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## Power, empowerment, and person-centred care: using ethnography to examine the everyday practice of unregistered dementia care staff

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**Abstract** The social positioning and treatment of persons with dementia reflects dominant biomedical discourses of progressive and inevitable loss of insight, capacity, and personality. Proponents of person-centred care, by contrast, suggest that such loss can be mitigated within environments that preserve rather than undermine personhood. In formal organisational settings, person-centred approaches place particular responsibility on ‘empowered’ direct-care staff to translate these principles into practice. These staff provide the majority of hands-on care, but with limited training, recognition, or remuneration. Working within a Foucauldian understanding of power, this paper examines the complex ways that dementia care staff engage with their own ‘dis/empowerment’ in everyday practice. The findings, which are drawn from ethnographic studies of three National Health Service (NHS) wards and one private care home in England, are presented as a narrative exploration of carers’ general experience of powerlessness, their inversion of this marginalised subject positioning, and the related possibilities for action. The paper concludes with a discussion of how Foucault’s understanding of power may help define and enhance efforts to empower direct-care staff to provide person-centred care in formal dementia care settings.

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**Keywords:** dementia, person-centred care, Foucault, power, ethnography

### Introduction

An estimated 46 million people currently live with dementia worldwide, and this number is projected to rise to 131.5 million by 2050 (ADI 2015). This means that a significant proportion of older adults receiving care across medical and residential care settings have dementia; for example, one quarter of National Health Service (NHS) beds are used by patients with dementia (RCP 2013), and more than 60 per cent of care home residents have dementia (Knapp *et al.* 2007). Dementia is caused by a number of underlying pathologies and is associated with progressive impairment across the domains of learning and memory, attention,

executive function, language and communication, perceptual-motor function, and social cognition. Historically, persons with dementia have been socially positioned in terms of their increasing impairments and treated primarily as dependent bodies requiring management and care (Innes 2002, Sabat 2001) or, worse, as ‘empty shells’ (Bryden 2005) enduring a ‘living death’ (Woods 1989).

‘Person-centred care’ challenges the stigmatised social positioning of persons with dementia and the associated, depersonalising care they receive (Kitwood 1997). Related to a wider movement to improve patients’ and service users’ care experiences and outcomes through increased engagement in assessment and treatment decisions (Harding *et al.* 2015), person-centred care emphasises the preservation of choice and dignity through specific care strategies. These strategies include privileging the individual’s preferences over organisational demands, for instance with regard to meals, bedtimes, occupational activities, and décor. In the long-term care sector, and particularly in nursing homes in the United States, person-centred care has been adopted as a central component of ‘culture change’, which is aimed at transforming nursing homes from medicalised, routine-driven institutions to personalised, home-like settings where care is organised around each individual, regardless of their cognitive or functional capacity (Koren 2010).

Person-centred approaches place new responsibilities on health-care providers to proactively elicit and address individuals’ preferences and goals for care (AGS 2016), rather than imposing their own. Person-centred care places particular responsibility on direct-care staff<sup>1</sup> to facilitate opportunities for choice and independence rather than prioritising tasks and routines (Fetherstonhaugh *et al.* 2016).<sup>2</sup> Most notably in long-term care settings in the United States, this responsibility has been framed as ‘empowerment’ of these otherwise marginalised workers (Bowers and Nolet 2011, Chalfont and Hafford-Letchfield 2010). It has been operationalised in a number of ways, including through enhanced autonomy for care staff in daily decisions, their increased participation in formal care-planning processes, and the introduction of consistent assignment to facilitate communication and relationship-building between staff and care recipients (Barry *et al.* 2005, Caspar *et al.* 2009, Castle 2011).

There is some evidence to suggest that attempts to empower frontline staff have had positive impacts on job satisfaction and job retention, as staff feel more valued, respected, and heard (Banaszak-Holl and Hines 1996, Kostiwa and Meeks 2009); on the provision of individualised care (Caspar and O’Rourke 2008); and on family members’ perceptions of service quality (Hamann 2014). However, other studies have highlighted the limitations of empowerment in the broader context of care delivery; for example, one longitudinal study of an intervention to empower certified nursing assistants (CNAs) in five nursing homes in the United States found generally positive effects on absenteeism and turnover, but mixed effects on job performance and attitude due to the competing priorities involved (such as attending meetings versus providing direct care) and inconsistent recognition of their empowerment by nursing leadership (Yeatts and Cready 2007).

A key challenge is that empowerment has been conceptualised and implemented inconsistently and with limited analysis of the mechanisms by which it operates (Bowers and Nolet 2011, Harding *et al.* 2015). Notably missing is an understanding of how the empowerment of direct-care workers (as implied or explicitly required by different person-centred approaches) aligns with their broader disempowerment as a workforce which carries out the ‘dirty work’ delegated by professional nurses, with little training, remuneration, or opportunity for advancement (Kessler *et al.* 2015, Twigg 2000). Further, the majority of evidence on empowerment focuses on direct-care workers in nursing/care homes who care for residents with a range of complex clinical and social care needs. Less attention has been given to the empowerment of direct-care staff who work exclusively with people with dementia in acute settings – despite

recognition of the potential benefits of person-centred dementia care beyond long-term care (Goldberg *et al.* 2013, Webster 2011).

This article will contribute to efforts to advance the provision of person-centred dementia care by examining the notion of empowerment within a Foucauldian understanding of power and knowledge (Foucault 1982), with reference to empirical data. Our specific aim is to determine whether a Foucauldian approach can help us better understand and conceptualise direct-care workers' empowerment in the context of dementia care. Drawing on fieldnotes and interview data from ethnographic studies of three dementia wards in the National Health Service (NHS) and one dementia care unit in a private care home, we examine whether Foucault's notion of power as relational and productive helps explain how staff constitute, and are constituted by, the relations of power in these settings. We begin by describing power in Foucauldian terms before presenting the empirical findings in a three-section narrative which describes the relatively disempowered positioning of care staff, their negotiation of this positioning, and the implications for their practical accomplishment of daily care. We conclude with a discussion of how our reading of the data through a Foucauldian lens can help inform and expand efforts to empower staff in ways that improve quality of care for persons with dementia without undermining job satisfaction or other outcomes.

### **Power, knowledge, and legitimacy**

To examine how direct-care staff experience and engage with their own empowerment/ disempowerment in the dementia care context, we start with Foucault's conceptualisation of power. Foucault (1984: 292) suggests that power is both 'relational' and 'productive': relational because it is present in all human relationships, whether 'amorous, institutional, or economic', and productive because, rather than merely repressing, it also produces or enables particular ways of being (while disabling others). Underpinning this conceptualisation is the essential connection between power and knowledge: 'there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations' (Foucault 1977: 27). According to Foucault, power/knowledge constitutes both what we are as subjects and what we know as objects of knowledge. The task of analysis, therefore, is to focus not on how one person or group wields power over another, but by what tools, techniques, and technologies power relations work 'through and upon individuals' (O'Malley 1996: 189).

Foucault (1977) identifies 'discipline' as a key mechanism by which power works through and upon individuals. Discipline has two closely linked meanings: first, discipline is a set of practices enacted upon the body or a group of bodies, including surveillance, distribution, and segregation. Second, a discipline is a body of knowledge that develops from the application of such techniques. At the heart of disciplinary power is 'normalisation', understood as the creation of norms against which 'individual uniqueness can be recognized, characterized and then standardized' (O'Malley, 1996: 189). Of particular relevance to this article is the mobilisation of these normalising forces within institutions, such as hospitals and 'asylums' as well as prisons, schools, and army barracks. Foucault (1981: 10) defined institutions as the 'crystallisations' over time of programmes of disciplinary power exercised to address specific problems. Dementia, as an example, can be understood as a category by which older persons who exhibit particular, 'problematic' signs and symptoms are defined and socially positioned through the disciplinary forces of power. Over time, as the disease progresses, they are likely to be moved into institutions (Alzheimer's Society 2007), in which their aberrant behaviour can be supervised and 'normalised' through caregiving routines and/or medication (Hyde *et al.* 2014, May 1992).

Foucault's account suggests that the social order which crystallises in institutions is both 'taken for granted' and, at the same time, highly fragile, contingent, and contestable. Institutional theorists following Foucault have developed the idea that there are micro-processes of both 'structuration' and 'destructuration', or deinstitutionalisation, thereby inherent in any process of institutionalisation (Clegg 2010). This strand of institutional theory suggests that the extent to which significant change may occur within institutions, however, is constrained by the formation of 'legitimate' ways of knowing and doing which preclude alternative possibilities for action. By bringing the concept of 'legitimacy' back to Foucault's dynamic notion of power/knowledge, we can consider the conditions under which particular 'legitimate' ways of knowing and doing become possible. We can then consider 'legitimacy' as the emergent property of ongoing conflict between different ways of ordering the world which are temporarily stabilised 'when it becomes the norm for authorities to structure institutions and actions relative to that order' (Clegg 2010: 5). From this perspective, change is not only possible but inevitable, as the struggle for legitimacy is never fully resolved; the degree and direction of change, however, is always contingent upon existing relations of power. To enact change, individuals or groups must act in 'entrepreneurial' (Clegg 2010) ways that not only diverge from the norm but question its very legitimacy. Following Foucault's (1980a: 141) view that an individual can never hold a position 'outside' power relations, the notion of institutional entrepreneurs does not suggest 'hypermuscular agency' (Clegg 2010: 5) on the part of individuals or groups, but it does help draw attention to the creative, opportunistic, and risky acts designed to temporarily 'escape' or 'disengage' power (Foucault 1980b: 138).

Through this lens, we can see that 'person-centred care', as a discourse inscribed in policy and practice, aims to disrupt the institutional order which positions persons with dementia as beyond cure or hope – by promoting instead their personhood and capacity for self-expression. In this paper, we consider how Foucauldian notions of power/knowledge and institutionalisation help us understand the position and practices of the staff who are responsible for directly providing dementia care and who are, in principle, 'empowered' to enact person-centred care. Considering the idea that power works 'through and upon individuals', the analysis that follows is guided by two broad questions: first, in what ways are care staff and their work shaped by disciplinary techniques in these settings (Brijnath and Manderson 2008, St Pierre and Holmes 2008), and second, what are the implications of this understanding of power for analysing attempts to empower staff and transform institutionalised patterns of care?

## Research design and methods

The analysis presented here draws primarily from a multi-sited ethnographic study of the challenges and rewards experienced by healthcare assistants (HCAs) working in hospital-based dementia assessment and treatment wards. Contrasting evidence is drawn from a second study of knowledge translation about person-centred care in long-term care homes. The first study was conducted in 2008–2009 by the authors across three wards within one mental health trust in the East Midlands of England, which we have called Wards A, B and C: Ward A (24 beds) was an assessment ward located within a large urban teaching hospital; Ward B (13 beds) was a specialist 'challenging behaviour' unit in a small suburban hospital; and Ward C (10 beds) was another assessment unit in a rural community hospital. From these wards, most patients were referred or returned to care homes, while a minority returned to the community. The second study was conducted in 2011–2012 by KS in a specialist, 20-bed dementia unit ('Vintage Vale') within a 65-bed skilled nursing and residential care home ('Forest Lodge') located in the East Midlands, which was owned by a large corporate provider.<sup>3</sup> The main aim of the

second study was to describe how ideas about person-centred care translated (or failed to translate) into frontline care practices in long-term care settings.

As ‘active participants’ (Spradley 1980) in both studies, the researchers undertook the required training for care assistants in each setting – namely, a four-day NHS induction and a two-day course on ‘managing violence and aggression’ for the HCA study and a half-day ‘moving and handling’ training at Forest Lodge – before providing hands-on assistance with the full range of direct care, including bathing, dressing, toilet/incontinence care, mobility and meals. The researchers in the first study spent four months each on their assigned ward, completing an average of three eight-hour shifts per week of participant observation as supernumerary care assistants. On Vintage Vale, KS completed approximately two months of participant observation, again adhering to a part-time shift pattern across the day, evening, and overnight shifts. In addition, in-depth interviews were conducted in both studies with care assistants, nurses, managers and administrators (35 across the three NHS wards, eight on Vintage Vale). Prior to the start of fieldwork in both studies, members of the research team introduced the research at staff meetings and placed posters within view of staff, residents, and visitors. In the first study, the research question was described in terms of the experiences, challenges, and rewards of the HCA role in dementia care; in the second study, KS described her interest in how staff acquire, apply, and share knowledge and expertise related to direct care in nursing homes. Direct-care staff were asked to give their consent to be included in the researchers’ written observations, and those who participated in interviews were asked to provide separate informed consent. Although fully participating as members of the care team, the researchers maintained transparency about the reason for their presence in the field through conversation and informal ‘member checking’ of their emerging findings with staff while on shift.

Observations were recorded as brief ‘jottings’ (Emerson *et al.* 1995) on shift and converted into full-length fieldnotes thereafter. Taking an inductive approach, the research team for the first study began by collaboratively analysing the fieldnotes and interview transcripts through line-by-line coding, then built these open codes into themes; examples included routines, challenging behaviour, humour, and the team. (See Scales *et al.* (2011) for a more detailed discussion of this study’s methodology.) KS followed the same process to analyse the data-set from the second study. In developing this manuscript, KS and SB reanalysed both data-sets in order to draw out comparisons between them with regards to the issues of power, positioning, and individualised care.

Formal ethical approval was granted for the HCA study by the local Research Ethics Committee and for the care home study by the School of Sociology and Social Policy at the University of Nottingham and the research-governance committee of Forest Lodge.

## Findings

Guided by Foucault’s concept of disciplinary power, we examine in the following sections how care assistants experienced but also actively engaged with their subject positioning within these dementia care settings, thereby generating new, albeit limited, possibilities for action.

### *‘Only a carer’*

As discussed in the Introduction, person-centred approaches place considerable responsibility on direct-care staff to promote the personhood of individual patients/residents. Such increased responsibility implies an ‘empowered’ workforce who are able to act creatively and autonomously to facilitate opportunities for choice, self-expression, and social engagement. The



evidence from the two studies described in this article suggests that the experience of empowerment for our participants was not clear-cut, but rather characterised by conflict and negotiation. In contrast to feeling empowered, participants from both settings more often expressed a sense of being undervalued and disregarded. ‘I have actually been told “you’re a shit shoveller”, well, I’m not’, reported an HCA from Ward A.<sup>4</sup> She went on to say that HCAs ‘deserve respect as well [as nurses], and sometimes we don’t get that’. HCAs often expressed this lack of respect as a reflection of the marginalisation of their patients. One HCA from Ward C asserted that dementia care was the ‘poor relation of the health service ... because they’re elderly and they’re mentally ill, nothing gets done’.

Care staff referred in particular to their lack of input into decisions about the organisation and delivery of care. This sense of exclusion related also to communication of information about patient/resident needs and generated considerable frustration among care staff. According to an HCA from Ward C: ‘sometimes we don’t get that respect, we don’t get seen, we can pass things on and it’s “what would you know?” ... You can pass it on again, and again, and you never know all the time if it’s been picked up on’. This and similar comments about feeling ignored or invisible indicate carers’ limited capacity to act, due to their perceived lack of voice or impact. As one HCA said about attempts to raise concerns: ‘you relay your views, it filters through ... but, you just think, “you’re not really listening to what I’m trying to say” ... we’re all feeling the same and yet we’re in the same situation, no change has been made’. The picture that emerged here was not consistent with empowerment in relation to communication and decision-making within these care settings.

To some extent, Forest Lodge presented a contrast to the NHS wards in terms of engagement and empowerment. All care assistants on Vintage Vale participated in person-centred dementia care training which emphasised their influential role in promoting residents’ personhood. Day-to-day, they participated actively in handover with qualified nurses or gave their own shift reports and they were encouraged to contribute directly to residents’ care notes and to collaborate in the organisation of daily care and activities.

However, the scope of their input remained limited. The practice of writing notes had quickly stalled because it was not considered an essential element of the carers’ role; that is, staff were not required to write notes nor evaluated for doing so. We observed that some carers who started working after the practice of note-taking had been discontinued were uncertain about whether they were authorised to even read the notes. Even when they had been writing notes, the carers felt constrained about what they were allowed to write. In the following field-note, KS paraphrases a conversation that she had with one care assistant about writing notes:

[The care assistant said] mind you, you’re not allowed to put negative things in, though, so it’s a matter of choosing your words. I [KS] asked for an example, and she said ‘for our residents who wander’, you’re not allowed to say they wander, say instead that they’re ‘exploring their environment’.

Paradoxically, the emphasis on using person-centred language may have limited the carers’ capacity to express, in their own words, what they had witnessed, experienced, or addressed, which may have had negative consequences for their feelings of empowerment.

Like the HCAs, care assistants on Vintage Vale also expressed a general sense of exclusion from decisions about care, including formal assessment and care-planning processes. One care assistant talked about being a ‘lowly employee’ on the ‘lower rung of it all’, linking this status to low reimbursement and job insecurity. Another said that progress towards achieving person-centred practices on the unit had been undermined by recent leadership changes, which she expressed as ‘rumblings with management’ which had compromised care quality. She qualified

her comments with disclaimers, however, such as ‘it’s just my opinion’ and ‘what do I know? I’m only a carer!’ Another carer made a similar point: ‘[W]e worked our arses off to get it to the unit that it was then, now we feel like our work’s just completely gone out the window’.

The fieldnote below, in which KS summarises a conversation that took place on Ward A, illustrates how HCAs characterised their ‘lowly’ status in us/them terms:

[The HCAs were talking about how] ‘nobody gets it’: nobody from outside Ward A understands what it’s like to work here . . . they don’t really even talk about their work to their partners, and if they have a bruise or mark from one of the patients, they’ll dismiss it as an accident – because ‘they don’t understand what it’s like here’.

The notion that ‘nobody gets it’ sometimes included managers and other health-care professionals as well as outsiders. As an HCA from Ward B explained: ‘[managers] don’t understand, how can they understand when they’re sat in an office? Not just managers here, even these people that come up with these surveys . . . how can they know?’ Similarly, on Ward C, an HCA referred to the modern matron (a registered nurse who holds supervisory responsibility over an area of care) as someone who ‘waltzes in’, lives in a ‘fairy world’, and ‘has no idea of what the ward actually needs . . . just wants it all to be pretty and lovely’. This discourse suggests that carers perceived that their work was largely unseen and unappreciated.

In summary, across both settings the dementia care staff referred to feeling unseen, unheard, overlooked, or dismissed. However, their acknowledgement of this subject positioning did not constitute unreflective acceptance; rather, they actively attempted to negotiate it through a number of strategies, as discussed in the next section.

*‘We’re the ones that see it’*

The carers challenged their marginalisation through careful maintenance of a strong collective identity. This can be read as an effort to reposition themselves in the power relations characterising each care setting, thereby opening up new opportunities for action. Central to this repositioning was the carers’ claim to superior – but largely unrecognised – experience and expertise. In other words, the care staff based their collective identity on the claim that, notwithstanding their lack of formal authority or recognition, they exercised informal authority over patient care and the ward environment. ‘I think that the running of the ward is down to the HCAs mainly’, said an HCA from Ward B in an interview. ‘I’m not just saying that because I’m an HCA – it’s because we understand the patients a lot better than management do because we’re hands-on. We know exactly what’s going on’. A carer from Vintage Vale made a similar point:

We’re the ones that see [residents] on a day-to-day basis, we’re the ones that . . . know what hurts us, what hurts them, what’s best for them, what’s not best for them. Although the nurses have the authority, they don’t always see it, you know, we’re the ones.

In this and many other examples, carers explicitly challenged the dominant biomedical discourse which positioned them as less knowledgeable or expert relative to nurses and other health-care professionals.

These strategies for repositioning themselves appeared, to some extent, protective and productive for the care staff. They were protective in the face of alternate, stigmatising objectifications (as described in the previous section), and they were productive because care staff drew on this alternate discourse of authority to act in ‘empowered’ ways, more or less overtly challenging the formal limits of their role. One HCA from Ward A, for example, talked about



working beyond her job description, saying ‘why as care assistants we can’t take what we’re capable of doing off [nurses], you know, it’s not their fault that we’re not paid to do that’. The implications of this productive repositioning will be discussed further in the next section.

Paradoxically, the strategies by which carers challenged their position in the social order also served to reinforce the occupational boundaries which delineated their exclusion from broader relations of multidisciplinary teamwork. That is, maintaining a favourable us/them distinction required carers to devalue the expertise or contribution of others, to a certain extent. This was indicated by their criticism of nurses who ‘shut themselves in the office’ rather than providing bedside care (Ward C); overt scepticism of medical expertise, expressed as ‘the white coat fallacy’ (Ward B); and censure of co-workers who crossed the boundary line, as with the HCA who was labelled a ‘brown-noser’ for waving to a consultant in the corridor (Ward A). The implication is that carers’ own efforts to maintain their occupational boundaries may have contributed to their exclusion from the interdisciplinary communication of information which is required for effective care. (For a further discussion of the HCAs’ in-group identity and interprofessional working, see Lloyd *et al.* (2011)).

Maintaining their occupational boundaries further limited the HCAs’ opportunity for participation in collective, multidisciplinary reflection. This helps explain practices that were observed to be individualised but not necessarily person-centred. For example, on Ward A, there was a patient who was known for her loud and repetitive vocalisations. The type of individualised attention that she received as a result was noticeably non-person-centred, as suggested by this fieldnote:

As we were talking, the patient came up to the table and began speaking to the HCAs in a loud voice. One HCA dismissed her quite sharply, then turned to say to me [KS] that ‘you just have to ignore this one – because otherwise she just gets worse’.

Although the carers were ‘empowered’ to see and interpret this patient’s behaviour in individualised ways, their interpretation (without the benefit of collective, interdisciplinary reflection) led to the reproduction of disciplinary power rather than promotion of the patient’s personhood. Other examples included open discussions of individuals’ anatomy, disposition, habits or proclivities, or sensitive details of their personal history – making them visible as persons (not just patients/residents) but without promoting the dignity that underpins personhood.

We also found evidence that maintaining an exclusive claim to the experience of providing dementia care risked obscuring problematic aspects of the work. One aspect was the prevalence of physical injury, which carers largely interpreted as an element of their occupational experience and identity rather than a problem. When KS was scratched during one of her first shifts on Ward A, one HCA remarked to another ‘she’s a real HCA now!’ – indicating that learning to tolerate violence was a rite of passage from novice to expert. An HCA from Ward C reflected: ‘it just becomes normal for them to boot, kick you, punch you and I think “oh you’ve done it again”. Whether that’s a good thing or a bad thing, I don’t know’. This comment suggests the dual implications of the caregivers’ claims to superior insight and expertise: being the only ‘ones who see it’ promoted their occupational identity and value, but may have also undermined the opportunity to identify and address the risks and challenges of their role.

In the first section, we suggested that the dementia care staff were constituted by the prevailing relations of power as low-skill, low-wage workers with minimal influence. Here, we have demonstrated how they re-engaged power to claim a different position characterised by informal authority over direct care and the treatment environment. We described the protective

and productive implications and highlighted some potentially divisive consequences. In the next section, we examine the possibilities for action that became available through this repositioning, focusing on the provision of individualised care (as central to person-centred care) within the institutional setting.

*'Knowing, watching and understanding'*

The carers' claim to authority and expertise, as described above, hinged largely on their extensive knowledge of each patient/resident as an individual, articulated in comparison to nurses who spent more time on 'paperwork' and other health-care professionals who visited infrequently. While such individualised knowledge can be misused, as noted above, it is nonetheless fundamental to person-centred dementia care, as expressed by this HCA from Ward B:

[T]here is a big difference in people with dementia; it's knowing, watching and understanding the parts of the illness and the different behaviours . . . it's just treating people with respect, with individuality.

Other respondents made similar comments such as 'it's getting to know them, isn't it, every patient's an individual' (Ward C) and 'they are still people at the end of the day, aren't they, even if they are severely impaired . . . it's all about their individual choice . . . you have got to give them as much choice or option as possible' (Ward A). They also highlighted individual needs and preferences when modelling the provision of personal care, as described in the following fieldnote from Ward A:

[The HCA] moved slowly and deliberately but with confidence as she removed the blood-soaked dressing, washed the wound, and applied fresh bandages. She was also careful to tell me exactly what to do, and to point out the patient's preferences; e.g. she prefers not to wear the net knickers because they are too tight, she prefers to leave her upper body and feet uncovered by the sheet, etc.

The following interview excerpt from Ward B illustrates how staff operationalised an individualised approach to care:

One patient was so used to going to work, he still believes that he should be working, he doesn't realise that he's retired . . . so he still gets up in the morning thinking he's going to work and we'd say 'no, you're not going to work' so . . . well, it was my idea actually, [we started] a rota where we give him a specific task to do and he did it and it did work . . . So we try each day and see which mood he's in, if he moans about his work we give him little jobs to do and if he don't, then we leave it.

In this example, the carers attempted to redirect the confusion and frustration of the patient into an activity that would be productive and satisfying for him, although still within institutional parameters related to routines and responsibilities.

On Vintage Vale, carers also pursued strategies to personalise residents' care within institutional parameters; one carer referred to this as being 'interchangeable', depending on the day, each resident's mood, and so on, and another expressed it as following a 'non-routine routine', balancing individual preferences against clinical standards of care. Echoing the example from Ward B (above), in this interview excerpt a care assistant discusses how she organised daily care around individual preferences and medical needs, taking personal history into account:

I've tried to think of . . . a balance between things, for example, I try to get Leo up early because Leo's diabetic, and I feel that . . . to sleep in is not very good for his diabetes, and I think that that affects his moods as well . . . he is an early riser, because that's always been his routine, when he was working.

The carer went on to describe other residents' morning routines in similar detail, concluding that 'all these things are running through my mind while I'm also on the floor working'.

Furthermore, there was also evidence of strategic efforts to break rules that were perceived as antithetical to individualised or person-centred care. The 'Dining Experience' programme at Forest Lodge provides a good example. Although promoted by the corporate provider as an alternative to conventional, depersonalising institutional mealtimes, the Dining Experience was perceived by care staff as a top-down mandate that sometimes restricted, rather than facilitated, their ability to personalise care. For example, as shown in the following fieldnote, the rules mandated that meals were served one course at a time, but carers made an exception for a resident who chose to eat in his bedroom:

[The care assistant] took the resident's lunch tray to him, then came back saying, 'I took both courses together but made sure to say loudly as I went in, 'here's your soup and main course together, [Resident], just the way you like it!' – because the nurse was in the office nearby.

Although it may have also saved time, this strategic transgression was framed in terms of promoting the preferences of the individual. As another example, a care assistant from Vintage Vale talked about resisting messages about 'efficiency' that he felt contradicted person-centred care:

I've refused to, in any sense, try to become more efficient, in inverted commas – I still take the time I think it takes. And if [the care home management] don't like that, I think morally I'm on the high ground, and they're not.

This same carer also openly admitted to small transgressions, such as applying skin cream without using gloves, to preserve the resident's dignity, as described in the following fieldnote:

[The care assistant] explained that 'you're probably supposed to use gloves' but spreading it on with latex 'just doesn't seem very nice'; adding that some rules were so risk-averse that he preferred to just bypass them and do what made sense to him, 'as long as you're careful'.

However, these efforts to individualise care were limited by the parameters of the existing institutional order. One HCA from Ward C described the limits of her ability to adapt morning care:

I don't agree that they should be up for half past 8. If that patient wants to stay in bed, that patient should be able to stay in bed. Where's the patient individuality? . . . I tried to talk this out with the deputy manager, and got bawled out . . . I mean, she's saying 'it's patient care' and 'you're not doing your job', but you are doing your job.

This example represents the HCA's struggle for autonomy and ownership over direct care, which as discussed is a key source of empowerment for this workforce – but from a disempowered position.

In summary, this empirical analysis has explored how the possible actions of direct-care staff were shaped by their subject positioning within the relations of power characterising different dementia care settings in the UK. The first section ('only a carer') explored carers' general experience of 'powerlessness' rather than 'empowerment'. The second section ('we're the ones that see it') suggested, however, that care staff attempted to negotiate this marginalised subject positioning by collectively claiming a privileged, if largely unrecognised, perspective on the experiences and challenges of dementia care. This renegotiation had mixed implications: although opening up new possibilities for 'empowered' action, it also risked perpetuating the carers' marginalised role. The third section ('knowing, watching, and understanding') looked further at these possibilities for action, exploring in particular how carers undertook the challenge of individualising care, in more or less subversive ways. In the next section, we discuss these findings in terms of Foucault's conception of power and the person-centred discourse of empowerment, drawing out implications for policy and practice change.

## Discussion

As described in the Introduction, person-centred dementia care challenges the stigmatised social positioning of persons with dementia by emphasising their enduring capacity for self-expression and social engagement and their right to dignity, respect, and choice. This denotes a shift away from routinised and task-oriented care practices in formal organisational settings. In Foucauldian terms, the person-centred discourse thus challenges the dominant power/knowledge regime that positions those with dementia according to a master narrative of inevitable decline, which has previously led to practices of containment and management (Sabat 2008). Person-centred care thereby also challenges the marginal status of those who provide dementia care: no longer unskilled labourers providing custodial care for persons with diminished personhood, care staff are credited with the capacity to directly facilitate (or undermine) person-centred outcomes. For example, in Kitwood's (1997) influential work on personhood in dementia, care staff carry the weight of responsibility for creating positive or malignant social psychology through their 'enabling' versus 'detracting' actions and behaviours; this implies much more than 'basic' care. This aspect of person-centred care is cast, more or less explicitly, in terms of the 'empowering' of the direct-care workforce to improve outcomes through more flexible, personalised caregiving techniques. The Foucauldian perspective suggests that becoming empowered in this sense entails more than individual-level practice change; rather, it entails a challenge to the immediate and extended relations of power that inform current, taken-for-granted ways of working in this context of care.

In the first section of empirical findings, we saw limited evidence that the 'destruction' (Clegg 2010) implied by staff empowerment had actually been achieved; rather, participants clearly expressed a sense of enduring disempowerment. Taking a broader view, we can see that their disempowerment is produced and maintained through various 'technologies' of the formal organisation that are distinct from the discourse of person-centred care; for example, their contractual status defines their low occupational status, low pay, and limited opportunities for training, and links to their lack of involvement in formal assessment and care-planning processes.

Nonetheless, the second empirical section suggested that care assistants engaged in collective attempts to resist their marginalised position by promoting their skilled contribution to care. These attempts at resistance could be described as 'institutional entrepreneurship', which Clegg (2010: 10) defines as 'a strategic face of power reliant on skilled analysis, deployments, and coordination grounded in local knowledge with which to outflank dominant actors with

superior resources'. In Foucauldian terms, this collective entrepreneurship is an important response to disciplinary power, which operates through processes of separation, division, and segregation. The care assistants' deployment of their ownership of 'basic care' is a prominent example. Although this ownership was linked to their structural disempowerment (as the 'dirty workers' who take on tasks relinquished by professional nurses), within the caring environment it also represented an important resource from which to develop a stronger and more autonomous (or 'empowered') occupational identity. Konrad (2011: 53) describes the development of 'group consciousness' among direct-care workers in the United States in a similar way: 'the members of this occupational group mutually recognise each other, positively affirm their own and each other's worth, and widely empathize with their fellows as participants in certain common tasks, among which are the securing of public recognition as members of an invigorated group that possesses and demonstrates collective agency'. For the HCAs on the dementia care wards, part of this collective effort involved identifying their marginalised status with that of their patients/residents, as expressed by comments like '[dementia care] is the poor relation of the health service'. In contrast with reports of 'dirty workers' distancing themselves from care recipients (Ashforth and Kreiner 1999, Isaksen 2002), our evidence indicates that care staff actively highlighted the parallels in their structural and social status.

From these collective attempts at empowerment, care assistants in our study found new local possibilities for person-centred actions, as described above. This involved different degrees of negotiation with the existing order: sometimes attempting to negotiate a 'non-routine routine' as one carer put it, and sometimes deliberately transgressing institutionalised norms such as 'efficiency' in order to provide more personalised care. However, these possibilities were limited by two interrelated factors: first, by their own disempowered subject positioning as described above, and second, by other 'legitimate' organisational demands. By this we mean that person-centred practices were not necessarily recognised as 'legitimate' when put alongside, for example, the predictable completion and documentation of tasks. We also found that an organisation-wide approach to 'person-centred care', such as the Dining Experience, sometimes proved counter-productive to the provision of personalised care. In response, carers' own assertion of person-centred practices could appear illegitimate rather than empowered. This finding aligns with Kontos *et al.*'s (2010: 11–12) observation that direct-care workers in a study in Canadian nursing homes broke certain organisational rules 'as a strategy to individualize care because full compliance with rules [constrains] their ability to do so'. The problem is that such situated rule-breaking or disruptive action, undertaken covertly to avoid disciplinary action, may have failed to disrupt the relations of power that have produced and legitimated non-person-centred norms.

These findings point to the need for better recognition of the care workers' collective claim to knowledge, skills and expertise as an important step towards meaningful empowerment. An affirmative response from those who are more 'empowered' within the current institutional order, that is, would help legitimise the carers' claims to authority. This legitimisation would necessitate a shifting of the power relations that currently, as we have shown, have adverse implications, such as carers' marginalisation within the multidisciplinary team and their associated defensiveness about their occupational boundaries and reluctance to reflect on their own practices. Legitimation represents a different mechanism of empowerment than 'giving' or 'allowing' more autonomy, since a gift – whether given or withheld – leaves existing relations of power intact.

The importance of external recognition is reflected to a certain extent in 'culture change' attempts to promote and formalise direct-care staff's involvement in organisational practices such as shift handovers and care-planning meetings. In the United States, the Green House model of long-term care (Loe and Moore 2012) provides a prominent example. Here, care staff have been promoted to 'universal workers' (known as *Shahbazim*) who take responsibility for running each small household, including creating work schedules and planning meals and

activities as well as providing direct care. Even in this model, however, evidence suggests that ‘empowerment’ is interpreted and implemented in quite different ways, with more or less favourable outcomes in terms of interdisciplinary collaboration and resident outcomes (Bowers *et al.* 2015). In challenging the view of power as a property which can be given or taken away, Foucault helps us consider how action and consequences are shaped by innumerable forces and relations, some of which may be beyond the individual or collective actors’ immediate field of vision. Thus, we can see that ‘culture change’ approaches to empowerment may not succeed if they do not adequately account for the complex power relations – including those related to quality, safety, accountability, profit, and so on – which inform the possibilities for action in any particular care setting while rendering other actions ‘unthinkable’ (Deetz 1992: 143). We must consider what actions are available to or ‘thinkable’ for staff, and with what outcomes; for example, how thinkable is the action of applying skin cream without gloves for someone whose responsibility is to enforce accepted standards of safety and hygiene? And if the transgressive act is ignored to ‘save’ the worker from disciplinary action, then power has been disengaged, to some extent, but without potential for the act to prompt further change. More radical change would require transgression to be treated as an invitation to collectively question disciplinary norms; however, this presupposes the existence of conditions of openness and mutual trust, which the evidence presented here does not support.

Another important step towards public recognition of the ‘invigorated’ direct-care role is the establishment of training and performance standards. The Care Certificate, which came into force in the UK in April 2015, is a notable example which establishes a minimum level of training for non-regulated care workers across health and social care settings. However, training standards alone, especially when minimally enforced, are not sufficient to offset the marginalisation of the workforce; this has been shown in the United States, where nursing assistants are required to complete a federal minimum of 75 hours of training and certification but who nonetheless remain an underpaid, undervalued workforce (PHI 2009). Further, it is important to remember that with recognition and formalisation comes an intensification of disciplinary power in the form of increased scrutiny; to empower is not to set free, following Foucault, but to set in motion a new set of power-knowledge relations which shape a new field of possible action. By recognising care staff as an occupational group, and beginning to regulate their practice through training and performance standards, there is a risk of further individualising what might otherwise be understood as the collective phenomena of practice – if recognition serves primarily to distinguish and discipline individuals who fall short of those standards, rather than legitimising the ‘generative and creative nature of care practices’ (Mol *et al.* 2011: 77) implemented by this workforce as a whole.

Person-centred care has substantial normative legitimacy (Scott 2001), as part of broader movements toward individualisation, anti-stigmatisation, and user involvement across health and social care. It is supported by national action plans and policy and practice guidelines (e.g., in the UK: Department of Health 2009, 2010, 2013, Department of Health, Cabinet Office and Prime Minister’s Office 2015, NICE 2006) and spelled out for nursing staff in particular in the NHS Commissioning Board’s (2012) *Compassion in Practice* report. Therefore, person-centred discourse provides an external force which could set in motion the wider ‘abandonment of widespread taken-for-granted practices’ (Maguire and Hardy 2009: 148) in dementia care, as in other settings, which is the necessary adjunct to deinstitutionalisation. However, we have argued that there is a limit to the reform or ‘abandonment’ that is likely to result from the locally empowered moves of caregivers, without simultaneous attention to their persistent structural disempowerment and the deeply rooted legitimacy of non- or pre-person-centred practices, such as economic rationalisation. In other words, if the responsibility to transform institutional norms through person-centred practice is placed solely on the shoulders of caregivers through their ostensible



‘empowerment’, limited change will result. Transformation of care requires changes in both the organisational settings where practices occur and the broader relations of power which produce them. Nevertheless, focussing on those everyday practices, as we have done here, draws attention to the creative capacity of this workforce and their potential role in collectively producing change. Realising this potential requires a sense of ‘balanced responsiveness’ (Deetz 1992: 338) in institutional dementia care, in order to recognise the tensions created by multiple interests and to encourage disciplinary power to be enacted in more collective and participatory ways.

## Conclusion

This article has examined the role of unregistered care staff in dementia care settings, with particular attention to the relations of power which define their experiences and possibilities for action. The starting point for the analysis was person-centred care, a concept with considerable traction in health and social care discourse which places the responsibility for promoting personhood largely on direct caregivers. The analysis was framed within Foucault’s work on knowledge and power, which emphasises the productive nature of these twin forces in shaping everyday realities and offers the means to analyse the possibilities, as well as the constraints, that actors face.

The empirical findings illustrated the various ways that direct-care staff enacted their own ‘empowerment’ from a position of persistent ‘disempowerment’. Through this examination, we considered the extent to which they could impact the legitimate order of the institution through their collective resistance and action, rather than ‘just’ the individual experience at the point of care. We concluded by suggesting that more needs to be done to recognise, support and develop the creative work of direct-care staff in order to generate greater correspondence between the everyday action we observed and broader normative shifts towards more empowering models of dementia care.

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## Notes

- 1 Direct-care staff comprise the largest practitioner group and provide the majority of hands-on care across health and social care settings (Moran *et al.* 2011). This workforce has many labels; here, we use ‘care assistant’, ‘direct-care worker’, and ‘carer’ interchangeably, but ‘healthcare assistant’ (HCA) when referring specifically to the NHS setting. ‘Caregiver’ is used when referring to informal care or

to caregiving in general. Finally, the term ‘patient’ is used for the NHS setting and ‘resident’ for long-term care.

- 2 It should be noted that informal caregivers, including family, friends, and neighbours, provide the majority of care for the two-thirds of people with dementia who live in the community. Although discussions about power, personhood, and person-centred care are relevant to their experiences and actions as well, the focus here is paid staff in formal organisational settings.
- 3 The second study comprised two comparative cases: Forest Lodge and a family-owned, 80-bed skilled nursing facility located in the north-eastern United States. Although the majority of residents at both facilities had some degree of cognitive impairment, those in the US nursing home and on the skilled nursing unit at Forest Lodge also tended to have more acute physical health needs, which impacted the organisation and delivery of care; therefore, the data discussed here are drawn exclusively from ‘Vintage Vale’, the secure dementia unit at Forest Lodge, where residents’ acuity was similar to that of the patient population of the NHS wards in the first study.
- 4 Quotation marks in fieldnote excerpts indicate verbatim wording of research participants; otherwise, the conversations described in fieldnotes have been paraphrased by the author of the fieldnote. False starts and repetitions have been removed from verbatim quotes to enhance readability. Ellipses signify omitted text from fieldnotes or interview excerpts, and square brackets are used for clarifying text.

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