Disciplinary power and the process of training informal carers on stroke units

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Abstract
This article examines the process of training informal carers on stroke units from the lens of power. Care is usually assumed as a kinship obligation but the state has long had an interest in framing the carer and caring work. Training carers in health care settings raises questions about the power of the state and health care professionals as its agents to shape expectations and practices related to the caring role. Drawing on Foucault’s notion of disciplinary power, we show how disciplinary forms of power exercised in interactions between health care professionals and carers shape the engagement and resistance of carers in the process of training. Interview and observational field extracts are drawn from a multi-sited study of a training programme on stroke units targeting family carers of people with stroke to consider the consequences of subjecting caring to this intervention. We interrogate the extent to which a specific kind of carer is produced through such an approach, and the wider implications for the participation of carers in training in health care settings and the empowerment of carers.

Keywords
Informal carers; stroke; training; empowerment; United Kingdom; Foucault; disciplinary power
Introduction

This article examines the process of training informal carers on stroke units from the lens of power. Informal carers, who are often family members (McKevitt et al. 2004) form an increasingly significant part of health care economies. Care is usually assumed as a kinship obligation, but the state has long had an interest in framing the carer and caring work. This has included concern about the negative effects of caring work - burden or stress - (for example, see Baert Ilse et al. 2008), leading to the development of interventions to support informal carers (hereafter carers). One approach is to provide training in health care settings so that carers are ‘empowered’ to carry out their work through the acquisition of skills and knowledge they are deemed to need (Clarke 2001). However, training raises questions about the power of the state and health care professionals as its agents to shape expectations and practices related to the caring role. Drawing on Foucault’s notion of disciplinary power (Foucault 1973, 1977) we show how disciplinary forms of power exercised in interactions between health care professionals and carers shape the engagement and resistance of carers in the process of training. Interview and observational field extracts are drawn from a multi-sited study of a training programme on stroke units targeting family carers of people with stroke to consider the consequences of subjecting caring to this intervention. We interrogate the extent to which a specific kind of carer is produced through such an approach, and the wider implications for the participation of carers in training in health care settings and the empowerment of carers.

The increased visibility of the carer

Social, economic and political contexts, including an ageing population, changing patterns of health and disease, and policy discourses have transformed caring as a private practice to a public concern (Fine 2006). This has led to the increased visibility of the carer as the subject of surveillance, with state policies defining how their needs are assessed and the ways in
which they are supported (Heaton 1999, Fine 2006, Larkin and Milne 2014, Sadler and McKevitt 2013). Drawing on the historical transformation of the medical gaze, i.e. the changing ways in which subjects as objects of disease are defined in relation to expert medical knowledge and practices (Armstrong 1995), Heaton in her analysis of policy discourses between the 1970s and 1990s proposes that the increased visibility of the carer has been shaped by the ‘devolution and extension of the medical gaze’ (Heaton 1999: 771) away from the hospital and operating through more generalised networks of surveillance in community settings. Here, carers are enlisted by the state as ‘relays of the medical gaze’ (Heaton 1999: 771) to survey and monitor those they are caring for, but are also subject to policies that regulate their own behaviour. How carers are managed by health care professionals during the process of training earlier on in hospital settings, and the implications of this approach for carers, has not been addressed.

Mirroring contemporary health care drives more widely, newer normative models of the ‘expert carer’ emerging in recent policy discourses place increased responsibility on carers to manage their own health and needs, including participation in training to equip them for their caring role. In the United Kingdom (UK), this is evident in Department of Health documents such as ‘Caring with Confidence’ (Department of Health 2008a) in which responsibility for supporting carers is devolved from the state to local communities and individuals through, for example, online training and participation in peer support programmes. The National Carers’ strategy ‘Carers at the heart of 21st families and communities’ (Department of Health 2008b) sets out the UK government’s 10 year strategy to support carers. A core part of this strategy is seeing carers as ‘expert partners in care’ by ‘training carers to enable them to strengthen them in their caring role and to empower them in their dealings with care professionals’ (Department of Health 2008b: 12). This suggests that
expertise derives from the training and support the state will provide rather than through experience per se. In other words carers become experts with the appropriate intervention.

Empowering carers through training

Training carers implicitly assumes that such approaches lead to the ‘empowerment’ of carers through the acquisition of new skills and knowledge. While the term empowerment suggests an emancipatory transformation, it may also be misleading because it assumes that carers’ choices are aligned with those of the state as providers of opportunities to acquire skills and knowledge defined by professionals as necessary for expertise (Clarke 2001, Larkin and Milne 2014). Drawing on Foucault (1977), Larkin and Milne (2014: 33) argue that ‘disempowerment occurs as a result of the knowledge of those subject to power being subordinated to the knowledge of those who have power’, leading to limited choice and agency among the former. This draws our attention to the nature and consequences of the empowerment that is promised in training.

The ‘burden’ of caring after stroke

A significant proportion of stroke survivors report long-term consequences, including reduced physical function and social participation, and poor quality of life (Wolfe et al 2011, McKevitt et al 2011), the majority of whom require support from carers (Forster et al. 2013). Caring for a person with stroke has been found to have deleterious effects on the health and well-being of the carer (Greenwood et al. 2009), with the burden on carers reported to be high (Rigby et al. 2009, Forster et al. 2013). Carers of stroke survivors also report positive experiences related to their role, including fulfilment and strengthening of family ties (Greenwood et al. 2009). Developing effective ways to support carers is therefore a priority in stroke care, including the provision of appropriate training (Intercollegiate Stroke Working Party (ISWP) 2016).
Theoretical framework

Foucault’s notion of disciplinary power provides a useful framework to examine the process and consequences of training carers in stroke care through the lens of power. Foucault proposed that in institutional settings such as hospitals and prisons, disciplinary power comprises discourses and practices serving to regulate the conduct of subjects (Foucault 1973, 1977). This involves ‘surveillance technologies’, defined as disciplinary forms of power related to hierarchical observation, normalising judgement and examination that render subjects visible to regulate their conduct (Foucault 1973, 1977, Wheatley 2005, Smart 2002). In The Birth of the Clinic (Foucault 1973), Foucault proposed clinical encounters between medical professionals and patients as a prime example in which disciplinary power is played out through mechanisms of surveillance, including physical assessment and training, which serve to create ‘docile bodies’, or subjects regulated and normalised in relation to a set of medical knowledge and practices (Foucault 1973, Wheatley 2005). During clinical encounters patients are also encouraged to reveal personal information about their bodies and themselves as subjects (Lupton 1994, Wheatley 2005), which Foucault later referred to as ‘confessional technologies’, reflecting practices of self-disclosure among individuals to an authority intended as techniques to promote self-knowledge (Foucault 1979). Such subtle forms of power result in the internalisation of disciplinary power by subjects and produce self-disciplining subjects who collaborate in the self-regulation and policing of their own conduct, what Foucault terms ‘technologies of the self’ (Martin et al. 1988). Thus, power is viewed by Foucault as transformative, leading to the shaping of new subjectivities.

A common criticism of Foucault’s work on disciplinary power is the limited attention given to how subjects in particular social contexts exercise agency to subvert disciplinary power intended to shape their conduct (Good 1994, Wheatley 2005). Foucault (1979) also proposed that where there is power there is resistance, to the exercise of disciplinary power
and the construction of new subjectivities (Lilja and Vinthagan 2014). A limited number of studies have shown how disciplinary power is exercised in interactions between health care professionals and patients (Bloor and McIntosh 1990, May 1992, Peckover 2002, Wheatley 2005), but there has been much less focus on carers (Sakellariou 2016). What these studies show is that subjects engage in professionally defined practices geared to shape their behaviour, but that there are also limits to the medical gaze. Rather than being passive recipients of health care, some actively resist disciplinary forms of power exercised by health care professionals, in a variety of ways. Foucault’s notion of disciplinary power has the potential to shed light on to what extent a specific kind of carer is produced through enlisting carers to participate in training, what is at stake in terms of what this work provides professionals and health care services, and what it gives or takes away from carers.

**The study**

Data for this paper come from a process evaluation of a multi-site randomised controlled trial of a training programme for carers of people with stroke - The Training Caregivers after Stroke (TRACS) study (Forster et al. 2013). This trial was undertaken in 36 stroke units in England and examined whether providing carers with skills training and information reduced burden for carers and improved functional independence among stroke survivors. The intervention comprised a structured training programme (the London Stroke Carers Training Course) in which carers were assessed in their knowledge of stroke and competency in various skills to support a disabled person with stroke. Of the 36 stroke units involved in the trial, half were randomised to the intervention arm and half the control arm (provision of usual care and support to carers in accordance with The National Clinical Guideline for Stroke at the time (ISWP 2008). Results from the trial demonstrated no difference in outcomes between intervention and control groups (Forster et al. 2013), raising an important question as to why this was the case.
The process evaluation used an ethnographic approach, drawing on a range of qualitative methods including observations of clinical practice (> 1200 hours), interviews with members of the stroke multidisciplinary team (MDT), carers and patients (N=91), and documentary analysis of clinical notes over a 16-month period (Clarke et al. 2014). An ethnographic approach was used in this study, as in other process evaluations (e.g. Bunce et al. 2014), because this enables immersion in the field over time, provides an opportunity to observe practices and understand different stakeholder perspectives (Hammersley and Atkinson 2007). Following NHS research ethical (Reference: 08/H1307/104) and governance approvals for the study, data were collected by four researchers from different professional backgrounds (physiotherapy/social science, nursing/social science, anthropology, sociology).

Each researcher undertook fieldwork in one intervention and one control stroke unit site, in four geographical regions of England. Observations first took place between February and July 2009 in four intervention and four control stroke unit sites, purposively sampled from higher and lower performing stroke units according to the scoring metric of the 2006 National Sentinel Stroke Audit (ISWP 2006). Detailed field notes were taken by each researcher of the processes of care on the stroke units, provision of training, and the organisational and social contexts shaping the delivery of stroke care. In addition, to test out emerging themes from the process evaluation, observations were undertaken by two of the researchers in two further intervention stroke unit sites between October and December 2009 (Clarke et al. 2014).

All stroke units met core Stroke Unit Key Criteria (see Table 1) as defined by the National Sentinel Audit for Stroke (ISWP 2006), but differed in terms of local policies, infrastructure and staff resources. Eight of the 10 stroke units were in acute hospitals and two were in community hospitals. Six were combined acute and rehabilitation stroke units, while four were rehabilitation only wards. The number of beds on the stroke units varied between 18 and 28 beds, with a range of 11 to 24 beds designated as stroke rehabilitation beds. In
seven of the 10 stroke units, therapy spaces (for example, physiotherapy gymnasiums and occupational therapy treatment rooms) were located on the ward, and in three stroke units off the ward. The stroke units differed in terms of their mix and availability of staff on the wards. All stroke units comprised core stroke MDT members, namely a stroke consultant and medical team, rehabilitation therapists (i.e. physiotherapists, occupational therapists and speech and language therapists), nurses, health care assistants, and dieticians, but only three had access to clinical psychologists and four had stroke liaison workers (trained volunteers). In addition, four of the stroke units had early supported discharge schemes, defined as community rehabilitation schemes comprising a team of nurses, rehabilitation therapists and support workers, which aimed to discharge stroke survivors earlier from hospital to continue rehabilitation in their home environment for a set period of time (Langhorne et al. 2005).

**Table 1**: Stroke Unit Key Criteria (ISWP 2006)

| 1) Consultant physician with responsibility for stroke |
| 2) Formal links with patient and carer organisations. |
| 3) Multidisciplinary team meetings at least weekly to plan patient care. |
| 4) Provision of information to patients about stroke. |
| 5) Continuing education programmes for staff. |

Follow-up face-to-face interviews were undertaken with members of the stroke MDT to investigate their perceptions of training carers, and with carers and patients to explore their views of professional support received and engagement in training (Clarke et al. 2014). Interviews were audio-recorded with participant consent. Thirty seven patient/carer dyads took part. All carers were family members, predominantly spouses (N=25) and adult children (N=10). One carer was a grandchild and one a parent of a younger stroke survivor. The vast majority (N=33) were new to the carer role, with only two carers having had previous experience of caring for their relative, and two having worked as paid carers. Of the 54 members of the stroke MDT taking part in the study, 12 were physiotherapists, 11
occupational therapists, 4 speech and language therapists, 18 nurses, two health care assistants, one medical doctor, one social worker, one dietician, and four stroke liaison workers.

All qualitative data were transcribed, managed and analysed in NVivo (version 8). Analysis used the principles of the constant comparative method to examine emerging themes grounded in the data (Strauss and Corbin 1998). First, data were analysed individually by each researcher in their respective field sites. This involved close reading and re-reading of field notes and interview transcripts and a process of coding and developing emerging themes from the data. This was followed by group discussion of the main themes among the four researchers, which involved joint interpretation, reflection and subsequent refinement of themes.

Findings

The process of training carers on stroke units

In the following sections, we show how the participation of carers in training on stroke units involved disciplinary forms of power intended to shape their conduct. This process was played out through three phases: identification of the main carer, co-opting the carer into surveillance, and assessing the competency of the carer to learn new technical skills. Similar elements of the training process were evident across both intervention and control stroke unit sites, suggesting these were embedded in existing care practices rather than related to a new training intervention. We then consider carers’ experiences of engaging in, or resisting training. In the discussion, we interrogate the extent to which a specific kind of carer is produced through enlisting carers in training on stroke units, and the wider implications for the participation of carers in training in health care settings and the empowerment of carers.
Identification of the main carer

Typically on admission to the stroke unit, health care professionals approached family members on the ward to identify which relative could be deemed a suitable candidate for the main carer role. At this early stage, as has been similarly reported in studies in hospital and other health care settings (May 1992, Peckover 2002, Wheatley 2005), professionals encouraged confessional practices (Foucault 1979) by establishing rapport with family members to ascertain who they were, and what their capacity to care was. Identifying the main carer as part of the training process was often observed and perceived by MDT members to be part of therapists’ work, reflecting the key role therapists played in the early rehabilitation of the physical body after stroke. Occupational therapists were usually viewed as among the first of the MDT to make initial contact with family members:

Quite often what we do, rather than making a big thing and phoning the relative, is wait, find out who the next of kin (NOK) is. So, for instance, it could be the spouse or it could be the daughter, and then I tend to sort of be around at visiting time and know whoever the daughter’s name is, and then find out who that person is… So, to sort of check it out informally rather than formally at the initial stage. (occupational therapist, intervention site)

As this interview extract suggests, professionals assumed there would be one family member willing to take on the role of main carer, with the assumption that whoever was NOK (commonly spouse or child) would be the designated main carer, followed by a process of assessing that person’s suitability. As described in other studies which have found that health care professionals hold implicit moral assumptions of patient characteristics that serve to constitute different categories of patients-good or bad (Jeffrey 1979), motivated or not (Maclean et al. 2002), deserving of access to health care resources or not (Hillman 2014)-, health care professionals had implicit criteria when deciding who would qualify as the main carer and likely potential candidate for carer training. This was based primarily on: 1) which family member was often present on the ward during visiting hours; and 2) the type of relationship with the patient, with spouses and daughters deemed most suitable.
Providing family members with opportunities to talk about their concerns early on and giving reassurance, was also perceived by therapists to be part of their role, rather than that of nurses who were often thought to be too busy attending to patients. Observations on the stroke units provide support for the more episodic nature of social interactions among nurses and other social actors on the ward (see also May 1992), including carers, due to competing patient care tasks and high patient turnover, compared to therapists who had more time to build rapport with carers. Therapists viewed it as their job to calm down family members who might be anxious and in a state of shock:

They [family members] need a bit of a calming influence to say, the patient’s just come, we’re doing our assessments, there’s probably lots of tests still taking place as well, but it’s far too soon to make judgements on what the capacity of that person will be on discharge. So quite often we do get involved initially because they’re anxious and the nurses are busy, they’ve not found anyone to sort of tap into. (occupational therapist, intervention site)

The example above shows a common strategy adopted by therapists on the stroke units when dealing with the psychological and emotional impact on carers of the uncertain nature of recovery after stroke. It was also a way of disciplining carers through reassurance, with anxious carers perceived to potentially impede the patient’s rehabilitation and hospital discharge process.

An initial primary task therefore among health care professionals on stroke units was to identify the likely carer from among a number of family visitors. The exercise of disciplinary power was evident in the early identification of the main carer during the use of ‘confessional technologies’ (Foucault 1979) through establishing rapport and providing reassurance and information at a time of uncertainty and distress for the carer. This enabled the professional to establish a candidate carer and assess their suitability and needs, but also to consciously use such interactions as part of seeking to ascribe a main carer role.
Co-opting the carer into surveillance

In the early stages of the patient’s rehabilitation, therapy as a normalising practice (Foucault 1973) was very clear, as therapists observed the patient and assessed her body against a standard:

The patient was sat on the edge of a plinth, with her feet on the floor. At the start of the therapy session one of the physiotherapists checked that the patient was sat correctly. She started examining the patient’s shoulders, intermittently asking her colleague what she thought of the alignment and position of the patient’s right hip and shoulder joints...The physiotherapist leading the session paused to explain to the patient their impressions. As the physical examination continued, they kept reminding the patient to sit up straight, sometimes guiding her into a better sitting position using their hands. (Extract from field notes, intervention site)

As the above field extract illustrates, mechanisms of surveillance used by therapists during assessment and re-assessment of the patient’s rehabilitating body represented professional strategies geared to normalise and regulate patterns of bodily movement, patient conduct and monitor risk. Such practices served to create ‘docile bodies’ (Foucault 1973, Wheatley 2005), defined in relation to a set of expert knowledge and practices. At the same time, therapists encouraged self-discipline among patients to adhere to self-management and self-regulation regimes (see also Wheatley 2005) geared towards optimising bodily postures and normative patterns of movement deemed to aid early recovery following the stroke. Evident from observations across stroke units was the common exclusion of carers from these early patient rehabilitation sessions, typically conducted out of site from the ward in separate gym or therapy spaces.

Family members were then gradually encouraged to participate in observational practices of their relative during therapy sessions to realise the extent of bodily damage sustained following the stroke and progress in recovery being achieved:

It’s a good opportunity when they [family carers] come in, I think you can sit and talk to them about what the patient’s able to do, but until they see it they haven’t really got a grasp perhaps or a concept of what they’re doing or how they’re doing. (physiotherapist, control site)
Evident in this extract, is the gradual co-opting of carers into the surveillance of the patient’s rehabilitating body. This served as a professional strategy to manage carer expectations of recovery and enhance self-awareness of the carer of their relative’s functional limitations, and likely future need for support.

Subsequently, carers were recruited by therapists to take part in surveillance and normalising practices of their relative’s body as an extension of the medical gaze to monitor and minimise risk during their early rehabilitation. This included reinforcement of good body postures and positioning of upper limbs when sitting in an armchair or lying in bed to avoid subluxation of the shoulder joint resulting from muscle weakness. Some carers were invited to carry out passive movements of a weaker limb to avoid muscle and soft tissue contracture, or simple massage techniques to reduce swelling of a hand due to muscle weakness. Ongoing disciplinary forms of power through regular surveillance rendered the conduct and behaviour of carers visible to professionals during the learning of these activities, reflecting a concern the carer might act inappropriately in activities judged to potentially compromise the patient’s early recovery. This was grounded in the expert clinical knowledge of the therapist which the carer did not have:

The wife continues to ask the physiotherapist questions. She asks her whether she could massage her husband’s hand, turning the palm of his hand over to reveal a visibly tight muscle tendon. The physiotherapist advises that the massage will not do any harm, but it will not correct the tightness in the tendon. The carer then asks whether she could encourage her husband to squeeze a small soft ball to improve the strength of his hand grip after his stroke. The physiotherapist draws on her knowledge of the conflicting research evidence in this area, and advises for now that this would not be appropriate. (Extract from field notes, control site)

Thus during the early stages of the patient’s rehabilitation, therapists began to instruct carers on what activities they perceived were safe or unsafe for them to do. Disciplinary power in the form of ‘surveillance technologies’ (Foucault 1973, 1977, Smart 2002, Wheatley 2005) served to monitor inappropriate carer activity and promote self-awareness among carers to police their own conduct. The process of engaging carers in learning activities to support
their relative at this stage was largely instrumental, attempting to normalise carer conduct and manage perceived risk, rather than empowering carers to acquire skills and knowledge in a new role, based on their needs and preferences (Larkin and Milne 2014).

Assessing the competency of the carer to learn new technical skills

As patient hospital discharge approached carers were increasingly recruited to learn new technical skills. Training typically entailed teaching carers manual handling skills to support safe movement and use of equipment, such as electronic hoists and percutaneous endoscopic gastrostomy (PEG) feeding tubes. Training carers in the ‘proper’ way to accomplish these tasks involved both surveillance of carers’ conduct and confessional practices geared towards the self-evaluation of their own conduct. Similar modes of engaging carers in this type of technical training played out across intervention and control stroke unit sites:

Miss Lawson, an elderly stroke patient confined to a wheelchair, was due to be discharged the following day to live with her niece. The physiotherapist had invited her niece to the stroke unit to learn how to transfer her aunt from her wheelchair to an armchair. The therapist first demonstrated how to carry out the transfer safely from the wheelchair to the adjacent plinth, as the niece watched intently. She then asked the niece to practice the transfer. The therapist helped her to place her feet and showed her again how to block her aunt’s weaker left knee with her own leg. The niece started to carry out the transfer. The therapist stood close by and talked her through each stage, adjusting the position of her upper body hold and knee position, saying ‘it needs to be here or she will not be supported and could fall’. The carer practiced the transfer three times with the therapist constantly observing and correcting her technique until the niece stated that she was quite sure she would be able to carry out the transfer at home by herself. (Extract from field notes, intervention site)

The occupational therapist first explained how to manoeuvre and position the hoist legs under the hospital bed. She then demonstrated to the wife and daughter how to use the sling and hoist to transfer Simon [stroke patient] from the bed to the armchair positioned adjacent to the bed. They watched closely during this demonstration. The therapist then invited them to have a go at transferring Simon from the bed to the chair using the hoist. They moved in around the bed, one either side. The therapist instructed, and the carers followed her commands, whilst also letting Simon know what is happening. ‘Roll Simon over to the left and put the sling in behind him. Make sure the straps are not digging into his skin and the sling is under his bottom and neck’, instructed the therapist, paying close attention to the carers’ technique. ‘Now roll to the other side’ the therapist assistant also advised. ‘He actually rolls quite well’ remarked his wife in a surprised tone. Once rolled onto his side they pulled the sling through and adjusted it so that it rested symmetrically under the patient’s back, bottom and neck. ‘Well done’ the therapist said encouragingly. ‘Are you happy doing
this?’ she enquired, to which the wife replied in a relaxed tone of voice that she was. ‘It wasn’t as bad as I thought’ said the wife. ‘Now attach the straps to the bar’ the therapist continued. The carers followed her instructions and completed the task.

(Extract from field notes, control site)

The above examples show how therapists were closely involved in judging the carer’s competence during training, according to their professional view of what they perceived as technically correct. Such practices typically involved a sequence of expert demonstration of skills to be learnt, observation and correction of carer technique, and evaluation of carer competency. The training professionals provided incorporated surveillance strategies and encouraged confessional practices, thus serving to discipline the conduct of carers through the acquisition of correct techniques and self-evaluation of their own competence.

A minority of physiotherapists, however, felt that it was not always possible to train carers to learn new technical skills. Some carers were perceived to lack the ability to comply with professional advice and instruction, and monitor their own conduct. For example, one physiotherapist commented:

I can think of one recent example where the wife would sort of try and do, for all the right reasons and she had the best will in mind, but I would try and show her how to do passive movements on her husband’s arm, shoulder, throughout the day, and handling wasn’t very good. How much you tried to explain to her that actually his shoulder joint was quite vulnerable and tried to advise her not to do it, and give her something to do that would be okay, she didn’t really take that on board.

(physiotherapist, control site)

Despite this carer’s desire to play a role in her husband’s rehabilitation following his stroke, she did not pass the competency test judged by professional standards when performing this activity, as a result of not responding appropriately to the instruction and direction of the therapist.

Disciplinary forms of power as part of the medical gaze (Foucault 1973) were therefore increasingly exercised by health care professionals during the training of carers to acquire various technical skills for the carer role. Such practices served to manage carers’ conduct, assess their competence and encourage self-discipline through self-evaluation of
competence in the skills learnt as hospital discharge approached. In the next section, we explore carers’ experiences of participating in training on stroke units.

*Carers engaging in, or resisting, training*

Most carers wanted to learn how best to care for their relative following the stroke and welcomed learning new skills and knowledge from health care professionals. The majority, notably spouse carers, viewed this as part and parcel of their kinship role:

- You just got on with it. I would expect her to do the same for me, what I would do for her, I mean that’s necessary, my family... It’s a role, it’s a part of the relationship. (male spouse carer, control site)

- Well he is my husband so what I do he would do the same if I was in the same position. (female spouse carer, intervention site)

For such carers, training to support them as a carer was easily integrated into the caring relationship, based on long-standing norms of reciprocity (Murray and Livingston 1998).

A number of younger spouse and adult children new to the main carer role, however, reported limited or lack of exposure to learning new technical skills as part of training provided by health care professionals. This was reflected in comments such as: ‘I thought that they would have asked me to come in and help’; ‘I would have come in if they had asked’; ‘I should have been more actively involved’. While some carers welcomed being engaged early on in activities to support their relative, they felt excluded by professionals. They were critical of the perceived minimal and often last minute training provision by professionals, feeling they required more time to develop their competency in technical skills.

As other studies have shown with patients and carers (May 1992, Peckover 2002, Wheatley 2005, Sakellariou 2016), we also found that a number of carers resisted the professional control of the training process. A minority did not want to learn how to provide care they perceived should be provided by professionals. For example, one carer said:

- It [therapy] just happened, they asked me whether it was okay and I said yes, go ahead. They’ll go and do their job and I’ll just sit there, listening to them if I wish to.
I’m not party to the therapy, I mean they are doing their job. (male spouse carer, control site)

This carer did not want to learn techniques that a professional should be doing, which he perceived was outside the remit of his role as spouse. Other carers resisted the pace at which training was introduced and wanted more control of what skills were taught, and the timing in which these were taught. The field note extract below is an example of professional attempts to discipline carers to understand the correct timing in which they are expected to engage in learning the skills for safe transfers. Engaging carers at the right time was evident among other professionals in the MDT besides therapists, here in the context of nursing staff’s working practices in which the patient was judged not to be safe enough as yet for carers to become involved. This spouse carer, however, resisted such professional control and exercised her own agency by secretly watching:

Actually we were watching it [transfer of spouse from bed to commode between nurse and health care assistant] and very often they put the curtains around when they did certain things and I would go into the curtain and they would say ‘oh no we don’t want you here’ and I would say ‘yes but I want to see what’s going on and how to do it’ and one or two would say ‘no thank you, we’ll tell you in time’…but we watched very carefully. (female spouse carer, intervention site)

Resistance to learning new technical skills perceived to be inappropriate was particularly apparent for one middle-aged woman who was expected by health care professionals to take part in training related to using a PEG feeding tube to support her husband who was unable to feed himself following his stroke. Resistance to learning such technical practices as part of the caring role has similarly been reported elsewhere (see Sekellariou 2015). This carer felt that this very technical task should be undertaken by professionals, which could not be reconciled with her role as wife:

I am not touching that PEG because I know [the dietician] could, and she said ‘well it would take as long as it takes, we’ll train you to do it’, I say ‘I’m not doing it, I can’t touch it’, I was so frightened…I said ‘no way am I touching that PEG, I’m telling you now’, that’s how I said it, because it just terrified me. I just think a nursing professional should be doing it, and she said ‘there’s nothing to be frightened of’ but
to me, can you imagine it being my husband and then he has to have water in it too, for fluid, it’s just not a wife’s job at 60 odd to have to do that. (female spouse carer, control site)

Thus there were limits to what some carers would take on as the main carer. Although this spouse carer initially accepted being designated the carer, at this point in her husband’s rehabilitation he was making slow progress, and the complexity of his needs was becoming clear. Her idea of what being a carer entailed was far apart from what professionals now seemed to expect of her.

In summary, disciplinary forms of power shaping the process of training carers to learn new technical skills and knowledge in general, however, were not oppressive. Carers’ resistance to disciplinary power turned on questions of agency and responsibility, in terms of expressing a desire to be more involved in training, as well as resisting the pace and type of skills in which professionals engaged carers in this process. We move on in the discussion to consider the extent to which training produced a particular kind of carer and reflect on the wider implications of this.

Discussion

The contribution of this paper is to identify that the process of training carers in health care settings is not simply a matter of transferring skills from professional to lay person, but entails disciplinary forms of power intended to shape the conduct of carers. The early identification of the carer involved ‘confessional technologies’ (Foucault 1979), including practices of establishing rapport and providing reassurance to enable the health care professional to get to know the carer and assess his or her suitability and needs as the main candidate carer for the stroke patient. Early rehabilitation practices focused on the patient in which ‘surveillance technologies’ (Foucault 1973, 1977), entailing hierarchical observation, normalising judgement, examination and (re)assessment practices were commonly exercised by professionals to normalise patterns of bodily movement, patient conduct and monitor risk.
Carers were gradually co-opted into the surveillance of the patient’s rehabilitating body and increasingly as hospital discharge approached, in training to acquire technical skills judged to be part of the caring role. Disciplinary forms of power as an extension of the medical gaze during the process of training carers served to render visible and regulate carers’ conduct during skills learnt, minimise risk to the patient’s rehabilitating body, and encourage carers’ participation in the evaluation of their own competence.

The MDT and stroke units stood to gain from this process of identifying, co-opting the carer into surveillance, and training and judging the carer’s competence because it was integral to determining when the patient could be safely discharged from hospital. Training carers entailed the health care professional’s regulation of carer behaviour in relation to the patient’s rehabilitation, determining which forms of skills and knowledge were required. This process reinforced the professionals’ ability to define and control what good care is (Clarke 2001, Larkin and Milne 2014), based on demonstration of competence in acquired technical skills as part of the caring role. The trial intervention did little to challenge health care professionals’ routine forms of engagement with carers, suggesting that such disciplinary forms of power shaping the conduct of carers were embedded in existing care practices (see also Martin et al. 2013).

Existing studies have demonstrated how subtle forms of power operating in health care settings serve to discipline the conduct of patients when managing illness, various health conditions or life transitions (May 1992, Peckover 2002, Wheatley 2005). Our study adds to this research, highlighting how the medical gaze extends to shaping the conduct of carers during their participation in training. Whereas Heaton’s (1999) analysis proposed carers as ‘relays of the medical gaze’ (Heaton 1999: 771) as part of generalised networks in community settings, our study provides support that such relays occur much earlier on in hospital settings as part of the tightly professionally controlled regulation of carer behaviour during the
patient’s early rehabilitation after stroke. A number of studies have found that there are limits to the medical gaze in disciplining the conduct of patients in health care settings (Bloor and McIntosh 1990, May 1992, Peckover 2002, Wheatley 2005). The analysis similarly found that this was also the case in the context of training carers on stroke units. The stroke unit was a social site through which family members were categorised in relation to professional and organisational practices of objectification and predetermined choices (Latimer 2007).

In policy documents, the state endeavours to make carers ‘experts’ and acquiring skills and knowledge through training in health care settings is assumed to empower them to do so (Department of Health 2008a, 2008b). In terms of whether training empowers carers, our analysis found that, on the one hand, some carers welcomed learning technical skills as part of fulfilling their kinship obligations. On the other hand, they were asked to be empowered to adopt a role that clearly some carers did not want, or to the extent that they were expected to adopt (for example, in using the PEG). Empowerment defined by health care professionals based on developing competence in technical skills ignores other kinds of empowerment, including experiential, social, political and economic forms (Larkin and Milne 2014).

With regards to whether training produced a particular kind of carer, training intended to produce ‘docile carers’ shaped by organisational and professional priorities (around a safe and expedient patient discharge). Acquiring new skills to incorporate into what it means to look after a disabled relative following a stroke could be interpreted as shaping a new subjectivity in a Foucauldian sense, becoming the expert carer of government policy. However, it is not apparent that this training intervention did shape new ‘subjectivities’ in this sense. Caring was self-evidently normative and skills training did not disrupt this normativity, but tended to enhance the relational dimensions of caring bound up in existing practices and meanings associated with notions of obligation and reciprocity (McKevitt et al. 2004, Sadler and McKevitt 2013). Resistance by some carers suggests that they did not want
their idea of what it means to look after a husband or wife to be changed by what professionals proposed they needed to know. However, we acknowledge that the data here are drawn from observations and interviews at a very early stage in participants’ caring career.

Our study has wider implications for future strategies to support family carers. Training approaches to support carers delivered and implemented in health care settings empower carers in a narrow sense based on professionally determined needs focusing on the assumed technical aspects of caring role, which may limit carers’ agency. Such approaches also raise questions concerning how tensions between diverse rationalities of professionals based on hegemonic knowledge and that of carers based on experiential knowledge can be reconciled (Mattingly 2014). To facilitate empowerment of carers through training, access to adequate training provided in health care settings needs to meet carers’ needs and choices (Larkin and Milne 2014), rather than primarily organisational and professional priorities and give consideration to the relationship between empowerment and the experiential nature in which the caring role is enacted.

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Conflicts of interest

The authors declare no conflict of interests.

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