"....Commission the service and then walk away"

Findings from a study examining access to resources for end of life care by nursing homes for older people

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- ....a story of unmet need, unacceptable variation and often poor quality of care provided by the NHS to the estimated 400,000 older people resident in UK care homes (British Geriatrics Society, 2011)[1]

- '....many examples of good practice which improve quality of life and end of life care for residents' (Mulley, 2011:481)[2]

1. British Geriatric Society (2011) A *Quest for Quality in Care Homes.* www.bsg.org.uk
2. Mulley G. (2011) Social care homes: what the media forget to tell us. *BMJ,* Aug 31st. .

Current picture

A lady we'd had with us for quite a few years. She was very up and down, very up and down …she used to get a number of chest infections and then she'd come round and then go back again. But, …after the last one… she didn't seem to be picking up from it…. We did let the next of kin know – [they said]:

'oh yes you've phoned a few times about this but she's always recovered, she always comes round'?

And we sort of said don't think so this time and we really think it would be nice if you come and see her. And it was oh right , right, well I can't come tomorrow…

(Care home manager's reflections on a patient – Seymour et al.) [1]

- England: 376,250 older people in 10,331 care homes.
- Northern Ireland: 9,485 older people in around 464 residential and nursing homes.
- Scotland: 39,150 residents in 943 care homes.
- Wales: 27,700 places in 1,164 care homes

(Figures cited in BSG, 2011 relating to sources 2009-11)

1. Seymour JE, Froggatt K and Kumar A (2009) *End of life care in care homes: Understanding and mapping innovative solutions.* Final report to the National End of Life Care Programme (available NEOLC website)

That's history

- Poor law: left a legacy of long stay geriatric hospitals after 1948
- Community Care Act 1990: 'the greatest change in the organisation and management of the NHS since it was established' (Robinson 1994: 2)[1].
- Ten fold increase in independent provision since 1970 for care of older people, making NHS and councils minor players
- Movement from 'housing option' to health/ welfare provider for people with highly complex and unstable needs
- Standards (as judged by CQC) gradually improving across sector , although instability obvious

1. Robinson, R. (1994) Introduction, in R. Robinson and J. Le Grand (eds) *Evaluating the NHS Reforms.* London: King's Fund Institute

Bupa survey (2003)[1]: 16,043 people in 244 homes

- 78% had at least one form of cognitive impairment.
- 22% were said to have a ‘normal’ mental state.
- 64% were confused or forgetful.
- 20% exhibited challenging behaviour.
- 19% were described as depressed or agitated.
- 71% were incontinent.
- 27% were immobile, confused and incontinent.
- 76% required assistance with their mobility or were immobile.

1. Cited in BSG ‘Quest for Quality’ report, 2011

Residents' entitlements

- Free general medical care, according to agreements with primary care providers
- According to need, fair access community health services (commissioning interpretation)
- Acute health care
- Nursing care according to need- 'bands' of funding
- NHS continuing care[1] and intermediate services

1. About 10% of residents get this

End of life care

Specialist palliative care provision:

(i) Clinical Nurse Specialists,

(ii) 'Hospice beds'

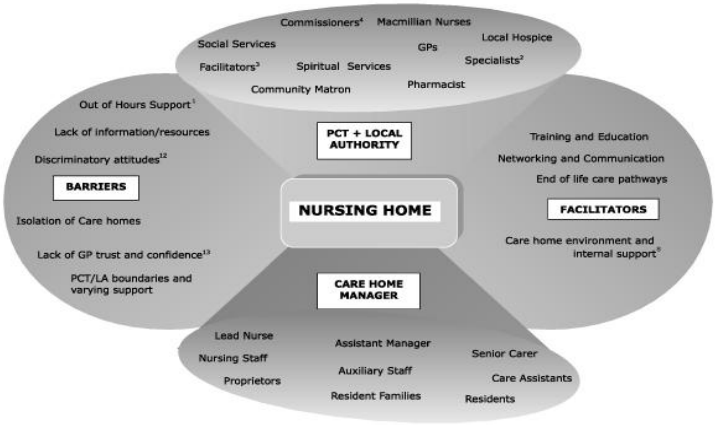
(iii) Palliative care education and training

(iv) Link nurse schemes.

General palliative care approach: National End of Life Care Programme/Strategy; the 'tools'; lots of local innovations

Study aim/ genesis

- To identify the key drivers and barriers within the wider health and social care system influencing quality of end of life care in care homes with nursing for older people.
- To identify the key drivers and barriers influencing quality of end of life care intrinsic to care homes with nursing for older people.



- Commissioned by NEOLCP

Steering group:

- The Palliative care lead for the Healthcare Commission (HCC) and The Commission for Social Care Inspection (CSCI) (now CQC)
- The National Programme Director for the End of Life Care Programme,
- The Director of Policy at English Community Council Association (ECCA)
- The coordinator of the ‘My Home Life’ Programme.
- The Nursing Director for the Registered Nursing Homes Association
- The Executive Director for the National Care Forum.

Mixed Methods[1] Study

1. A postal questionnaire survey

- 180 homes registered to provide nursing care for older surrounding two index case study homes in N England (90 in each area)
- Sampling frame: database held by The Commission for Social Care Inspection (CSCI)
  - Questions about support requested and accessed, barriers experienced and perceived priorities for end of life care/ quality

2. Two in depth case studies

- Purposively selected as 'instrumental cases'
- Documentary analysis and interviews with senior care home staff and care home stakeholders (n=16)

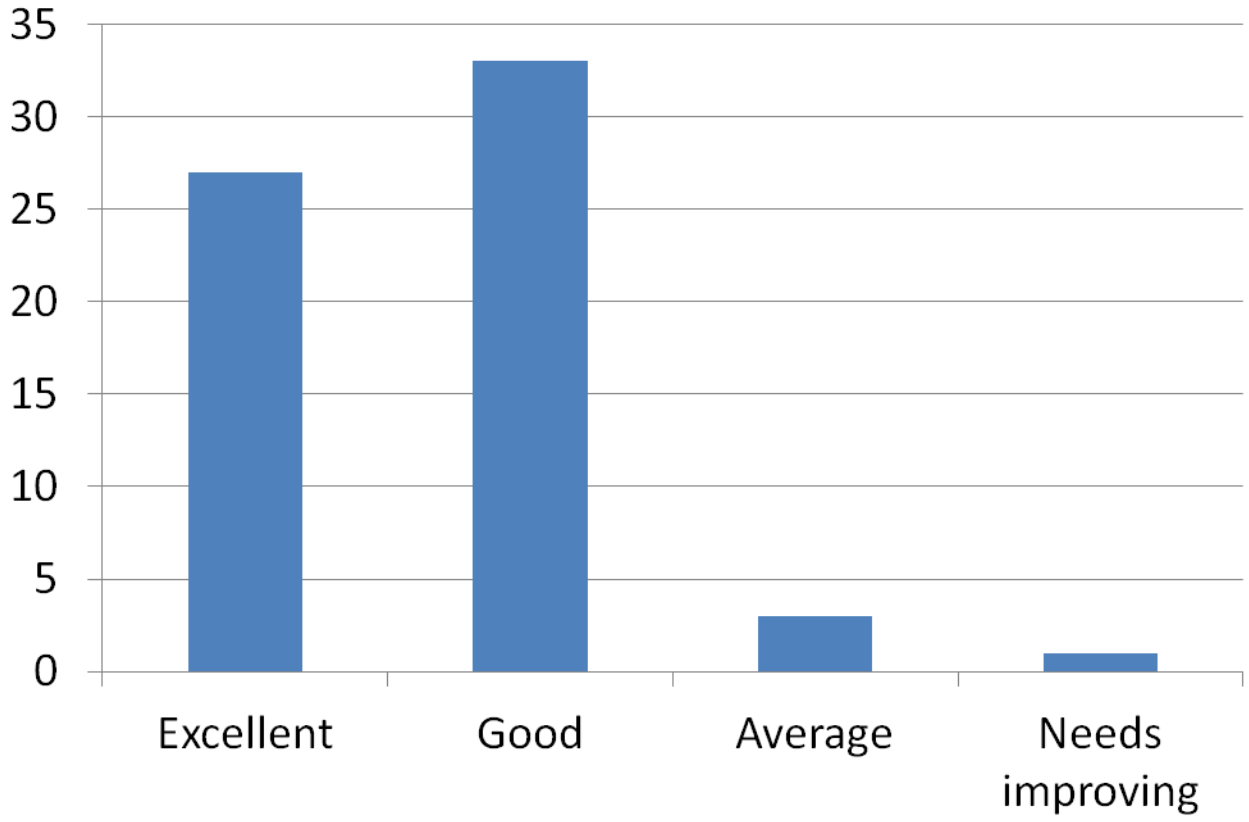
1. Cresswell (2009) 'Transformative' approach to study: ...under-represented or marginalised groups or individuals' (p123)

Profile of survey responder homes and deaths in these

- 46% (n=82) of homes responded; 62 were joint nursing/ residential
- Size of homes: 19-180 beds
- 1182 deaths in 2007
- Mean of 18 deaths per home in 2007 (range: 2-90)
- During 2007, 76% (n=904) deaths occurred in the care home; 23% (275) hospital; 0.25% (3) in hospice
- 77% of deaths attributed to non cancer disease

Self rating of end of life care

- 64/82 responders rated the quality of end of life care they provided

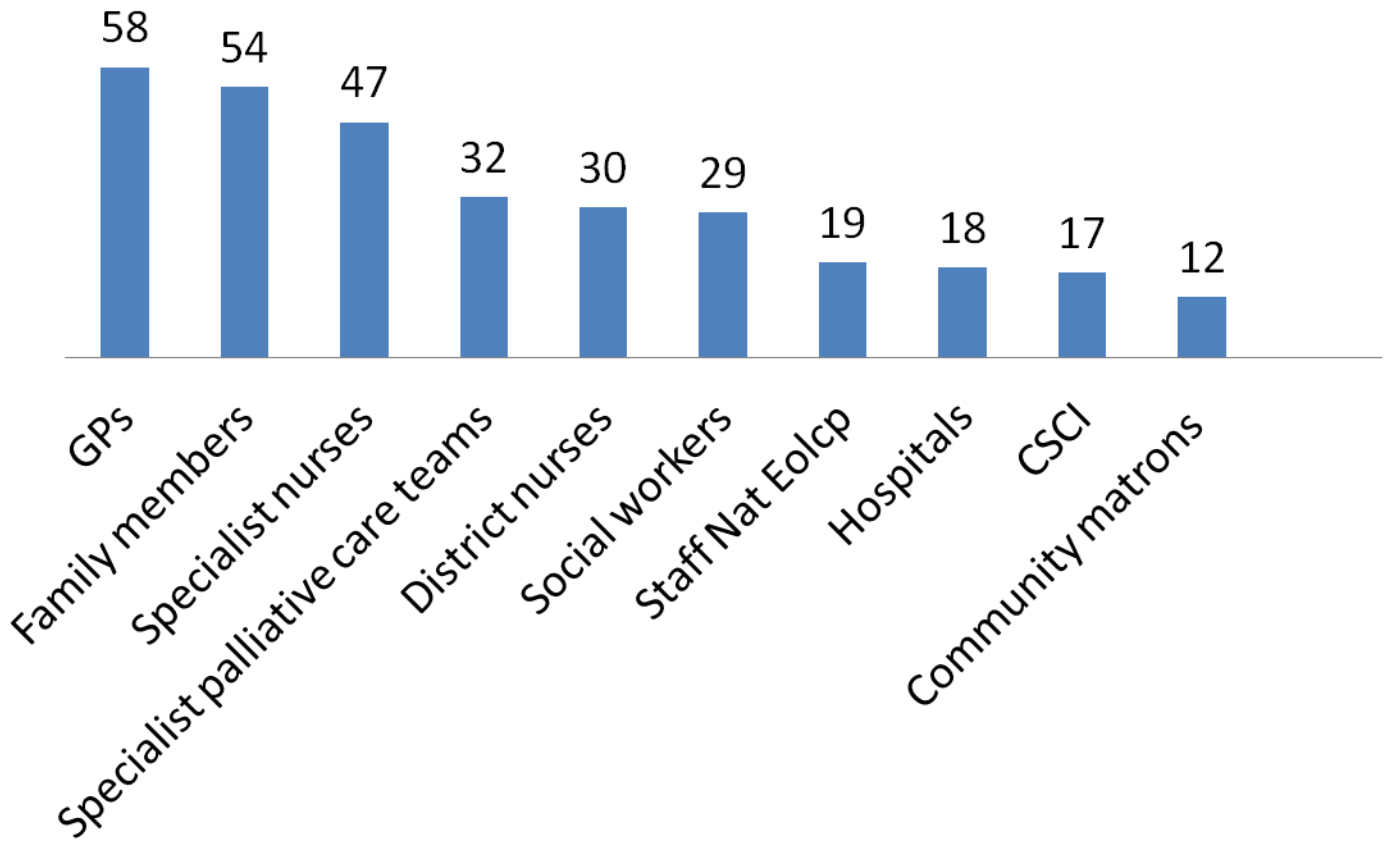


46/ 60 homes self rating as good or excellent reported use of a care pathway

Priorities perceived

- Most homes had clear views about priorities for enhancing end of life care :
  - *meeting residents and families' needs;*
  - *improving the care home environment;*
  - *staff training and education;*
  - *using end of life pathways;*
  - *networking with other care homes*

Sources of ‘some’ or ‘alot’ of support



59/82 homes responded to Q about support-

14 of these said they did not request help from specialist palliative care teams

How was support accessed?

- 53 homes reported accessing SPC by a direct advice line to a hospice or community based service
- Gp practices liaison: range of 1-11
- Individual GPs: range of 1-34*
- 43 homes said that support varied according to a resident's disease type and stage

*76/ 82 homes reported how they liaised with GPs

Barriers

Variable and inconsistent GP support

'Some GP's do not appear to support end of life care.'

Systems factors

'Sometimes too many different people involved. I.e. Community Matron, GP liaison, NHS, making communication difficult at times.'

Lack of information/resources

- *'To help staff plan end of life care, we would benefit from up to date information regarding residents' past treatment from hospitals, clinics, etc. We are dependent on information from GPs, they don't always think that we need this information but it is vital.'*
- *'Financial - Cost of syringe drivers.'*

Out of hours support

- *'Getting medications for LCP at night/weekends/Bank Holidays.'*

Case Studies

Case study 1: 'City' home providing care to 58 residents
Case study 2: 'Rural' home providing care to 44 residents

Qualitative interviews with seven care home staff: (manager/ matron (n=2), assistant manager (n=2), lead nurse , lead carer; activity co ordinator

Ten 'stakeholders' nominated by homes: GP (n=2); end of life care education or pathway lead (n=3); continuing care commissioner; another care home manager; specialist or community nurses (n=3)

Key features in both homes:

Intrinsic

•Strong clinical leadership and management
•Known as innovators: LCP; GSF; one home had a continuing
•care unit (*sustained in City; fragile in Rural*)
•Understood the importance of training/ education/ communication
•Stable workforce
•Support of care home owners

Extrinsic

❖Outside 'champions'
❖Networking: *at different stages of development*
❖GP and OOH problems: *largely overcome in City; variable in Rural*
❖Syringe driver access- *sorted in City; a struggle in Rural. A symbol of wider resource issues*

Year	Event -City Home
2003	City Home tenders for a continuing care contract. PCT second a former Community Macmillan nurse to the post of Liverpool Care Pathway (LCP) Facilitator.
2004	City Home formally implements the LCP.
2005	City Home joins the national GSF in care homes programme. A steering group is formed to help guide and assist the implementation of the LCP and GSF within the PCT, meeting regularly every three months
2006	Two more care homes within the PCT join the GSF in care homes programme
2007	A former hospice nurse becomes an Education Facilitator for end of life care n the PCT. A local group initiated by the PCT Supportive Palliative Care Strategy Group, begins to meet every six weeks to help enhance collaboration and promote multi agency working. A syringe driver library is installed in City Home to hold; training and access for other nursing homes in the local area.

Year	Event (Rural home)
2004	A Macmillan Nurse starts a 'care home project' targeting older residents with cancer related palliative care needs.
2006	End of life care facilitator for care homes is appointed by the PCT and begins to roll out the LCP into care homes. Rural home implements the LCP. A Community matron post is established with a specific remit for care homes. The Macmillan nursing team provide supplementary training for the LCP to care home nurses.
2007	LCP meetings set up with 12 care homes, including Rural home. A Community mental health nurse role is initiated to support the community matrons. The Macmillan nursing team begin healthcare assistant training programme for care home staff.
2008	LCP meetings disbanded due to poor attendance and support. Fixed term contract of End of life care facilitator ends. Macmillan team training programme for LCP, delivered to care home nurses, ends due to budget constraints. Rural home senior staff attend training every three months at local hospice in using and calibrating syringe drivers, and cascade training within the care home. Rural begins to host a single syringe driver, loaned by the local PCT Long term conditions team.

Influence of ‘Pathways’

Staff within the Home felt that the care that we were providing although was good to the best of our abilities did vary. So depending how experienced the nurse was or how well they knew that person or how good their rapport, empathy, recognition of symptoms was that their care that you then provided would vary… we wanted to provide a better standard of care and the LCP seemed a way of providing that standard of care and actually, not exactly standardising but promoting the nurses’ [care] regardless of how much knowledge and experience they had -to actually pre-empt problems rather than allow them to run on.

Care home manager observing the role of the LCP in end of life care, Rural case study

Access to syringe drivers

I had a patient down in intermediate care, which is where I was working, and she needed, over a Bank Holiday weekend, she needed a syringe driver and she needed something like the Pathway that we didn't have at the time. And she begged me not to send her into hospital and she ended up going to the hospice because we hadn't a clue where to get a syringe driver from. The doctor didn't know anything about the drugs or what we should be using. It was the day before Good Friday, which was a long Bank Holiday weekend, and that lady died at [the local hospice] 48 hours later with staff that she didn't know and she didn't want to go. And I think it's from then I decided that I didn't want this to happen again to anybody and that we needed to sort it out here so that even if it was just our home we actually knew where we were going and where to get the equipment from.

Care home manager describing a pivotal experience, City case study

Relationships with GPs

I think it [the GP and nursing home relationship] is excellent with [Rural care home]. It's not quite so good with others I don't think. I think we get much poorer communication and the information sharing's not as good. So sometimes you go and nobody seems to know why you've been called or what's going on or, you just get the impression that nobody really knows, you know, has got a particular handle of what's going on in certain patients... I think just to make sure that, you know, you have all the information to hand on both sides really. Because, [] there have been occasions where they've passed on a message here and it hasn't necessarily got through to us and then you go and you're not quite sure what you're looking for.

GP explaining why relationships with care homes are sometimes strained, Rural case study

Leverage through 'key' contacts and changes in commissioning practice

People in care homes are the most vulnerable, or one of the most vulnerable of our population. They tend to have more healthcare needs than a lot of people in the community. Yet again, historically, we commissioned the service and then walked away. … I sensed when I came into post a lot of frustration that care homes often knew that there were services out there but they couldn't access them. So in [the PCT] we've worked, and it's a team of people that have worked really hard to break down those barriers ….we look at how the PCT can *support the providers in that care home to deliver the best service that they can. It's a real team effort."*

Lead commissioner for continuing care, talking about ensuring access to PCT resources, City case study

Access to training and education

I think there should be more training about palliative care and end of life care than there is at the moment and I think that it's quite difficult to access it or to hear about it. We're a private nursing home so NHS courses, sometimes we hear about sometimes we don't. If we do hear about it we have to pay to go on them which isn't a problem but quite often you don't get to hear about them…There aren't enough courses to promote best practice.

Deputy Sister observing lack of access to training opportunities, Rural case study

Communication about residents

Admitting back from hospital, our main problem isn't to make sure that we can cater for their needs because we actually go and see them or do a verbal over the phone. It usually tends to be a verbal over the phone for an update but it's to make sure that they're asymptomatic of C.diff [Clostridium difficile] because we have had a gentleman that was admitted from hospital that was C.diff positive that we didn't know about…They'd sent off a sample we didn't even know that they'd sent. And we were informed I think it was three days after admission that he was C.diff positive.

Care home manager describing lack of communication by the local hospital; Rural case study

Concluding themes from whole study

- **The importance of leadership**
- **Inequalities in capacity to implement end of life care tools: a catalyst for compounding isolation**
- **Variability in access to outside resources: key staff critical**
- **Variability in access to outside resources: information, funding, equipment, resources and training**
- **Facilitators to end of life care**
- **Commissioning practices**

- The challenge of improving end of life care in care homes is usually described in terms of inadequacies in knowledge and training among care home staff. However suggesting that training of care home staff will solve the issue of quality is a error of simplistic thinking . Rather, attention should in addition focus on challenging those discriminative attitudes, beliefs and practices in the wider system that contribute to the isolation of nursing homes and enhancing the ability of homes to demonstrate leadership in practice development (Seymour et al, 2011)

References not cited in slides

- Seymour JE, Kumar A and Froggatt K (2011) Do nursing homes for older people have the support they need to provide end of life care? A mixed methods enquiry in England. *Palliative Medicine*, 25 (2):125-138 (Open Access)
- Cresswell J (2010) *Qualitative, Quantitative and Mixed Methods Research Designs. London*: Sage.