Reid, L., Kydd, A. and Slade, B. (2018) An inquiry into what organised difficult advance care planning conversations in a Scottish Residential Care Home using Institutional Ethnography. *Journal of Research in Nursing*, (doi:10.1177/1744987118756477)

This is the author's final accepted version.

There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

http://eprints.gla.ac.uk/155288/

Deposited on: 27 April 2018

An inquiry into what organised difficult advance care planning conversations in a Scottish Residential Care Home using Institutional Ethnography

Abstract

This paper provides an institutional ethnographic analysis of how Advance Care Planning (ACP) discussions which included advance decisions about serious illness, hospital admission and Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) forms were systematically placed into the hands of Senior Social Care Workers (SSCWs) in a Residential Care Home (RCH). RCHs are care settings where there are no on-site nurses and access to hospital and/or community doctors and nurses is limited.

The paper traces the organising features of day-to-day work gathered from interviews with SSCWs (n=4) and others (n=6) whose (well-intentioned) work shaped what happened in the RCH. It shows how the experience of SSCWs was socially organised to happen as it did as they (and others) complied with powerful organising texts such as national and local policy document, care plans and audit forms.

The paper concludes that although SSCWs decision-making conversations were out of alignment with the national DNACPR policy they cannot simply be described as poor practice. This is because they were socially organised by a complex web of institutional practices related to the occupancy rate in the RCH, the inspection process of the care home scrutiny body, the quality assurance process of the RCH company, the funding of palliative care education, and powerful political and fiscal drives to reduce spending on over 75s. These practices had little to do with the actual care needs of RCH residents or the actual support needs of RCH staff.

The paper points towards necessary policy changes. It also highlights how 'competent' work driven by ideological institutional practices can result in ethically troubling situations in day-to-day working life. This emphasises the importance of carefully examining the social organisation of situations typically described as 'poor practice' if we are to understand how they are (re)produced. It also offers a different account of care home deaths than is typically presented in the professional literature.

Key Words

Residential Care Home, Palliative Care, End-of-Life, Do Not Attempt Cardiopulmonary Resuscitation Forms, Advance Care Planning, Institutional Ethnography, Decision-Making

Introduction

This paper reports on one part of a wider doctoral research study (Reid 2017) using Institutional Ethnography (IE). The focus of the wider study was to uncover: a) the organisation of work processes that placed discussions and decisions about serious illness, hospital admission and the Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form inappropriately but systematically into the hands of Senior Social Care Workers (SSCW) – a group of RCH staff who had insufficient support from healthcare professionals for those important decisions to be made safely and/or effectively (the focus of this paper); and b) the organisation of work processes which (mis)directed the allocation of healthcare resources to the RCH (the focus of a future paper).

The paper will show that although SSCWs' (and others) work produced ethically troubling outcomes it was work which had been administratively and institutionally organised to happen in the way that it did by a complex range of institutional practices.

Although IE has been taken up in studies of nursing and healthcare internationally (Melon *et al* 2013, Rankin 2003, 2009, Rankin and Campbell 2009, 2014) it is a relatively new method of inquiry for nurse researchers in the UK. Therefore it is also hoped that this paper will introduce IE as a useful method of inquiry to a new audience of nurse researchers interested in understanding how difficulties are produced in real life situations.

Background

Older adults in need of long-term care live in one of two types of care home in Scotland. One type employs care staff with vocational qualifications to provide services classified as personal or social care - which includes assistance with washing and dressing. These care homes used to be called Residential Care Homes (RCH). The other type of care home also employs care staff and provides personal care, however it also employ nurses with a professional qualification to provide on-site nursing care (Seymour *et al*. 2011). These care homes used to be called Nursing Care Homes (NCH). After publication of the National Care Standards for Care Homes for Older People (Scottish Executive 2001) the statutory distinction between NCH and RCH was abolished in Scotland and these two distinct care settings were reclassified under the generic title of *care home*. Reclassification of these care settings was significant, as this paper will show. For clarity, the terms RCH and NCH will be retained throughout the paper.

Studies suggest that residents in both RCHs and NCHs are becoming increasingly frail and disabled, with complex co-morbidities, and often high levels of cognitive impairment (Bowman *et al*. 2004; Froggatt *et al*. 2009; Laing and Buisson 2009). Many RCH residents now have a range of conditions, treatments and functional disabilities which produce needs broadly equivalent to residents more traditionally cared for in NCHs (Goodman *et al*. 2010). This is a significant change from the past when the needs of RCH and NCH residents were different. In UK RCHs, there are no qualified healthcare professionals on-site. This means staff and residents in RCHs are completely dependent upon the support of National Health Service (NHS) doctors and nurses for support.

ACP Research and Policy

There are longstanding concerns that care home residents could be receiving sub-optimal care in the final phase of their lives (Hockley *et al*. 2008, Hall *et al*. 2011, Seymour *et al*. 2011) and that there is poor advance/anticipatory care planning (ACP) for what is considered a foreseeable event (Moriarty *et al*. 2012).

ACP is described as a voluntary process of discussion/s between an individual (or their proxy decision maker) and their care provider/s. It aims to agree and document realistic options and preferences for future care so wishes can be honoured when that person can no longer speak for her/himself (Henry and Seymour 2012).

A 2014 systematic review on the effects of ACP discovered most studies were observational (95%) and originated from the United States (81%), many were carried out in hospital (49%) or NCHs (32%), with do not resuscitate orders (39%) and documented advance directives (34%) being the topics most studied (Binkman-Stoppelenburg *et al*. 2014). The review suggested that in so far as it reduced medical interventions such as CPR and reduced hospital admissions ACP positively impacted the quality of end-of-life care. As the aim of ACP is to document discussions and decisions about future care, however, the review recorded as noteworthy the focus on quality outcome measures related to medical interventions and place of care rather than patient/family experience or satisfaction. It also recorded as noteworthy that few studies assessed whether the care received was in line with documented preferences.

CPR as a default position

Cardiopulmonary Resuscitation (CPR) has evolved from an emergency procedure for those who have been the *"victim of acute insult"* (Kouwenhoven *et al*. 1960:1064)

to the current position where CPR is the default position, as such it is carried out on virtually any patient in whom cardiac and respiratory function has failed - unless a prior decision not to attempt CPR has been documented (Lannon and O'Keeffe 2010). People who are dying with advanced diseases have also become caught up in these emergency procedures because the terminal event of advanced disease *is* cardiac and respiratory failure ((BMA, Resuscitation Council (UK) and RCN 2016).

No studies of CPR in RCHs were found, however, a review of CPR in older adults reported that the survival to discharge rate in those over 70 was between 3.0 – 5.6% with NHC residents having poorer outcomes after CPR than the non-NCH population - highlighting that CPR is typically a minimally effective intervention for frail elderly people in need of long-term care (Van de Glind *et al.* 2013).

DNACPR Policy

Policies making CPR the default position have made advance decisions to with-hold CPR vitally important for two groups: those in whom it is unlikely to be successful and those who wish in advance to refuse it.

There is considerable variation in DNACPR law, policy and ethical attitudes and beliefs among the international community. While most countries lack a clear legal and/or policy framework for CPR decision-making (Santonocito *et al.* 2013), the UK has had professional guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing since 2001. CPR decisions have become a highly charged and contestable area of practice in the UK in recent years, however, with the latest revision of the guidance being made in response to public, professional and legal debates about CPR decisions (BMA, Resuscitation Council (UK)

and RCN 2016). The most recent Scottish Adult Integrated DNACPR Policy is based on this revised professional guidance. It states:

> *The overall responsibility for making an advance decision about CPR rests with the senior clinician (doctor or nurse) who has clinical responsibility for the patient during that episode of care. This will usually be the consultant (in general hospitals) or the general practitioner (in the community-based hospitals, care homes or the patient's home)* (Scottish Government 2016: 18)

In UK RCHs, accessing support from healthcare professionals is described as a negotiated rather than co-ordinated process (British Geriatrics Society 2011, Handley *et al.* 2014). This means there is currently no clear system of NHS clinical support and leadership with ACP in RCHs which is concerning in light of current Scottish policy drives to promote ACP conversations in **all** care settings (Scottish Executive 2008, Scottish Government 2010a, 2010b, 2011a, 2011b). ACP conversations are also advocated more widely within the United Kingdom (UK) by the Department of Health through the Gold Standards Framework in Care Homes (GSFCH) programme for frail older people living/dying in care homes (Department of Health 2008).

Adopting a critical stance

Rather than regarding taken for granted practices, such as ACP, as neutral, IE requires researchers to adopt a critical stance toward the knowledge which drives those practices. This is because the way people take up and use powerful forms of knowledge in policy and research is considered key to understanding how the material conditions of the group under study are organised. For example, Institutional ethnographer and Canadian activist George Smith (1995) inquired into the experience of people with HIV/AIDs and the public health response to that group in Ontario Canada in the 1990s. Everyday people affected by HIV/AIDS knew that

their condition was not always fatal, they also knew that in places other than Ontario treatments were available which prolonged life. Smith interviewed government and public health workers and explored texts which organised their working practices. He noted as significant authorised sources of knowledge such as research and policy documents which contained clinical definitions of HIV/AIDS as a fatal condition appropriate for palliative rather than curative treatment. The everyday knowledge of people with HIV/AIDS about survivorship and prolongation of life with treatment was not included in policy documents, however, nor did it feature in the governmental response to the epidemic. Smith did not regard documents containing the definition of HIV/AIDS as a terminal condition as neutral. Rather, he explored how these documents actually organised thinking and acting among government and public health workers. As a result he discovered that there was no clear infrastructure to deliver experimental treatments to people living with HIV/AIDS. He also discovered that government resources were primarily directed toward palliative care services. Knowledge about how things actually worked in the material world was then used by grassroots activists who lobbied for a treatment infrastructure to be agreed and for services to be offered to people with HIV/AIDS that were not predominantly organised around care of the dying. This example demonstrates how 'problems' and the analysis of those problems is constructed differently in IE.

Currently, there are few studies on the impact of ACP for people in RCHs, however, drawing from research on ACP in NCHs, a common theme is the positive link between ACP documents and improved quality of care. As previously highlighted *quality* of care is not typically based on patient, family or staff experience but on numerical data about reduced hospital deaths and increased documented decisions not to attempt CPR (Caplan *et al*. 2006, De Gendt *et al*. 2013, Livingston *et al*. 2013,

Vandervoot *et al*. 2012). While it might seem desirable to seek to avoid hospital admission in the context of incurable disease and end-of-life situations a 2015 Dutch study found that hospital admission in the last 3 months of life was typically initiated by General Practitioners with the most common reason for admission being symptom control rather than curative treatment (Pringle *et al*. 2015). This suggests that in some cases symptoms cannot currently be managed sufficiently in community settings. The limitation of community based services tends not to be acknowledged in palliative care policy documents which advocate ACP to promote care in the community (Robinson *et al*. 2016). Where community based services are insufficient to manage symptoms of a person who is sick and dying a reduction in hospital deaths may not actually demonstrate an increase in the quality of care suggesting that quality is a contestable concept and numerical measurements about place of care are limited when not linked to clinical data (Sleeman *et al*. 2017). Furthermore, older and more recent studies in NCHs suggest that many NCH staff feel ill-equipped and uneasy about raising the topics of death and dying with residents and/or families (Hockley 2006, Livingston *et al*. 2011, Kinley *et al* 2013). Reported reasons for this discomfort include: awareness of gaps in knowledge and expertise about clinical and ethical issues such as withholding and/or withdrawing treatments including CPR (Fahey-McCarthy *et al*. 2009); and uncertainty about communicating and managing the unpredictability in a dementia dying trajectory (Livingston *et al*. 2011).

The aim of this research

Avoiding hospital admissions, increasing documented DNACPR decisions and experiencing discomfort about discussing these matters had resonance with the experience of SSCWs in the RCH selected as the research site – a site chosen because it had been awarded high quality scores by the care home regulatory body. As SSCWs

are not registered healthcare professionals it was considered particularly important to trace and map how they had become involved in difficult decision-making conversations about serious illness, (avoiding) hospital admission and organising DNACPR forms with family members of residents with dementia. Therefore, this research aimed to first trace and map what SSCWs did and then trace and map how their work was textually organised to happen as it did.

Method of Inquiry

Smith (2005, 2006) developed IE over many years as a systematic method of inquiring into experiences that are somehow troubling for/to a particular group. They become the standpoint group. Establishing a standpoint, or subject position, is an important first step in IE. The purpose of adopting this position is to root the inquiry firmly in the social location of a group experiencing a problem and to trace and map how this problem came to happen as it did.

In IE authoritative administrative and governance texts such as research, protocols, pathways and policies are known as *relations of ruling*. This is because they contain knowledge which rules over people's thinking, talking and acting at work (Smith 2005, 2006). There are two sites of significance to the institutional ethnographer. Firstly, s/he is interested in the local setting where the issue under inquiry has arisen. Secondly, s/he is interested in what happens beyond-the-local setting where the text-based administrative and governance texts that organise the working practices of the standpoint group leads. Investigating an issue from the local and beyond-the-local sites means that IE can be used to uncover the extended bureaucratic, legislative, professional and economic practices impacting and

directing the production of local events and local activities – as those activities have been organised and co-ordinated through the use of various kinds of texts.

To illustrate how knowledge contained in texts enters and rules over the knowledge of those present in an actual situation there now follows a data-vignette. This was constructed from an account reported to the researcher in the course of her day-to-day work as a hospice-based palliative care educator.

resuscitation (CPR) and continue until the paramedics arrived. The SSCW said she was uncomfortable about commencing CPR on this woman. The call handler acknowledged the difficulty of the situation, but repeated the instruction to commence CPR and continue until the paramedics arrived. Against her better judgment the SSCW told her colleagues to start CPR.

About ten minutes later two paramedics arrived at the RCH in an ambulance with a blue flashing light and siren. They ran to reach the woman as quickly as possible. They removed her from the soft surface of her bed and placed her on the hard surface of the floor before re-commencing firm chest compressions and rescue breaths. They cut her nightdress and placed defibrillator paddles on her exposed chest to administer electric shocks. RCH staff said they did not know how long the paramedics alternated between chest compressions and rescue breaths and electric shocks – but it felt like a long time.
The attempted resuscitation was unsuccessful.
The paramedics then verified that the resident was dead.
The RCH staff moved the deceased resident's body from the floor back to the bed. They said they were unsure how to tell the family about the failed resuscitation attempt. They also said the way events played out left them traumatised and distressed because they felt they had let the resident and her family down.

This experience was deeply troubling to all who needed to become involved. It was one of many difficult experiences of death and dying in care homes that the researcher became aware of. An attempt to understand these difficult experiences was the motivation for her doctoral research.

Dorothy Smith (2005, 2006) argues that typical explanations for happenings such as poor practice or personal incompetence do not recognise the way that the knowledge contained in pre-determined policies and protocols is typically considered more important than the knowledge of individuals on the ground. For

example, the SSCWs had knowledge that a frail elderly woman with dementia had died peacefully in bed at her home, however, this knowledge was considered less important than the system-wide policies and procedures about who could officially confirm a death, and what needed to happen in the absence of a DNACPR form. If the SSCW had acted on her own (good) knowledge rather than following these system-wide policies and procedures she would have placed herself in a difficult position in relation to the call handler acting on behalf of the out-of-hours service, the funeral director and her employer – and may have faced disciplinary or legal consequences.

There is nothing unusual about following protocols and policies, indeed 'competence' at work is typically measured on compliance with these powerful ruling texts. The data-vignette shows how protocols and policies do not always suit individual circumstances, however, which causes problems when those with useful knowledge about what is happening in the moment are not allowed much in the way of discretionary range.

Data sources and analysis procedures

Ethics

The study underwent ethical review from a university ethics committee. Approval was given to interview staff in a RCH and to interview those identified by RCH staff using a snowball technique. Fully consensual audio-taped conversations with staff were made. Data was anonymised throughout the study.

Participants within and beyond the RCH described disturbing events which were not in alignment Scotland's Adult Integrated DNACPR Policy (Scottish Government

2010c, 2016). Where misalignment occurred the researcher highlighted this with participants and their managers. However, the researcher only observed and heard reports of people carrying out their work 'competently' in relation to how the systems of work within and beyond the RCH organised them to respond to the inevitably of death in the RCH. Therefore, rather than describing these events as poor practice, or blaming the SSCWs (or the RCH Managers or any other group of workers) for being out of alignment with Scotland's Adult Integrated DNACPR Policy (Scottish Government 2010c, 2016), the inquiry maintained a methodological commitment to following the traces of social organisation within participants accounts of work to discover how that work was actually organised. This was imperative to trace, map and then demonstrate how 'competent' work was resulting in ethically troubling situations in the RCH. Understanding how 'competent' work which (re)produces difficult outcomes is organised is important if the systemic problems are to be more widely understood and addressed.

Interviews

This research gathered data about routine working practices from open-ended interviews with SSCWs (n=4) and other staff whose work shaped what happened in the RCH selected and recruited as the research site (n=6 and including the RCH management team, an advisor from the care home regulatory body, a General Practitioner, a community based Palliative Care Facilitator, and a Palliative Care Consultant Physician).

In the first interviews SSCWs were asked to describe their work when people were admitted to the RCH and when they were sick and dying. Interview transcripts were examined to uncover SSCWs accounts of work along with the characteristic tensions,

frustrations and contradictions embedded in those accounts. The interviews revealed SSCWs concerns about text-based work which led them to discuss the topics of serious illness, hospital admission and the DNACPR form with family members. SSCWs described this as being *"pushed"* into difficult decision-making conversations about future care with family members. This became the focus of the research. Interviews took between one and two hours and were conducted between March 2014 and March 2015. Follow up interviews were organised with RCH staff to check the accuracy of the data vignettes constructed from interview transcripts in relation to how work was organised in the RCH.

Textual Analysis

All accounts of work were matched with the text-based policies and procedures organising them. All texts were either given or indicated to the researcher by research participants, or they were known to her because she worked as a palliative care nurse with a role in care home based education.

Results

IE is an ethnographic approach which never deviates from peoples' accounts of work – where work is defined as any thinking or acting that people carry out on purpose and with intention. It avoids any move to categorise, theorise or re-conceptualise people's experiences of work (Smith 2005). Therefore the results section will use further data-vignettes to build a descriptive unfolding and empirical account that shows how SSCWs work during family meetings was linked – or not linked - with the well-intentioned work of others across different locations in the health and social care system. Key phrases from data-vignettes will be used throughout the following

sections. This is to highlight the points of tension in accounts of work and to focus attention on the process of analysis used in IE.

Step One: Noticing how SSCWs work is organised during the admission process

SSCWs reported that in the previous ten years their work had changed.

> *When I first started here ten years ago…we didn't even have a hoist…as soon as a person was unable to walk they were moved to a nursing home…it was a regular occurrence ten years ago…then thinking changed…we are not so strict about not admitting people who are not mobile now…we need to keep beds filled…and we are a home for life now…it's very rare for people not to be admitted now…and its very rare to move someone now (SSCW).*

Something powerful changed *"thinking"* in the RCH to the extent that residents were frailer on admission. We see from the data-vignette above that now SSCWs have to be less concerned about mobility when they are assessing people for admission and more concerned about keeping *"beds filled"*. In this way fiscal concerns about occupancy rates were inserted into the work of SSCWs and less mobile (but more frail) people came to stay in the RCH. (For an extensive institutional ethnographic analysis of the political and economic forces drawing NCH care staff in the United States into a similar process of commodification of older people in need of care see *Making Grey Gold* (Diamond 1992)).

We also come to understand that residents were no longer transferred to NCHs as their condition deteriorated. This meant that the majority of older people would now inevitably deteriorate and die during their term of residency in the RCH.

SSCWs reported that they now had to initiate a different kind of conversation with families during the admission and review processes.

> *I've worked in social care for twelve years and we never used to speak about DNACPR forms and things – never. Not even the manager. But things are changing with the Care Inspectorate and trainings and things …and now we need to do it. (SSCW)*

We now see the powerful something that changed *"thinking"* and produced non-negotiable requirements to speak about *'DNACPR forms and things'* is related to the *"Care Inspectorate and trainings and things"*. On further investigation the material nature of some of these *"things"* becomes clear.

> *On admission we follow a checklist and talk about polices and standards we are working in line with…we discuss the care plan with the family…including what they want in the event of a serious illness…because of palliative care trainings and the Care Inspectorate and things we've been pushed to talk about… anything that required a person to go to hospital…and the DNACPR form… (SSCW)*

We now discover how the non-negotiable requirement to discuss *"serious illness"* and hospital admission and the DNACPR form has been inserted into SSCWs' everyday working practices. SSCWs follow a company *"checklist"* to discuss the *"policies and standards"* and agree a *"care plan"* with a family member previously granted decision-making powers in a power of attorney (PoA) document. A PoA is a legal document registered with the Office of the Public Guardian (Scotland) in which a person with capacity lists the names of people and the individual powers they are to be granted on behalf of that person if/when they are deemed incapable by a registered medical practitioner. All residents at the research site had been deemed incapable by a registered medical practitioner as it was a home which specialised in care of people with dementia. The care plan had to be agreed and reviewed every six-months to comply with one of the many standards SSCWs must work *"in line"* with. For example, The *National Care Standards* (Scottish Executive 2007: 26) state:

> *Your personal plan will be reviewed with you every six months, or sooner if you want or if your needs change.*

Discussing *"serious illness"*, *"anything that required a person to go to hospital"* and the *"DNACPR form"* during the hour long admission meeting when there was also a *"checklist"* to follow, a range of *"policies and standards"* to discuss and a *"care plan"* to agree was far from straightforward.

> *We'll try and discuss a DNACPR form on admission...it's our policy that we should be doing that...we have to remember sometimes we only meet people [family members] once in the four week assessment period, and you're discussing the DNACPR form at the end of the review meeting...and you know, that's a really hard thing to talk about at that time...and I know it's important, but it's also important not to be saying some stuff to people...(SSCW)*

We see here that the knowledge of the SSCW is good: she recognises the importance of discussing future care and identifies this as having difficult conversations; she also recognises the importance of timing and rapport building when discussing care that touches on sickness, death and dying. Nevertheless, her sense that it is important *"not to be saying some stuff to people"* is not considered as important as the requirement to follow the care home *"policy"* of discussing a DNACPR form on admission.

To ensure compliance with this *"policy"*, the RCH Manager reported that she regularly audited residents' personal files for the presence/absence of DNACPR forms. When they were absent she would raise this with SSCWs at their regular performance review meetings. The presence/absence of the DNACPR form was also periodically audited by another manager from the care home company. The RCH Manager described this as an additional *"Quality Assurance Measure"* the outcome

of which was used by the area manager as an indication of the RCH Managers' work performance.

The RCH Manager's account demonstrates that the DNACPR form was a highly visible artefact not only within the work processes in the specific RCH, but also in the work processes of the care home company. It also demonstrates how the presence/ absence of this form set off various activities not only for residents and family members, but also for SSCWs, the RCH manager and other managers in the company acting in a quality assurance role.

What is significant to notice at this point is that no senior clinician is routinely present at the care planning meeting where serious illness, hospital admission and DNACPR forms are discussed.

> *Mostly we (RCH staff) lead it. We get the ball rolling. We have the conversation with families then we phone to ask the GP for the form. Only one time that I remember did a doctor lead the process...none of the doctors we work with [in nine different GP practices] have raised the subject with us, other than that one year when the GPs did a project and they all came out to review their residents (RCH Manager)*

This conversation brought RCH staff into misalignment with both their own sense of what was important and with the Scottish Adult Integrated DNACPR Policy - the most recent version of which states (Scottish Government 2016: 28) that:

> *Those close to the patient must not be burdened with feeling that they are responsible for the decision as **this responsibility rests with the senior clinician**.*

That GPs, the senior clinicians' responsible for RCH residents' medical care, did not typically lead these conversations was noted as significant. We see in the SSCWs account that, other than during a year when they carried out a (funded) *"project"*,

no GP working with the RCH led on conversations about the DNACPR form. That either all GPs or no GPs working across nine different GP practices led the DNACPR process at any given time suggests that their presence or absence for this aspect of work was directed by some organising feature of their working practices as a group.

These threads were followed in the wider study, and the findings will be reported in a future paper focussing on how medical and nursing work was (dis)organised in relation to the care of sick and dying residents in the RCH.

Step Two: Noticing how conversations about "serious illness" and DNACPR forms became a compulsory feature of SSCWs' work.

SSCWs and RCH Managers said they needed *"the form"* to comply with *"Care Inspectorate"* requirements and to enact something they had learned at *"palliative care training"*.

> *...the seniors (SSCWs) need to have the conversation (about "serious illness" and hospital admission and the DNACPR form)...it's a concern with some of them...and families are sometimes surprised when we bring it up...but now we need to do it because things are changing with the Care Inspectorate and things... some families can't bear to speak about it...but we raise it at every six-month review...(Deputy Manager)*

That the RCH Deputy Manager expected SSCWs to have this particular conversation to meet *"Care Inspectorate"* requirements was noted as significant. Therefore, the study gathered and used the knowledge of Care Inspectorate Advisor to inquire further.

> *I know there are resource implications, but for us a care home is a care home. Whether it's residential or nursing it will be inspected in the same way. The inspection is the same. I would expect people to have the same care. We need to...because, for example, anticipatory/advance care planning would be just as relevant in a residential care home as a nursing home...people take*

ill in a residential care home…so our expectations are the same…(Care Inspectorate Advisor)

We now begin to see how the decision to abolish the statutory distinction between RCHs and NCHs produces troubles for staff in the RCH. They are expected to provide the *"same care"* and meet the same inspection requirements as a NCH despite the actuality that while *"people take ill"* in a RCH, nurses (and doctors) are routinely absent from their workplace.

The Care Inspectorate Advisor reported that:

The service provider will be sent a self-assessment form. It's…a massive document. The manager will assess their service against the quality themes and quality statements in the self-assessment document…so we have a steer before we go. The service provider will also have the annual return, an electronic annual return, an inspector would look at that…there's a lot of information they've got to provide to us…it gives them a steer to what we are looking for in the inspection…(Care Inspectorate Advisor)

We already understand from her own account that to be considered competent in her job the RCH Manager must engage in the text-based audit processes of her company. We now understand from the account of the Care Inspectorate Advisor that to be considered competent the RCH Manager must also engage with the *"steer"* in the text-based Care Inspectorate inspection processes. To satisfy (one aspect of) the requirements of the Care Inspectorate she was obliged to supply information on *Quality Statement 1.8* in the self-assessment document. This includes providing evidence on the following:

- *How do you ascertain the service user's and family's wishes for care at the end-of-life?*

- *How are staff supported to feel confident to discuss end-of-life issues with relatives and family?*

The RCH Manager was also required to supply the following information in the annual return document under the section headed *Palliative Care*:

- *Have you implemented the NHS Scotland "Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Integrated Adult Policy (2010) Yes/No*

- *How has the DNACPR policy been implemented in your service? Please describe any education and training provided and who delivered the education. The dates on which the training and education was provided should also be included.*

- *How many of the residents who died in your care home between 1 January and 31 December had an NHS Scotland DNACPR form?*

The Care Inspectorate Advisor reported that what the RCH Manager recorded in these pre-inspection documents would be used to inform the on-site inspection.

> *Before an inspection happens the inspector would look at the self-assessment...that gives us a steer for when the inspector gets out [to visit the home]...we also ask questions about DNACPR, and where they get their palliative care education from.* (Care Inspectorate Advisor)

This means that, in relation to conversations about end-of-life care and DNACPR forms, the care home inspection process held RCH staff accountable for what could more reasonably be described as medical/nursing work. This is unfair because although RCH staff rely on the professional knowledge of doctors (and nurses) to care for sick and dying residents, doctors and nurses are typically absent from RCHs. This absence is beyond the control of RCH staff.

The RCH Manager understood that the outcome of the Care Inspectorate's Inspection would be a quality grade score. She also understood that quality grade scores and inspection reports from the Care Inspectorate are publically available. Poor quality grades produced troubles for the RCH Manager for a number of reasons: they could

impact the reputation of the RCH as a quality care provider; they could impact the occupancy rate; and they could impact the income generating potential of the RCH.

As a result, it was important for the RCH Manager to source and access training where SSCWs could learn about palliative care, and DNACPR forms and ACP work. The RCH Manager reported she had responded to an invitation to participate in a palliative care education project to promote ACP in care homes. The study noted this project as significant and so gathered data from a Palliative Care Facilitator:

> *...the concern was that care homes were not co-ordinated enough...and advance/anticipatory care planning was...both a national priority and a local priority....we decided to...help the staff know what was meant by advance/anticipatory care planning...we had limited funding so we applied for funding...through the Change Fund...so we had a pot of money that was to be used to try and re-structure and re-shape care for the older population. Again it was with a focus on...trying to prevent hospital admissions by re-structuring care...which is where care homes come in...(Palliative Care Facilitator)*

In this account we begin to see how political and fiscal concerns about the cost of care for older adults was inserted into the work of the Palliative Care Facilitators who were charged with *"co-ordinating"* care home staff (including SSCWs at the research site) to *"prevent hospital admissions by re-structuring care"* through ACP work - which included advance decisions on CPR. This project work was financed by the Change Fund which supported work that could reduce:

> *...rates of emergency bed days used by those aged 75+ by a minimum of 20% by 2021* (COSLA, The Scottish Government and NHS Scotland 2010:18).

One means of achieving these targets was to encourage:

> *...care providers in CHPs to support the use and sharing of Advance/Anticipatory Care Plans* (COSLA, The Scottish Government and NHS Scotland 2010:20).

The Palliative Care Facilitator was required to produce numerical data on the number of care homes participating in the ACP project to managers within the Community Health Partnership (CHP) - who had been enlisted to promote ACP work to reduce hospital admissions by the Scottish Government. This numerical data was also reported to the ruling body tracking the progress of *"Change Fund"* projects within the Scottish Government.

This means that political and fiscal purposes were inserted into the work of SSCWs as they were enlisted to take up ACP work and become more *"co-ordinated"* in their efforts to prevent *"emergency bed days"* and hospital admissions. As the ACP project focused on changing practice in care homes without changing practice among doctors and nurses, SSCWs were enlisted to this work without routine support from healthcare professionals on whose knowledge safe and effective practice depended.

Discussion

This paper reported on an inquiry into text-based practices that put discussions and advance decisions about how to manage serious illness, hospital admission and Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) forms firmly into the hands of Senior Social Care Workers (SSCWs) who had insufficient support from healthcare professionals for those important healthcare decisions to be made safely and/or effectively.

This study used SSCWs knowledge about happenings in the RCH. This highlighted that the admission criteria in the RCH had changed to *'keep beds filled'* and that the RCH was now a *'home for life'* which meant that RCH residents were frailer on admission

and that they typically stayed in the RCH until death. It also highlighted that SSCWs were now *'pushed'* into difficult conversations about *"serious illness"*, hospital admission and DNACPR forms as a result of *'the Care Inspectorate…and recent trainings and things'*. Key *'things'* which led SSCWs to this conversation were: a) the need to comply with the audit requirements of the care home company and the Care Inspectorate to be deemed *'competent'* at performance reviews; b) what was enacted in relation to ACP as a result what SSCWs learned at palliative care *'training'* and; c) the routine absence of doctors and nurses at mandatory six-monthly care review meetings with family members.

The study then traced and mapped the social organisation of these happenings. It noted as significant that admission to the care home was linked with concerns about occupancy rate, that NCHs and RCHs were inspected in the same way in relation to the implementation of ACP and DNACPR policies by the Care Inspectorate, and that ACP and palliative care education was linked with funding to reduce emergency bed days among over 75s.

This study did not accept the textual practices associated with ACP as neutral, but explored how they actually organised thinking and acting in and beyond the RCH under study. In so doing it uncovered how older adults with increasing levels of need who will inevitably die during their term of residency come to be cared for in the RCH where there are no healthcare staff on-site. It uncovered how the current care home inspection process holds RCH staff accountable for what could more reasonably be described as medical/nursing work. It uncovered how fiscal concerns of the care home company and the Scottish Government were inserted into SSCWs work as they were enlisted to take up pre-admission assessment work infused with

the need to *"keep beds filled"* and take up ACP work as a means of reducing *"emergency bed days used by those aged 75+"*

The study showed how these conversations were also linked to other institutional practices including: quality assurance processes within the care home company; the decision to abolish the statutory distinction between RCHs and NCHs; and need for Palliative Care Facilitators to find and apply for funding to deliver palliative care education in care homes.

The combination of this complex mix of textual practices ruled the thinking, talking and acting of people in and beyond the RCH. It activated a series of complex ideological practices about the way theoretical residents should be cared for – i.e. with a DNACPR form and in the care home rather than the hospital - which did not align with the actual medical and nursing resources needed to respond appropriately to the support needs of RCH staff, or the inevitability of declining health and death of actual sick and dying residents in the RCH. All of this made the supposedly voluntary process of ACP into a compulsory activity for SSCWs and family members in the RCH – which is concerning on a number of fronts.

The recommendations made on the basis of this study are: a) RCH companies should review their admission and transfer policies to ensure actual residents needs match the capacity of staff employed to care for them; b) changes should be made to the inspection processes of the care home regulatory body to differentiate between NCHs and RCHs, this change should focus on ensuring medical/nursing staff rather than RCH staff are held accountable for medical/nursing work; c) changes should be made to the organisation of medical/nursing support for RCH residents and staff to ensure residents and staff have routine access to the level of support now needed

to plan and deliver appropriate care for this increasingly frail patient group and; d) palliative care educators should have access to reliable sources of funding so they can focus on supporting staff to improve the experience of residents and families rather than meeting financially driven targets to reduce emergency bed days among the over 75s.

The findings from this paper are currently being presented to key stakeholders in and beyond RCHs. It hoped that this paper will raise awareness of the troubles faced by SSCWs in RCHs and highlight how 'competent' work driven by ideological institutional practices can result in ethically troubling situations in day-to-day working life. This emphasises the need to carefully explore situations typically described as 'poor practice' if we are to understand what influences how they are actually organised.

Conclusion

The paper concludes that, while SSCWs conversations about serious illness, hospital admission and DNACPR forms were out of alignment with national polices and with what SSCWs thought was appropriate, they cannot simply be described as poor practice. This is because they were socially organised by a complex web of institutional practices related to the occupancy rate in the RCH, the inspection process of the care home scrutiny body, the quality assurance process of the RCH company, the funding of palliative care education, and powerful political and fiscal drives to reduce spending on over 75s. These practices had little to do with the actual care needs of RCH residents or the actual support needs of RCH staff.

Study limitations

IE is elaborate method of inquiry which looks at the world through a distinct and currently poorly understood lens. It claims to be a method of inquiry *for* the standpoint group in so far as it aims to trace, map and explain how their experience is shaped and organised as it is so that group can then work to change the material conditions of their lives.

When taken up by well-funded and well-organised research and activist groups such as groups seeking to improve the safety of women experiencing domestic violence (Pence 1996, Sadusky *et al*. 2010), and groups seeking to improve access to experimental treatment for those with HIV/AIDS (Smith 1995) IE has been a very useful approach with practical outcomes. The findings reported in this paper will be used to raise awareness of problems in RCHs among key stakeholders to hopefully start the process of change, however it is unclear how the findings could be used **by** the standpoint group to change the complex and powerful institutional practices dominating their working lives. This suggests that while IE can be a useful method of inquiry for nurse researchers who are interested in understanding how difficulties are produced in real life situations, to achieve the most effective outcomes it may best be taken up by influential and well-funded research bodies and activist groups rather than individual researchers with limited resources.

Key points for policy/practice/research

- The paper showed how conversations about serious illness, hospital admission and DNACPR forms arose in the RCH. It then showed how this conversation pulled SSCWs, and others, into a complex web of institutional practices had little to do with the actual care needs of people in RCHs, or the support needs of RCH staff.

- RCH staff are being held accountable for what could more reasonably be described as medical/nursing work under the current care home inspection process. This is unfair because although RCH staff rely on the professional

knowledge of doctors (and nurses) to care for sick and dying residents, doctors (and nurses) are typically absent from RCHs. This absence is beyond the control of RCH staff.

- It is recommended that changes should be made to the admission and transfer policies in RCHs so residents needs more closely match the capacity of RCH staff to care for them. It is recommended that changes be made to inspection processes of the care home regulatory body to ensure RCH staff are not held accountable for medical/nursing work. It is also recommended that changes should be made to the organisation of medical/nursing support for RCH residents and staff to ensure residents and staff have routine access to the level of support now needed to care appropriately for this increasingly frail patient group.

- IE can be a useful method of inquiry for nurse researchers who are interested in understanding how difficulties are produced in real life situations, however to achieve the most effective outcomes it may best be taken up by well-funded research and activist groups rather than individual researchers with limited resources.

References

Bowman, C.E., Whistler, J., Ellerby, M. (2004) A national census of care home residents. *Age and Ageing* 33 (6) 561–566.

British Geriatrics Society. (2011) Quest for Quality Joint Working Party Inquiry into the Quality of Healthcare Support for Older People in Care Homes: A Call for Leadership, Partnership and Quality Improvement. Available from: http://www.bgs.org.uk/campaigns/carehomes/quest_quality_care_homes.pdf [accessed July 2017]

British Medical Association, Resuscitation Council (UK) and Royal College of Nursing. (2016) Decisions relating to Cardiopulmonary Resuscitation (3rd edition, 1st revision). Available from: https://www.rcn.org.uk/professional-development/publications/pub-005688 [accessed June 2017]

Brinkman-Stoppelenburg, A., Rietjens, J.A., van der Heide, A. (2014). The effects of advance care planning on end-of-life care: a systematic review. *Palliative Medicine*. 28 (8) 1000-1025.

Caplan, G.G., Meller, A., Squires, B., Chan, S., and Willett, W. (2006) Advance care planning and hospital in the nursing home. Age & Ageing. 35 (6) 581-586.

COSLA, The Scottish Government, NHS Scotland. (2010) Reshaping Care for Older People: A Programme for Change 2011-2021. Available from: http://www.gov.scot/resource/0039/00398295.pdf [accessed June 2016]

De Gendt, C., Bilsen, J., Stichele, R.V. and Deliens, L. (2013) Advance care planning and dying in nursing homes in Flanders, Belgium: a nationwide study. Journal of Pain and Symptom Management. 45 (2) 223-234

Department of Health (2008) *End of Life Care Strategy – promoting high quality care for all adults at the end of life* DoH London

Diamond, T. (1992) Making grey gold: Narratives of nursing home care. Chicago: University of Chicago Press.

Fahey-McCarthy, E., McCarron, M., Connaire, K. and McCallion, P. (2009) Developing an education intervention for staff supporting persons with an intellectual disability and advanced dementia. *Journal of Policy and Practice in Intellectual Disabilities*. 6 (4) 267–275.

Froggatt, K., Davies, D. and Meyer, J. (2009) Research and Development in Care Homes: Setting the Scene. In: Froggatt, K., Davies, D., and Meyer, J. (eds.) (2009) *Understanding Care Homes: A Research and Development Perspective*. London: Jessica Kingsley Publishers.

Goodman, C., Mathie, E., Crang, C., Wright, J., Handley, M., Barclay, S., Froggatt, K., Thompson, D., Cowe, M., Fenner, P., Gage, H., Garlick, R., Iliffe, S., Manthorpe, J., Mendoza, A., Munday, D. and Westwood, D. (2010) *The Experiences and Expectations of Older People Resident in Care Homes, Their Carers and Professionals of End of Life Care and Symptom Relief Needs: A Prospective Study*. A report for the National Institute for Health Research for Patient Benefit Programme PB PG 0906 11387. NHS Hertfordshire.

Hall, S., Kolliakou, A., Petkova, H., Froggatt, K. and Higginson, I.J. (2011) *Interventions for improving palliative care for older people living in nursing care homes : Cochrane Database of Systematic Reviews*. 3, CD007132.

Handley, M., Goodman, C., Froggatt, K., Mathie, E., Gage, H., Manthorpe, J., Barclay, S., Crang, C., and Iliffe, S. (2014) Living and dying: responsibility for end-of-life care in care homes without on-site nursing provision – a prospective study. Health and Social Care in the Community. 22 (1) 22-29.

Henry, C. and Seymour, J. (2012) *Advance Care Planning: A guide for health and social care staff*. London: Department of Health, End-of-life Care Programme.

Hockley, J. (2006) *Developing High Quality End-of Life Care in Nursing Homes: An Action Research Study*. PhD Thesis. Edinburgh: University of Edinburgh.

Hockley, J. Watson, J., and Murray, S.A. (2008) The Midlothian "Gold Standards Framework in Care Homes" Project. Available from: http://www.goldstandardsframework.org.uk/cd-content/uploads/files/Midlothian%20GSFCH%20full%20report%202008.pdf [accessed July 2017]

Kinley, J., Hockley, J., Stone, L., Dewey, M., Hansford, P., Steward, R., McCrone, P., Begum, A., and Sykes, N. (2013) The provision of care for residents dying in UK nursing care homes. *Age and Aging*. Available from: http://ageing.oxfordjournals.org/content/early/2013/10/15/ageing.aft158.full.pdf [accessed June 2016].

Kouwenhoven, W. B., J. Jude, Knickerbocker, G.G. (1960) Closed chest cardiac massage. JAMA. 173: 1064-1067.

Laing and Buisson. (2009) Care of Elderly People UK Market Survey 2009. Cited in: Hockley, J., Watson, J., Oxenham, D., Murray, S.A. (2010) The integrated implementation of two end-of-life tools in nursing care homes in the UK: an in-depth evaluation. Palliative Medicine. 24 (8) 828-838.

Lannon, R. and O'Keeffe, S.T. (2010) Cardiopulmonary resuscitation in older people: a review. Reviews in Clinical Gerontology. 20 (1) 20-29.

Livingston, G., Lewis-Holmes, E., Pitfield, C, Manela, M., Chan, D., Constant, E., Jacobs, H., Wills, G., Carson, N., and Morris, J. (2013) Improving the end-of-life for people with dementia living in a care home: an intervention study. International Psychogeriatrics. 25 (11) 1849-1858.

Melon, K.A., White, D., and Rankin, J. (2013) Beat the clock! Wait times and the production of "quality" in emergency departments. Nursing Philosphy. 14 (3) 223-237.

Moriarty, J., Rutter, D., Ross, P.D.S. and Holmes, P. (2012) *SCIE Research briefing 40: End of life care for people with dementia living in care homes.* London: Social Care Institute for Excellence.

Pence, E. (1996). Safety for battered women in a textually mediated legal system. (Doctoral dissertation). Retrieved from Proquest Dissertations and Theses. (NQ28298)

Pringle, J., Johnstone, B., Buchanan, D. (2015) Dignity and patient-centred care for people with palliative care needs in the acute hospital setting: a systematic review. Palliative Medicine. 29 (8) 675-694.

Rankin, J. M., (2003). Patient satisfaction: Knowledge for ruling hospital reform – An Institutional ethnography. Nursing Inquiry. 10 (1) 57-65.

Rankin, J.M., (2009). The nurse project: Strategies for taking back our work. Nursing Inquiry. 16 (4) 279-286.

Rankin, J.M. and Campbell, M. (2009) Institutional Ethnography, nursing work and health care reform: IE's cautionary analysis. Forum of Qualitative Research FQS. 10 (2) Art 8.

Rankin J.M. and Campbell, M. (2014). "Three in a bed": Technologies of bed utilization in a hospital. In Dorothy Smith and Susan Marie Turner (eds) Incorporating Texts into Institutional Ethnographies. Toronto. University of Toronto Press

Reid, L. (2017) The Social Organisation of Exclusion, "Abandonment" and Compulsory Advance Care Planning Conversations:

How Ruling Concepts and Practices about Death, Dying and the Do Not Attempt Cardiopulmonary Resuscitation form entered, organised and ruled the working practices of Senior Social Care Workers in a Residential Care Home in Scotland: An Institutional Ethnography. PhD Thesis. Edinburgh: Edinburgh Napier University.

Robinson, J., Gott, M., Gardiner, C., Ingleton, C. (2016) The "problematisation" of palliative care in hospital: an exploratory review of international palliative care policy in five countries. BioMed Central Palliative Care. Available from: https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-016-0137-0#Sec3 [Accessed April 2017]

Sadusky, J.M., Martinson, R., Lizdas, K. and McGee, C. (2010). The Praxis Safety and Accountability Audit: Practicing a 'Sociology for People'. Violence against Women. 16 (9) 1031-1044.

Santonocito, C., Ristagno, G., Gullo, A., Weil, M.H. (2013) Do-not-resuscitate order: a view throughout the world. Journal of Critical Care. 28 (1) 14-20.

Scottish Executive. (2001) *National care standards: care homes for older people.* Edinburgh: Scottish Executive.

Scottish Executive. (2007) *National care standards: care homes for older people.* Edinburgh: Scottish Executive.

Scottish Executive. (2008) *Living and Dying Well: a national action plan for palliative and end of life care in Scotland.* Edinburgh: The Scottish Government.

Scottish Government. (2010a) *Reshaping care for older people.* [Online] Available from: http://www.scotland.gov.uk/Resource/Doc/1095/0097691.pdf [accessed Jan 2015]

Scottish Government. (2010b) The Healthcare Quality Strategy for NHS Scotland. Available from: http://www.gov.scot/resource/doc/311667/0098354.pdf [accessed June 2016]

Scottish Government. (2010c) *Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): Integrated Adult Policy.* Edinburgh: Scottish Government.

Scottish Government. (2011a) Living and Dying Well: Building on Progress. Edinburgh: Scottish Government.

Scottish Government. (2011b) *Scotland's National Dementia Strategy.* Available from: http://www.scotland.gov.uk/Resource/Doc/350188/0117212.pdf [accessed Jan 2015]

Scottish Government. (2016) *Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): Integrated Adult Policy*. Edinburgh: Scottish Government.

Seymour, J., Kumar, A. and Froggatt, K. (2011) Do nursing homes for older people have the support they need to provide end-of-life care? A mixed methods enquiry in England. *Palliative Medicine* 25 (2)125–138. Available from: http://www.nottingham.ac.uk/nmp/documents/open-access-publication-eol-in-nursing-homes.pdf [accessed June 2016]

Sleeman, K.E., Perera, G., Stewart, R., Higginson, I.J. (2017) Predictors of emergency department attendance by people with dementia in their last year of life: Retrospective cohort study using linked clinical and administrative data. *Alzheimer's and Dementia*. Available from: http://www.alzheimersanddementia.com/article/S1552-5260(17)32520-7/fulltext [accessed Nov 2017].

Smith, D.E. (2005) *Institutional Ethnography: A Sociology for People*. Lanham, Maryland: Altamira Press.

Smith, D.E. (ed) (2006) *Institutional Ethnography as Practice*. Lanham, Maryland: Rowman and Littlefield.

Smith, G. (1995). Accessing treatments: Managing the AIDS epidemic in Ontario. In M. Campbell and A. Manicom (Eds.), Knowledge, experience and ruling relations Toronto: University of Toronto Press.

Vandervoort, A., Van Den Block, L., Van Der Steen, J.T. Van Der Stichele, R., Bilsen, J. and Deliens, L. (2012) Advance directives and physicians' orders in nursing home residents with dementia in Flanders, Belgium: prevalence and associated outcomes. International Psychogeriatrics 24 (7) 1133-1143.

Van de Glind, E.M.M., Van Munster, B.C., Van De Wetering, F.T., Van Delden, J.M., Scholten, R.J.P.M. and Hooft, L. (2013) Pre-arrest predictors of survival after resuscitation from out-of-hospital cardiac arrest in the elderly: a systematic review. BMC Geriatrics. Geriatrics. 13 68.