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# An inquiry into what organised difficult advance care planning conversations in a Scottish residential care home using institutional ethnography.

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# Analysing difficult conversations about Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Forms in a Scottish Residential Care Home using Institutional Ethnography

Lorna Reid, Angela Kydd and Bonnie Slade

## Abstract

This paper provides an institutional ethnographic analysis of how discussions and advance decisions about serious illness, hospital admission and Do Not Attempt Cardio Pulmonary Resuscitation forms have been systematically placed into the hands of Senior Social Care Workers (SSCWs) in Residential Care Homes (RCH) with insufficient support from healthcare professionals for those important healthcare decisions to be made safely and/or effectively. 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 follows clues found in data vignettes of day-to-day working practices that had been constructed from interviews with SSCWs (n=4) and others (n=6) whose work shaped what happened in the RCH. This careful detective work uncovered the empirical links that tied SSCWs work into a complex web of socially organised institutional practices and purposes through the use of powerful organising texts such as national and local policies, care planning documents and audit forms.

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 were not simply isolated incidences of poor practice by incompetent staff. This is because these conversations pulled SSCWs (and others) into a complex web of institutional practices that were infused with powerful political and fiscal drives to reduce government spending on the care of older adults - which had little to do with the actual care needs of RCH residents or the support needs of RCH staff.

The analysis reported in this paper provides insight into necessary policy changes. It also offers a different account of care home deaths than is typically represented in the professional literature.

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

## Introduction

This paper reports on one part of a wider 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 how SSCWs' work was administratively and institutionally organised to happen in the way that it did. It will also show how powerful political and fiscal initiatives to reduce state spending on the care of older people permeated and controlled the day-to-day work of SSCWs – and others. But did so in ways that were not immediately obvious from the standpoint of SSCWs in the RCH.

Although IE has been taken up in studies of nursing and healthcare internationally (Bresalier *et al* 2002, Melon *et al* 2013, Rankin 2001, 2003, 2009, Rankin and Campbell 2009) 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

Most people in Scotland in need of long-term care live in one of two types of care home. 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. Most care homes in England are RCHs (Care Quality Commission 2012).

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; Green et al. 2017). 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 change from the past. In UK RCHs, there are no qualified healthcare professionals on-site. This means staff and residents in RCHs are completely dependent upon National Health Service (NHS) support when residents and sick and dying.

There are longstanding concerns that care home residents could be receiving sub-optimal care in the final phase of their lives (Hall et al. 2011, Hockley 2006, Hockley et al. 2008, Seymour et al. 2011). There are also concerns that reluctance to discuss dying in care homes has led to poor advance/anticipatory care planning (ACP) of what is considered a foreseeable event (Hockley 2006, 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 wishes about future care so wishes can be honoured when that person can no longer speak for her/himself (Henry and Seymour 2012).

## ACP Policy context

ACP discussions are increasingly being advocated in Scotland's healthcare policy

documents including: *Living and Dying Well* (Scottish Executive 2008), *Improving Complex Care* (Scottish Government 2009) *Living and Dying Well: Building on Progress* (Scottish Government 2011), *The Healthcare Quality Strategy for NHS Scotland* (Scottish Government 2010), *Reshaping Care for Older People* (Scottish Government 2010), and Scotland's *National Dementia Strategy* (Scottish Government 2011). These discussions 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).

A 2014 systematic review of studies 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).

## 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 1960:1064) to the current position where CPR 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 NCHs reported that NHC residents have poorer outcomes after CPR than the non-NCH population - highlighting that CPR is a minimally effective intervention for frail elderly NCH residents (van de Glind 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 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, Goodman *et al.* 2012, Handley *et al.* 2013). This means there is currently no clear system of NHS clinical support and leadership available to support RCH staff with ACP conversations – including advance decisions about CPR – which is concerning in light of current policy drives to promote ACP in all care settings, including RCHs.

The research reported in this paper aims to fill a gap in knowledge about how current policies about ACP and DNACPR impact on SSCWs in RCHs.

## Method of inquiry: Institutional Ethnography

Smith (2005, 2006) developed Institutional Ethnography (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.

There are two sites of significance to the institutional ethnographer. Firstly, s/he is interested in the local setting where the issue under investigation arose. 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. In IE administrative and governance texts such as 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). 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.

## Data Vignette: A Difficult Experience of Death

A 96 year old woman (Resident A), with a diagnosis of advanced dementia, was dying in RCH B. Her death was not unexpected by the care home staff, or her family. She died peacefully at 9pm, with a care home staff member holding her hand. The family were en-route to the care come.

Shortly after the death, the SSCW in charge of the shift followed the care home protocol and called the out-of-hours healthcare service. She did this because she needed a doctor to come and verify the residents' death. Verification of death requires a clinical examination by a qualified healthcare professional to confirm the fact of death. The SSCW knew this had to take place before she could officially tell the resident's family that that resident had died. She also needed an official confirmation of death before the deceased resident's body could be moved from the RCH to a funeral director's premises.

The SSCW knew that the resident had died peacefully in her bed. She was not a qualified healthcare professional, however, so she was not permitted to use that language when she called the out-of-hours service. She was permitted to say that she could not find a pulse on a resident who was not breathing.

The call handler's questions and responses were based on standard prompts and flow charts on her computer screen. After hearing the resident was not breathing and had no pulse, the call handler asked if the resident had a "Do Not Attempt Cardiopulmonary Resuscitation" (DNACPR) form. The resident did not. The call handler then instructed the SSCW to commence cardiopulmonary 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 difficult 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 which took the standpoint of SSCWs in one of Scotland's RCHs.

It would be easy to blame individual staff members for the disturbing events in this data-vignette. However, Dorothy Smith (2005, 2006) argues that explanations of 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 texts. The data-vignette shows how protocols and policies do not always suit 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. Neither is it clear from the standpoint of those experiencing some kind of difficulty what the wider institutional purpose of these powerful ruling texts might be. Therefore, IE uses difficult experiences of a standpoint group to trace and map those unknown wider institutional purposes.

The focus of the study will now be outlined.

### Data sources and analysis procedures Interviews

The study gathered data about routine working practices from ten open-ended interviews with SSCWs (n=4) and others (n=6) whose work shaped what happened in the RCH. These were conducted between March 2014 and March 2015.

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. The aim was to discover what SSCWs did and how that work was textually organised.

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. That care staff should be "pushed" into leading a decision-making conversation about serious illness, hospital admission and the DNACPR form was out of alignment with the wishes of the SSCWs. It was also out of alignment with the guidance in the Adult Integrated DNACPR policy (Scottish Government 2010, 2016).

### 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.

### 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.

When participants described events which were not considered good practice additional information was offered. Rather than 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 2016), however, the inquiry maintained an ethical and methodological commitment to following clues to discover what was considered most important - in relation to how work in the RCH was actually organised. This allowed a wider investigation into how problems were being produced, which was important if systematic issues were to be uncovered and addressed.

## 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 1990, 1991). 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 work of others across different locations in the health and social care system.

### 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).*

Key phrases from this and other 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.

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 similar work of commodification 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 as a result of changes in the residents now living and dying in the RCH 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 – 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 is related to the *"Care Inspectorate and trainings and things".* On further investigation the material nature of some of these *"things"* are 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 *"checklist"* to discuss the *"policies and standards"* and agree a *"care plan"* with the family - because to be admitted into this RCH the resident must have a medically confirmed diagnosis of dementia and a legally appointed proxy-decision maker. This care plan must 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* (2002, 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 once in four weeks, 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 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 clinician 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 clues 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 funded 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 then 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

The study reported in this paper inquired into how SSCWs at the research site were *"pushed"* into ACP conversations about *"serious illness"*, hospital admission and DNACPR forms that brought them into misalignment with their own sense of what was appropriate and also into misalignment with the Adult Integrated DNACPR Policy (2010, 2016). The paper has shown how these conversations pointed to a complex range of textual institutional practices linked to: changes in the client group now being cared for in the RCH; concerns of the care home company about occupancy rates; what happened when RCH residents died in the absence of a DNACPR form; documented processes to assess staff competence at work; quality assurance processes within the care home company and the regulatory body; the reputation and income generating potential of the RCH as a business; national drives to support and monitor the uptake of textual practices associated with ACP and DNACPR forms; and national drives to reduce hospital admissions among older adults specifically.

A common theme in studies on ACP is the seemingly positive link between ACP documents and improved quality of care - where *quality* is measured by 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). What we now understand more clearly as a result of the analysis in this paper, however, is the direct link between drives to promote ACP work in care homes and drives to reduce government spending on the care of older adults as a group.

In relation to cost of care, Georghiou and Bardsleym (2014) state: that hospital admission is the most expensive aspect of care in the final three months of life; that cost of care is related to emergency (*unplanned/unscheduled*) hospital admissions; and that such admissions increase rapidly in the final few weeks of life – at an average cost of £4,500 per person who died. They compared this to the cost of care in a NCH or RCH, which was averaged at £1000 per person who died during the last three months of life- demonstrating that it is considerably less expensive if people die in private, or voluntary, or Local Authority care homes than if they die in state funded hospitals. What we also come to understand as result of the analysis in this paper is how fiscal concerns of the Scottish Government were inserted into SSCWs work as they were enlisted to take up ACP work as a means of reducing “emergency bed days used by those aged 75+”

The combination of textual practices uncovered in this paper ruled over the thinking, talking and acting of people in and beyond the RCH. The way these practices were taken up by well-intentioned people throughout the health and social care system not only made the supposedly voluntary process of ACP into a compulsory activity for SSCWs and family members in the RCH, it also activated a series of complex and ultimately financially driven ideological practices where there was insufficient allocation of medical and nursing resources to respond appropriately to the inevitability of declining health and death in the RCH.

This paper provides insight into needed policy changes about how RCHs are inspected and how healthcare support is organised in RCHs. The paper also offers a different analysis of care home deaths than is typically represented in the professional literature, one that traces work processes to discover what is actually organising troubling events rather than blaming those events on a lack of knowledge or competence or care.

According to the UK nursing regulatory body the Nursing and Midwifery Council, nursing work aims to prioritise people, practise effectively, preserve safety, and promote professionalism and trust (NMC 2015). Therefore it is important that nurses and others involved in promoting ACP work in RCHs realise how their own and other's well-intended actions are being infused with political and fiscal concerns that have little to do with the care of sick and dying people. This realisation is important so they can consider how to push back against moves that may not promote safe and effective care that values and prioritises the actual care needs of people in RCHs and the actual support needs of RCH staff.

## Conclusion

The research reported in this paper inquired into text-based practices that put discussions and advance decisions about how to manage serious illness 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.

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 were not simply isolated incidences of poor practice by incompetent staff. This is because these conversations pulled SSCWs (and others) into a complex web of institutional practices that were infused with powerful political and fiscal drives to reduce government spending on the care of older adults that had little to do with the care needs of RCH residents or the support needs of RCH staff.

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 that were infused with powerful political and fiscal drives to reduce government spending on the care of older adults. These drives had little to do with the actual care needs of people in RCHs, or the support needs of RCH staff.
- Nurses and others involved in promoting ACP work in RCHs must recognise how concerns that are not their own are being inserted into their well-intended work. This is important if they are to push back against moves that may not promote safe and effective care that values and prioritises the actual needs of people in RCHs, and/or has little to do with professional nursing practice.
- 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.
- IE can be a useful method of inquiry for nurse researchers who are interested in understanding how difficulties are produced in real life situations.

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