the gold standards framework in care homes

The Midlothian ‘Gold Standards Framework in Care Homes’ project

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EXECUTIVE SUMMARY

1. Background

Effective palliative care for frail older people living and dying in nursing care homes is essential. This may be less straightforward than organising cancer palliative care; nonetheless it is vital that palliative care is part of the public health agenda for the rapidly increasing number of frail older people living and dying in nursing care homes.

In March 2007, seven nursing care homes in Midlothian, Scotland agreed to take part in a feasibility project to develop palliative care within their individual care homes using the GSFCH framework alongside primary care teams. The project formed part of Phase 4 of the national GSFCH work in England.

The aim of the project was to optimise the organisation, proactive planning, and communication with residents, their relatives, the nursing home team, and general practitioners using the GSFCH framework in order to develop a culture of cooperation, and reduce the number of admissions to hospital in the last stages of life with more residents dying well in their nursing care home. An in-depth evaluation in all seven nursing care homes was undertaken.

2. Implementation

The GSFCH is a framework that helps to promote seven important aspects to enhance a palliative care approach to nursing care homes: continuity of care; communication; co-ordination of care; control of symptoms; carer support (both family and staff); continued learning; and, care of the dying. The adapted Liverpool Care Pathway for care homes (Hockley et al 2005) was used.

Each nursing care home were asked to appoint ‘key champions’ who would help co-ordinate the project in their own nursing care home and help to embed various systems being implemented. They also attended training in palliative care. A facilitative learning course: *‘Foundations in Palliative Care for Care Homes’* (Macmillan 2004) was used; key champions were then encouraged to cascade the training down to their own staff with or without the help of the facilitator.

All ‘key champions’ were encouraged to attend GSFCH network workshops held in London through which new material was introduced.

Two main systems were introduced. Firstly, a ‘*supportive/palliative care register*’ was implemented into each nursing care home. The register helps highlight needs in relation to anticipatory care planning, DNAR status, family and resident communication, and symptom control. The names of *all* permanent residents in the nursing care home were on the register as they were seen to have progressive, far advanced, incurable disease requiring 24-hour nursing care. General practitioners were encouraged to use the register to guide this wider discussion of residents on a monthly basis. Secondly, the '*adapted Liverpool Care Pathway for the last days of life*' was implemented.

The implementation of both systems involved a considerable amount of support and training across the homes involved. This training was linked to and complemented by the learning that occurred through the '*Foundations in Palliative Care Course*'.

Planning was required in relation to where and how registers and/or documents would be kept and updated; especially when there were no administration staff and/or a nurse manager lacked computer literacy.

3. Evaluation

The purpose of the evaluation was to assess the uptake and feasibility of implementing such a major project, and to evaluate its impact on the end of life care being given by staff in all nursing care homes in a geographic area. A 'realistic' evaluation approach (Pawson & Tilley 1997) was adopted.

Quantitative data were collected through:

- Staff audit questionnaire. Analyses was performed on 'matched' pairs of those who returned both the pre and post audit questionnaire.
- Documentary evidence of the last 8 weeks of life from the notes of residents who had died. A total of 228 residents' notes (pre and post) were examined.

Qualitative data were collected through interviews with:

- Twenty-one relatives (whose loved one had died in one of the homes) were interviewed 'pre' project; and, thirteen relatives 'post' implementation.
- Nursing home managers and general practitioners

To aid data-collection and analysis in the interviews with relatives, a matrix corresponding with the 7C's of the GSFCGH was used to identify any changes in these salient areas.

4. Results of the project

Many of the residents were notably frail. Ages ranged from 66yrs - 103yrs with over a third of residents in their nineties. 51% of residents had multiple co-morbidities of 3 or more diagnoses. 66% of residents had dementia as their main diagnosis.

There was significant improvement in the following areas: care of the dying, control of symptoms, continuity of care, carer support (families) and continued learning. There was a noticeable drop in 'negative' averages regarding all seven C's of the GSFCH framework in each nursing home.

Managers recognised an increased confidence in their staff, including carers, particularly in communicating with relatives about death and dying and actually caring for a dying person. Using the ABCD register with the GP was felt to be very useful in helping staff in the nursing home to be more organised and prepared for end of life care. Attitudes had changed; staff were more accepting of dying and more able to recognise it.

As a result of improved discussion around end of life care, some of which could be called anticipatory care planning alongside better collaboration with general practice, there was:

- Increase in DNAR status across all nursing care homes from 8 to 71%
- Increase in explicit decision-making in end of life care across all nursing care homes from 4 to 55%
- Fewer deaths in hospital: a reduction of around 50% (from 15% to 8%) of residents dying in hospital in the 12-months preceding the project compared to the year of the intervention.
- A reduction of inappropriate hospital admissions by over 40%.

These results occurred despite a high staff turnover (between 11% - 72%) during the year of the project. The majority of nursing care homes had a staff turnover of over 35%. Because of this, sustainability of improvements after only 18-months may be at risk.

5. Key Recommendations:

Systems:

- The Liverpool Care Pathway for care homes should be used to ensure that a resident is regularly assessed during the dying period
- Appropriate communication regarding DNAR status should be addressed when a resident is first admitted to a nursing home
- Advance care planning should be offered as part of routine care at or soon after admission as a way of reducing inappropriate admissions
- The use of assessment charts for the management of pain and depression is advised
- ‘Review’ meeting with families need to emphasise ‘anticipatory care planning’ and the appropriateness of allowing natural death in the very old and frail at the end of life.
- Provision of monthly organised reflection times for staff following the death of a resident.

Organisation:

- The Gold Standards Framework for Care Homes can help improve the quality of end of life care to residents and families. However, sustaining the quality needs to be done through ‘*accreditation*’ status with GSFCH programme
- Palliative care needs of residents dying in nursing care homes can be complex and require greater availability of palliative care support
- Formal links between nursing care homes and palliative care support need to be established
- GP Direct Enhanced Service payments for nursing care homes have been beneficial and should be continued. Monies saved from inappropriate admission to hospital could be ring-fenced to pay for such a service.

Training:

- ‘Foundations in Palliative Care for Care Homes’ facilitation by senior nursing staff will help cascade down knowledge learnt through the GSFCH project
- All new staff require palliative care training

Future Plans for Midlothian:

- A ‘step-down sustainability’ project for 2 days/week for 2 years is needed to consolidate and embed the changes that have been made
- A ‘palliative care forum’ will help support local nursing homes involved in the project

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This summary can be downloaded from the Primary Palliative Care Research Group website. For further information contact: Scott.Murray@ed.ac.uk

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1 BACKGROUND

"How people die remains in the memory of those who live on"

Dame Cicely Saunders

The care for frail older people has changed considerably since the 1990s. Now the majority of frail older people in the UK are cared for in care homes rather than long stay wards for older people. In Scotland there are 944 care homes (those providing nursing & personal care; and those providing just personal care) accounting for around 31,000 beds for the long term care of older people. Sixty-six percent of the care homes in Scotland are privately owned (www.scotland.gov.uk).

The population of older people living and dying in care homes providing nursing care is increasingly frail (both physically and mentally) and they are amongst the neediest of our society (Brazil et al 2004). Recent figures in the End of Life Care Strategy (DoH 2008) record that 16% of people over the age of 65 years die in a care home although others (Davies & Seymour 2002; Teno 2003) speak of higher figures

During March 2006 - February 2007 there were 7,506 deaths in privately owned nursing care homes in Scotland. The relative isolation of nursing care homes from the development of palliative care elsewhere in the NHS, and the lack of medical cover (Jacobs 2003), raises concern that care homes may be providing sub-optimal care at the end of life (Hall et al 2002; Hockley 2006).

Retention and recruitment of staff in these organisations is problematic (Redfern et al. 2002). Most care staff in these homes are untrained; yet staff are caring for people with complex and multiple diseases – the majority of whom will now die within two years of admission (Katz & Peace 2003). With little education and support around death and dying, carers are not surprisingly frightened by the responsibility. More recently, dying has been found to be 'peripheral to the care home culture' (Hockley 2006). As a result old and frail residents can be admitted inappropriately to hospital in their last weeks of life and consequently die away from familiar surroundings and the people who have cared for them.

Studies have reported a rehabilitative culture in the long term care of older people (Hanson et al 2002; Travis et al 2002). A palliative care approach has been suggested as an appropriate model of care for care homes (Maddocks & Parker 2001; Tuch et al 2003). However, changing the culture of care homes is complex because of the 'weak' context (McCormack et al 2003). Education programmes in care homes, in isolation of any change initiative, are not sufficient (Froggatt 2000).

As part of the Department of Health's 'End of Life Care Strategy' (2008), three tools are being advocated in order to help organise care for people facing the end of their life. *The Gold Standards Framework for Care Homes* [GSFCH] (Thomas 2006) is one tool that provides a detailed framework for staff working in nursing care homes to help plan care in the last year of life. Alongside educational initiatives such tools have been found useful in bringing about change. Recently, the national GSFCH team have introduced ‘accreditation’ to ensure ongoing quality improvement, quality assurance and quality recognition (Thomas 2008).

2 THE PROJECT

The Midlothian project formed part of Phase 4 of the National GSFCH work involving nursing care homes in London, England. Midlothian is a geographical area close to the City of Edinburgh with both high and low deprivation. Nursing care home managers from all seven nursing care homes (totalling just under 400 beds) in this primary care trust were invited to take part; all agreed and were happy for the project to be fully evaluated. The project was undertaken over an 18-month period. Ethical approval to involve relatives in the evaluation was given. Local GP practices were familiar with the Gold Standards Framework [GSF] project for primary care.

The GSFCH emphasises the importance of a good quality of life during the last year/s that an older person might have in a care home prior to their death.

The five goals of the GSFCH are:
1. Physical symptoms are anticipated and reduced where possible
2. Residents/families have some choice and control particularly around the preferred place of care at the end-of-life
3. Residents feel supported and informed; problems are anticipated and reduced
4. Families feel enabled, informed and involved in the care as much as they would like to be
5. Communication in relation to end-of-life care between staff in nursing care home, the GP and primary care team is improved

The GSFCH highlights the importance of 7Cs that help towards achieving a gold standard of care at the end-of-life for older people dying in nursing care homes, namely:

C1: Co-ordination
C2: Communication
C3: Control of symptoms
C4: Continuity
C5: Continued learning
C6: Carer support (family & staff)
C7: Care of the dying

The Midlothian GSFCH framework used a ‘high’ facilitation model because of the reported ‘weak’ context in nursing care homes (Hockley et al 2005). One full-time facilitator (JH) worked alongside the seven NHs over an 18-month period.

2.1 Aims of Midlothian GSFCH project

The Midlothian GSFCH project proposed to optimise the organisation, communication, and proactive planning that is necessary for high quality end of life care for frail older people in seven nursing care homes. The aims of the programme were:

1. To improve the quality of care provided for all residents from admission to the home
2. To improve collaboration with GPs, primary care teams and specialists
3. To reduce the number of hospital admissions in the final stage of life, enabling more to die with dignity in the home, if that is their wish.

[www.goldstandardsframework.nhs.uk/care_homes]

A realistic evaluation methodology (Pawson & Tilley 1997) was used to evaluate the project.

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3 FACILITATING THE PROJECT

The seven nursing care homes (NCHs) taking part in the project ranged from small 'family' run homes to large, private corporate 'for profit' organisations (see Table 1). Nursing home managers (NHMs) were sent the GSFCH documentation pack which included a DVD of the programme. They were asked to appoint key champions (KCs) who would, alongside the nursing home manager, take responsibility for leading and embedding the project within the home. KCs needed to be very interested in palliative care, and willing to champion new tools and the education within the NCH.

NCH	Size of NCH	Ownership of NCH	No. KCs involved + NHMs
A	Medium	Corporate	4
B	Large	Corporate	4
C	Small	Family run [multiple NCHs]	3
D	Large	Corporate	3
E	Small	Corporate	3
F	Small	Family run [single NCH]	2
G	Large	Corporate	4

Table 1: Size, ownership and number of KCs and NHMs involved in the NCHs

A meeting open to all staff within each of the NCHs was given to explain the project before it commenced. Staff were encouraged to watch the DVD about the GSFCH project in order to raise awareness. For those NCHs that had a regular 'relatives' meeting', an opportunity was offered to share about the project at such a meeting. Two nursing care homes arranged such a meeting.

KCs were invited to attend a 4-day '*Foundations in Palliative Care Course*' (Macmillan Cancer Relief 2004) in order to refresh their knowledge about palliative care. The course was held once a week at one of the NCHs during the month of May 2007. KCs completed a pre/post evaluation of the course. They were also encouraged to obtain the education pack and cascade training down through their NCH.

In June 2007, KCs from six out of seven NCHs attended the first of four London workshops organised by the national GSFCH team. It was at these four ‘gear’ meetings (getting started; moving on; gaining speed; cruising) (see Appendix 1) that information about the next part of the framework was communicated. Key tasks of the framework were introduced through implementing two main systems:

- The *supportive / palliative care register* for *all* residents in the nursing home and organise a monthly review.
    - Implementing a ‘coding system’ and ‘needs matrix’ in order to plan care for residents at whatever stage on the register they might be
    - Addressing the DNAR status with resident and family
    - Providing on-going anticipatory care planning with residents and/or families about their wishes in relation to what may or may not be appropriate in light of the quality of life of the resident (this includes discussion about preferred place of care in the last few weeks of life)
    - Collaborating with local GPs on a regular basis and with local specialist palliative care to address symptom control and complex communication issues with residents and/or families
- The *adapted Liverpool Care Pathway for the last days of life* for care homes (Hockley et al 2005).

3.1 Implementation of the supportive / palliative care register

A ‘*supportive/palliative care register*’ (see Appendix 2) was implemented in each NCH. This involved entering the names of *all* permanent residents on the register because of their progressive, far advanced, incurable disease and the requirement of 24-hour nursing care. Residents who were in for respite care were not included.

A major part of such a register is the coding of residents (see 3.1.1) according to their likely prognosis. The register also collects information in relation to DNAR status, anticipatory care planning and symptom control issues. Staff with their general practitioner/s were encouraged to use the register at a monthly meeting to guide the wider discussion of residents while nurses and care staff within the home were encouraged to update it during the month on specific residents as appropriate.

Local GPs had had previous experience of a supportive/palliative register, but it was a completely new concept and system for the NCH staff. Starting the register and updating it on a monthly basis was a considerable undertaking for all NCHs. This was mainly due to the lack of computer facilities and/or computer literacy of many of the NHMs & KCs.

The register was easier to establish in the small NCHs; however, at the beginning of the study the majority of small homes had no established weekly meeting with a GP practice. In the medium/large NCHs where regular weekly review meetings did occur, it was only the medium-sized NCH that could manage a review of all residents in one weekly session. It was necessary for the larger NCHs to split the review over two weeks – e.g. doing the ‘top’ floor one week and the ‘bottom’ floor the next.

3.1.1 Coding and the supportive / palliative care register

As an integral part of the supportive / palliative care register each resident’s prognosis was reviewed regarding a ‘best guess’ scenario using a code:

- Code ‘A’ indicated there was no change since the previous month’s discussions with the likelihood that the resident would still be alive in a year’s time;
- Code ‘B’ highlighted some deterioration where prognosis was now likely to be ‘months’;
- Code ‘C’ highlighted clear deterioration since last month and the resident may only have weeks of life;
- Code ‘D’ denoted that the resident was now actively dying and that the adapted Liverpool Care Pathway for care homes (LCP) should be commenced.

The coding was useful in highlighting those residents who were clearly deteriorating and entering the dying phase. However, some staff did not feel confident talking openly to families about a resident’s deterioration even at the 6-monthly resident’s review meeting with the family.

The *‘care needs matrix’* (Appendix 3) that guided staff to what needed to be achieved during the different coding stages was placed in the front of the register.

3.1.2 Do Not Attempt Resuscitation (DNAR)

At the beginning of the project, knowledge of the success of cardiopulmonary resuscitation (CPR) on people over the age of 65yrs old was extremely limited. Few people (staff, residents *and* families) realised that the likelihood of a successful outcome of CPR on a frail older resident living in a care home was 5% (BMA 2007). However, following communication staff soon understood the futility of such extreme intervention and realised the appropriateness of a DNAR form.

Lothian Health has one of the more forward-thinking policies regarding DNAR, with specific DNAR forms that are used across all healthcare settings (http://www.nhslothian.scot.nhs.uk/). The forms were readily accepted by the NCH staff and were kept within the folder of the supportive/palliative care register making them readily available at the monthly multidisciplinary register review meeting.

3.1.3 Anticipatory care planning:

Anticipatory care planning requires ascertaining residents and family/next of kin wishes regarding what they would like and would not like to happen during the last year/s of life; It also requires appropriate oral and written communication among nursing home staff members and with the wider clinical team (Happ et al 2002).

The following scenario (see Box 1) taken from fieldnotes highlights the unnecessary distress and waste of resources when anticipatory care planning, and DNAR status, are not discussed on a resident’s admission to a care home.

Box 1: Scenario

An 85yr old gentleman was admitted to NHC suffering from advanced Mesothelioma & pulmonary emboli. He had no written evidence of discussion re DNAR (despite his diagnosis and age). Because of breathlessness he required assistance to transfer from bed to a recliner chair – it was his preference to sleep in the recliner chair overnight because of the severity of breathing.

Three weeks after admission, the nursing kardex records at 14.00hrs '*a better day, continues to have a productive cough; antibiotics continue as charted'*. At 19.40hrs while being transferred to the bed, he '*became dyspnoeic and cyanosed, skin clammy; BP 156/100; pulse 88*.' The oxygen is increased and NHS24 is called as '*no DNR form was in place'*. He then stopped breathing with no pulse and recorded as having died. Fifteen minutes later the ambulance arrives and resuscitation is attempted but to no avail. The ambulance men inform the police.

The niece is informed & arrives at NHC 30minutes before the police who arrive at 21.08hrs. Both staff nurse, who insists that resuscitation was totally inappropriate but felt she had to 'cover her back' as she was an agency nurse and the niece are interrogated by the police – both feel humiliated by the process and feel it is a waste of police time and money. [NHC, Sept 07]

The time and emotional energy spent because appropriate anticipatory care planning had not been acted upon on admission for this gentleman who was clearly very ill was considerable; not least the fact that the care to other residents was diminished because the only nurse on duty was being interviewed by the police. The impact on other relatives seeing a police officer visit the NCH was considerable. There is concern that the presence of police contributes to a lessening confidence in the nursing home management. The above scenario was not an isolated event in the early weeks/months of commencing the project.

It is important to stress that for many staff anticipatory care planning (ACP) was something that staff had never come across before and there was much debate as to the appropriate time for such discussions. Some nurses felt comfortable having the ACP discussion on admission, others used the first 6-month review meeting, still others chose a time when the resident was clearly deteriorating. Having the discussion when a resident was imminently dying however provoked anxiety as often inexperienced staff were left to speak with families. Sometimes it was the OOHs doctor who stepped in. Omitting such discussions ran the danger of inappropriate admissions and sometimes a death in hospital.

3.1.4 Symptom Assessment tools

Undertaking specific assessment of symptoms was new to many of the nurses, as the majority had relied on this being the doctor's role. However, with the limited amount of clinical input of GPs to NCHs, nurses now need to take responsibility for such assessments.

The major symptom issues that required regular attention during the project were: pain, constipation and depression. Two main assessment tools were highlighted but there was little time during the project for them to be actually embedded within the culture of the NCHs. The first tool was a *pain assessment and management chart* specifically for care homes (see Appendix 4). This chart has an assessment page for residents without cognitive impairment as well as one for residents with impairment. For the latter, the DOLPLUS-2 behavioural pain assessment tool is included. The second tool was the *Geriatric Depression Scale* (see Appendix 5). This is widely available and some of the nurses had used in long-stay wards for older people but had never used such a tool within the care home setting.

3.2 Implementation of the adapted LCP for the last days of life

The second main 'system' to be introduced was the adapted Liverpool Care Pathway for the last days of life in care homes (see Hockley et al 2004). It was implemented at participating NCHs at different times during the project. One NCH had already been involved in a previous project concerning the adapted Liverpool Care Pathway and only required an 'up-date'. Two further homes wanted to introduce the documentation right at the beginning of the project.

A base review was carried out in each home; results were reported back to individual care homes prior to training and implementation of the documentation. Training around the documentation of the LCP is of vital importance with over 80% of staff in any care home attending. KCs helped alongside with training. Each training session lasted 2hrs and used a 3-page scenario that staff used to practice filling in the LCP documentation. Considerable emphasis was also given to the storage of new care pathway documentation with one person (often reception staff) taking on this responsibility. This ensured that when a resident was diagnosed as dying the documentation was readily available.

The *implementation of both these major systems* involved a considerable amount of support and training across all seven NCHs. The 'high' facilitation of the project meant making contact with each NCH on a weekly or bi-weekly basis. Visits to the NCHs were made to:

- help staff fill in the ADA (After Death Analysis) form on-line to fulfil requirement for the national GSFCH evaluation
- help staff set up the supportive/palliative care register on-line and guide them with updating it
- attend monthly overview of residents alongside GP
- undertake a base review of the 5 most recent deaths prior to training and implementation of the adapted Liverpool Care Pathway
- train 80% staff in each NCH in the use of the adapted Liverpool Care Pathway alongside their KCs plus support staff with its use
- support KCs with cascading down the *Foundations in Palliative Care* course
- introduce and teach on the various assessment tools;
- lead reflective de-briefing meetings with staff in the NCH following a death
- role-model how to speak about death and dying with families at review meetings
- follow up on the clinical care and/or communication issues with a resident and/family
- organise and attend the four London workshops with the KCs

Although the above were the standard things to be addressed in each NCH, it was also important to be flexible. In one NCH where a new manager had just started and where staff had been particularly traumatised through previous management issues, it was necessary to work alongside staff on two mornings a month for the first few months in order to gain their confidence. In a further NCH it was difficult to know how much to continue the training until greater stability amongst staff had been achieved. Further discussion concerning outcomes in relation to poor retention of staff is addressed later in the report.

3.3 Two spin-off projects

During the facilitation of the GSFCH, two NCHs undertook further work. NHA was involved with discussions to get a *Home Office Licence* to keep ‘prn’ medication as stock for the last days of life. This arose as a result of implementing the adapted LCP documentation that requires prescribing three medications (an anxiolytic, an analgesic, and a drug to control rattly breathing) to be available in case of distress. However, often drugs are not used and then there is wastage when drugs are destroyed following the resident’s death. Having a licence to hold these drugs therefore is useful as it prevents wastage. Drugs useful for distress in the last days of life are kept ‘as stock’ in a separate cupboard and available ‘prn’ for residents who have been commenced on the LCP documentation and who have been prescribed them by their GP. If continuing discussions are successful with various stakeholders in Lothian, NHA will be the first nursing care home in the UK who has such a licence.

A second project undertaken by NHD involved the writing of a booklet for relatives explaining what to expect when someone is dying, and the procedure to follow once they have died. The booklet is being formally printed and will hopefully be used throughout the organisation. The compiling of such a booklet exemplifies that the culture in this NCH has changed to one that openly acknowledges dying as part of the care.

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4. EVALUATION

The purpose of the evaluation was to assess the feasibility of such a project, and to evaluate the implementation of the GSFCH framework and the impact it had on the end-of-life care being given by staff in the seven nursing care homes.

4.1 Aim and methodology

The aim of the evaluation was to explore the extent whereby implementing the GSFCH framework (along with the adapted Liverpool Care Pathway for care homes documentation, and the ‘Foundations in Palliative Care for Care’ course) is able to develop practice and help bring about a change in culture towards adopting a palliative care approach for nursing home residents in the last year of their life.

A ‘realistic’ evaluation (Pawson & Tilley 1997) was adopted. Pawson & Tilley (1997) highlight the importance of understanding the context when bringing about change and how the existing social processes are counteracted by the mechanism of change. In this project, the mechanism of change was the GSFCH framework and more particularly the 7C's of the GSFCH framework as a way of measuring more discretely the effect of the intervention. A case study approach of each of the NCHs enabled an individual care home analysis to occur alongside the overarching evaluation.

4.1.1 Data collection:

The evaluation used both quantitative and qualitative methods. The facilitator (JH) of the main project undertook the quantitative data collection. A research associate from St Columba's Hospice (JW), working one day a week for the project, undertook the qualitative data collection.

4.1.1.2 Quantitative data from three sources:

- *Retrospective review of notes:* The names of all residents who had died either in hospital or in the nursing home the year before the project (June '06 – May '07) and those who died during the first year of the project (June '07 – May '08) were requested. A retrospective review of the last 8-weeks of life was then undertaken. A proforma (see Appendix 6) collected general demographic data such as age, length of stay, diagnoses and type of death. It also collected specific data relating to the use of the supportive / palliative care register: the presence of DNAR notification, anticipatory care planning, number of inappropriate admissions / 'bed-days' and deaths in hospital; and, the use of the adapted LCP documentation.
- *Staff audit questionnaires* (Hockley et al 2004) (see Appendix 7) were sent to all care staff and nurses at the seven NCHs at the beginning of the project. Following the project those who had returned the previous questionnaire were sent a 'post' project audit questionnaire. Analysis was performed on 'matched' pairs.
- *Questionnaire* (see Appendix 8) to nine KCs post intervention

4.1.1.3 Qualitative data:

- *Interviews with relatives:* Semi-structured interviews with 36 relatives were conducted (see Appendix 9). Relatives were recruited for interview through the nurse managers of each NCH. Each nurse manager was given a template of a letter which they then adapted. Letters were printed on the headed notepaper of each individual NCH, signed by the nurse manager and sent to bereaved relatives. There was a tear-off slip and a stamped addressed envelope for the relative to reply straight to the research associate. During the interview family members were asked to tell the story of the last months, weeks and days of their relative's life with prompts in relation to the 7C's of the GSFCH. All interviews were recorded and transcribed verbatim.
- *Interviews with GPs and nursing home managers*: Semi structured interviews with 7 GPs (pre project) and 6 nursing home managers (post project) were undertaken. Only the nursing home managers' interviews (see Appendix 10) were analysed.

4.2 Analysis

The quantitative data was analysed using descriptive statistics.

The qualitative data was analysed using thematic and content analysis. Corner et al (2003) suggests that narrative-based data can produce new insights into the nature and quality of care when patients and carers stories are analysed for the number of spontaneous reports of ‘instances’ of care. A matrix was therefore developed around the 7C’s of the GSFCH framework in order to measure changes post implementation. The relatives’ interviews were scrutinised for ‘instances of care’ in relation to the 7C’s and analysed using content analysis. The 7C’s were designated as having *positive*, *negative* or *equivocal* outcomes. A positive outcome would be recorded if, for example, there was evidence of good symptom control. Likewise, a negative outcome would be recorded if there was a lack of communication about dying. A situation was recorded as equivocal if there was insufficient information to judge. At the end the positives and negatives were added up to give an overall balance of care.

Analysis was carried out as case studies within each of the individual NCHs as well as across all the NCHs.

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5. RESULTS

This section reports the results of the evaluation. Firstly, an overview is given in relation to the facilitation of the project that includes aspects of staff retention and the teaching of the *Foundations in Palliative Care* course for care homes. The quantitative and qualitative results are then reported.

All seven nursing care homes remained involved with the project until the end. However, due to staff shortages and staff retention, a number of NCHs struggled to keep apace with all developments. One nursing home in particular had 3 different NHMs with 72% of staff leaving during the 18-months of the project (see Table 2). It is therefore not surprising that making progress with the project was difficult for them. The majority of NCHs had over a 25% staff turnover during the year of the project. Only two NCHs had 16% or less staff turnover. In one of these NCHs three members of the nursing team died during the project.

NH	**NHMs &/or KC leaving**	**No. of staff leaving NH during project**	
		Staff	**%**
A	0	12	25.5%
B	1NHM	15	42%
C	2 NHMs + 1KCs	18	72%
D	1KC	23	36.5%
E	2KCs	15	53%
F	0	3	11%
G	1KC	8	16%

Table 2: Staff turnover

The facilitation of the *Foundations in Palliative Care* course for care homes gave key champions' time in which they could speak about their experience in caring for dying residents and their families. However, the majority of KCs also had significant personal losses they wanted to share. Out of the fifteen KCs who attended the 'Foundations in PC Course', 73% attended the whole course.

A pre-course questionnaire was used to measure nurses' knowledge, confidence and skill in different aspects of palliative care. Results of this averaged 50%; following the 4-day course this rose by over a third to 85%. Course feedback was extremely positive:

"I am very grateful for the opportunity to be chosen to be involved in this course as it has really helped me in a lot of areas. I was not as confident as I am now. The presentation [of the course] was absolutely fantastic".

"Caring for the dying is one of the nicest last things you can do for the person. This course has made me more aware [of things] that I wasn't always are of."

The full 4-day course was cascaded down in five out of seven NCHs. In these homes there was opportunity to relate the course to the specific issues of anticipatory care planning, talking about death and dying and other aspects specifically related to the GSFCH framework. Two NCHs with a high staff turnover struggled to find time to complete the course. However, staff commented on the constructive and easy to understand format of the course.

5.1 QUANTITATIVE RESULTS:

5.1.1 Retrospective review of notes:

The year *prior to* the project [June '06 to May '07] 110 residents died across all seven NCHs [nine residents' notes were unable to be accessed and six were incomplete]. Notes from 95 residents were fully examined.

During the main project year [June '07 to May '08] 138 residents died [five notes were incomplete]. A total of 228 residents' notes were therefore examined.

Residents were notably frail. Ages ranged from 66yrs - 103yrs. The predominant age range was 85-99yrs with over a third of residents falling into this category. Fifty-one percent of residents had multiple co-morbidities of three or more diagnoses, with dementia being the primary diagnosis in 66% residents. Considerably more residents died within two years of admission during the project year (see Table 3). This could be due to the increasingly frail population of older people now being admitted to nursing care homes.

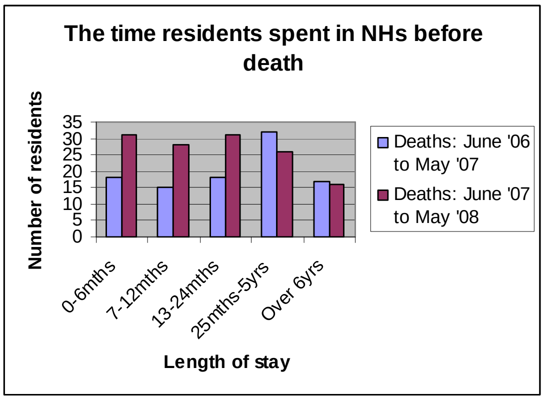
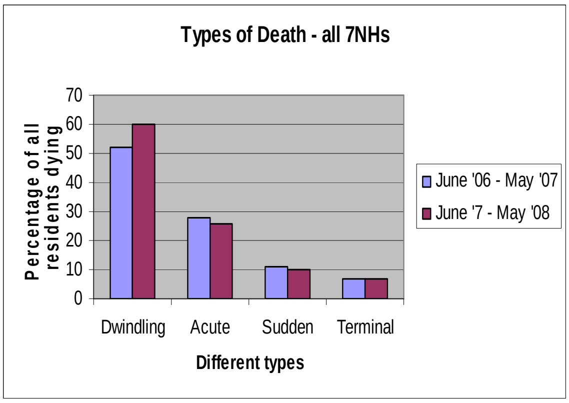


Table 3: Time residents spent in NH

Four ‘types’ of death were evident in the review of notes (see Table 4). Before the intervention, the type of scenario that was most likely to cause admission to hospital within the last 8-weeks of life was an acute event (e.g. extension of a stroke; silent pneumonia). A sudden death was likely to precipitate ‘999’ calls including cardiac resuscitation. Such a scenario was often followed up by a ‘police’ inquiry to the NCH because the resident had not been seen by their doctor in the last 10 days. A ‘sudden’ death in a frail elderly resident in the homes was not seen as part of natural dying prior to the project.

However, the majority of residents both the year prior to the project and during the project died from a ‘dwindling’ death. Deterioration happened slowly over a matter of months/years. The least common type of death was that of an easily diagnosed ‘terminal’ condition such as cancer or Parkinson’s disease.

Table 4: Type of death



5.1.1.2 Supportive / palliative care register:

The supportive/palliative care registers and the ABCD coding played an important role in being able to discuss on a regular basis the individual needs of all residents in the NCH and, in particular, address the needs of those residents who were seen to be deteriorating and possibly only had weeks to live . Four out of the seven NCHs had the register set up and reviewed on a monthly basis within 3-months of starting the project[1].

By the end of the project, all NCHs had a register being updated monthly. GPs/nurses with the exception of a GP to one NCH, valued getting an overall monthly review and being able to receive support regarding difficult family dynamics and communication. In the NCH where the GP was not so keen, the NHM decided to specify a regular time each month when she would sit down on each of the wards with the register; this was then reported to the GP as appropriate. During the project there were two episodes where staff in the NCH could not find the register prior to a monthly meeting and the register had to be re-started.

Considerable effort was required to help staff understand how the register could help them anticipate care needs using the care needs matrix rather than the register just being a monthly coding/check list. In some of the less robust NCHs, having a resident 'C' on the register (only 'weeks' to live) did not always guarantee that communication with families had been established especially if the GP had not initiated such a conversation. There was therefore still a danger that the resident could be inappropriately admitted to hospital in the last 8 weeks

a) 'Do not resuscitate' orders [DNAR]

Prior to the study only 7% of residents notes had an instruction about 'do not resuscitate'. One NCH in particular had developed a culture of phoning for a 999 ambulance for any emergency in order to 'cover their backs'. There was little judgement in relation to the individual appropriateness of such a call. On one occasion an 87yrs lady with very advanced dementia collapsed and died on her way to breakfast. Because an ambulance had been called resuscitation was attempteded for 20 minutes before the resident was pronounced dead.

By the end of the project, however, there was much greater confidence in acknowledging the appropriateness of a palliative care approach for residents' with advanced progressive incurable diseases. Staff were much more comfortable with the dignity of allowing natural death of an old frail resident with advanced disease. A DNAR form or written evidence was present in over 60% of residents' notes in five of the seven NCHs (see Appendix 11).

b) Anticipatory Care Planning [ACP]:

Although DNAR forms were used very successfully in the NCHs, anticipatory care planning was more complex to introduce. This was highlighted in the *lower* percentage of notes having written evidence (either in the care plan or using an ACP form) compared to DNAR forms by the end of the project (see Appendix 11). Three quarters of the notes

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[1] Two of the other NCHs had requested commencing the project by implementing the adapted Liverpool Care Pathway. The final NCH was slightly delayed because of a change in management (albeit within the family) just when the project was commencing.

from NHG had evidence of ACP but they had already been involved in a previous palliative care project, and were already more confident in discussing end-of-life care.

An anticipatory care planning form (Appendix 12) that had been adapted from the GSFCH documentation was available. Some nurses found the form useful to commence initial discussions. However, not every NCH used a form. Many nurses who had trained overseas did not feel competent talking about an anticipatory care planning with residents and/or relatives.

When anticipatory care planning was not being practised there was a greater likelihood that deterioration towards dying was then not recognised. This prevented appropriate communication both with the families and the primary care team. In NHB ‘striving to keep alive’ and a culture of phoning 999 was endemic at the commencement of the project. Staff in this home had achieved a considerable amount; however, despite the project, there were incidences where deterioration towards dying was still not recognised or acknowledged (see Box 2).

Box 2: An outline of a 88yr-old resident who had been in NHB for 3 yrs – he was suffering from Parkinson’s Disease, COPD, Hypertension, Depression and Dementia.

10th March – Long lie again as per James’s request. Needs air mattress as skin marking.
11th March – Unchanged – he was a bit sickly this morning but no vomiting noted.
12th March – Appetite good at breakfast. Appears bright.
13th March – Remains frail. Had a fall from his chair 11.30hrs.
14th March all care given – ate well at breakfast
15th March – Remains frail – noted to be chesty – for doctors review on Wednesday.
16th March – In the dining room for breakfast
17th March – looked tired. Ate breakfast independently but swallowing worse.
18th March – continue to encourage to eat and drink
19th March – seen by GP – observe regarding chest problem
20th March – restless – took off pyjama top
21st Remains frail – on bed rest when requested. Dietary and fluid intake minimal. Still chesty but not problematic
22nd March – brighter to-day. Family been to visit
23rd March – Still needs more encouragement to eat and drink. More settled to-day
24th March – no new problems
25th March – still appears frail
26th March – choking episode at breakfast while eating porridge. S/B GP – Adcal discontinue – refer to SALT
27th March – chesty with secretions. Remains unwell
28th March – Brighter this morning
29th March – more settled
30th March – All care given
31st march – Unable to bath due to not looking so well.
1st April – Remains brighter – up in comfy chair for a while
2nd April – Looks frail. S/B GP re deterioration and distress. GP will speak to family
3rd April – Remains frail
4th April – Fever – 37.3 – Paracetamol given – remains chesty and frail. Spoke with GP – he had spoken with the family and they have decided to give another course of antibiotics
5th April – on antibiotics – up in dining room for breakfast – moderate amount – still chesty
6th April – Ate all breakfast
7th April – Remains very frail
8th April – good appetite
9th April – Chesty
10th April – Choking episode
11th April – Remains very tired and frail
12th April – Very bright – ate all breakfast with assistance
13th April – Remains frail – had a long lie on bed
14th April – needs airflow mattress
15th April – Fluids given with difficulty
16th April – Ate breakfast in dining room – still frail
17th April – Good appetite taken at breakfast – still very frail looking – keep observing
18th April – Remains frail – dietary & fluids intake as charted – all care continues as planned
19th April – 17.10hrs Looking tired, remains frail. Obs taken: B/P 90/70; Pulse 88: Resp 22; Temp 39°C – paracetamol given.
18.10hrs Found unresponsive & breathing absent – no pulse or heartbeat.

Box 2 highlights the euphemisms used instead of recognising dying – euphemisms such as ‘frail’, ‘looks tired’, ‘not looking so well’. This gentleman had his blood pressure taken one hour before his death and yet there is no comment on how he appears. There is no mention that this gentleman might be in his last few weeks of life despite the subtle changes occurring in being unable to feed himself, requesting to stay in bed, being chesty, choking on fluids. GPs and nurses alike in this project found it difficult to acknowledge ‘pneumonia as the old man’s friend’ even when a resident was very frail and old and suffering multiple co-morbidities. The repetition of antibiotics in the last weeks of life of a very frail older person colludes with the denial that the person is not dying. Prior to the study the majority of notes showed at least 2 different courses of antibiotics in the last month of life. This was still an issue during the project although not quite so prevalent.

Embedding the GSFCH framework in order to develop a palliative care approach in such a weak context requires considerable persistence that may not be possible in short term projects. Collaboration and support therefore from local specialist palliative care who can then reinforce what has been demonstrated and help to sustain changes is very important.

c) Inappropriate admissions and deaths in hospital in last 8-weeks of life:

As a result of the use of the supportive / palliative care register encouraging the completion of DNAR forms, coding of residents and an increased discussion re anticipatory care planning meant that ‘inappropriate admissions’ to hospital were reduced.

An inappropriate admission to hospital was categorised if the resident was over 88yrs, had dementia and been gradually deteriorating over a number of weeks and died within 2 or 3 days of admission from a pneumonia. The project reduced these from 141 (82%) inappropriate bed-days ‘pre’ GSFCH to 84 (44%) inappropriate bed-days ‘post’ GSFCH (a reduction of just under 40%). Prior to the project 15% of all deaths across the NCHs occurred inappropriately in hospital. During the year of the project this was reduced by almost half to 8% (see Table 5).

These results do not include two ‘equivocal’ incidences. One was a 66-year old gentleman with dementia who had only been in the nursing care home for 2 months who was admitted to hospital for PEG-tube feeding. He died 32 days later in hospital without insertion of the tube. From reviewing the age of the residents who died in hospital, it was more likely that a resident was admitted inappropriately to hospital ‘post-intervention’ if he was aged 74yrs or under.

The second case is highlighted in the qualitative data where the resident wanted to die in the care home but his wife wanted him admitted to hospital. Even adding these equivocal cases into the inappropriate hospital bed days ‘post’ GSFCH there is still a reduction of 21% in bed days.

Table 5: Hospital admissions and deaths Pre/Post GSFCH implementation

	Pre- GSFCH [June 2006 - May 2007] n=95		**During GSFCH [June 2007- May 2008] n=133**	
Number of hospital admission in LAST eight weeks of life	29 admissions	31%	32 admissions	24%
Inappropriate* days spent in hospital in last two months of life	141/171 Inappropriate bed days	82%	84/190 inappropriate bed days	44 %
Hospital Deaths	14/95	15%	11/133	8%
*Inappropriate:	Residents (over 88yrs) with advanced dementia who had been gradually deteriorate over a number of weeks requiring full 24hr nursing care being admitted to hospital with suspected pneumonia/dehydration and/or dying in hospital within 3 days of admission.			

5.1.1.3 Liverpool Care Pathway [LCP] documentation

NHG was the only care home that had had previous experience using the adapted LCP documentation. The NCHs (NHA, NHB & NHG) that implemented the documentation early on in the project (see Appendix 11) were confident users by the end of the project. There was considerable support from staff for the documentation. Care staff felt using the adapted LCP documentation gave them a chance to put down on paper the care that they were giving. For the nurses, the documentation was more succinct and it gave them a guide to the particular aspects of care that were important. The intensive training of the adapted LCP documentation around the last days of life meant staff were more confident when chatting with families about what was happening at any point in the dying trajectory. Care staff felt more involved and ‘part of the team’ as a result of using the documentation. Because the documentation was kept in the resident’s room (unless being used for a handover meeting), there was then no denying that the person was dying.

Two NCHs never got the opportunity to use the documentation with a dying resident as the training was too late in the project for them to get supported in its use. Because of this, it is likely that the teaching will now need to be repeated.

5.1.2 Staff Audit Questionnaire:

The 50-question staff audit (see Appendix 7) was analysed using returns from staff who had returned both the pre and post audit. Sixty-eight staff returned both audit questionnaires across the seven NCHs; five forms were incomplete so not included. In two NCHs (NHC and NHE) - both of whom were less robust homes as far as the implementation of the whole framework was concerned - only one staff member returned both pre and post audit. It is important to recognise that those staff who had returned the questionnaire were likely to be the one specifically interested in the subject or who felt that they had benefitted from the project.

In five out of seven NCHs represented by the returned audit questionnaires, there was evidence from that staff's attitude towards a palliative care approach was changing. How sustainable this influence will be in the future is discussed later in the report.

The breakdown percentage of each statement of the audit is presented (see Appendix 7). A total of 88% of staff returning questionnaires stated that the project had helped them realise the importance of 'quality of life' for residents rather than striving to keep alive (Q.2). Giving unrealistic hope to residents and/or families (Q.7) was now much more likely to be challenged. A third of people returning the questionnaires had only received teaching on end of life care (Q.3) since taking part in the project. Staff felt much more confident in addressing the psycho-social & emotional needs (Q.9).

Staff felt more confident not only talking to relatives about dying but also to residents (Q.20). Whereas before, staff had wanted to 'cheer up' residents, now they were prepared to listen and continue a conversation if death/ had been mentioned.. However, in the less robust homes partly as a result of changing staff, there was still a lot of fear in talking about death and dying in case they got it wrong. The adapted Liverpool Care Pathway documentation had broken the collusion about dying since it was kept in the resident's room for all to read but the two less robust NCHs had not used this documentation yet. Staff were much more confident about what they had learnt about viz a viz recognising the different stages of the dying process (Q.22) – a quarter had never done this before. Over half of those returning the audit said that the study had helped them prepare new staff for caring for dying residents and families (Q.39); with staff from NHA saying that this had never been done before.

There were still areas where the project had not been able to influence the culture. This was mostly in relation to management issues (Q.33; 36; 37). When it came to being able to get more staff to sit with a dying resident or have a specific member of staff looking after a resident – the project had not really had any influence over this. Unless the nursing home manager's attitude (and the nursing home provider) towards caring for the dying had changed sufficiently, more sympathetic care towards staff in the care of dying did not occur. There were also some equivocal scores that revealed that there may still be issues to do with an openness after a resident's death (Q 42; 45; 46 47) and informing residents and also staff (not on duty at the time) about the death.

5.1.3 Key Champions Questionnaire

There were considerable cultural issues especially in the area of communication and symptom control where KCs struggled at the beginning of the project. For many these areas of care were traditionally the domain of the doctor not the nurse.

Six out of nine key champions returned a questionnaire at the end of the project (NHC no longer had a KC and NHE did not return). Those who returned their questionnaire highlighted how they now had a deeper understanding and/or greater confidence in practising palliative and end-of-life care as a result of being part of the project. All of them stated that there had been a change in end of life care in the NCH with a greater *openness towards death and dying* being stated as the main change. Not only were staff more comfortable talking to residents and relatives, but the practicalities of bodies leaving a NCH had been challenged in some of the NCHs; instead of using body bags, undertakers were now being asked to use a coffin and take bodies out of the front door instead of a back door.

Key champions from three NCHs reported that the project had highlighted difficulties communicating with GPs. However, one key champion had felt that the project had directly helped in this communication. There were a number of other difficulties experienced by KCs: staff were seen to be ‘set in their ways’ and reluctant to change; difficulties getting to the KC workshops in London; lack of NCH support; and, lack of computer access.

Key champions rated all three systems (Supportive / palliative care register; the adapted Liverpool Care Pathway documentation; and, The Foundations in Palliative Care course) as being useful. The London workshops were seen as the least useful – the long journey to London may have contributed towards this result.

Issues that still remained challenging for KCs were: coping with an unexpected death; speaking about end-of-life decision making; communicating with relatives who still wanted cardiac resuscitation or did not believe that their loved one was dying; getting ‘prn’ medication prescribed even when a resident was on the LCP.

5.2 QUALITATIVE RESULTS:

5.2.1 Interviews with Relatives and Nursing Home Managers

Thirty six relatives were interviewed from six NCHs; 22 pre-intervention and 14 post-intervention. No relatives were recruited from two of the nursing care homes post-intervention. One of these homes did not recruit any relatives to the pre intervention interviews (see Table 6).

NH	Response Rate Pre GSFCH	Response Rate Post GSFCH
A	87.5%	40%
B	33%	33%
C	67%	-
D	57%	67%
E	-	-
F	16%	25%
G	67%	86%

Table 6: Response rate by relatives to being interviewed

Interviews lasted between 30 minutes and 80 minutes. Relatives were relaxed about sharing their experiences even though they were at times quite emotional. Several relatives wanted to show a picture of their relative. There was a range of bereavement times (2 months – 13months) and also the relationship to the person who had died;

however, the majority were daughters. Most people praised nursing home staff and were very grateful for the care they had received.

A matrix was designed as Corner et al (2003) suggest to measure changes in the balance of outcomes of the 7C's as a result of the GSFCH intervention. Results from *all* the NCHs highlighting each aspect of the 7C's are shown in Appendix 13.

Analyses *within* cases (i.e. NCHs) is illustrated in Appendix 14. In the pre intervention interviews with relatives, all NCHs had some positive outcomes in all categories of care denoted by the 7C's of the GSFCH. However, they tended to be cancelled out by negative outcomes. Following the intervention, the number of positive outcomes increased and the number of negative outcomes reduced, contributing to an overall increase in the balance of positive outcomes (see Appendix 14). This suggests that overall the project has had a positive impact in terms of the 7Cs.

When the data is analysed *across* all NCHs, there is significant improvements in the following areas: care of the dying, control of symptoms, continuity of care, carer support (families) & continued learning. This confirms results of some of the quantitative data previously addressed.

Changes in the 7Cs across cases (NCHs) are now reported under the heading of the 7Cs.

i) Coordination

Although there was not an obvious change in coordination post intervention in terms of leadership, looking at this aspect was useful in identifying which homes had a stronger context at the beginning of the project. Those homes where relatives identified strong and consistent leadership were much more successful in implementing the changes, for example NH D:

> *"I think the manager Sarah was very nice, I think a lot of it's to do with the management and that, it just seems to have… the staff all seem to get on well, there was no, I never seen any bad feeling towards one another…"* [Pre Rel.D1]

NH F had the strongest performance before and after the intervention:

> *"Looking back on it, I think if everybody's end could be like that you'd have nothing to fear"* [Pre Rel.F1]

> *"The end was so dignified, it was so well done, I couldn't fault them."* [Post Rel.F1]

It seems that good leadership set the tone for this:

> *"I must mention Mrs Smith, [the owner] …she sets the guidelines, she set the rules and its run to that…cleanliness and everything …I remember once we came out and my husband said to me 'do you realise how lucky you are to have your mother there?' and I said 'every day"* [Pre Rel.F1]

There are a few examples from managers' interviews where coordination has improved though better working relationships with GPs, particularly brought about by the use of the ABCD register:

> *"[The ABCD register] has actually worked out quite well here…we have the GP involved, Jo is usually here, myself, a staff nurse and a member of staff…the GP coming in has been great…she has actually got more of a rapport with the staff now."* [NHE Manager]

ii) Continuity of Care

Many of the '*pre-intervention*' interviews highlighted a lack of continuity of care particularly in terms of advance care planning and inappropriate admissions to hospital:

> *"When we got to the home the doctor said the ambulance will be on its way but I can cancel it if you like. Do you want your mum to stay here? Or do you want her to go to hospital? I said well it's difficult to know, is mum suffering? If she is suffering then we better have her in hospital and see what they can do for her…I said to him is she in pain? He says well I really can't tell if she is. This is what I'm trying to find out."* [Pre Rel.A3]

This lady did go to hospital but was transferred immediately back to the NCH where she died a day later. This scenario highlights where palliative care education could promote confidence in diagnosing dying, symptom management and taking responsibility for these decisions. Alongside the use of the LCP, continuity of care could be promoted among all staff particularly out of hours and at night, and thus avoid unnecessary transfers such as described here.

A similar scenario below seems to suggest an absence of advanced preparation or planning or any understanding from the relative of the resident's likely disease progression. It is interesting that again it is the GP having this discussion at a moment of crisis.

> *"It was the GP who actually phoned me and he asked me, what do you want to do? And I thought well, I didn't understand the question to be honest, because it was such a surprise. I thought well, he said 'do you want her to get medical attention?', I said 'well yes, obviously'. So it's a bit strange the way he put it across. I don't know if I just wasn't ready for that sort of question. Obviously I was looking for her to get the best attention she could get."* [Pre Rel.A4].

However, '*post-intervention'* there was signs that things could be different.

> *"…. NHS24 don't know the people & sometimes that can end up where they say, 'have you got a DNAR order' or 'have you got any idea of what the wishes are?', and we didn't at that point. Where now, yes, we are able to say, we have this, this and this and we have had these discussions and you know, we are able to express what the family and the person would want. Its much more confident."* [NHA Manager]

There were more examples of staff proactively speaking with relatives and guiding them appropriately in their decision-making:

> *"And Nurse Jane talked about the difficulty of moving to a hospital and the unfamiliarity of that and the kind of anonymity and the fact that the staff in the hospital*

wouldn’t know her and her ways and what she liked and didn’t like… so it made absolute sense to me that she should be in NHG if at all possible.” [Post Rel G6]

iii) Control of Symptoms

In terms of the control of symptoms [such as pain or nausea - common symptoms within a hospice setting] these were rarely mentioned by relatives. There were however some negative examples pre intervention in relation to pain:

“And then my daughter was in at night time. The pain was that much that she was pulling her hair out. My daughter had to go away and say ‘can you not give my gran another injection, because she is in absolute agony here’. I had to ask them to call in the emergency doctor…he took one look at her leg and he doubled the dose right away…he says ‘its quite obvious that she needs it.” [Pre Rel B2]

Also there were examples of where a review of medication was not considered when swallowing became difficult:

“Oh she was sore, in her back at the base of her spine…she was on painkillers yes but I found they were quite big and she had trouble swallowing them. She was on quite a few tablets at that time with the antibiotics and painkillers and I don’t think she could take them all.” [Pre Rel A1]

Issues more likely to be identified by families prior to the intervention were in terms of comfort measures such as positioning in the bed or mouth care. There seems to have been an improvement in all of these post intervention in that they were rarely mentioned. There was recognition of expertise and knowledge in most of the care homes, about managing dementia.

iv) Communication

Communication could be considered to be an integrative theme that underpins all the 7C’s so, in a sense, it is somewhat artificial to look at it as an entity in itself. However there were various dimensions of communication identified and categorised in the matrix such as discussions about death and dying, proactive discussions about current condition, and dealing with particular problems. Overall communication did improve as a result of the GSFCH project. Nonetheless, there were still difficulties with complex communication. Post intervention there was a situation where the resident wanted to stay in the care home but the wife wanted her husband transferred to the hospital to die. Communication had been done separately with husband and wife even though each knew the others wishes. The consequence of this was that the resident died alone in hospital and his wife has ongoing unresolved issues relating to this.

“So there’s a concern in my mind and it’s a question which I have asked myself for a while after that and no doubt I’ll be thinking about it again tonight is, was he lonely in that time.” [Post Rel G5]

This unfinished business underlines the importance of good end of life decision-making. Complex communication issues such as this, which the multidisciplinary staff of a hospice can deal with adequately, are often very difficult in a NCH setting without more adequate teaching and role-modelling.

v) Continued Learning

Pre intervention there were times that relatives identified that the staff did need to improve their knowledge of care of the dying:

> *"I think they all need to go on a care of the dying course."* [Pre Rel C3]

Post intervention there was evidence of continued learning and areas where the staff were being challenged in their thinking and practice:

> *"It's come more to light with me where I can now stop antibiotic therapy if I feel that, you know this resident, it is not really going to benefit this resident through the dying process. Whereas before I would always persevere with antibiotics, I always had an element of, oh there could be hope, there could be hope. And I was just really going through false hope then. So realistically there's areas in it where I have become more aware of situations which only really prolong the dying process instead of giving the resident their dignity that they deserve at the end."* [NHF Manager]

However, the challenge of learning in a NCH were clearly identified by one manager:

> *"You seem to be in a constant cycle of training without any consolidation or application…four of our carers this year who did VQ2 training and participated in all the palliative care training that was going…at the end of it, when they have got that, it makes them a very attractive proposition to the NHS and everybody else who can pay up to £2 an hour more than we can."* [NHC Manager]

vi) Carer Support

There were times pre intervention when families did not feel supported while their relative was dying:

> *"I don't think they really expected people to be there when a death took place. I think there has to be a provision for when people do die…that you are made at home really. I don't think we got a cup of tea the whole time."* [Pre Rel.C3]

On the whole however there were many good examples of how relatives were supported while their relative was dying and in their bereavement. Poor examples such as that above greatly diminished post intervention:

> *"They were all great. All the nursing staff came up and gave us a cuddle and said they were sorry…they had her all nicely changed and cleaned up. Flowers in her room. So they were lovely."* [Post Rel.D4]

An important aspect of GSFCH is the recognition that staff will have support needs when a resident dies and that they need an opportunity to say goodbye. There were examples of this pre intervention and they increased post intervention. NHG, who had taken part in a previous palliative care project, were particularly good at this aspect of end of life care even before the project:

"The undertaker wheeled my dad out in the coffin and I walked behind with Sister Sandra…all the doors were open and the residents that could were sitting at their doors...the night staff were coming on and the day staff… every single one that had looked after him was actually there. And that was absolutely lovely." [Pre Rel.G2].

vii) Care of the Dying

In some of the nursing care homes like NHD, good palliative care already underpinned the philosophy of the home as illustrated by positive balances for all the 7C's of the GSFCH (see Appendix 13a & 13b). However, when examining post intervention data there was a *stronger* performance overall, particularly in the care of the dying category. An intervention such as the GSFCH has the potential to give the staff in nursing homes the confidence and the knowledge to be able to care for dying people without doubting themselves. Many relatives are not articulate, or sure of what they want for their loved one as the relative quoted below:

"And I think the other thing is…hold your nerve when somebody is dying. You could panic, you could panic and say I want a doctor……like with nurse Susie [who said] 'do you think we should phone the doctor?" [Pre Rel.D3]

If staff do not feel confident communicating about dying it is easy to see how inappropriate transfers of dying people to hospital occur. A growth in **confidence** in the staff in end-of-life care and communicating about dying was perceptible, despite in this case in NHD, not using the LCP.

"I just felt part of it. They kept me so well informed" [Post Rel.D2]

There were also more positive and more emphatic descriptions of good physical care after the intervention:

"But as to when she was dying and when she died, the care was definitely excellent. They made her comfortable…her bed was changed every single day. She was changed, she was washed, you know given a bed bath and everything was done for her." [Post Rel.D3]

The openness of death and dying was something in particular that needed to be challenged for the intervention to be successful in some homes:

"Nurse Beatrice had again given me the option of having her taken up to the hospital. Because I think nurse Beatrice is a person that a person's life should be prolonged regardless… and she had said that as long as she was on duty she'd be making my mum eat and not have her doped up and passed away. Which I thought was, you know…not the way, if I had chosen for my mum to be left peacefully she should really have been left peacefully." [Pre Rel.B2]

The study shows that staff did become more aware of these cultural issues and that they are starting to be addressed.

> *"We have a large number of [nurses who haven't trained in the UK] & one of the biggest challenges for them was the idea that you could actually have a planned death. Because in their culture you do everything you can to sustain life…so that was a bit of a challenge there for them to understand that there was a time to die…that we weren't assisting death but planning for the inevitable."* [NHB Manager]

Pre intervention it was often relatives who recognised dying and realised that their loved one had reached the natural end of their life:

> *"And he stopped wanting to take the antibiotics, you know, and although, they were still trying to give them to him. And I said to them at that time that I did not want my father to go into hospital, I did not want him to have (CPR), you know, I really didn't. If he was going to die I wanted him to die peacefully with dignity and quietly without being rumbasted off to hospital and being fought over. You know I just couldn't bear all that, and they honoured us."* [Pre Rel.C1]

A lack of recognition of dying was an issue pre intervention in NH C, something which throughout all the homes did improve after the intervention. The acting NHM recognised how the ABCD register could help with this problem.

> *"Because, when you are very, very busy, and sometimes these changes, the gradual deterioration, may pass you by. But when you actually have to sit and focus on, you know, updating the register…you think, oh yes, something has happened there, it's time to move onto the next stage. And that's a prompt to say…when I next see the relatives I must make sure we are ready for that and talk it through with them."* [NHC Manager]

6 DISCUSSION

In recent years there has been a welcome breakthrough whereby nursing care homes have been included in the strategic development of palliative and end of life care. The Department of Health's End of Life Care Strategy (DoH 2008; Scottish Government 2008) highlights the importance of collaboration of primary care with nursing care homes. It is hoped that as a result of this Midlothian GSFCH project, nursing care homes' profile in relation to the expertise that can be gained through the implementation of these end-of-life care tools will be raised in Scotland.

The results section highlights the changes that occurred through implementing two systems advocated by the GSFCH framework: the *supportive and palliative dare register*; and, the *adapted Liverpool Care Pathway* for the last days of life in care homes, namely:

- Increase in explicit end of life decision-making
    - Use of anticipatory care planning rose from 4% prior to the project to 55%

    - Use of DNAR forms rose from 8% of all notes reviewed prior to the project to 71% during the project year
- Fewer inappropriate admissions to hospital:
    - A reduction of inappropriate ‘bed-days’ in hospital by 38%
    - A reduction of deaths in hospital from 15% residents preceding the project compared to 8% residents dying in hospital during the year of the intervention.
    - An improvement in the quality of end of life care delivered from the perspective of bereaved relatives

However, the authors strongly believe that some of these results would not have been attained without the relatively ‘high’ facilitation (Kitson et al 1998) used; namely, the experience of the specialist nurse facilitating the framework and the time spent with individual nursing care homes. The facilitator worked on average 4-days a week across the seven NCHs. Because of this there was an opportunity to role model complex communication situations, work alongside staff, support the key champions with cascading education and training through the ‘Foundations in Palliative Care’ facilitative learning pack *within* each of the care homes. These were major attributes of the facilitation. The implementation of systems alone is not likely to bring about change. It is the support and valuing of staff and the appointed key champions that play an equal part.

Despite these seemingly encouraging results, issues to do with the poor retention and recruitment of staff will clearly undermine further development of palliative care in at least three of the less robust care homes taking part. What made nursing care homes less robust? Change in leadership and/or care home provider was a major cause for staff to leave a home and seek other employment. If staff did leave, they often left to work in other nursing care homes within Midlothian – some left to go back into the acute hospital setting because of better pay, pension and ‘sick pay’ provision. However, the majority of staff did not work in care homes because of the money they received. They longed to feel more appreciated for the work which included having more ‘hands on deck’. Care staff in one home had their pay increased a small amount to £5.99p/hr and not £6; staff commented how getting the extra ‘p’ would have made all the difference to morale but it had been refused.

There is considerable pressure from regulators for nurse managers to keep up with the statutory training on moving and handling, nutrition, health and hygiene etc. This meant that prior to the project palliative and end of life care training in the home was rarely arranged. It was significant that over 30% of staff across the project had never received palliative and end-of-life care training in the home before. The recent ‘Making Good Care Better’ document (SPPC 2006) containing practice statements for generalist palliative care in adult care homes being used by the Care Commission to assess quality of palliative care in care homes, meant that nurse managers were keen and made an effort to carve out time for staff to attend training in palliative care during the project. However, when palliative care is not so high on the regulators agenda, or if nurse managers in the project homes change, unless a palliative care approach has been established there is a danger that interest will wane in line with the societal taboo towards death and dying.

Working more collaboratively with GPs was something that the project achieved. This was aided by the fact that DES (direct enhanced service payments) for GPs for work in the nursing care homes was introduced in Lothian during the project. There is considerable debate in the literature on medical services to care homes providing nursing care (Jacobs 2003). Historically nursing care homes have not had sufficient medical input considering the frailty and extensive co-morbidities of residents. Now that the majority of residents in nursing care homes are likely to die within two years of admission (Katz & Peace 2003), an increased clinical support from GPs is important if inappropriate admission to hospital is to be avoided. It could be argued that the monies saved as demonstrated through this project on inappropriate admission to hospital should be ring-fenced to provide more adequate medical support in nursing care homes.

The analysis of the relatives' interviews highlighted improvement in five out of seven categories of the 7C's of the GSFCH framework: care of the dying, control of symptoms, continuity of care, carer support (families) and continued learning. The category that saw the most improvement (care of the dying) may be related to the actual adapted LCP documentation that was introduced alongside the intensive training.

The matrix (adapted from Corner et al, 2003) that was used to capture the 7C categories from within the transcription of the relatives' interviews, and thus analyse data as part of the evaluation of the implementation, was novel. Such a tool could be further adapted to help in the evaluation of some of the other end of life care tools being recommended by the End of Life Strategy (DoH 2008). Interviews with relatives show that families are a very rich source of information that can help inform gaps in end-of-life care, gauge how staff are doing and also a source of great encouragement when things are done well.

It was evident from the relatives' interviews that it was often the GP who was taking the lead in initiating discussions when a resident was dying if anticipatory care planning had not already been discussed. Staff in some nursing care homes did not feel confident talking openly about death and dying even at the 6-monthly resident's review meeting with the family. Having a resident 'C' on the register did not always guarantee that communication with families had been established. There was therefore still a danger that the resident could be inappropriately admitted to hospital in the last 8 weeks. It is the multidisciplinary working relationship that is actually key to good anticipatory care planning. Nurses within the nursing care homes need to feel more confident about the concept of a palliative care approach.

Despite the high facilitation, the authors believe that eighteen months is not long enough to bring about a sustainable change in a context that is 'weak'. Nursing home managers and key champions are therefore keen for a local 'NCH palliative care forum' to be established in order to sustain the work. The forum's role would be to help organise continued training for both new and old staff alongside local specialist palliative care. A step down project to help establish the Nursing Care Homes Palliative Care Forum is proposed:

6.1 Sustainability of the Midlothian GSFCH project:

Eighteen months for this project and the recommended GSFCH accredited two-year programme, is too short a time to bring about sustained changes in any but the most robust and enthusiastic nursing care homes. Sustainability is not without cost. Because of staffing retention and leadership issues, particularly in three of the nursing care homes, more help is required through a ‘step-down’ sustainability initiative.

The ‘step-down sustainability’ project would be for 2 days/week for 2 years and has the potential to consolidate and embed the changes that have been made and help those nursing care homes go forward for GSFCH accreditation. The formation of a local ‘*NCH palliative care forum’* would help support NCH managers and key champions in embedding the palliative care training and skills that they have acquired during the Midlothian GSFCH project. The NCH palliative care forum would work very closely with a nurse specialist from Marie Curie Hospice Edinburgh over a 2-year period. During this period the following would be established:

The step-down project holder needs to empower the nursing home managers to introduce:

- *Palliative Care Induction Day* (twice a year) – all new staff to a nursing care home in Midlothian will undertake this day within six months of starting. The content of the days would include explanation of the ABCD register, DNAR forms, teaching on communication, assessment tools with regard to pain and depression, LCP documentation
- On-going palliative care training (for those staff who have been in the nursing care home for more than one year) using: ‘*Foundations in Palliative Care for Care Homes’*
- Role-model ‘communicating about death and dying’ in the less robust nursing care homes or in complex communication situations as a way of transferring skill when speaking with families and/or residents about death and dying

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7 Conclusions & Recommendations

The ‘high’ facilitation model used to implement the GSFCH framework in all seven nursing care homes in Midlothian has obtained significant results. There was an increase in DNAR status from 8% to 71% across all seven NCHs. As a result of increased anticipatory care planning there was a reduction from 15% to 8% of residents dying in hospital, with a reduction also of inappropriate hospital bed days by over 40%.

Some of the nursing care homes taking part in this project could go forward for GSFCH ‘accreditation’. Accreditation requires conclusive evidence of the on-going use of the GSFCH framework and the production of a portfolio. However, because there was significant staff turnover in a number of nursing care homes this may prevent all seven nursing homes achieving on-going accreditation without a ‘step-down’ initiative to embed the changes over a longer period of time.

7.1. Key Recommendations:

7.1.1 Organisation:

- The Gold Standards Framework for Care Homes can help improve the quality of end of life care to residents and families. However, sustaining the quality needs to be done through '*accreditation*' status with GSFCH programme
- Palliative care needs of residents dying in nursing care homes can be complex and require greater availability of palliative care support
- Formal links between nursing care homes and palliative care support need to be established to empower staff in nursing care homes
- GP Direct Enhanced Service payments for nursing care homes have been beneficial and should be continued. Monies saved from inappropriate admission to hospital could be ring-fenced to pay for such a service.
- A 'palliative care forum' of local nursing homes would support those who have taken part in the project to continue to embed palliative care within their homes
- Provision of monthly organised reflection times following the death of a resident would help support staff alongside increased learning

7.1.2 Systems:

- The use of the supportive/palliative care register helps staff with the 'coding' of residents deterioration and therefore anticipate the care needs of residents and their families in the last months of life
- Appropriate communication regarding DNAR status should be addressed when a resident is admitted to a nursing home
- Advance care planning should be offered as part of routine care at or soon after admission as a way of reducing inappropriate admissions
- 'Review' meeting with families need to emphasise 'anticipatory care planning' and the appropriateness of allowing natural death in the very old and frail at the end of life.
- The use of assessment charts for the management of pain (Doloplus-2) and depression (Geriatric Depression Scale) is advised
- A review of more realistic dependency scales for frail, elderly residents and the necessary attention to adequate staffing
- The Liverpool Care Pathway for care homes should be used to ensure that a resident is regularly assessed during the dying period
- Provision of monthly organised reflection times for staff following the death of a resident would help support young, inexperienced staff in care homes.

7.1.3 Training:

- Pre-training and competencies in palliative care for care assistants prior to employment in nursing care homes should be considered to improve palliative care understanding and retention of staff
- '*Foundations in Palliative Care for Care Homes pack*' facilitation by senior nursing staff will help cascade down knowledge learnt through the GSFCH project
- Specialist palliative care nurses need to 'role model' good communication about death and dying in struggling nursing care homes to assist complex family situations
- All new staff require palliative care training

- All nurses working in care homes providing nursing care should hold a certificate for ‘verification of death’ training

7.1.4 Further Research:

- Further research into sustainability of the implementation of end-of-life care tools
- Research looking at ‘nursing home providers’ understanding of the level of palliative care within their organisations.

October 2008

Further copies of this report can be downloaded from the Primary Palliative Care Research Group website at the University of Edinburgh. For further information contact: Scott.Murray@ed.ac.uk or J.Hockley@stchristophers.org.uk

APPENDIX 1

Projected 18-month timetable

[March 2007 – August 2008]

Preparation:	**July '07**	**October '07**	**January '08**	**May '08**	**Final evaluation:**
Visits to NHs & contacting GPs	Central workshop 1 *Introduction*	Central workshop 2 *Consolidation*	Central workshop 3 *Extension*	Central workshop 4 *Embedding*	
Contacting NH managers and gaining their support for the project. Applying for ethical approval Appointment of research associate to help with qualitative evaluation	**3 key tasks:** Setting up: ▪ Supportive Care Register (C1) ▪ Regular proactive planning meetings (CI) ▪ Establishing the co-ordinators role within each NH (C2)	**3 key tasks:** Introducing: ▪ Assessment tools & Advance Care Planning (C1, C3) ▪ OOHs handover & preparation (C4) ▪ Reflective learning (C5)	**3 key tasks:** Introducing: ▪ Support initiatives for all NH staff (C5) ▪ Family support & bereavement initiatives (C6) ▪ ICP for last days of life (C7)	**Overall consolidation** of NHs who have managed to achieve each gear level Further time for other NHs to 'catch up'	
Collection of base-line data	Collection of process data	Collection of process data	Collection of process data	Collection of process data	Summative evaluation & writing report

Appendix 2
The GSFCH Supportive / Palliative Care Register

Register Prompts for Discussion at Case Management Meeting

Name of Resident + age & date of admission	Diagnoses	Code A-D	GP	Key Worker: named nurse /carer	DNAR Status completed + date	Advance Care Plan completed Y or N (date)	Problems / concerns: i.e. pain, depression, family difficulties	Other Specialists? Y or N	SPC Involvement ? Y or N	OOHs' form – Confirm date sent	Actual place death + date	Further bereavement support : 'Y' (yes) or 'N' (no)	Any gaps in care/ crises/ other notes

Appendix 3
Care matrix for end-of-life care

(adapted from GSFCH, Thomas et al 2006)

	Goal	**Activity**
A = years	• Adjustment to living well in a new home, with regular review of care. • Assessment of disease progression to optimise care	• Assessment of residents needs in relation to: co-morbidities, dependency, frailty • Address 'losses' of individual with family & staff team • Introduction & preparation for GSF by staff & relatives • Advance care plan + preferred place of care + DNAR discussion with resident, family or advocate • Communication opportunities to discuss issues as they present themselves • *Holistic care*: nutrition, hydration, mobility, continence assessments. Pain & symptom assessment. Spiritual and social needs assessment – 'what is important to you'
B = months	• Regular proactive review of individual resident's needs & care	• Monthly communication with MDT/staff (e.g. GP, CNS, psychologist etc) • Review of Advance Care Plan e.g. DNAR, preferred place of care/death • Monthly assessment of pain/symptom control (POS; Doloplus2) & assessment of family needs as frailty of resident increases • Assessment and/or Continuing Care Funding review
C = weeks	• Preparing for final stage • Focus on comfort care • Regular contact and discussion with family	• Continue regular pain & symptom control assessments (POS; Doloplus2) as appropriate (may need to be weekly) • Increased proactive review by GP, CNS etc • Send OOHs form to NHS24 re 'end-stage' if not already done • Increased contact with family – discuss prognosis – consider 'unfinished business' within family • Advance care plan rechecked + preference of place of care (not admitting to hospital) reassessed + inappropriate use of antibiotics discussed
D = days	• Preparation for death in preferred place – resisting transfer to hospital	• Diagnosing dying • Remember resident is likely to be aware that they are dying – be prepared to answer their questions – do not 'fob them off' • Use of 'care pathway' e.g. *Liverpool Care Pathway for the Dying* with 4hrly assessment/recording • Close contact with GP (check they have sent OOHs form to NHS24) • Consider spiritual care aspect of holistic care • Contact with family increased – discuss prognosis
Aftercare		• Verification of death procedure clarified • Staff protocol for after death care • Guidance for family for funeral arrangements + awareness of bereavement emotions: additional loss, guilt issues • Openness about death with other residents – their need for support • Staff support – debriefing • Audit of care provision – 'After Death Analysis'

Appendix 4

NURSING HOME PAIN ASSESSMENT CHART

[Hockley J (2004) Bridges Initiative, St Columba's Hospice, Edinburgh]

NAME OF RESIDENT:

DATE:

DIAGNOSES/PROBLEM LIST:

1. Where is/are the pain/s ?
(*mark 'body chart' below*)
2. How long has the pain been present?
3. What makes the pain worse?
4. How bad is the pain on the intensity scale ?
5. Does anything make the pain better?

CURRENT MEDICATIONS:

10	**Worst pain possible**
9	
8	**Very severe pain**
7	
6	**Severe pain**
5	
4	**Moderate pain**
3	
2	**Mild pain**
1	
0	**No Pain**

PAIN INTENSITY: if '0' out of '10' = NO PAIN; and '10' out of '10' = WORST PAIN you have ever had in your whole life, what score out of '10' would you give the pain you currently have?

Appendix 4 - continued

DOLOPLUS 2 SCALE - BEHAVOURAL ASSESSMENT

		DATE			
SOMATIC REACTIONS:					
1. Expression	No complaints……	0	0	0	0
of pain by	Complaints expressed upon inquiry only……	1	1	1	1
word, gesture,	Occasional involuntary complaints……	2	2	2	2
tears, moaning	Continuous involuntary complaints……	3	3	3	3
2. Unusual	No protective body posture……	0	0	0	0
protective body	The person occasionally avoids certain position……	1	1	1	1
position adopted	Protective postures continuously & effectively sought……	2	2	2	2
at rest	Protective postures continuously sought, without success……	3	3	3	3
3. Protection of	**No protective action taken……**	0 1	0 1	0 1	0 1
sore area by	**Protective actions attempted without interfering against investigation/nursing……**	2	2	2	2
defensive	Protective actions against any investigation or nursing……	3	3	3	3
gesture	Protective actions taken at rest, even when not approached……				
4. Facial	Usual expression……	0	0	0	0
expression:	Expression showing pain when approached……	1	1	1	1
grimace, drawn	Expression showing pain even without being approached……	2	2	2	2
or atonic	Permanent and unusually blank look (voiceless, staring, looking blank)……	3	3	3	3
5. Sleep pattern	Normal sleep……	0	0	0	0
	Difficult to go to sleep……	1	1	1	1
	Frequent waking (restlessness)……	2	2	2	2
	Insomnia affecting waking times……	3	3	3	3
PSYCHOMOTOR REACTIONS:					
6. Washing	Usual abilities unaffected……	0	0	0	0
and/or	Usual abilities slightly affected (careful but thorough)……	1	1	1	1
dressing	Usual abilities highly impaired, washing and/or dressing is laborious & incomplete……	2	2	2	2
	Washing and/or dressing rendered impossible as the patient resists any attempt……	3	3	3	3
7. Mobility	Usual abilities & activities remain unaffected……	0	0	0	0
	Usual activities reduced (person avoids certain movements & reduces walking distance)…	1	1	1	1
	Usual activities & abilities reduced (Even with help the patient cuts down on movements)	2	2	2	2
	Any movement is impossible, the patient resists all persuasion……	3	3	3	3
PSYCHOSOCIAL REACTIONS:					
8. Communication	Unchanged……	0	0	0	0
	Heightened (the person demands attention in an unusual manner)……	1	1	1	1
	Lessened (the person cuts him/herself off)……	2	2	2	2
	Absence of refusal of any form of communication……	3	3	3	3
9. Social life	Participates normally in every activity (meals, entertainment, therapy workshop)……	0	0	0	0
	Participates in activities when asked to do so only……	1	1	1	1
	Sometimes refuses to participate in any activity……	2	2	2	2
	Refuses to participate in anything……	3	3	3	3
10. Problems of	Normal behaviour……	0	0	0	0
behaviour	Problems of repetitive reactive behaviour……	1	1	1	1
	Problems of permanent reactive behaviour……	2	2	2	2
	Permanent behaviour problems (without any external stimulus)……	3	3	3	3
	A SCORE OF 5 or more INDICATES PAIN				
Copyright: Lefebvre-Chapiro & the DOLOPLUS group, 2001	**SCORE:**				

Appendix 4 (continued)

ON-GOING PAIN ASSESSMENT CHART

Resident's Name: **DATE:**

10	**Worst pain ever**
9	
8	**Very severe pain**
7	
6	**Severe pain**
5	
4	**Moderate pain**
3	
2	**Mild pain**
1	
0	**No pain**

PAIN INTENSITY

CURRENT MEDICATIONS for PAIN:

REGULARITY OF ASSESSMENT:

DAILY at 10.00hrs at medicine round ☐

WEEKLY at 10.00hrs medicine round ☐

Date	**Time**	**Pain Intensity**	**Doloplus Score**	**ACTION TAKEN**	**OUTCOME**	**State of bowels**	Signature + review time/date

Appendix 5

GERIATRIC DEPRESSION SCALE (GDS)

NAME: **DATE:**

1	Are you basically satisfied with your life?	**No** Yes
2	Have you dropped many of your activities or interests?	**Yes** No
3	Do you feel that your life is empty?	**Yes** No
4	Do you often feel bored?	**Yes** No
5	Are you in good spirits most of the time?	**No** Yes
6	Are you afraid that something bad is going to happen to you?	**Yes** No
7	Do you feel happy most of the time?	**No** Yes
8	Do you often feel helpless?	**Yes** No
9	Do you prefer to stay at home, rather than going out and doing new things?	**Yes** No
10	Do you feel you have more problems with your memory than most?	**Yes** No
11	Do you think it is wonderful to be alive?	**No** Yes
12	Do you feel pretty worthless the way you are now	**Yes** No
13	Do you feel full of energy?	**No** Yes
14	Do you feel that your situation is hopeless?	**Yes** No
15	Do you think that most people are better off than you are?	**Yes** No
> 5 problems (answers in BOLD) indicates probable depression TOTAL:		

THE GERIATRIC DEPRESSION SCALE (GDS)

1. The GDS short form (15 questions) has been derived from the 30 question version. It has been designed for the assessment of depressive symptomatology in elderly people and excludes any questions relating to the physical symptoms of depression common in old age.

2. The GDS is a screening device an+

3. d should not be used as a diagnostic tool. It can be used to monitor the client's emotional state in relation to treatment or change in physical health. The questionnaire can guide further clinical interviews and when used this way has been found very acceptable to clients.

4. **The questions are read out** and the patient is asked how they have felt over the past week using a Yes/No response format. No further explanation or interpretation should be given to the questions.

5. Each answer indicating depression (bold 'yes' or 'no) counts one point. Scores greater than 5 are indicative of probable depression.

Appendix 6

Proforma of Retrospective Review of Notes

2 cohorts:
Pre-implementation: June 2006 – May 2007
Post-implementation: June 2007 – May 2008

NH Code	Initials of resident	Gender - F/M	DOB	DOA	DOD	Length of time in NH	Diagnoses	Presence of dementia Y/N	DNAR form Y/N	Doc. evidence of ACP	No. of hospital admissions in last 8wks of life	No. hosp. days appropriate /inappropriate		No. of OOHs contact in last 8 wks:	LCP: Y or N	Place of death: NH or hospital	Type of death: D, S, A, T[2]

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[2] **D** = dwindling; **S** = sudden (totally unexpected ie heart attack in dining room); **A** = after ‘acute’ episode (ie extension of stroke; fractured femur); **T** = diagnosed terminal condition

APPENDIX 7

STAFF QUESTIONNAIRE (post-GSFCH project)

[Adapted from Bridges Initiative, Hockley et al 2004]

NH code: **Personal code:**

Instructions: Please be honest and put a tick in the square that you think best describes *each* of the following 50 items in relation to how you believe it represent the end-of-life care of residents and families in your nursing home

		The effect of the Midlothian GSFCH project		
LAST PHASE OF LIFE		**The project has had no effect on this**	**The project has helped us do this better**	**We've only done this since the project began**
1. All staff are aware that 'time' for most residents in the home is very limited		33%	62%	5%
2. An emphasis on 'quality of life' which concentrates on good symptom control rather than 'striving to keep alive' underpins our care		12%	83%**	5%
3. We regularly have teaching on end-of-life care within the care home		14%	44%	32%**
4. Residents/families wishes are sought in relation to end-of-life care planning (e.g. living wills/advance directives; cardiac resuscitation; transfer to hospital) on admission or at a review meeting		31%	54%	15%
5. The naturalness of dying in old age is openly acknowledged in our unit		32%	57%	11%
6. 'Do Not Attempt Resuscitation' forms are in regular use with our frail residents		37%	52%	11%
7. Giving unrealistic hope to a resident or family would be challenged in our unit		25%	75%**	-
8. Residents who may want to speak about 'end-of-life' issues are encouraged to do so and we do not try to avoid the subject of death and dying.		20%	76%**	4%
9. Staff are skilled to address the psycho-social & emotional needs a resident may have in relation to end-of-life care		7%	85%**	8%
10. Staff are skilled to help address the spiritual needs a resident may have in relation to end-of-life care		23%	71%	6%
11. We regularly seek help & advice from other experts when it is required i.e. specialist palliative care nurses; physio.		39%	57%	4%
12. We immediately dial 999 if a frail resident collapses		Ambiguous	question	
13. Residents remain in the nursing home to die where they are known by the staff		60%	40%	-
14. We feel able to manage situations where there is some disagreement between key parties involved e.g. staff, GPs, families		21%	74%	5%
15. Management aware of the significance and consequence of losses for residents, families and staff working in the home		38%	59%	3%

**** indicate the strength of change to aspects of care**

THE DYING PHASE		**The project has had no effect on this**	**The project has helped us do this better**	**We've only done this since the project began**
16. The team are confident about recognizing when somebody is dying		41%	56%	3%
17. Staff are actively involved in end-of-life decision-making of a resident & their family		24%	68%	8%
18. Staff are confident communicating with families the ineffectiveness of continuing antibiotics/going to hospital in the last days of life		24%	68%	6%
19. Staff know when to stop inappropriate interventions e.g. blood pressures; TPR; blood sugars etc		32%	57%	11%
20. Staff are supported to talk openly to residents who are dying		16%	73%**	11%
21. We have a shared plan of care & document specific goals to achieve when a resident is dying		4%	67%**	29%**
22. The different stages of the dying process are regularly observed and documented		15%	62%	25%**
23. We regularly assess & document three common symptoms (agitation, rattly chest & pain) when a resident is dying.		25%	60%	15%**
24. We anticipate the above 3 symptoms a dying resident may have and have PRN medication written up & available		23%	63%	14%
25. Our residents die without distress		38%	60%	2%
26. Staff collaborate with families to discuss how much they would like to be involved		21%	73%	6%
27. We explain to each family exactly what is happening when their loved one is dying e.g. breathing changes & the reason for using any medication		29%	69%	2%
28. Staff regularly assess the support needs of families of dying residents		32%	59%	9%
29. We always have the right equipment to support the resident who is dying e.g. pressure relieving mattresses; different bed		56%	43%	1%
30. We are able to strike a balance between giving the family privacy & letting them know you are there to support them when a resident is dying		40%	60%	-
31. We feel confident when a resident is dying to talk openly about it & share information with family members		28%	69%	3%
32. We ensure the family are comfortable and have food and drink when a resident is dying		56%	43%	1%
33. We are able to put forward a case to management about the staffing levels to meet the changing needs when a resident is dying		46%	45%	9%
34. All team members feel included when a resident is dying		37%	60%	3%
35. We ensure good teamwork & good communication between all staff including domestic/kitchen staff/activity leaders etc. & helped to have a role if appropriate when a resident is dying		37%	59%	4%
36. We organise staffing so that those who 'really know' the resident are with them in the last days of life - especially those residents who have dementia		52%	46%	2%
37. We ensure there is always somebody sitting with an imminently dying resident		56%	43%	1%
38. There is fear in our unit about caring for a resident who is dying		Ambiguous	question	
39. New staff are prepared for caring for dying residents and their families as a specific aspect of care		30%	58%**	12%**

POST DEATH PHASE		**The project has had no effect on this**	**The project has helped us do this better**	**We've only done this since the project began**
40. We have good training in relation to what to do after a resident has died, e.g. last offices; preparing the room for the family/friends		46%	54%	-
41. Staff know how to behave ‘openly’ following the death of a resident when the body is being removed from the NH		51%	48%	1%
42. There is agreement about what happens when a resident’s body is removed from the NH		51%	48%	1%
43. The family are given information about what to do after a death		40%	51%	9%
44. Staff have an understanding about the grieving process and the importance of families saying ‘goodbye’ after a resident has died.		46%	51%	3%
45. We offer an opportunity to share with families details of what happened in the final hours if the family were absent.		44%	53%	3%
46. Other residents in the care home are informed that a resident who they know is dying/has died		41%	52%	7%
47. All staff are informed when a resident has died and no-one finds out by chance		50%	50%	-
48. We always offer assistance to the family to carry out practical arrangements i.e. clear the room after a resident has died		59%	40%	1%
49. Staff have the opportunity to pay their respects to the family/resident by going to the funeral and/or having time to say goodbye		53%	46%	1%
50. There is a forum for open discussion/reflection after a death to support staff and further develop the care given to dying residents & their family		35%	55%**	10%**

THANK YOU VERY MUCH INDEED FOR COMPLETING THIS QUESTIONNAIRE

Please now put it back in the envelope, seal it and put it in the box provided

**** indicate the strength of change to aspects of care**

Appendix 8

Key Champions Post GSFCH Questionnaire

I would be most grateful if you could complete the following questionnaire and have it returned to me by 22nd July. <u>Please be REALLY honest</u>!

1. What three things have YOU *benefited from* being a key champion in this Midlothian GSFCH project?
   a)
   b)
   c)

2. What three things have been *most difficult* for YOU personally as a key champion in this Midlothian GSFCH project?
   a)
   b)
   c)

3. What gaps has this project highlighted in your home?

4. Do you think end of life care in your care home has changed as a result of being involved the Midlothian GSFCH project? No / Yes

   If *'no'*, what has prevented any change?

   If *'yes'*, in what way do you see changes?

5. In terms of '*usefulness*' to implementing a greater palliative care approach in your nursing home, how would you rate 'out of ten' the following parts of the project? ['10' being the most useful]

   - ABCD Register /10
   - LCP /10
   - Macmillan Foundations in Palliative Care Teaching Pack /10
   - London Workshops /10

   Please feel free to comment on the 'least' useful:

6. What gaps still remain in the practice of end of life care in your home…
    - In the last year of a resident's life?
    - In the last months/weeks of a resident's life?
    - In the last days of a resident's life?

7. Why do you think these gaps persist?

8. What will help you to sustain the changes you have made as a result of the project?

Thank you very much indeed for completing this questionnaire. Please return it to Julie Watson in the SAE enclosed.

Appendix 9

Relatives Interview Schedule

How long was your ……………..in the nursing home?

How well did you get to know the staff in the nursing home? How well do you think they got to know you?

Would you like to tell me the 'story' of your ………………last year and last weeks of life?

- What went well?
- What could have gone better?

Did you have the opportunity to discuss options for care in the event of your ………..becoming seriously ill in the nursing home?

- What did this involve?

In the last weeks/days of your……..life, where did you feel the 'best place' of care was for………? Why did you think that?

How much contact did you have with the GP in the last year?

- What was this about? Did you ask to see them or did they initiate the meeting?

Before your …………………….died, were there other times when she was very poorly and then 'bounced back'? Can you tell me a bit more about these times?

How would you describe 'good care' in a nursing home?

What factors do you think help staff deliver good care, especially in the last weeks and days? What stops them giving good care?

When ……………………..was becoming more poorly, did the staff talk to you about this? How were these conversations?

- Do you remember a particular conversation that stands out?

Were you aware that they were dying before the staff spoke to you?

- Do you think……….knew they were dying? What did they say that makes you think that?

Did the staff talk to you about your feelings or how well you were coping?

How well prepared did you think you were?

What were your needs during the last weeks and days?

- To what extent were your needs met?

How supported did you feel by the staff when………………..had died?

What advice or information did the home give you when ………………died? E.g. what to take to the registrar, opening times etc

Now looking back at the whole time your………was in the nursing home, what had been your expectations? Were they met?

If you had the power to change how very frail older people are cared for in general, what would you change? In the care home what would you change?

Appendix 10

Nursing Home Manager's Interview Schedule

Some general questions:
Generally what has it been like for you/your home being part of the GSFCH project?

  - Was it as you expected?
  - In what way did it differ from your expectations?

Has being part of the project highlighted possible gaps in your end of life care?

  - What have these been?

What impact has the project had on the staff? How have they changed over the last year?

More specific questions about the GSFCH project:
The GSFCH has also been about helping people to plan ahead, assess and act on issues and situations: Looking back at the whole year, what has been the most useful part of the project?

The GSFCH highlighted 7 C's:

- communication and care planning; co-ordination; continuity of care; control of the dying; control of symptoms; continued learning; carer support

When thinking about these, do you see progress in any of these in your home? Are there any that stand out?

What do you feel the benefits of the ABCD register have been?

Are you aware of any change in attitudes about death and dying in yourself? If so…what?! Has the Liverpool Care Pathway had anything to do with this or has it been other things?

Are you aware of any change in attitudes about death and dying among your staff since the beginning of the project? If so…what?

Finally, taking a wider focus again:
Looking back over the year, what has been the most DIFFICULT part of the project?

Is there any part of the project you think could or should have been done differently?

What has helped your NH in implementing the GSFCH?

  - Has got in the way of implementing the GSFCH?

Which aspects of the changes that have taken place do you hope to sustain?

  - What would help you to do this?
  - Will anything prevent you from doing this?

Anything else you would like to say?

Appendix 11

Frequency of documentation regarding DNAR, ACP and LCP pre and post project by NCHs involved

NH	DNaR		Anticipatory Care Planning			Liverpool Care Pathway for the Last day of life	
	Pre	Post	Pre	Post		Pre	Post
					Quality of recording		
A	6.3%	80%	6.3%	50%	**Medium level:** Written evidence using specific NH's ACP form re families wishes many wks before death	0%	72%
B	35%**	59%	0%	36%	Written evidence of ACP but only a few days before death – many involving OOHs	0%	57%
C	0%	69%**	0%	62%	Written evidence of ACP but only a few days before death	0%	13%
D	–	88%	–	46%	**Medium level**: on-going written evidence using specific CP	0%	12.5%
E	0%	50%	0%	50%	Written evidence: 'for TLC' but no evidence of family discussion	0%	0%
F	8%	73%	15%	60%	Written evidence: 'for TLC' but no evidence of family discussion	0%	0%
G	4%	79%	4%	79%	**High level**: on-going written evidence using specific CP	12.5%	63%

** includes 'handwritten' instruction rather than DNAR form

Appendix 12

Midlothian nursing care home palliative care forum

(adapted from GSFCH documentation)

Discussions relating to 'advance care planning' and DNR forms
(on admission or at first review meeting)

Name of resident: **Date of birth:** **Date of admission:** **Care Home:**	**GP name & address:**

The emphasis on quality of life underpins the care in this care home. This is about making sure that your priorities about your future care are understood and that any symptoms and/or issues that might be worrying you or your family are talked about and dealt with. We will work with you, your family and your GP in order to achieve as good a quality of life as possible. We want you to feel you can ask any questions that you might have and specifically at 'review' meetings.

A willingness to speak and think ahead on issues (anticipatory care planning), enables people's wishes to be discussed and ensures that you and your family's wishes are known and followed through. Documenting these wishes is important so that all those within the caring team including the GP are clear about what you and your family would wish *in advance* of any deterioration and therefore what has been planned. Ideally 'anticipatory care planning' is used to inform future care at an early stage, preferably on admission to a home. Of course one can **re-visit** any decisions at any date in the future or at subsequent review meetings.

i) At this point in your/your loved one's life what is really important to you?
ii) Is there anything that you worry about?
iii) Do you require information regarding lasting power of attorney? Yes No *(This is unlikely to be necessary if family together are able to make decisions)*
iv) Do you have a 'living will'? Yes No *(If 'yes' please give details e.g. who has a copy)*

v) In the event of a cardiac arrest what might you like to happen, or what would you ***not*** like to happen? *[It must be stated that cardiac massage on a frail older person is rarely successful and attempts to resuscitate can result in brain damage and fractured ribs.]*

v) So that we can be aware of your preferences in the event of increased frailty where would you prefer to be cared? *[i.e. this care home, or another care home; hospital; hospice (if diagnosis of cancer)]*

vi) Are there any further comments you would like noted?

Resident's signature and/or family member /NOK signature:

Healthcare professional signature: Date of signing:

Date of further review:

NB: If artificial resuscitation in the event of a cardiac arrest is not desired, then the Lothian DNR form needs to be completed by care home staff and signed by GP

Appendix 13a – Collated Matrix [Pre GSFCH]

Category of Care Area of Care	A n=7	B n=2	C n=4	D n=4	E n=0	F n=1	G n=4
Coordination Leadership of nursing home staff							
Positive	6	0	3	5		2	1
Negative	1	6	6	0		0	3
Equivocal	0	0	0	0		0	0
Contacts with health professionals outwith the NH e.g. GP							
Positive	2	1	0	3		1	2
Negative	2	0	1	0		0	3
Equivocal	0	0	0	0		0	1
Overall Balance	POS	NEG	NEG	POS		POS	NEG
Control of Symptoms							
Assessment and control of symptoms/frequency of symptoms							
Positive	0	0	0	3		0	1
Negative	4	1	1	1		0	2
Equivocal	0	0	0	1		0	0
Staff knowledge of medications and syringe drivers							
Positive	0	0	0	0		0	0
Negative	0	1	2	0		0	2
Equivocal	0	0	0	0		0	1
Prescribing of medications at the end of life							
Positive	0	0	0	0		0	2
Negative	1	0	0	0		0	0
Equivocal	0	0	1	0		0	0
Overall Balance	NEG	NEG	NEG	POS		EQUI	NEG

CATEGORY OF CARE	A n=7	B n=2	C n=4	D n=4	E n=0	F n=1	G n=4
Communication							
Dealing with issues							
Positive	3	0	1	3		1	0
Negative	2	2	2	0		0	1
Equivocal	0	0	0	0		0	0
Emotional/Spiritual care of the resident							
Positive	2	0	2	4		2	2
Negative	4	1	4	0		0	4
Equivocal	2	0	0	0		0	0
Proactive discussion with the family about the residents current condition							
Positive	4	0	2	5		2	4
Negative	4	0	4	0		0	3
Equivocal	0	1	0	0		0	0
Overall Balance	NEG	NEG	NEG	POS		POS	NEG
Continuity of care							
Named Nurse or key worker							
Positive	7	0	1	3		1	4
Negative	0	2	3	0		0	0
Equivocal	1	0	0	0		0	0
Place of death							
Positive	6	2	2	2		1	4
Negative	5	0	0	0		0	2
Equivocal	2	1	0	0		0	0
Future Care Planning, DNAR, ACP							
Positive	3	2	1	1		0	2
Negative	7	0	4	3		0	2
Equivocal	2	0	1	0		1	2
Overall Balance	POS	POS	NEG	POS		POS	POS

CATEGORY OF CARE	A n=7	B n=2	C n=4	D n=4	E n=0	F n=1	G n=4
Care of the dying							
Discussions about death and dying with the resident and family							
Positive	2	1	0	3		1	4
Negative	6	3	9	2		0	0
Equivocal	1	0	0	1		0	2
Open culture around death and dying							
Positive	0	0	0	0		1	1
Negative	1	1	0	0		0	1
Equivocal	0	0	0	0		0	0
Physical care during and after dying							
Positive	5	2	1	5		0	1
Negative	4	2	5	0		0	4
Equivocal	0	0	1	0		0	1
Staff recognition of dying							
Positive	2	0	0	4		1	3
Negative	5	1	8	2		0	2
Equivocal	1	0	0	0		0	0
Overall Balance	NEG	NEG	NEG	POS		POS	POS
Carer Support (Staff)							
Attending funeral/ saying goodbye							
Positive	2	0	2	0		0	2
Negative	0	1	0	0		0	0
Equivocal	0	0	0	0		0	0
Overall Balance	POS	NEG	POS	EQUI		EQUI	POS
Carer Support (Family)							
Family relationship with staff							
Positive	6	0	2	4		3	5
Negative	1	2	0	0		0	0
Equivocal	0	0	1	0		0	1
Pre and post bereavement care							
Positive	7	2	3	7		3	9
Negative	3	5	5	1		0	0
Equivocal	0	0	0	0		0	1
Overall Balance	POS	NEG	POS	POS		POS	POS

CATEGORY OF CARE	A n=7	B n=2	C n=4	D n=4	E n=0	F n=1	G n=4
Continued Learning							
Staff knowledge about all different aspects of palliative care including symptom control							
Positive	0	0	0	2		0	1
Negative	2	0	3	0		0	5
Equivocal	0	0	1	0		0	0
GP knowledge about medications at the end of life							
Positive	0	1	0	0		0	0
Negative	1	0	0	0		0	0
Equivocal	0	0	0	0		0	1
Overall Balance	NEG	POS	NEG	POS		EQUI	NEG
OVERALL BALANCE OF NURSING HOME PERFORMANCE	NEG	NEG	NEG	POS		POS	EQUI

Appendix 13b - Collated Matrix [post GSFCH]

Category of Care Area of Care	A n=2	B n=1	C n=0	D n=4	E n=0	F n=1	G n=6
Coordination Leadership of nursing home staff							
Positive	1	0		1		2	3
Negative	0	0		0		0	0
Equivocal	1	0		0		0	0
Contacts with health professionals outwith the NH e.g. GP							
Positive	0	0		2		0	3
Negative	1	1		0		0	0
Equivocal	0	0		0		0	0
Overall Balance	EQUI	NEG		POS		POS	POS
Control of Symptoms							
Assessment and control of symptoms/frequency of symptoms							
Positive	0	0		3		0	5
Negative	0	0		1		0	0
Equivocal	0	1		2		0	0
Staff knowledge of medications and syringe drivers							
Positive	0	0		0		0	1
Negative	0	0		0		0	0
Equivocal	0	0		0		0	0
Prescribing of medications at the end of life							
Positive	0	0		0		0	2
Negative	0	0		0		0	0
Equivocal	0	0		0		0	0
Overall Balance	EQUI	EQUI		POS		EQUI	POS

CATEGORY OF CARE	A n=2	B n=1	C n=0	D n=4	E n=0	F n=0	G n=6
Communication							
Dealing with issues							
Positive	1	0		2		0	0
Negative	0	0		0		0	0
Equivocal	0	0		1		0	0
Emotional/Spiritual care of the resident							
Positive	0	0		6		3	3
Negative	3	1		2		0	0
Equivocal	0	0		0		0	1
Proactive discussion with the family about the residents current condition							
Positive	1	1		3		1	6
Negative	1	0		0		0	0
Equivocal	0	0		2		0	0
Overall Balance	NEG	EQUI		POS		POS	POS
Continuity of care							
Named Nurse or key worker							
Positive	2	0		11		2	7
Negative	1	0		2		0	0
Equivocal	0	0		1		0	0
Place of death							
Positive	0	1		7		1	5
Negative	0	0		0		0	1
Equivocal	1	0		0		0	0
Future Care Planning, DNAR, ACP							
Positive	2	0		4		0	7
Negative	2	2		4		1	3
Equivocal	0	0		1		0	0
Overall Balance	POS	NEG		POS		POS	POS

CATEGORY OF CARE	A n=2	B n=1	C n=0	D n=4	E n=0	F n=0	G n=6
Care of the dying							
Discussions about death and dying with the resident and family							
Positive	5	1		11		2	12
Negative	1	1		2		1	4
Equivocal	0	1		0		0	3
Open culture around death and dying							
Positive	0	0		0		0	2
Negative	0	0		0		0	0
Equivocal	0	0		0		0	0
Physical care during and after dying							
Positive	1	0		11		2	11
Negative	0	0		2		0	0
Equivocal	0	0		0		0	0
Staff recognition of dying							
Positive	1	0		7		1	2
Negative	0	0		1		0	2
Equivocal	0	1		0		0	1
Overall Balance	POS	EQUI		POS		POS	POS
Carer Support (Staff)							
Attending funeral/ saying goodbye							
Positive	2	0		2		1	6
Negative	0	0		0		0	1
Equivocal	0	0		0		0	0
Overall Balance	POS	EQUI		POS		POS	POS
Carer Support (Family)							
Family relationship with staff							
Positive	0	0		2		1	4
Negative	1	0		0		0	0
Equivocal	0	0		0		0	0
Pre and post bereavement care							
Positive	1	0		8		3	12
Negative	0	0		0		0	0
Equivocal	1	0		0		0	0
Overall Balance	EQUI	EQUI		POS		POS	POS

CATEGORY OF CARE	A n=2	B n=1	C n=0	D n=4	E n=0	F n=0	G n=6
Continued Learning							
Staff knowledge about all different aspects of palliative care including symptom control							
Positive	0	0		0		1	4
Negative	0	0		1		0	0
Equivocal	0	0		1		0	0
GP knowledge about medications at the end of life							
Positive	0	0		1		0	0
Negative	0	0		0		0	0
Equivocal	0	0		0		0	0
Overall Balance	EQUI	EQUI		EQUI		POS	POS
OVERALL BALANCE OF NURSING HOME PERFORMANCE	POS	EQUI		POS		POS	POS

Appendix 14:

Average number of negative and positive outcomes on ALL 7C's as reported by relatives (pre/post data)

NH	Pre NEGATIVE	Post NEGATIVE	Pre POSITIVES	Post POSITIVES	Pre EQUIVOCAL	Post EQUIVOCAL
A	7.5	5	8.1	8.5	1.2	1.5
B	14	6	5.5	2	1	3
C*	-	-	-	-	-	-
D	2.5	3.75	13.7	19.7	0.5	2
E*	-	-	-	-	-	-
F	0	2	19	20	1	0
G	8.5	1.8	12	15.8	2.5	0.8
OVERALL	**32.5**	**18.5**	**58.3**	**66**	**6.2**	**7.3**

* = No 'post' interviews volunteered

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