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Power, ethics, and person-centred care: Using ethnography to examine the everyday practices of unregistered dementia care staff

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the everyday practices of unregistered dementia care staff**

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 institutional settings, person-centred approaches place particular emphasis on 'empowering' unregistered care staff to translate this idea 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 and the ethical constitution of subjects, 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. By examining the daily dilemmas that care staff navigate, this paper contributes to our understanding of the complex risks and responsibilities entailed in direct care work, with implications for the provision of ethical and person-centred dementia care.

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Introduction

The term 'dementia' refers to a range of symptoms, primarily loss of memory and cognitive skills, which

are caused by several different degenerative neurological conditions, including Alzheimer's disease.

Although 'loss' and 'degeneration' may be clinical indicators, they also underpin the social positioning of

persons with dementia. Those with the diagnosis become defined according to their actual or

anticipated deficits and positioned, at best, as 'patients' or 'residents' requiring management and care

(Innes 2002, Sabat 2001), at worst as 'empty shells' (Bryden 2005) enduring a 'living death' (Woods

1989). Admission to an institutional care setting – whether an acute hospital ward or long-term care

home – can accelerate this process, as individuals are removed from the roles and contexts which

reinforced their history, identity, and social personae (Goffman 1961, Hyde et al. 2014).

Within recent decades, proponents of 'person-centred dementia care' have challenged the dominant

neuropsychiatric explanation of dementia (Downs et al. 2005) that posits loss of self as both

symptomatic and inevitable. Central to person-centred care is the argument that 'personhood' persists

throughout every stage of cognitive decline (Kelly 2010). Kitwood, a key instigator of person-centred

care, defined personhood as 'a standing or status bestowed upon one human being, by others, in the

context of relationship and social being' (1997, p.8), clearly establishing its relational foundation.

Similarly, in his multi-dimensional concept of 'selfhood' in dementia, Sabat includes 'social personae'

which 'require, for their very existence, interpersonal interaction and the social recognition given by

others' (2001, p.18). Kontos (2005) developed the notion of '*embodied* selfhood' to account for the body

as an enduring expression of selfhood. The unifying theme, with relevance to our discussion throughout

this paper, is the social construction/constitution and maintenance of the self (including in dementia)

through engagement with the other.

Person-centred care has been operationalised in numerous care models (e.g. Eden Alternative 2014) and

quality improvement tools (e.g. Edvardsson and Innes 2010), as well as inscribed in policy and practice

guidelines (e.g. NICE 2006). These various approaches all place significant responsibility for preserving

and promoting (and, by implication, erasing) personhood on those who interact with people with

dementia at the 'point of care' – in hospitals and care homes, this predominantly means unregistered

care assistants.[1,2] Dementia Care Mapping, for example, which is an observational tool designed to help

carers improve the wellbeing of patients and residents, highlights carers' 'enhancing' actions such as

acceptance and inclusion, but also 'detractors' such as infantilisation and stigmatisation (Fossey et al.

2002).

Throughout the person-centred discourse is, in other words, an emphasis on 'empowering' direct care

staff to transform the environment and delivery of care (Bowers et al. in press, Chalfont and Hafford-

Letchfield 2010); this resonates with the broader rhetoric of staff 'empowerment' and 'engagement' in

the English National Health Service (NHS; King's Fund 2014, McDonald 2004). Empowerment seems

largely aspirational, however, for this workforce. Direct care staff are predominantly female and up to

30% from black and minority ethnic groups. They receive limited training and career progression

opportunities and earn significantly less than professional colleagues such as nurses, physiotherapists,

and social workers (Cavendish 2013). Their recognition and remuneration has not kept pace,

furthermore, with their increasing level of 'bedside' responsibility delegated from nurses (Kessler et al.

2012, 2015). Ubiquitous but marginalised, relatively little is known about the experiences of this

workforce in the specific context of dementia care – particularly regarding the complex relations of

power through which they interact with care recipients.

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Working within a Foucauldian understanding of power and the ethical constitution of subjects (Foucault

1982, 1984), this paper examines empirically how the disempowered positioning of people with

dementia and direct care staff is (re-)negotiated through everyday care in institutional settings.

Specifically, drawing on fieldnotes and interview data from ethnographic studies of three NHS dementia

wards and one private long-term care dementia unit, this paper examines how staff constituted, and

were constituted by, the relations of power in these settings. The paper begins by establishing the

theoretical framework for this analysis before discussing the methodology of the two studies. The

findings are then presented as a three-section narrative which describes the disempowered positioning

of the care staff, their negotiation of this positioning, and the implications for their practical

accomplishment of everyday care. The paper concludes with a discussion of the risks and responsibilities

brought to light through these findings and the related implications for efforts to promote person-

centred dementia care.

Power, knowledge, and the ethical subject

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 suggests that power is both 'relational' and 'productive': relational because it is present in all

human relationships, whether 'amorous, institutional, or economic' (1984, p.292), 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, p.27). According to Foucault, power/knowledge constitutes both what we *are* as subjects and

what we *know* as objects of knowledge. Considering power in these ways requires us 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, p.189).

Foucault (1977) describes this embodied and external form of power relations through the concept of

'disciplinary power', describing 'discipline' in two closely linked ways. First, discipline is a set of practices

enacted upon the body or a group of bodies, such as 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, p.189). Of

particular relevance to this paper is the mobilisation of these normalising forces within institutions,

which Foucault defined as the 'crystallisations' over time of programmes of reform responding to

specific problems (1981, p10), such as the 'problem' of dementia. Organisational routines provide an

example of how activities become institutionalised and thus normalised over time: as particular tasks

are accomplished repetitively by designated individuals in particular ways and at particular times, a

relatively predictable sense of order/normalcy is produced. Departures from this sanctioned order – for

example, completing a task outside one's remit or on a different schedule – thus become visible and

problematised ([authors' ref]). Indeed, Foucault (1973, p.105) described the combined action of power

and knowledge as the creation of a 'domain of clear visibility' – visibility in terms of watching/regulating

(the institutional order) and, more deeply, in terms of seeing/knowing (those who challenge it).

Although maintaining awareness of the implications of this argument for patients/residents (see, for

example: May 1992, McColgan 2005), we focus in this paper on the staff responsible for their direct

care. Considering the idea that power relations work 'through and upon individuals', we are interested

in the ways that care staff and their work are shaped by disciplinary techniques in these settings

(Brijnath and Manderson 2008, St. Pierre and Holmes 2008), but also the ways in which power works

through them and the extent to which they can influence such processes.

Considering how care staff might influence the disciplinary forces that work upon/through them

requires us to consider the problematic status of 'the subject' in Foucault's work. The concept of

power/knowledge is often understood by Foucault's critics (e.g. Taylor 1986, Allen 2000) to imply a

determining structuralism which eradicates any notion of agency – 'the individual is an effect of power'

(Foucault 1980b), and nothing more. While acknowledging that individual actions are not just shaped

but *made possible* by power, we are concerned here with the situated ways that 'similar' individuals

understand and engage differently with the actions available to them. We consider this individual

engagement as a 'practice of freedom' because, although not occurring outside disciplinary power, it

nonetheless entails the development of an awareness of self as constituted by those relations of power.

Thus freedom is not total autonomy but reflection and reengagement in relation to specific activities:

'freedom in relation to what one does, the motion by which one detaches from it, establishes it as an

object, and reflects on it as a problem' (Foucault 1984, p.388).

Foucault used the term 'ethics' to describe this relationship between self and power, arguing that 'ethics

is the considered form that freedom takes when it is informed by reflection' (1984, p.284). Put another

way, how to 'practise freedom' within existing relations of power is an *ethical* question. Foucault's

understanding of ethics – which draws from the Greek term *ethos*, meaning 'a way of being' – diverges

from similar constructs such as 'medical ethics' or 'ethical codes of conduct'. Whereas the latter imply a

universal and singular truth regarding 'right' and 'wrong', Foucault argued instead that truth is always

situated; in other words, truth is 'a thing of this world … linked in a circular relation with systems of

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power which produce and sustain it' (1980c, p.131). This prompts our empirical interest in how truth is

situated within, and reproduces, particular relations of power in dementia care settings.

In this paper, we examine these issues of power and ethics through data from two ethnographic studies

of direct care workers in institutional dementia care settings, exploring the possibilities for these

apparently disempowered subjects to engage creatively with the institutional relations that produce and

constrict them. In the Discussion, we revisit the problematic terrain of disciplinary power and individual

capacity to act with attention to the risks and responsibilities entailed.

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, with contrasting evidence drawn from a second study of knowledge translation

about person-centred care in long-term care homes. The 'HCA study' was conducted in 2008-9 by the

authors across three wards within one mental health trust in the East Midlands of England, which we

call 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 2011-2 by [author's initials] in two private care homes: a family-

owned skilled nursing facility with approximately 80 beds in a small town in the northeastern United

States ('Richardson's') and a 65-bed skilled nursing and residential care home located in a village in the

East Midlands ('Forest Lodge'), which was owned by a large corporate provider. The data discussed here

are drawn exclusively from 'Vintage Vale', a 20-bed specialist dementia care unit at Forest Lodge, where

residents' acuity was similar to that of the patient population of the NHS wards described above.

Although the majority of residents on the nursing units at both Richardson's and Forest Lodge had some

degree of cognitive impairment, they also tended to have more acute physical health needs, which

impacted the organisation and delivery of care; therefore, data from those units have not been included

in this analysis.

As 'active participants' (Spradley 1980) in both studies, the researchers undertook the required training

for care assistants in each setting – including 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. Observations were recorded as brief 'jottings'

(Emerson et al. 1995) on shift and converted into full-length fieldnotes thereafter. In addition, in-depth

interviews were conducted in both studies with care assistants, nurses, managers and administrators

(31 across the three NHS wards, 8 on Vintage Vale). Taking an inductive approach, the HCA research

team 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 [authors' ref] for a more detailed discussion of this study's methodology.)

[Author's initials] followed the same process to analyse the data-set from the second study. In

developing this manuscript, [first two authors] 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 University of Nottingham, the research-governance committee of Forest

Lodge, and the Social and Behavioral Sciences Institutional Review Board at the State University of New

York at Buffalo.

Findings

Guided by Foucault's concepts of knowledge/power and ethical practice, we examine in the following

sections how care assistants experienced (section one) but also actively engaged with (section two) their

subject positioning within these dementia care settings, thereby generating new, albeit limited,

possibilities for action (section three).

'Only a carer'

As discussed in the Introduction, person-centred approaches place considerable responsibility on direct

care staff to promote individuals' personhood. Although this is often expressed in terms of caregiver

'empowerment', the evidence suggests that empowerment remained more of an ideal than a sustained

practice change in the research settings. Indeed, whether working on an NHS ward or in a care home,

staff expressed a sense of being undervalued if not disregarded. 'I have actually been told "you're a shit

shoveller", well, I'm not', reported an HCA from Ward A.[3] 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 often referred in particular to their lack of input into decisions about the organisation and

delivery of care. 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 her own and co-workers' 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'.

To some extent, Forest Lodge presented a contrast to the NHS wards in terms of engagement and

empowerment. All care assistants on Vintage Vale received 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 stalled months

earlier, and some carers were uncertain whether they were authorised to even *read* the notes –

indicating their perceived exclusion from assessment and care planning processes. Like the HCAs, care

assistants on Vintage Vale also expressed a general sense of exclusion from decisions about care. One

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 peppered 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'.

In these and many other examples from both research settings, dementia care staff referred to feeling

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. To some extent these strategies created space for the type of empowered caregiving which is

central to person-centred care; however, these spaces tended to be temporary and contingent rather

than institutionally supported, with implications for sustained change.

'We're the ones that see it'

The carers challenged their marginalisation through careful maintenance of a strong collective identity,

which can be read as repositioning 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. The fieldnote below exemplifies many

conversations in which HCAs articulated their experience in us/them terms:

> [They talked 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
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> 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' 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 do it, how can they know?' Similarly, on Ward C, an HCA referred to the modern

matron 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.' In short, the care staff claimed to have mastered, as

Collins and Evans (2008, p.23) put it, 'a tacit-knowledge-laden specialism to a high level of expertise'

through their exclusive experience of the 'frontlines' of dementia care provision, with its attendant risks

and challenges.

Drawing on this expertise and experience, the care staff 'recalibrated' (Ashforth and Kreiner 1999) their

role to emphasise their informal authority over patient care and the ward environment, despite their

lack of formal influence. 'I think that the running of the ward is down to the HCAs mainly', said an HCA

from Ward B. '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
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> 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 the latter comment, the carer specifically inverted the formal hierarchy between care assistants and

qualified nurses. In both studies, the relationship between direct carers and nurses was relatively

complementary and cooperative; nonetheless, as this comment suggests, there *was* evidence of the

tension and territory disputes within the nursing team that have been well-documented in numerous

settings (see for example Bach et al. 2008, Jervis 2002, Thornley 2008).

These strategies for repositioning themselves were, to some extent, productive and protective for the

care staff. 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'. In an example from Vintage Vale, a carer illicitly made colour photocopies for a special event that she had planned for the unit, acknowledging that the expense may be noted (with disapproval) by her superiors but the intention and effort would not be: 'she said right away that she knew we wouldn't get thanks for it, not from *them* (indicating out there) – but that *they* (indicating the residents …) would enjoy it'. These diverse examples illustrate carers' attempts to step outside the formal parameters of their role for the benefit of care recipients. However, such expressions of 'empowerment' did not necessarily affect the balance of power in the institution in any sustained way. Indeed, these 'above and beyond' actions could be seen as a reengagement of the broader, gendered power relations which position care work as natural or vocational (Twigg 2004), thereby legitimating inequalities in recognition, training, support, and remuneration.

The carers' repositioning strategies were also protective in the face of alternate, stigmatising objectivisations (as described in the previous section). Paradoxically, however, they also served to reinforce the occupational boundaries which delineated carers' exclusion from the multidisciplinary care team. That is, maintaining a favourable us/them distinction required carers to devalue the role or expertise 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). (For a further discussion of the HCAs' in-group identity and interprofessional working, see [authors' ref].)

Furthermore, maintaining an exclusive claim to the experience of providing dementia care risked obscuring problematic aspects of the work that might otherwise require addressing. For example, carers

described physical injury as par for the course: when [author's initials] 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'. In writing about the moral labour of care workers, Johnson (2015, p.122) similarly argues that carers' ability to remain 'calm, tolerant, and sympathetic' meant that incidents and accidents went 'under-reported and under-recorded', thus precluding efforts to uncover and resolve their structural causes. Therefore, the carers' strategic repositioning risked placing them (and in some cases, their care recipients) beyond the protections offered by the institution in the form of, for example, risk-management and reporting guidelines. Conversely, however, individual carers' attempts to resist this repositioning also entailed risks, such as losing the solidarity and support of co-workers.

Positioning themselves as the only ones 'who see it' – claiming exclusive insight into the daily realities of care – furthermore limited the potential for collective, interdisciplinary reflection. This helps explain evidence of problematic practices, such as care that was managerial or personalised without being 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 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 that 'you
> just have to ignore this one – because otherwise she just gets worse.' … Later in the
> morning, I heard another HCA also raise her voice to the patient, and then she said to us
> something like 'she turns me into a bad woman, that one does – I don't usually shout at

people'. And later in the day, I saw two other HCAs shout at her from different seats in

the dayroom. One HCA said 'that's it, one more word out of you and you're going down

the end.'

In this case, there was some general agreement among the HCAs that the patient's behaviour was wilful

and controllable, which 'justified' the adoption of a fairly harsh, chastising response. This example

illustrates the complexity of the relation between empowerment and person-centred perspectives.

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 her 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*.

In the previous 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. We have now demonstrated

how they reengaged power to claim a different position characterised by informal authority over direct

care and the treatment environment, discussing the protective and productive but also potentially

divisive implications. 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

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more time on 'paperwork' and consultants 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:

> I don't think that everyone should be tarred with the same brush … there 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' (Ward A).

The following interview excerpt from Ward B illustrates how staff operationalised this 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 conducted within institutional

parameters related to routines and responsibilities, this represented ethical practice in the Foucauldian

sense because the care staff, rather than enacting a singular or universal truth of 'good' patient care,

sought to act truthfully according to the fluctuating reality of the particular patient.

However, such efforts were infrequently realised in practice, given the power of the institution relative

to individual carers (referring back to the first section). 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,
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> that patient should be able to stay in bed. Where's the patient individuality? … I tried to
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> talk this out with the deputy manager, and got bawled out … I mean, she's saying 'it's
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> patient care' and 'you're not doing your job', but you <u>are</u> doing your job … One patient
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> never used to like to get up first thing in the morning, but when he got up he had his
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> drink, he had his breakfast, he had his dinner, whatever, and he was in such a good
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> mood, but get him up, you totally turn that man into somebody that he wasn't…

This example represents the HCA's struggle for ownership over direct care, which as discussed is a key

source of power for this workforce. Moreover, it highlights the conflict between the psychosocial logic

of person-centred care, as invoked by the HCA, and the biomedical logic by which care is organised and

standardised. In this example, although the carer attempted to reengage power to challenge the

depersonalising effects of the institution, the impact was negligible.

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. Furthermore, there was also evidence of strategic efforts

to break rules that were perceived as antithetical to person-centred care. The 'Dining Experience'

programme provides a good example. Although promoted by the corporation 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, 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. This example substantiates Kontos et al.'s claim that direct care workers

break rules 'as a strategy to individualize care because full compliance with rules [constrains] their

ability to do so' (2010, p.11). In this case, the carers broke an ostensibly person-centred rule in order to

serve one resident's meal 'the way he liked it'.

To summarize, the intention of this empirical analysis has been to explore how direct care staff

experienced and engaged with 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'. The second section ('we're the ones that see it') suggested, however,

that care staff inverted this marginalised subject positioning by claiming a privileged, if largely

unrecognised, perspective on the experiences and challenges of dementia care, with mixed implications:

although opening up new possibilities for 'empowered' action, it also risked perpetuating their

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 the next section, we discuss these findings in terms of our theoretical framework, drawing out in

particular the mutually constitutive themes of risk and responsibility.

Discussion

The data presented above illustrate a number of different ways that dementia care staff understood and

fulfilled their 'capacity to act' in the institutional context. One option was to limit action, given the

perception that their efforts – such as patient advocacy or enhanced care – would not be heard, seen, or

recognised; consider the disclaimer 'what do I know? I'm only a carer'. Repositioning themselves as

experts with authority over direct care afforded another possibility, which was to act for the immediate

benefit of patients/residents without any expectation of institutional response; for example, by going

'above and beyond' their job description. Although sometimes these situated actions were clearly

person-centred, at other times they were personalised in ways that tended to perpetuate the

stigmatised positioning of persons with dementia. In some cases, carers pursued person-centred

practices that fit neatly within the legitimate order of the institution, as when they developed a 'work

schedule' to occupy a patient who otherwise tended to disrupt the ward routine. In others, they

challenged the institution through these practices, as when one HCA argued with her manager about

allowing a patient to determine his own morning routine, or when Vintage Vale staff broke the Dining

Experience rules for a particular resident.

Examining these different actions in context of the 'total structure of actions' generated through

disciplinary power (Foucault 1982, p.220) brings to light the layers of risk involved. 'Risk' is a dominant

theme across health and social care, not least in dementia care settings; this is reflected in increasingly

extensive monitoring and regulatory policies and related risk-averse practices, especially in long-term

care (Kapp 2003), which are designed to keep patients/residents safe from harm. The physical risks of

direct care work, such as assault (Estryn-Behar et al. 2008) and musculoskeletal injury (Guo et al. 1995),

are also well-documented. Additional risks identified here include exclusion from the interdisciplinary

team (paradoxically, by claiming a more empowered subject positioning); lack of recognition for

surpassing the job description (again driven by the claim to greater informal authority); and the

potential for repercussions for transgressing institutional norms and routines. Notably, enacting person-

centred care could be 'risky' when it involved challenging the existing institutional order, even if

sanctioned by the person-centred discourse itself. The important point here is that asking or expecting

direct caregivers to mitigate the depersonalising tendencies of the institution through the provision of

individualised care – according to the person-centred discourse of 'empowered caregivers' – also entails

asking them to step outside the persistent, pre-person-centred institutional order. In that case, they

become 'visible' and thereby culpable if, for example, choosing to facilitate a patient's choice results in a

reportable incident and related penalties. Rather than judging their actions as 'good' or 'bad' – as

person-centred or not – this suggests that we must consider the potential risks and repercussions that

carers face when negotiating complex caregiving interactions.

Recognising these layers of risk leads to consideration of the responsibility inherent in Foucault's

suggestion that subjects should 'respond to every advance of power with a movement of

disengagement' (1980a, p.138). Foucault suggests that subjects are able to exercise freedom through

practice, with ethics being the considered, reflexive expression of that freedom. This puts some (limited)

responsibility back onto the individual, which as discussed earlier is not recognised in many readings of

disciplinary power. Through the empirical data, we have suggested that carers' primary responsibility

was not to enact a singular 'truth' of good care but to reflect on how to best provide care in a given

moment to a particular individual, arbitrating between different and sometimes contradictory

discourses (including biomedical, risk-management, and person-centred discourses). Part of this

responsibility, in the specific context of dementia care, was not only 'promote' (per the realist ontology

of person-centred care) but 'produce' personhood – because, in Foucauldian terms, 'seeing' the other is

a power-laden and productive process. Overall, the caregivers' responsibility was *ethical* because it

required reflective engagement with their subject positioning and capacity to act within existing but

mutable power relations in conditions of moral and practical uncertainty.

The findings also demonstrated the responsibility of the institution to create legitimate space for such

ethical practice. As already stated, carers' attempts to enact person-centred care were sometimes at

odds with existing norms and routines and, without institutional response, were therefore unlikely to

meaningfully affect the organisation and delivery of care. In the study of strategic rule-breaking

mentioned above, Kontos et al. (2010, p.12) made a similar point: because covert and situated, the

carers' rule-breaking actions failed to achieve lasting change because 'rule violation and supervisor

complicity remained nondialogic, thus undermining the potential for their combined reflexive

capabilities to transform the legislative' (and, we would argue, day-to-day) 'landscape of long-term

care'.

In summary, recognising the partially autonomous and creative acts of care assistants in these settings

carries both theoretical and practical significance. It allows us to consider how individual subjectivity can

be enacted within the determining context of power relations, an idea that Foucault largely repudiated

(although occasionally tempering his hostility to conventional notions of autonomy/agency with the

assertion that the subject must be understood 'to the very end as a person who acts' (1982, p.789)). In

the context of dementia care, this creative ethics often played out as a struggle between opposing

discourses which carers were required to resolve through their moment-by-moment decisions – and

therein lies the potential for change. As carers envision and embody their 'capacity to act' in modest,

situated ways – through the 'local reasoning' that can be seen in Foucault's work (Bevir 1999) – we

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would argue that they also challenge the existing institutional order, at least to the extent of opening

space for reflection on dominant patterns of normalisation and the alternatives.

Conclusion

This paper 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

'empowered' caregivers. The analysis was framed by a particular reading of Foucault's work on ethics

and freedom, by which we suggest that there is always some degree of freedom within power relations

and that practices of freedom become ethical when they reflect the 'truth' in a situated, specific sense.

This framework helped specify how, in the necessary absence of a universal gold standard for person-

centred dementia care, we may nonetheless recognise and support ethical practices as enacted in the

diverse and fluctuating daily care environment.

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 their situated ethical actions could impact the legitimate order of the

institution, rather than 'just' the individual experience at the point of care. We conclude by suggesting

the importance, in terms of improving dementia care provision, of opening up more spaces for critical

reflection and discussion on 'good' versus 'bad' care – in order to interrogate and problematise not only

the traditional biomedical discourse but also newer discourses such as person-centred care and

empowerment. As Perron (2013, p.160) writes, 'when one discourse replaces another, critique must be

renewed, its rationalities exposed, as well as its intended and actual effects', in order to help each

individual understand how they are situated within the discourse, what it requires of them, and whether

it aligns with their own ethos. Furthermore, these spaces must make 'visible' direct care staff as

knowledgeable and skilled contributors. Neither the challenge nor the importance of creating such

reflective, empowering, 'de-institutionalised' spaces in the power- and risk-saturated contexts examined

here can be over-emphasised.

Footnotes

1. This workforce has many labels across health and social care. 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 institutional settings.

3. False starts and repetitions have been removed from data excerpts to enhance readability. Ellipses

signify omitted text and square brackets are used for clarifying text.

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