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Legal Constructions of Dementia: Discourses of autonomy at the margins of capacity

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Abstract: This paper explores the 'right to autonomy' for people with dementia. The provisions of the Mental Capacity Act 2005 (MCA) sought to allow more decisions to be made by those who are situated at the margins of capacity. This paper explores conceptual approaches to autonomy to highlight the limitations of contemporary regulation and the shortcomings of legal understandings of autonomy. Discourse analysis is used to analyse judicial language in a key recent case about where a person with dementia should live. It is argued that how the MCA approach has been operationalised by the courts does little to facilitate decision making for people with dementia. Possibilities for autonomy at the margins of capacity may be closed down through the discursive strategies used to determine disputes about the best interests of people with dementia. I argue that relational autonomy should be revised to include insights from person-centred care in order to empower decision making for people with dementia, and that judicial decision-makers should engage with the relationality of autonomy at the margins of capacity.

Keywords: Autonomy, Dementia, Discourse Analysis, Mental Capacity Act 2005, Person-centred care.

Word Count: 9,563 excluding references

People with dementia and those who care for them are some of the most vulnerable, disadvantaged and powerless people in our society. As such, people with dementia require special attention in both law and society to ensure that their voices are heard, their rights are respected, and their interests are protected. Yet, as with older people more generally (Duffy *et al.* 2012) little sustained attention has been paid to the unique position of people with dementia in law. Dementia is a generic term used to describe a range of terminal, organic, degenerative brain diseases, which have common symptoms including declining memory, reasoning and communication abilities and a gradual loss of the skills required to carry out activities of daily living. These symptoms are believed to be caused by chemical and structural changes in the brain, though biomedical understandings of the causes of dementia are still somewhat limited. There is no cure for any form of dementia, and there are but a few drug therapies available that slow the rate of cognitive decline (NICE 2007). Research commissioned by the Alzheimer's Society (Knapp *et al.* 2007) which has been accepted by the National Audit Office (NAO) as providing the most accurate figures available (NAO 2007), estimated that there were over 700,000 people with dementia in the UK in 2007. Updated figures from the Alzheimer's Society (2012) suggest that total numbers will increase to over 1 million by 2021. The total financial costs of dementia for the state and families in the UK have been estimated at £23 billion per annum, £8 billion of which can be attributed to the value to the UK of care work done by informal and familial carers (Alzheimer's Society 2012).

Despite the increasing social and economic impact of dementia, it is also widely recognised that contemporary social support and healthcare systems for people with dementia are inadequate. As the authors of the Dementia UK report note: "despite areas of good practice, the UK's current health and social care system is characterised by a widespread failure to support people with dementia and their families" (Knapp *et al.* 2007, p. xix). Therefore, dementia poses significant challenges for medicine, for society and for law. This paper examines one area where improvements in legal understanding of dementia could make a positive difference to the lives of people with dementia: by embedding the insights from social psychological approaches to 'person-centred care' into legal constructions of autonomy for people with dementia at the margins of capacity.

In this paper, I explore the operation of the Mental Capacity Act 2005 (MCA) for people with dementia through a discursive analysis of how different conceptual understandings of autonomy in law can make a difference to the lives of people with dementia. I begin with an interrogation of conceptual approaches of autonomy, highlighting two contrasting frameworks for understanding the capacity to make decisions: 'individual' and 'relational' autonomy. I critique both of these approaches to autonomy, and argue that combining the insights from relational autonomy with a person-centred approach would be more helpful when considering decision-making by and for people with dementia. I then provide an overview of discourse analysis, before using this analytic approach to situate conceptual understandings of autonomy in a judicial consideration of the capacity of a person with dementia to make decisions for herself: *Dorset County Council v EH* [2009] EWHC 784. Utilising discourse analysis to interrogate judicial language, I argue that a person-centred, relational approach would allow a more sensitive balancing of the individual and relational contexts that underpin autonomy for people at the margins of capacity. I conclude by suggesting that this person-centred approach to relational autonomy can empower people with dementia, and better realise the aims of the MCA and the National Dementia Strategy.

Making Decisions: Legal subjects, capacity and autonomy

As Naffine (2005, p.1-2) has argued, 'law works with an overarching presumption of reason: a presumption that we are rational subjects.' Whilst this is clearly an overstatement, as there are undoubtedly aspects of legal subjectivity that do not require capacity (for example in law relating to the rights of children who have not yet attained Gillick competence) the rational legal subject is a powerful construct. When we are concerned with issues such as decision making and consent, the preferred adult legal subject is one that has the capacity to weigh up the advantages and disadvantages of a particular course of action, and to use higher-order reasoning to arrive at an informed decision. The competent legal subject has the right to refuse healthcare or treatment even when it would be in her best interests to follow her doctor's advice. Equally, a rational legal subject has the capacity to understand the difference between right and wrong, and to choose to do wrong, to make an unwise decision, to commit a crime. As such, 'law is for rational human subjects, for sane rational adults, intelligent agents who because of their capacity to reason can assume moral as well as legal responsibility for their actions and so enter into moral and legal community with others of a similarly rational nature' (Naffine 2008, p. 23). How to regulate and protect adults who do not conform to this ideal of an objective, rational individual therefore poses challenges for law.

Since 2005, these challenges have been addressed in English law through the MCA, which takes as its starting point the presumption that people have the ability to make their own decisions and exercise autonomy (Coggon and Miola 2011). The MCA framework was developed to codify and consolidate a succession of health care case law (Donnelly 2009) and to provide an expanded approach to determining capacity in English law. The MCA thus applies to all kinds of decision making, not solely medical decision making. Under the MCA framework, capacity determinations are decision-specific, subjective, and concerned with an individual's ability to make a particular decision at a particular time (s.2(1)). The MCA Code of Practice states: 'The Act's starting point is to confirm in legislation that it should be assumed that an adult (aged 16 or over) has full legal capacity to make decisions for themselves (the right to autonomy)' (DCA 2007, p. 15). As a result, even though the text of the MCA does not explicitly use the term 'autonomy', the test for capacity in the MCA is a codification of previous common law understandings of the operation of the 'right to autonomy'. Few would now deny that we have a 'right to autonomy' in the decision making sense. Indeed, such a right has been recognised by the European Court of Human Rights (ECtHR) as forming part of Article 8 of the European Convention on Human Rights, in the cases of *Evans v United Kingdom* (Application no. 6339/05); *Pretty v United Kingdom* (application no. 2346/02). It is also explicitly included in the United Nations Convention on Rights of Persons with Disabilities (UN-CRPD, Article 3).

The question of what it substantively means to have and to exercise autonomy has been the subject of extensive philosophical attention. Rather than re-tread the vast and varied legal and ethical debates surrounding the concept of autonomy (for which, see e.g., Beauchamp and Childress 2008; Coggon and Miola 2011; Donnelly 2010; Dworkin 1988; MacKenzie and Stoljar 2000; McLean 2010; O'Neill 2002), my concern here is much more circumspect. Here, I critique the applicability of two contrasting approaches to autonomy, 'individual autonomy', and 'relational autonomy,' to the lives and experiences of people with dementia. 'Individual autonomy' draws on liberal approaches to individual self-government, and has been conceptualised as 'a second-order capacity of persons to reflect critically upon their first-order preferences, desires, wishes, and so forth and the capacity to

accept or attempt to change these in light of higher-order preferences and values' (Dworkin 1988, p. 20). Arguably, this constitutes the mainstream philosophical understanding of autonomy as the capacity to make an individual decision, free from coercion or compulsion. Relational autonomy (Nedelsky 1989) on the other hand, is an alternative approach to autonomy, predominantly expounded by feminist scholars (e.g. Fineman 2004; MacKenzie and Stoljar 2000; Richardson 2007), which rejects the liberalism of individual autonomy, and requires that attention is paid to the ways that individuals exist within relations of social support and community. Importantly, neither version of autonomy includes a right to having ones' wishes carried out, simply the right to make the relevant decision. In the next part, I outline the limitations of both of these versions of autonomy for people with dementia.

Individual Autonomy

Individual autonomy, the mainstream liberal version of autonomy, has become firmly embedded in English healthcare law (Donnelly 2010). As Prialux (2007, p.9) has argued, 'the value of autonomy in medical law therefore encapsulates the notion that the right to physical integrity and the ability to make voluntary decisions must be respected.' The precise meaning of autonomy as it is currently figured in these contexts is interesting, however, because it is difficult to identify the philosophical foundations upon which the popular understanding of individual autonomy in healthcare decision making rests. As McLean (2010) argues, the Kantian foundations of autonomy (as a decision made on the basis of duties, principles of obligation, and backed up by morality) seem to bear much less relation to the modern usage of the term than the Millian approach, which is (simply put) the freedom to make an individual choice, even though the Kantian foundation is the preferred approach of many bioethicist commentators. Christman and Anderson (2005, p.3) argue that irrespective of the nuances of different versions of autonomy: 'the notion of autonomy still finds its core meaning in the idea of being one's own person, directed by considerations, desires, conditions, and characteristics that are not simply imposed externally on one, but are part of what can somehow be considered one's authentic self'.

Notwithstanding academic debate about the theoretical foundation of contemporary understandings of autonomy in healthcare law, it is clear that the understanding of autonomy in the MCA is that of freedom to make one's own choices, so long as the person understands the choice being made (DCA 2007). This seems to accord more with the Millian approach. This is also the approach enshrined in the UN-CRPD, which at Article 3(a) sets out the right to 'respect for inherent dignity, individual autonomy including the freedom to make one's own choices' and the ECtHR, who have described autonomy as 'an important principal underlying the interpretation of [Article 8]' and as 'the ability to conduct one's life in a manner of one's own choosing' (*Pretty v UK*, paras 61-62). Given that legal approaches to autonomy in medical law, mental capacity law and international disability rights law cohere, therefore, around having the freedom to make one's own choices, the question then is how this understanding of autonomy can be understood when considering people with dementia. Arguably, Ronald Dworkin's (1993) 'integrity view' of autonomy is the approach to individual autonomy which pays most heed to nuances of dementia. For Dworkin, the autonomous individual is exemplified by a way of being and behaving that prioritises the self, and includes aspects of self-determination, self-preservation and self-awareness:

Recognising an individual right of autonomy makes self-creation possible. It allows each of us to be responsible for shaping our lives according to our own coherent or incoherent – but, in any case, distinctive – personality. It allows us to lead our own lives rather than be led along them, so that each of us can be, to the extent a scheme of rights can make this possible, what we have made of ourselves. We allow someone to choose death over radical amputation or a blood transfusion, if that is his informed wish, because we acknowledge his right to a life structured by his own values (p. 224)

Prior to the MCA, the common law approach to medical decision-making in English law seemed to follow this view of autonomy (see Dodds 2000). This was achieved by prioritising the competent individual's right to refuse any medical treatment, whether or not it would be in their 'best interests,' based on their own value system and appraisal of the relative risks. Few would challenge this elucidation of individual autonomy as it applies in a healthcare setting to persons with full mental capacity. Indeed, this view of individual autonomy may be positively appealing: many people would presumably like to think of themselves as having the capacity to choose their own path in life, to make decisions free from constraints and to decide which values they base their life on.

Dementia, however, poses challenges to this 'integrity view' of autonomy, because key symptoms of dementia can include loss of the ability to rationalise one's actions. This may be apparent through confusion or the inability to grasp new ideas, or a person with dementia may behave in ways that seem odd, or lose the ability to communicate coherently (Alzheimer's Society 2011). As such, if the right to autonomy is dependent on this 'integrity view' of an individual, then it follows that a person with dementia, who may not be able to verbally rationalise their decision to refuse medical treatment, would be likely to be denied their 'right to autonomy', irrespective of whether, on the relevant legal and medical tests that person is determined to have or to lack capacity to make that particular decision. This seems in conflict with the stated aims of the MCA. The MCA regime highlights the need to support decision-making on a decision-specific basis, with all possible avenues for supporting individual decisions to be explored before a person is declared incompetent (DCA 2007). In many respects, the MCA approach to decision making entails a rejection of the need for a coherent, overall integrity across individual decisions. So, under the MCA, a person can retain competence to make decisions about minor, everyday financial expenditure, but not the management of their investment portfolio; or to consent to a blood test, but not to major surgery. Either way, communication of a decision is key, and where a person with dementia is struggling with communication they may be at greater risk of having their decisions ignored.

In situations where a person lacks capacity, they may have provided an advance directive setting out their views about what they would and would not consent to in that specific instance. Dworkin (1986) argued persuasively that advance directives should be respected, by outlining a two-fold classification of interests: critical interests and experiential interests. He argued that because a person with dementia does not have the capacity to elucidate new critical interests, although they are likely to retain experiential interests, any advance directive which seems in conflict with their demented experiential interests should be respected, even where this would do them harm. Perhaps understandably, Dworkin's approach has been the subject of sustained criticism. One critique discussed by Herring (2009a) is that a competent person has no right to speak for their incompetent self, because the nature of losing capacity is that one becomes a different person. Another objection

is that it is not possible to divide up a person's interests into 'critical' and 'experiential' ones, because people generally live each day as it comes, rather than living their lives in a way that can be seen as a coherent narrative (Dresser 2006).

These critiques of Dworkin's approach to advance directives would be similarly applicable if we were to drawing a distinction between capacity and incapacity for people with dementia depending on their ability to demonstrate a rational worldview. We do not generally require people without dementia to demonstrate a religious, political or other entrenched worldview in order to respect their decisions. A higher standard is required for refusal of life-saving treatment, as set out in *Re B (Consent to Treatment: Capacity)* [2002] EWHC 429 (Fam), but in day-to-day decision making, the rational bases behind decisions are rarely interrogated. It follows, therefore, that a person with dementia, who may have communication difficulties, should not be required to demonstrate that their decisions are embedded within a coherent narrative. Nor should blanket determinations of (in)capacity be used to overrule all decisions by a person with dementia. The MCA is explicit that a decision is not invalid simply because it is unwise (s. 1(4)); but it is probable that people with dementia are given less scope to make unwise decisions than others, simply because of their condition. Whenever a person with dementia retains the cognitive capacity to make a particular decision, respecting their right to autonomy requires us to allow them to make that decision. So, for example, so long as they are able to understand the information given, a vehement and explicit refusal from a person with dementia to undergo a medical procedure must be thought of as no less valid than a vehement and explicit refusal from any other person, irrespective of whether they are able to justify their decision with reference to a coherent world view. As such, even Dworkin's 'integrity view' of individual autonomy provides insufficient respect for the autonomy of people with dementia.

Using the individual approach to autonomy to understanding the legal framework regulating decision making by people with dementia is problematic for a number of different reasons. Firstly, like us all, people with dementia are not, in reality, atomistic individuals: they exist in social relations which influence their reasons for making particular decisions. Secondly, people with dementia are more likely than most adults to be in specific relations of dependency: they are likely to be reliant on others for the provision of care and for support in order to retain their independence and dignity. Thirdly, people with dementia are likely to be disempowered, in the sense that their ability to effect change on their own lives and environments may be more likely to be overruled or limited by the relationships of care and dependency that support them. These limitations of understanding autonomy in the individual sense are established critiques of liberal autonomy, and they are not unique to people with dementia. Rather, for the last two decades, feminist commentators and others have been arguing for a move away from considering autonomy as an individual concept and towards recognizing the inherently relational character of autonomy.

Relational autonomy

Jennifer Nedelsky (1989) argued that the liberal ideal of autonomy fails to recognise the inherently social nature of individuals, and that we should thus re-conceive autonomy as relational. Rather than considering adults with capacity as atomistic individuals, we should consider autonomy as created by, dependent on, and exercised through relationships with other people. She suggested that we must 'think of autonomy in terms of the forms of human interactions in which it will develop and

flourish' (Nedelsy 1989, p. 21). This view of autonomy, that individual decision making should be situated within 'values based on care, responsibility and interdependence' (Herring 2009b) has become known as 'relational autonomy.' Much of the relational autonomy literature has focused on arguing on an abstract level for a reconsideration of autonomy to include attention to the relationships and interactions surrounding the individual. In the theoretical domain this invariably makes sense: as Linda Barclay (2000, p.57) has argued, 'our ongoing success as an autonomous agent is affected by our ability to share our ideas, our aspirations and our beliefs in conversation with others.' Indeed, it is almost self-evident that individual approaches to autonomy fail to respect the inevitable relationships that constitute everyday life.

When attempts have been made to situate relational approaches to autonomy, a significant portion of the feminist literature has been concerned with the issue of reproductive autonomy. In this domain, relational autonomy has exposed the 'choices within constraints' model that epitomises women's experiences of pregnancy, birth and child-rearing (Priaux 2007). The relational approach to autonomy has provided persuasive arguments that help to interrogate the continuing inequalities between women and men in reproductive endeavours. It does this, according to Priaux (2007), through providing a richer account of decision-making than is possible under an individual understanding of autonomy:

What a relational perspective provides is a close attention to *context*; it highlights those moments where the law has lost its moral compass in attempting to understand human decision making through a narrow (economic) lens based upon values which fail to fit the context – culminating in determinations of reasonableness that twist or exclude other ways of seeing, being, trivialising other moral frameworks, which guide our actions and choices in life. A relational perspective challenges such narrow approaches to humanity: renders visible the broad spectrum of concerns that motivate human decision making; makes understandable what law sees as contradiction and can explain those instances where individuals are caught between yes/no, black/white and choice/no choice (p. 170)

Priaux sees a relational view of autonomy as providing a means towards developing a legal solution to some of the more intractable dilemmas of wrongful birth cases. It is less obvious, however, how this more nuanced, relational, approach can be applied to the social relations that surround people with dementia. Looking to the first two problems with individual approaches to autonomy identified above (that people with dementia exist in social relations, and that these social relations are likely to include relations of dependency) it is far from clear what a relational perspective offers over and above an individual account of autonomy. One aspect of relational autonomy that is often highlighted is the beneficial nature of relational life, and the importance of supporting people's relationships in order to support their autonomy, but as Herring argues, 'although beneficial relationships are an important part of people's lives and essential to autonomy, relationship and social structures can be oppressive and destructive of autonomy' (2009b, p. 56-7). So, if a person with dementia lives within a relational context where her carers do not allow her to leave her home alone for fear of her 'wandering', then it is hard to consider relationality beneficial to her autonomy.

A key limitation, therefore, of the 'relational' view of autonomy is the lack of definitional interrogation of what relationality means in the everyday, situated, lives of individuals. Much of the feminist literature on relational autonomy, seeks to provide a critique of a 'masculine' account of autonomy (i.e. the idea that individuals are free from constraints in how they make decisions) (e.g. Friedman 2000), but does not actually go far enough in excavating what it means for individual decision making to be placed in a relational context. Rather, as Christman (2004) argues, this literature too often seems to hold the self to an unrealistically high standard, requiring even greater capacity for self-awareness and rationality than most approaches to individual autonomy. Further, if relationality is equivalent to plurality, or 'autonomy' is not individual because there are a number of different things that influence decision making, then this is not substantively different from the Kantian version of autonomy. Liberal approaches do not require that people are free from any external influences when making decisions, rather that these influences are considered as internal to the decision making process, evaluated in that context and that a decision is made having had regard to them. If relationality means something else, perhaps that rather than having the ability to come to any decision that we want on any given issue, our decision is pre-determined by the social relationships or relations of power in which we as individuals are immersed, then it seems to be too far removed from any possible common sense understanding of 'autonomy'. Such a view of relational autonomy also seems to be a purely negative approach, both deterministic and disempowering, and as such not a view of either autonomy or relationality that would be compatible with the current use of the concept in law. Bearing these critiques in mind, the utility of taking a relational view of autonomy is to provide explicit recognition of the relational context in which the individual (taking account of her social situation) is situated when making decisions that are compatible with her approach to life.

When thinking about relational autonomy from the perspective of the person with dementia, the potentially negative effects of considering social relationships come to the fore. If autonomy is premised on the ability to share, converse and communicate with others, it inevitably follows that a person who has problems with communication would be in danger of losing her right to autonomy. Similarly, if interpersonal relationships are foregrounded, then it is possible that a person with dementia could find herself oppressed by the social relationships surrounding her. This is particularly the case where carers are under considerable strain from caring, or the best approach to a problem concerning care for a person with dementia conflicts with the best approach for the wellbeing of their carer (see further, Herring 2008). The MCA is clear that every effort must be made to facilitate decision making for those on the margins of capacity (s. 3). This is not to say that we should always carry out the decisions of people with dementia. Rather, we must be careful that where express views of a person with dementia are overruled it is indeed because they lack capacity to make the decision they purport to make, not because they are a person with dementia, nor for the sake of convenience.

A person-centred relational approach to autonomy

Given the limitations of both traditional individual understandings of and relational approaches to autonomy, I would argue that legal understandings of autonomy for people with dementia would do well to engage with the social psychological literature (Kitwood 1997) and social care practice (Innes and Surr 2001) that seek to promote respect for the continued personhood of people with

dementia. It is important to be clear that people with dementia do not lose capacity immediately upon diagnosis of dementia. The early stages of dementia are marked by particular and specific losses of certain aspects of cognitive function; not by an immediate loss of ability to process information, or to make reasoned and informed choices. Supporting autonomy and decision making in the early stages of dementia is mandated by statute (MCA 2005, s.2 (3)(b)) and likely to be supported in practice. It is only when the symptoms of dementia progress to the point where they present difficulties in communication that capacity determinations become a question. Consider the following example:

When being tested, the person with AD [Alzheimer's Disease] may fail to answer correctly certain simple questions that would have posed no problem in previous decades. The person may react with anger, might cry, possibly leave the room or insist on not continuing. Such reactions are often termed 'catastrophic' and the person may be described as being 'emotionally labile', both being symptomatic of the pathology of AD. Another way to interpret such behaviour would be to recognize that the person with AD has correctly judged that: (i) she was unable to answer a question that was quite simple; (ii) tremendously negative connotations are understood; and (iii) she wants to avoid further exposure to a humiliating situation. Reacting with anger or sadness to such a situation is quite appropriate and wanting to avoid experiences of this kind is a sign of self-respect. (Sabat 2005, p. 1031-1032)

Here, Sabat seeks to show that can be conflicting interpretations of the same event. The first interpretation calls into question the competence of the person with dementia, on the basis of her failure and her cognitive deficits; the second interpretation situates her behaviour in understandable responses of embarrassment, sadness and fear. The first approach coheres around deficit, the second around self-preservation and autonomy. Whilst it is perhaps impossible to tell which interpretation is most accurate in any given situation, the existence of a right to autonomy should mean that in lieu of incontrovertible evidence to the contrary, the most positive interpretation should prevail.

In social care practice, one way that autonomy and self-worth are maintained for people with dementia is through care practices which draw on the concept of 'person-centred care' (Kitwood and Bredin 1992). The theoretical basis of person-centred care is that dementia is more than biomedical cognitive decline; rather, a complex interplay of biography, personality, health, social relationships and neurological impairment create the lived experience of dementia for the person (Kitwood 1997). Kitwood (1997) maintained that 'personhood', which he defined as 'a status or standing bestowed upon one human being by "others", in the context of social relationship and social being. It implies recognition, respect and trust' (p. 8) subsists in people with dementia, right through to the severe and final stages of the disease. Similarly, Sabat (2002) has argued that there are three forms of self, and that people with dementia can hold onto their singular self, but may need the cooperation of caregivers to uphold their publicly presented self. Importantly, given the primacy of Kitwood's ideas around personhood and dementia in the health and social care field (Dewing 2008), the development and application of the MCA must be understood in relation to these approaches to understanding of the lived experience of dementia. Undoubtedly, this person-

centred approach has been brought inside the more diffuse health service regulatory framework, as 'Putting People First' was a key rhetorical strategy and policy commitment of the previous Government in shaping plans for social care reform (Govt 2007).

Kitwood's person-centred approach to dementia care was derived from research about the damage that carers could be causing to people with dementia as a result of thoughtless interactions with them. Initially Kitwood's research focused on negative aspects of dementia care, which he labelled as 'Malignant Social Psychology' (Kitwood 1990). His later work sought to provide concrete suggestions for improving the ways that caregivers interact with people with dementia. Rather than communicate with people with dementia in ways that were: 'treacherous, disempowering, infantilising, intimidating, labelling, stigmatising, outpacing, invalidating, banishing, objectifying, ignoring, imposing, withholding, accusatory, disruptive, mocking, and disparaging' (Kitwood 1997, p. 46-7), he argued that person centred care could involve 'positive person work', drawing on approaches that would be beneficial to people with dementia. Such 'positive person work' involves: 'recognition, negotiation, collaboration, play, stimulation [direct and pleasurable stimulation of the senses], celebration, relaxation, validation, holding, facilitation, creation and giving' (p. 119-20). While approaching health and social care for people with dementia in this way may be considered simply aspirational or utopian, Kitwood's approach has been applied in practice to enhance the well-being of people with dementia (Innes 2009). The question therefore arises as to whether the regulatory frameworks surrounding dementia care can also engage with this person-centred approach to empower and support people with dementia, and whether by embedding a person-centred understanding into relational autonomy, we can provide an approach to understanding decision making at the margins of capacity that recognises the relational context of people with dementia, whilst simultaneously avoiding the danger of erasing the person with dementia by focusing too heavily on their social relationships.

In summary, neither the individual or relational approach to autonomy as they have been configured in the academic literature to date, are able to deal effectively with the position of people with dementia in law, though relational approaches to autonomy do seem to provide a more nuanced account of how decision making operates in everyday life. In the next part, I demonstrate that combining a 'person-centred' understanding of dementia with relational autonomy can provide a solution to the problem that people with dementia are likely to be disempowered from making their own decisions by the relations of dependency that they are embedded in. By understanding autonomy at the margins of capacity in a person-centred yet relational sense the aims of the MCA to support independent decision making by people with limited capacity can be more effectively realised.

Legal constructions of dementia through judicial language

Discourse Analysis

I turn now to analyse a case which determined where a person with dementia should live. The methodological and analytic focus of this part is discourse analysis (DA), which focuses on language as performative, following the work of Austin (1962). DA was coherently developed into a social science analytic method by Potter and Wetherell (1987), who demonstrated that: language is

utilised in a variety of ways for a variety of means; that language is both 'constructed and constructive'; that the same things can be described in multiple ways, and argued that 'the constructive and flexible ways in which language is used should themselves become a central topic of study'. At heart, DA assumes that language has an "action orientation," in that it is used to 'perform particular social functions such as justifying, questioning and accusing.' As an analytic approach, DA considers language as constitutive of the social world, and asserts that the ways objects are spoken and written about creates the way they *are* in society. Discourse, in this analytic method is 'a systematic, coherent set of images, metaphors and so on that construct an object in a particular way' (Burr 2002, p. 202).

Although discourse analysis was developed as a social psychological analytic and methodological framework, the insights that it provides can easily be translated to interrogate legal texts (Black 2002). In addition to the linguistic focus of the psychological approach to discourse analysis, critical discourse analysis (van Dijk 1991) seeks to be explicitly emancipatory (Wilton 2009), paying close attention to the ways that power relations, understood in a Foucaultian sense (Foucault, 2002) are constructed and operationalized, as well as uncovering possibilities for resistance. As Harvie and Manzi (2011) explain, 'Critical Discourse Analysis examines how competing interpretations achieve hegemony and how meanings of language are accepted and applied within practical contexts.' Given the clear utility of discourse analysis for law, it is surprising that this methodological approach has not been as comprehensively adopted in socio-legal work as it has elsewhere in the social sciences, where it has become part of the mainstream cannon of qualitative methodology and analysis.

As Black (2002, p.182) argued, discourse analysis can uncover the ways that 'social communicative interactions position actors and constitute their identities.' Whilst Black's research focused on regulatory conversations, it is a short leap to apply the principles of discourse analysis to judicial language, as this is an arena in which language is explicitly intended to create an action, both in respect of the parties in the instant case and, where applicable, in future cases that would follow a precedent. Indeed, analysis of feminist judgments and feminist judging has exposed the performative work that judicial language does in constructing the legal subject (Hunter *et al* 2010). In the next section, I explore the ways that judicial discourse constructs and positions people with dementia, through analysis of the language used in the *Dorset County Council v EH* judgment. Importantly, is essential to be clear that the analysis that follows is discursive, rather than doctrinal. My aim is to expose the problematic constructions of dementia inherent in the language used, rather than to interrogate the legal basis for the decision arrived at by the court.

Autonomy in Judicial Discourse about Dementia

Judicial considerations of autonomy and decision making have been dominated by questions of consent to medical treatment (McLean 2010), and therefore are replete with issues to do with medical paternalism (e.g., *Chester v Afshar* [2004] UKHL 41), rights to bodily integrity (Scott 2000), the right to refuse life-sustaining treatment (e.g., *Re B*), or reproductive rights (Jackson 2001; Priaux 2007). It is rare for disputes about decision making and dementia to reach the courts. There are number of reasons for this, predominantly that courts would not be best placed to make decisions about the care requirements of people with dementia, in spite of their inherent jurisdiction to do so. Legal consciousness studies and access to justice research have demonstrated that legal disputes

also require significant resources, legal advice and representation, as well as a particular type of approach to, and understanding of, law (Ewick and Silbey, 1998; Genn 1999; Harding 2011). Understandably, therefore, there is a very limited amount of case law concerning non-medical decision making for people with dementia. When cases do arise, they are more likely to be concerned with financial transactions (e.g., *D v R (the Deputy of S), S* [2010] EWHC 2405 (COP); *Hill v Fellowes Solicitor s LLP* [2011] EWHC 61 (QB)), or testamentary capacity and statutory wills (e.g. *In re M (Statutory Will)* [2009] EWHC 2525 (Fam)), rather than social care decisions.

As such, it is vitally important to give due attention to those occasional cases that do arise. The *Dorset County Council v EH* case has been chosen for analysis because it is one of very few cases that explicitly concern decisions made by, and about, a living person with dementia. There are other recent and important decisions concerning the living arrangements of people with reduced mental capacity (e.g. *P and Q v Surrey County Council; sub nom Re MIG and MEG* (2011) EWCA Civ 190; *Cheshire West and Chester Council v P* [2011] EWCA Civ 1257), but these do not involve people with dementia. *Dorset* concerned the living arrangements of an elderly woman (aged 82) with Alzheimer's dementia who was living alone in her own home. EH was subject to proceedings compelling a move into residential care against her express wishes. The applicant was the County Council responsible for the provision of social care services to EH. EH was represented by the Official Solicitor; her family supported the council and the move into residential care. The case concerned deprivation of liberty, and would now be considered under the Deprivation of Liberty Safeguards (DOLS), inserted into the MCA by the Mental Health Act 2007 (see further *A County Council v MB (by the Official Solicitor as her Litigation Friend), JB, A residential home* [2010] EWHC 2508 (COP); *MIG and MEG; Cheshire*). The questions put before the court sought to resolve a disagreement about whether EH should be supported to continue to live at home, or whether it was in her best interests to be deprived of her liberty, in locked residential accommodation. The question of moving a person with dementia from a familiar to unfamiliar environment is never straightforward as there are risks of worsening confusion, deterioration in cognitive function, and depression, which must be balanced against the risks of remaining in a familiar environment without appropriate self-care skills. The court found in favour of the applicant, and EH was placed in a care home. The outcome of this case was unsurprising, and probably correct. Of more interest are the contrasting ways that the concept of autonomy was discursively deployed in order to construct the arguments for and against placing EH in residential care against her wishes.

Making decisions about the best interests of people with dementia who retain some capacity to express their preferences is a difficult thing to do. It is not straightforwardly possible to make decisions about what is in the 'best interests' of a person with dementia without also considering the people around her who provide her with informal care and support. It is important to note that under the relevant legislation, legal responsibility to provide care for vulnerable people falls not to family members, but rather to the local authority and social services department who have assessed a person as requiring care. As such, where a person requires care, and a local authority has assessed that person, if family members can no longer cope, or feel that they can no longer provide care, or even simply do not wish to provide physical care themselves, the local authority must decide on the best course of action in terms of the provision of the care required. A person with dementia cannot force their friends or family to provide physical care for them; neither can a local authority compel a family member to provide physical care. If, therefore, those who have

been providing informal care to a person with dementia cease to be able to do so, then the responsibility for providing or replacing all of that care and support necessarily falls to the relevant local authority.

In a sense, this case positioned EH's rights to autonomy in conflict with her welfare, and it was her welfare that was ascendant in the final judgment (Dunn and Foster 2010). But in many respects this is more due to the adversarial nature of a case of this type, than because these two concepts (autonomy and welfare) are necessarily in conflict. The complex web of social relations that support individual autonomy meant that the most feasible way to support EH to continue to live as independently as possible and to reduce the risk of her causing harm to herself (given the inability of those who were providing informal care to continue to do so) was, perhaps counter-intuitively, to provide care in a residential care setting. This is not to say, however, that the decision in this case was wholly unproblematic.

Discourses of dementia, autonomy and relationality

I now turn to analysis of the language used in *EH* to expose some of the problems with both individual and relational approaches to autonomy, and to demonstrate how a 'person-centred' approach to relational autonomy that empowers people with dementia, simultaneously balancing their needs and wishes with their relational context and avoids some of the more negative constructions of dementia that permeate contemporary discourse. Parker J was careful to attend to all of the relevant sections of the MCA in formulating her decision, and a doctrinal analysis of this case would not uncover significant problems. Yet, as we go on to see, there are some aspects of the judgment which are rather reminiscent of the negative interactions identified by Kitwood (1997).

Prior to this case arising, EH had consistently expressed a desire to retain her independence, and to continue to live in her own home, but she routinely resisted social care interventions and support from community carers, was found to be unaware of certain risks to her health and wellbeing, and was described as prone to 'wandering'. In the judgement, 'EH's current circumstances' were described by Parker J as follows:

EH has lived in her present home for many years. PH [her son] lives permanently in Brazil and can do little to help. CR [her daughter], who works and has her own family commitments, does what she can, but has found her mother's resistance to help, and her increasingly erratic and irritable behaviour, very difficult to cope with. The only regular source of family support comes from EP and WP who live locally. They have found providing support more and more difficult. Dorset County Council has tried to put in resources to help EH over the last 2 years, with limited success (*EH* paragraphs 12-13).

In contrast, in the course of the court proceedings, a consultant in Psychiatry of Old Age, Dr Jeffreys, provided written evidence that:

At the present time it is in EH's best interests to remain at home with close support from Dorset CC and her family. I have considered the pros and cons and given weight to her previous wishes, the comparative stability of her cognitive impairment and the

positive features of her current support arrangements. The likelihood of a significant worsening of her quality of life if she moved to a secure residential home is high, and in my view currently outweighs the benefits (*EH* paragraph 76).

From a discourse analytic perspective, it is interesting to note the contrasts between the judicial language describing EH and Dr Jeffrey's language. These differential discursive positions construct EH, an elderly woman living with dementia, in particular ways. The court's language, which seeks to demonstrate the need for EH to be deprived of her liberty, focuses on the negative effects of her dementia (e.g. "her increasingly erratic and irritable behaviour"), and the limitations of her relational context (e.g. CR finding EH "very difficult to cope with", or EP and WP being described as being "at the end of their tether" [at para 99]). In contrast, the quotations from Dr Jeffreys, as an expert witness called on EH's behalf, seem to focus on the positive aspects of her dementia ("comparative stability of her cognitive impairment") and relational context, and the potential for negative outcomes from EH if she were to be moved to a secure residential home ("significant worsening of her quality of life"). Clearly, both of these quotations are engaging with EH's relationality in the context of making decisions about and for her, but there is a clear difference between the two. Parker J's approach falls in to the critiques of relational autonomy outlined above, namely that a person's relational context may be disempowering and deleterious of their autonomy. Dr Jeffrey's approach, in contrast, keeps the person with dementia at the centre of his appraisal of relationality and has the potential to be more empowering and facilitative of autonomy (if understood in a person-centred, relational way).

Another example of problematic and disempowering discourse within the judgment is the following statement: 'so far as [EH's] present wishes and feelings are concerned, her present beliefs are not based in reality' (*EH*: paragraph 101). Statements such as this are reminiscent of Kitwood's concept of malignant social psychology, and particularly the more problematic ways of communicating with and about people with dementia. To say that a person's beliefs are 'not based in reality', involves stigmatising, invalidating and disparaging that person's experience. Stigmatisation arises through the implicit negativity in this statement; invalidation by assuming that the reality for a person with dementia is less authentic because it does not map on to external ideas; and disparaging by comparing the reality experienced by a person with dementia in a negative light to the experiences of others. This does, however, seem to be a common way of describing people with dementia in court proceedings – exactly the same phrase is used in a more recent case as part of a quotation from a social worker's assessment of capacity (*Cardiff County Council v Ross*, unreported, 2 November 2011 at [6]). A different approach to this would be to attempt to utilise a person-centred approach and to understand the attempts at communication that the person with dementia is engaging in, by utilising Kitwood's (1997) 'positive person work'. Person centred care practices engage people with dementia by recognising their experiences and differential reality, by validating their experience and by negotiating through differential experiences and facilitating communication on the terms of the person with dementia (Brooker 2004). The same ideas could be conveyed by stating, for example, that "EH expresses her reality in a way which is incongruous with an objective appraisal of her situation". This linguistic formulation would recognise the internal validity of EH's experience, but still highlight that there are issues with her understanding of her life, and as such would potentially represent a person-centred approach to this issue.

A third example of the power of language in this case concerns the issue of walking/wandering. Consider, for example, the following excerpt:

I accept that EH has always been a keen walker and that she walks long distances now. The evidence does not support the view that she always does so because she wants to go for a long walk. Often what seems to happen is that she leaves the house for one purpose but then forgets where she is going, and sometimes cannot recognise where she is, so she continues to wander. There are a number of recorded instances of EH being found in distress saying that she is lost (*EH* at paragraph 89).

It is, of course, a significant element of the judicial decision-making task to weigh up the evidence before the court and present the facts, as they appear to the judge. But the ways that EH's subjective experience is described in the judgment has elements of invalidation and labelling, if not active disempowerment or disparagement. Consider the different linguistic connotations of 'walking' and 'wandering': 'walking' is usually construed as a beneficial activity, with positive health benefits associated with it (Peel *et al* 2010); 'wandering', on the other hand, is understood as a pathological activity, a 'problematic behavioural disorder' (Klein *et al* 1999) which causes significant distress to informal carers and family members of people with dementia. EH's walking was also referred to earlier in the judgment, in the following terms:

EH is a physically active person. She has always enjoyed walking. She goes out every morning to the paper shop to buy a paper (that seems to be her only routine) but it is not clear that she reads it or appreciates its date. Sometimes when she goes out she forgets where she is, gets lost, and wanders off (*EH* para 46).

And somewhat later:

I take into account that EH has always been a fiercely independent person, and according to her brother EP, she has always manifested a stubborn trait. I am certain that she will find disturbance to her routine distressing and that restriction of her liberty will have an impact on her, possibly a profound impact. However, much of her physical activity, particularly the wandering, is at the moment caused by her illness, as is her irritable and sometimes aggressive behaviour (para 112).

EH's daily routine of walking to the paper shop, is thus discursively constructed as being a pathological behaviour, caused by her dementia, which places her at increased risk of harm, rather than a normative and beneficial practice associated with healthy and active ageing. Her practice of buying a paper is disparaged by raising questions about whether she reads the paper or "appreciates its date"; her routine invalidated and labelled as being caused by her dementia, in spite of it being a long standing activity that pre-dates her illness. My argument here is not that the legal process has either overstated or invented the risks to EH of 'wandering': such risks are real. Rather, it is that the problematic aspects of the behaviour are discursively exaggerated, and the beneficial aspects downplayed, in order to construct a persuasive judgment.

A person-centred approach to the issue of walking and 'wandering' for a person with dementia would likely focus on ways to preserve the beneficial behaviour whilst safeguarding against the possible risks. Possible interventions could include the use of technological aids such as property exit sensors, alarms and messages or GPS tracking devices. Advances in mobile technology mean that GPS trackers in everyday items such as footwear (e.g. www.gpsshoe.com) are now becoming available, and can be used to improve the safety of people with dementia. There are, of course, some moral and ethical concerns around surveillance and the invasion of privacy, but non-invasive solutions such as embedding GPS trackers in everyday items may facilitate greater levels of physical activity and independence for longer periods, with consequent quality of life benefits to people living with dementia. In contrast, for EH, the proposed solution was that the social worker co-ordinating the placement for her 'believes that the home staff would try to positively engage EH and take her for walks...there was every likelihood that the applicant could employ a specific worker to walk with EH on a regular basis' (*EH* paragraph 55). As such, following her placement, EH will only be able to walk when the local authority worker is available to walk with her, and as this is an aspect of her community care assessment, it will be limited by the cost implications of paying such a worker to provide this support, and the level at which this need is assessed (DoH 2010).

Preserving autonomy for people with dementia

In the justification for her decision, Parker J held that the risks to EH's health and welfare outweighed any right that she may have had to autonomy. The theoretical approach to autonomy which underpins the decision in this case is undoubtedly therefore the liberal, individual, atomistic, all-or-nothing approach to autonomy. Indeed, in order to justify her decision in the case, Parker J held that EH did not have what she described as 'true independence or autonomy,' and that:

Many of her actions and reactions are not volitional. When she wanders it is because she gets lost and distracted, when she does not eat or drink it is because she mistakenly believes that she is waiting for her family to come home. Her independence and autonomy is causing her emotional and physical distress. It is her "independence and autonomy" that puts her at risk (*EH* paragraph 128).

The approach to autonomy evident in the MCA, on the other hand, is more akin to a relational understanding of autonomy. The legislative framework for making decisions in the best interests of a person who lacks capacity includes a requirement to 'permit and encourage the person to participate,' (MCA s. 4(4)), consider their 'past and present wishes and feelings', as well as their 'beliefs and values,' (MCA s. 4(6)) and importantly to also consult carers and others with interests in the person's welfare as to their views (MCA s.4(7)). If the decision in *EH* had been made with a person-centred and relational approach to autonomy in mind, then the justification for the decision would, in my view, have been more in keeping with the ethos both of the MCA itself and the principles of person-centred care that underpin it.

Rather than requiring that autonomy is sacrificed in the name of best interests, a person-centred relational approach to autonomy allows welfare to be considered as interior to a person's autonomy, and draws attention to the complexities of the power relations that an individual inhabits. Respecting autonomy in a person centred and relational sense does not require that any

decision made by a person with limited capacity is necessarily carried out, particularly if it requires significant input from others. Rather, respecting this version of autonomy means that a person's wishes and feelings are not excluded or overridden unnecessarily, even if the outcome is the same. In all likelihood, the decision to place EH in residential care was the 'right' outcome for EH, the applicant council and for EH's family. Rather, the problem with this case is that the discursive approach objectifies the person with dementia. EH is discursively converted from an autonomous legal person, worthy of respect, into a person whose actions are entirely dictated by her dementia, and for whom respect for independence and autonomy operates as a harm rather than a good. If a person-centred, relational approach to autonomy were utilised in the judicial decision making, as it is in the text of the MCA, it is possible that the same decision could have been reached, without so fully denying the EH's rights to autonomy, or her capacity to engage in some elements of decision making. A person-centred approach may have avoided the complete disempowerment and exclusion of EH from the decision making process.

As I argued above, relational approaches to autonomy are imperfect. Such an approach can prioritise the values of discussion, communication and interpersonal relationships over individual values. For a person with dementia, relational approaches to autonomy may not mean that there is any lesser likelihood of being moved into residential care against their express wishes. But embedding insights from person-centred understandings of dementia into relational approaches to autonomy could serve to improve the ways that dementia is understood in law, and to provide more distinct legal understandings of autonomy at the margins of capacity.

Concluding Remarks

In this paper, I have used discourse analysis to interrogate the positioning of people with dementia in a judicial text. As the above analysis demonstrates, taking a discursive approach to case law can highlight areas where judicial decision making is in conflict with the aims of the regulatory framework guiding those decisions. By premising judicial decisions about where people with dementia should live on the dangers posed to them by exercising their autonomy, the scope for 'living well' with dementia is eclipsed and the probability of seeing dementia solely as a social problem is increased. This is contrary to the aims and intentions of the MCA framework. As David Lammy, the minister responsible for introducing the Mental Capacity Bill to the House of Commons, stated at the commencement of the second reading debate: 'The Bill will empower, protect and support people who lack mental capacity. We can and should no longer dismiss people by simply labelling them incapable' (Hansard 2004, col 22). The Minister went on to state that 'the intention is to give people with impaired mental capacity the chance to express their individuality, as everyone else does' (col 26). It is debateable whether judicial applications of the MCA allow it to fulfil these aims, particularly in relation to those for whom mental capacity is neither unquestionably present nor unquestionably absent.

People with dementia inhabit a position at the intersections of capacity and incapacity, autonomy and heteronomy, and mental health and mental capacity legislation. In order to better serve people with dementia, judicial considerations of autonomy, capacity and best interests would do well to be attentive to the inherent relationality of autonomy. But relational approaches to autonomy may also present challenges for people with dementia, and those who care for them. Striking the right balance in respecting autonomy, facilitating independent decision-making and

maximising capacity for people with dementia is a difficult challenge. There are few things that are easily achieved in this complex realm, but a small step could be made if, rather than dismissing the insights that can be found in social care literature and practice, judicial decision makers paid more heed to the impact of their discursive and rhetorical approach, and the need for person-centred practices in order to support people with dementia to retain their (relational) autonomy.

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