become a buzz word and is a slippery concept in policy debates. He argues that policy debates about compassion are divorced from the realities on the ground, unclear about what the concept means and ill-equipped to deal with the issue of transforming the value into action.

Medical ethicists have debated how to transform compassion as a value and concept into action. For example, Ana Smajdor (2013) and Paquita de Zulueta (2013) have expressed a concern about a compassion deficit among practitioners and the insufficient attention that policy has paid to this issue. Smajdor argues that it is dangerous and unfair to expect practitioners to maintain compassion in challenging circumstances of long working hours and limited resources. This has promoted her to go as far as questioning whether compassion is even a necessary component of care. Smajdor argues that other sociotechnologies, such as checklists and guidelines, are more effective in ensuring that tasks are carried out and care is achieved. She argues that in some circumstances, care requires detachment from feelings (e.g. technical knowledge rather than empathy is crucial for a surgeon performing an operation). However, Code (2015), in her study of advocacy, challenges an assumption that effective practitioners are dispassionate about, and disconnected from, the people and topics under consideration. Indeed, she describes this assumption as a ‘curiously implausible image of human subjectivity’ and argues that, on the contrary, knowing requires caring about what and how one knows (see also Myers, 2015). For Code, caring, affect and knowing are intimately interwoven: empathy does not compromise the ability to care; rather, care entails an ‘affectively charged’ mode of attention (Martin et al., 2015). Similarly, de Zulueta (2013) asserts the need to rethink biomedical ethics as everyday practices that are interdependent with and productive of social relations and context. She draws attention to the need for policy to acknowledge that compassion is an affective and physical engagement that requires considerable personal and material resources.

In summary, an intensification of attention towards understanding compassion in locations of health care has led to increased scrutiny of compassion (as a concept, a value and a set of practices). Particular attention has gone to both the question of what causes a lack of compassion and how compassion is being put into policy. Widespread support is emerging for a shift towards attending to compassion and away from the damaging past focus on quantity of care, targets and financial balance. Still, there is no clear sense of how to do this well. The new formulation of health care policy seems to couple an intensification of calculative rationalities with new affective intensities, but, as can be seen in other policy domains such as education, this coupling can be problematic.
Practitioners and medical ethicists have expressed scepticism that policy can capture what compassion is in locations of practice; many predict that incorporating compassion within policy will result in it being used as a means of surveillance and control. Given the limited resources for health care and existing demands on practitioners, a debate exists as to whether compassion is even an essential component of quality care. Representatives of practitioner and patient organisations, educators, health care researchers and medical ethicists are all calling for greater understanding of the complexity of compassion, especially in locations of care practice, and for this to be visible in policy debates. Yet, it seems that compassion remains rather elusive in practice (Brown et al., 2014). Below we draw upon science and technology studies to think through compassion as a series of practices that emerge in specific sets of relations between heterogeneous entities. This suggests that compassion not only takes many forms but also may be embedded in relations of harm.

Technoscience studies on care: Unsettling compassion

The relationship between policy and care is entangled in complex ways and neither should be taken for granted as good or harmful. For example, Murphy states that care ‘can work with and through the grain of hegemonic structures’ and here we suggest that policy is one such hegemonic structure (2015, p. 4). By way of explication, the following account is taken from the testimony of a nurse at the Nuremberg trials. She had knowingly given lethal doses of sedatives to people with learning disabilities in Hadamar hospital during the euthanasia period. This vignette serves to complexify the relation between policy and care and unsettles understandings of compassion. The nurse stated:

When giving the dissolved medicine, I proceeded with a lot of compassion. I had told patients that they would have to take a cure.... I took them lovingly and stroked them when I gave the medicine. If, for example, a patient did not empty the entire cup because it was too bitter, I talked to her nicely, telling her that she had already drunk so much that she would drink the rest, otherwise her cure couldn't be finished. Some could be convinced to empty the cup completely. In other cases, I gave the medicine by the spoonful. Like I already told you, our procedure depended on the condition of the patients. Old women, for example, who had to be fed couldn't drink on their own so it wasn't possible to give them the medicine by the spoonful. They were not to be tortured more than necessary and I thought it would be better to give them an injection. In this connection, I would like to say that, like me, Luise E. [Erdmann], Margarete Ratajczak, and Erna E. thought that the patients were not to be tortured more than necessary. (Ebbinghaus, 1987, p. 239, cited in Benedict and Kuhla, 1999)

This vignette appears to present a grossly uncompassionate act (state-sponsored murder) carried out with compassion. The nurse used the word ‘compassion’ when describing her own behaviour, yet her compassionate act is deeply disturbing because it promotes death rather than healing. Her work was performed in a policy context in which the goal was the eradication of people with learning disabilities. The service targets were clear. The following event took place when Hadamar hospital achieved its 10,000th killing:

On the order of the physicians, the entire staff assembled at the basement crematorium to participate in the burning of the ten thousandth victim. A naked corpse lay on a stretcher,
covered with flowers. The supervisor Bunger made a speech and a staff member dressed up as a cleric performed a ceremony. Every staff member received a bottle of beer. (Friedlander, 1995, 110)

The vignette reminds us that compassion should be explored in its specific instantiations and enactments, in policy and in located practices. Policies, in their diverse forms, reflect, produce and are supported by the social, political, institutional and material context in which they are embedded. Furthermore, the relationship between policy and care is complex and non-linear. Policy takes the form of strategic documents and principles as well as practices in situated sets of relations. In this section we draw upon feminist technoscience studies to figure both compassion and policy as situated and explore the implications of this.

Annemarie Mol’s (2008) ethnographic study of care for diabetes patients in clinics in the Netherlands defines care through accounts of practices. Mol asserts that good care consists of artful, persistent practices of tinkering that involve collaboration between humans, technologies, documents, knowledges and skills (see also Mol, Moser, and Pols, 2010; Pols, 2014). Care is not a purely human endeavour but is rather mixing (rather than purification) of humans and non-humans. All of our vignettes highlight care as relational, collaborative and material through and through. For example, the oxygen was a crucial actor in the care of the woman in the vignette above. Mol (2008) asserts that crucial and mundane care practices are often silently incorporated and not articulated. She suggests that this is a consequence of the dominant logic framing care in the ‘West’: patient choice. For Mol, the ‘logic of patient choice’ is problematic because it conceptualises good care as a capacity of individuals (practitioners and patients) and an effect of the well-argued choices that they make, rather than relational, material and responsive.

In feminist technoscience studies, the concept of ‘critical care’ has been introduced to attend to the politics of compassion and to a commitment to build more lively care-full policy. Critical care acknowledges a tension between, on the one hand, caring for the human and non-human animals, ideas, relations and materials that we study and, on the other hand, critically interrogating them (Martin et al., 2015; Puig de la Bellacasa, 2011). It understands that care entails an ‘affectively charged and selective mode of attention’ towards particular objects of care and simultaneously away from others (Martin et al., 2015, p. 627). An excellent example is Murphy’s (2015) discussion of ways in which ‘care’ has been performed in the history of North American feminist health activism and the entanglement of these performances of care in histories of persistent racisms, class privilege and American imperial ambitions in the 20th century. She cautions against equating care with positive feelings and calls for ‘a vexation of care’, stating that

...there is an ongoing temptation in feminist scholarship to view the affective and care as a route to emancipated science and alternative knowledge-making without critically examining the way positive feeling, sympathy and other forms of attachment can work with and through the grain of hegemonic structures. (Murphy, 2015, p. 4)

She argues for unsettling care as a critical practice. Her work understands that care is always circulating within particular institutions and carries specific affects, practices, materials that constitute norms and assumptions about care. Below we pursue a critical engagement with compassion as a political and cultural concept that can be appropriated.
A politics of compassion: Beyond private empathy towards response-ability

Berlant (2004) and Vitellone (2011) argue that how compassion is represented and appropriated enacts (in specific and sometimes problematic ways) who or what is the proper object of compassion, who can be compassionate and what practices are designated as compassionate. For example, Berlant argues that ‘the compassionate’ is enacted as having social privilege over the sufferer, from whom the compassionate has a comfortable distance. Compassion is considered a highly political and cultural emotion that has been used by politicians and advertisers in the service of seeming to promote equality while reproducing asymmetries. A case in point is the British government, whose focus on ‘lack of compassion’ as the central cause of poor care overlooks other factors, such as service cuts and management’s emphasis on targets. McRobbie (cited in Vitellone, 2011) argues this is a particular risk when the attention is focused on the individual and their experience of pain rather than the social and cultural context in which compassion is lacking or present. Vitellone extends the point to describe how specific materials might be used in political documents, such as a syringe appropriated to promote disgust and lack of compassion for drug users. The health care policy we discussed above conjures ‘vulnerable patients’ and ‘unnecessary suffering’ without the detail about social, material and political context that the Francis Report and subsequent inquiries and academic and activist commentaries have drawn attention to.

Berlant, McRobbie and Vitellone – each in different ways – are concerned to move beyond private compassion or sympathy to a politics of compassion that promotes an understanding of structural conditions of inequality and injustice and creates the potential for structural change. The challenge is how to use private empathy in order to forge a ‘personal relation to a politics of the practice of equality’ (Berlant in Vitellone, 2011, p. 580). Attention to both everyday life experiences of pain, suffering and compassion – and to wider context – can create the possibilities for intervention in the structural conditions that promote suffering, such as those produced in policy. Rather than a private emotion, compassion is figured as relational and instantiated and performed in a social, material and cultural context. Similarly, Donna Haraway (2008) refers to mundane practices of caring as world building because they create the possibility for more equitable relating. She argues that compassionate acts, as ethical relating, involve ‘becoming subject to the unsettling obligation of curiosity’ (36) about how entities relate with one another, the differences between entities and the broader social, political and geographical conditions in which relations of care and suffering are produced.

There are two central points here. Firstly, compassion is responsive. Compassionate acts are attentive to our inter-implication with others and require a willingness to respond without knowing what that response is ahead of time (Martin et al., 2015). They involve touching and being touched by others, physically, emotionally, socially and politically. Secondly, compassionate acts are response-able. They are performative and affective engagements, committed to ‘an ethics of flourishing’ and to producing more liveable worlds, rather than primarily the relief of suffering (Haraway, 2003, 2008; Barad, 2007). Compassionate care, revisioned through a feminist technoscience studies lens, is ethical relating that facilitates thriving, growth and resilience. It is not necessarily relief of individual suffering. Inspired by the work of these feminist scholars, below we tell our final vignettes that situate compassion and in doing so draw attention to the complexity of practicing compassion.
Ethical relating: Situated compassion

Singleton and Law carried out an ethnographic study of care of patients with Alcoholic Liver Disease (ALD) in a series of clinical locations in an acute hospital Trust (1999, 2005). The disease causes much patient suffering and can cause death. It is also a concern to the health-care system because many patients require frequent repeat hospital admissions and they occupy beds in acute hospital wards. The research aimed to map out the processes involved in diagnosing, treating and following-up a ‘typical’ patient in order to improve care. The Trust has one of the highest number of alcohol related patient admissions in the UK, in large part because the geographical area is associated with a large transient population and with high alcohol and drug misuse. Even so, the number of patients admitted with the disease was higher than the Trust expected. During the research twenty-five professionals were interviewed. One of those interviews has remained especially vivid to Singleton, that of a community doctor. Hospital doctors had said that a local community doctors practice was failing and providing poor care because a higher than expected number of patient referrals for hospital care came from the practice. Consequently a doctor from that practice was interviewed. During the interview Singleton was moved by how hard the doctor was trying to provide care in very challenging social and economic circumstances. Below is Singleton’s account of her experience of the interview.

We arrived at the community doctors’ surgery in the middle of a run-down housing estate on the edge of town. This is known as a problem estate with a high level of chronic unemployment, a high crime rate and poor quality housing. The estate is recognised as having a large number of people with drug and alcohol dependency and widespread chronic illness. We walked to the door of the surgery. Taken by surprise, we realised we had to ring the bell in order to be let in. We were admitted into a holding space while the door closed behind us and we waited for a second door to open. We were aware that a receptionist inside was assessing us for admission. We learned later that there have been a high number of attempted break-ins to steal the drugs and also that the doctors have been attacked on numerous occasions, hence the two locked doors. Once in we waited to be shown into a consulting room to carry out the interview we had arranged with one of the doctors. During the interview we asked the doctor how she informs patients about the physical effects of alcohol. She rather wearily replied by telling us about a patient who’d been told by a hospital consultant that she would die if she did not stop drinking. She explained that the consultant had expected the warning to scare the patient into abstinence. But instead the patient had visited her and asked ‘How many months have I got to live, doctor?’ She said, ‘I cannot talk about such things [effects of alcohol] to many of the clients – this might provoke a violent response. It just is not relevant to them. Long term issues are not considered. Many people have accepted that they will never work again and do not aspire to a fancy car or different housing.’ She went on to say, ‘For many, alcohol is the least of their problems: the consequences of alcohol abuse are minor compared with the alternatives that include heroin addiction…. They’d be better off on alcohol’ (Research fieldnote, community doctor, Dr F, 11th June, 1999, page 55).

As stated above we were aware that a higher than expected number of patient referrals for hospital care for serious alcohol-related medical problems came from the practice in which this doctor
worked and that the practice was said to be failing. Singleton was upset by the suffering, not only of
the patients in this location, but also of the doctors. It was clear to Singleton that the doctor was
trying hard to do the best for her patients in challenging circumstances and without adequate
support. Singleton was struck how difficult it was for the doctor to care as she had been trained to
do and at the same time to be responsive to patients’ needs. Paradoxically, in order to care she
didn’t inform some patients about the physical effects of their alcohol use. She even went so far as
suggesting that alcohol use may be preferable to some other ways (such as heroin use) through
which people survive within their specific socio-economic environments. The doctor’s practices are
incongruous with medical guidelines about care, alcohol use and disease. Her account suggests that
she is aware that her own medical knowledge and expertise are wanting and that elsewhere her care
could be seen as harmful. Yet, her practices are responsive and alert to the ways in which illness and
bodies are entangled with socio-material and political context. However, her care has been
evaluated as failing, perhaps because crucial aspects of it are not visible, or at least not as visible as
the number of patients admitted to the hospital with symptoms related to alcohol misuse.

She subsequently spoke of the clinic’s low morale and high doctor turnover, both of which suggest
that doing compassionate care can be deeply affective, challenging and even risky, especially in
locations where there is incommensurability (such as medical guidelines conflicting with patient
values and survival strategies). In this example, compassion required attentiveness to the social,
affective and economic specificities of ill health, rather than application of medical knowledge and
general guidelines. We suggest that this vignette explicates some characteristics of, what we call,
‘situated compassion’.

To give a further example of the complexities and constituents of situated compassion, we offer the
following vignette from Mee’s current research exploring how paramedics and other practitioners
are trained to deal with affectively challenging situations. This vignette suggests that compassion
may sometimes be collaborative practices rather than an individual capacity.

Mee was interviewing a paramedic about how he trains other paramedics. He spontaneously
began speaking about his own past experiences. He described attending a serious road
accident in which a young boy was killed. He described that some of the boy’s internal organs
were on the road, visible and separate from his body. He described the horror of the scene
and the terror of the realisation that he or one of his team members must collect the body
parts and carry them to the ambulance. He described how he drew his team together,
huddled behind the ambulance and tossed a coin. At first it was ‘best of three’ but the loser
did not like the outcome so it became ‘best of five’ and then ‘best of seven’. He described
feelings of being watched during this process and that he felt this behaviour could be
evaluated as lacking compassion by an outsider. It was a way of coping that recognised and
shared the awfulness of the situation and the anxiety within the team. They had deep
compassion for the boy and his family and perhaps this coin tossing game could be seen as
mutual compassion, making the situation bearable. He subsequently broke down saying that
he had never told anyone else about this experience. After the team had put the boy and his
body parts into the ambulance he rang the control centre and received details of the next job
they were to attend. There was no time to reflect upon or discuss the episode (Interview with
paramedic, June 2015).
Compassionate care may be focused on colleagues rather than patients. Further, the paramedic describes feeling that he is being watched, that what he should be doing contrasted with what he was doing and that his action could be seen as uncompassionate. Yet his behaviour could also be understood to promote flourishing and resilience within the paramedic team. In this example, situated compassion seems to be collaborative rather than an individual characteristic and, as in the previous example, it is affective and requires discretion.

Discussion: Entangling policy and care

British health care is currently characterised by debate about a care crisis evidenced by patient suffering, failures in care and unnecessary deaths. The influential Francis Report described this crisis as a consequence of two key interrelated problems: professionals’ disengagement from responsibility and practitioners’ lack of responsiveness to patient needs. The report and subsequent national investigations diagnosed a widespread lack of compassion in care practices. These have culminated in policy that aims to create a culture of compassion in health care. However, despite widespread agreement that compassion is crucial to providing ‘good’ care, a series of tensions persist. In particular, it seems to us that current policy documents and interventions couple compassion with calculation in harmful ways. They seem to enact a model of ‘The Compassionate Practitioner’ that responsibilises practitioners and disengages state accountability. The policies seem to be working towards standardisation, codification and quantification of compassion. Paradoxically, because the policies aim to promote compassion as a core value shared alike across all locations of practice, they may be unable to accommodate situatedness (such as relational, affective and discretionary aspects) without seeming to undermine their own legitimacy. In this way, current policy may seem to work but, in practice, it emerges as vulnerable, self-limiting and uncaring; in effect, it has been set up for failure.

By way of an alternative engagement with compassion and policy, we have brought together recent work in science and technology studies and in feminist technoscience studies to explore compassion as relational practices involving human and non-human constituents (Mol et al., 2010) and as ethical relating that requires alertness to otherness-in-relation (Haraway, 2003, 2008). However, responding to a recent call for work on critical care, we have argued that compassion cannot be taken as a self-evident good (Martin et al., 2015). Further to Murphy (2015), we have begun to explore diverse instantiations and enactments of compassion in order to explore how they reflect and produce arrangements of care that can promote relations of harm and suffering.

The vignettes of ‘situated compassion’ describe diverse practices and suggest that compassion is difficult to capture, codify and quantify. Taken together, the vignettes show practices of compassionate care to be demanding, affective and transformative entanglements that sometimes promote harm and do not necessarily relieve the suffering of individual patients. What would it mean to acknowledge that compassion in health care is ethical relating that is committed to flourishing and creating more liveable worlds? The specific policies we have engaged with don’t adequately acknowledge relationality, affect and discretionary tinkering as aspects of compassion. By way of contributing to debates about compassion in health care, we have sought to ‘raise the status of “telling stories”’ (Mol, 2008, p. 89). The vignettes have tried to make visible some of the work of doing situated compassion that is undervalued or not articulated in current debates and
policies. Compassionate care is not an effect of achieving shared-alike values and establishing sameness. On the contrary, it demands on-going alertness to otherness-in-relation and to specificity.

The challenge for future work is to bring care and policy together analytically, methodologically and practically, perhaps by understanding both as practices of selective attention towards specific objects of care and simultaneously away from others. The articles in this monograph are beginning this work by exploring policy-care entanglements in diverse domains to understand which promote the best possible care. The latter we understand as relations that support and facilitate ethical relating, on-going alertness to otherness and flourishing of all those in relation.

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Finally received date – 7th April 2017

Acknowledgements: We appreciate the feedback from the two anonymous reviewers and from the editors of the monograph. We also wish to thank participants in our individual research projects over the past fifteen years and our academic research collaborators.
Notes

1 This is the British Government website definition of policy (https://www.gov.uk, accessed 8 May 2016). However, this characterisation of policy has been interrogated through Critical Policy Studies as well as through work in Science and Technology Studies that explores policy as translation and as enacted into being, hence as multiple (e.g. Freeman, 2009; Levendai and Stubbs, 2009; Law and Singleton, 2014).

2 The vignettes (apart from the one about the nurse in Hadamar hospital) are from research published in in Law and Singleton (1999, 2005) and Mee (2012), from Singleton’s fieldnotes from a public event about compassion and health care organised by Singleton (Lancaster, UK., 5 March 2015) and from one of Mee’s current research projects.

3 The other key policy recommendations are: Values and Standards, Openness and Transparency, Leadership and Information. These recommendations informed the revised constitution which maintained the emphasis on compassion as a core value. Additional policy interventions into professional practice by NHS England, such as the 6Cs strategy, similarly emphasise compassion.

4 The other values are Working together for patients, Respect and Dignity, Commitment to quality of care, Improving lives and Everyone counts.

5 The other ‘Cs’ are Competence, Communication, Courage, Commitment, and Care.

6 The event, organised by Singleton, aimed to gather, collate and share the experiences and views of carers, practitioners and people cared for about the multiple and diverse practices and things that make up compassionate care. The event included a ‘Comments Wall’ where people wrote a word, phrase or experience that they consider to be relevant to compassionate care and care. Some people stayed and talked about their experiences. A group of primary school children engaged in an activity of selecting news stories and headlines about compassionate care from newspapers and magazines then displaying these on the walls. During the activities the visitors were encouraged to talk about their understanding and experiences of compassion in care practices. There were 96 visitors, many of whom chose to leave their name and address for future contact. All the visitors said that they hoped their stories would contribute to understanding and promoting compassionate care. The event is references in a Lancaster University Report https://www.lancaster.ac.uk/media/lancaster-university/content-assets/documents/fass/enterprise/reports/CITCBrochureFinal.pdf ( p6, accessed 7th April 2017)

7 There are numerous newspaper articles published between 2011 and the present that refer to NHS failure, patient suffering and lack of compassion. (For example, see Daily mail online, 15th February 2015).

8 Derbyshire Healthcare NHS Foundation Trust have established a Centre for Compassion through which practitioners can access training on providing and evaluating compassionate care.

9 Feminist technoscience scholars have long argued that the imaginary of the dispassionate, disconnected knowing subject that has been used to produce hierarchies of knowledge (see Martin et al, 2015 for a review of this critique).

10 This work owes much to a long tradition of work on feminist ethics of care that has exposed the politics inherent in caring relations and in definitions of care (Gilligan, 1982; Sevenhuijsen, 2003; Tronto, 1993). Care is essential to producing liveable worlds and yet is undervalued and has been consistently seen as secondary and supportive to technical expertise. This is certainly the case in health systems, where those professions focused on ‘caring’ are paid less and have lower status that those deemed to be technical. Moreover, a feminist ethics of care has attuned us to how care work is often hidden (as in the case of domestic care work) and how invisibility has obscured inequities in distributions of who does the caring and who or what is deemed worthy of being cared for.

11 This would support Lingard and Sellars’s (2013) conclusion that “The intensification of calculative rationalities in policy is coupled with new affective intensities” (p276).

References


Department of Health, (2013b) Protecting patients from avoidable harm, Parliamentary statement to House of Commons, London: HMSO.


Department of Health (NHS England/Nursing Directorate), (2013g) Compassion in Practice – One year on, London: HMSO.


