

# Networking to Improve End of Life Care

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## Key messages

- Networking across organisational and professional boundaries can facilitate learning and sharing of best practice that significantly improves end of life care.
- Successful networking needs to be based upon credible evidence-based clinical guidelines and policy-driven incentives at the national level and at the local level clinical ownership, personal communication and 'distributed leadership'.
- End of life care can fall down due to poor communication where responsibility for care is passed between primary care organisations, 'out of hours' agencies, social services and hospitals.
- Learning through networking is fragile and can easily be undermined by short-term pressures to cut costs.

## Abstract

Network organisations are increasingly common in healthcare. This paper describes an example of clinically led networking, which improved end of life care (EOLC) in care homes, differentiating between a 'network' as a formal entity and the more informal process of 'networking'. The paper begins with a brief discussion of networks and their development in healthcare, then an overview of EOLC policy, the case setting and methods. The paper describes four key features of this networking; (1) how it enabled discussions and implemented processes to help people address difficult taboos about dying; (2) how personal communication and 'distributed leadership' facilitated learning; (3) how EOLC occasionally lapsed during the handover of patient care, where personal relationship and communication were weaker; and (4) how successful learning and sharing of best practice was fragile and could be potentially undermined by wider financial pressures in the NHS.

## Why this matters to me

Dying may be the most important event in every person's life and yet it is often hidden in our society, health and social care. This paper describes how an End of Life Care project, involving networking across organisational and professional boundaries, addressed this taboo and improved care for people who were dying.

## INTRODUCTION

### Networks in healthcare

**N**etwork forms of organisation were first reported in the 1980s in the Italian textiles industry and IT companies in Silicon Valley in the USA. They were seen to be the most appropriate form of organisation in condition of uncertainty, because they

were more flexible and able to adapt to uncertain conditions<sup>1</sup>. Networks were also seen to be able to address complex or ‘wicked’ social problems, beyond the scope of one agency, requiring diverse organisations to work together. Networks require professional ownership, with active and value-driven ‘leadership’<sup>2</sup>, so also promised to re-engage public sector staff with change agendas. Accordingly, networks have become more common in the public services since 1997 under the New Labour governments, as part of the ‘network governance model’<sup>3</sup>. In this paper we examine one example of networking to improve end of life care.

### End of Life Care Policy

500,000 people die each year, predominantly over 75s, and mostly in hospitals, despite evidence that people prefer to die at home or in care homes. Death remains a taboo in the UK, making planning EOLC often difficult. The NHS EOLC Strategy (2008) aimed to address this taboo and to improve EOLC using a “whole systems” approach, involving inter-professional and inter-organisational networking<sup>4</sup>.

One of the tools suggested in the EOLC Strategy was the ‘Gold Standards Framework’ (GSF) - guidelines about primary care teams should improve EOLC involving: (1) identifying people approaching end of life; (2) assessing their care needs; (3) putting a care plan in place; and (4) communicating this plan across all relevant agencies involved<sup>5</sup>. There is also a specific GSF for Care Homes (GSFCH), focused on improving collaboration between care homes, GPs/primary care teams and palliative care teams to reduce inappropriate admissions to hospital at end of life.<sup>6</sup>

There are incentives for care homes and GPs to improve EOLC. Care homes can use GSFCH accreditation to attract residents and the Commission for Social Care Inspection’s (CSCI) is becoming more interested in EOLC as a home manager in our study reported:

*“CSCI are saying that they would like it [GSFCH] more and more. Yes, it is something that is coming into play and that factor is something that will affect our star rating.”*

There are also ‘palliative QOF points’ awarded for developing palliative care registers and holding regular multi-disciplinary palliative meetings. So GPs have a financial incentive to network with other organisations and professionals to develop palliative care in these two ways.

### **QUALITATIVE METHODS AND THE CASE STUDY**

The author was involved in a three-year project examining eight ‘Networks in Healthcare’<sup>7</sup>, which

was funded by the National Institute for Health Research Service Delivery and Organisation Programme (NIHR SDO). The case described in this paper is an example of a clinically led networking around care for older people, which contrast with other formal mandated networks in the wider project (such as managed cancer networks).

We examined a project led by a London-based PCT about the implementation of the GSFCH in local care homes, involving networking between two independent homes (with predominantly local authority funded residents), a NHS hospice and a local GP practice. Our qualitative research involved observation, analysis of documents and 18 semi-structured interviews with a representative range of stakeholders involved in the project, conducted between October 2008 and Feb 2009. In one care homes the GSFCH was due to be implemented in Spring 2009, whereas the other home was beginning the process when we conducted interviews, so the two homes were at different stages of implementing the GSFCH. Unfortunately for pragmatic reasons we were not able to observe the whole process in the second home. Our research did however highlight a number of interesting issues.

### **RESULTS**

#### “Forcing that conversation” about EOLC

One of the first issues the EOLC project faced was acknowledging and addressing taboos around death and how it affected the provision of EOLC. Palliative nurses described the anxiety care home staff often felt about dealing with dying residents:

*“Nurses going to work in care homes just want to do basic nursing, I’ve seen nurses absolutely petrified about palliative care.”* (Palliative Nurse)

So palliative nurses and GPs involved in the project began normalising the dying process by getting staff talking about it:

*“We have educated and really taught the nurses with regards to end of life and the fact that it’s not wrong to die in a nursing home, because nurses do panic when a patient ... is deteriorating and clearly they [patients] are dying and they [nurses] quite often call for an ambulance if it’s out of hours, because they feel as if they don’t do something, they’ve been a failure.”* (GP)

Interviewees also talked about struggling to deal with the relatives of dying patients:

*“Often you’re treating the family, not the patient... families do feel guilty and they do transfer that guilt to the staff and they can sometimes be very difficult to the staff and very demanding and may have unrealistic expectations.”* (GP)

Both homes had introduced a 'death and dying' form for new residents but staff had previously avoided completing it:

*"On the form it does talk about death but we tended not to ask that bit because not a lot of people want to talk about that."* (Carer)

The GSFCH requires that patients and relatives' EOLC wishes are discussed and recorded and mandating the completion of form made a difference to EOLC:

*"I used to be afraid to ask it. And when I do ask them they [patient and relatives] said they don't wish to talk about it... but we explain it is part of the procedure, we have to do that because someone can die tomorrow."* (Carer)

Consequently staff the care homes had become more comfortable talking with relatives about dying, which had enabled them to better prepare for it:

*"We're prepared, so we speak to the relatives and say, I know it's a very difficult area but we have made a policy... let's talk... Do we resuscitate when they [patients] get that that [dying] stage? ... Is it that someone has a special religious thing to perform?"* (Nurse Clinical Director)

So a balance of people and processes, initiating conversations about EOLC and mandating the death and dying form, had enabled care staff to speak with patients and their relatives about EOLC, which in turn reduced the number of inappropriate hospital admissions. A Nurse Clinical Director described the GSFCH as:

*"Brilliant guidelines... because it forces that conversation."*

#### "It's not about ticking the boxes": Improving EOLC through 'distributed leadership'

Evidence-based guidelines, particularly where credible clinicians develop them, play an increasing role in implementing best practice in healthcare networks, and NICE evidence appears to be increasingly legitimate<sup>7-9</sup>. Similarly, palliative nurses leading the EOLC network saw the EOLC programme and GSF guidelines, which were developed by respected primary and palliative care clinicians, as legitimately diffusing best practice about palliative care into the wider healthcare system:

*"I hugely believe in spreading the word of palliative care... we've been doing this for years but to put it on paper and to make it useful... it's a wonder really, because it's how we [in palliative care] practice... it's a template for outsiders to adopt really and it's tried and tested."* (Palliative Nurse)

However, unwillingly forcing processes upon front line clinicians in organisational context that are not open to them can be ineffective or even counter productive<sup>10</sup>. A palliative nurse leading the EOLC project commented:

*"The tool is only as good as the person who uses it... to me it's not about tick boxes... It's translating it into practice... it's mentorship, it's about learning from people, particularly with communication skills... I could walk onto a ward and I would tell you whether you could do [EOLC] Pathways ... whether people smile at you ... say hi... it's just about being human, genuine, caring, honest, open and if you haven't got that... end of life care is irrelevant... If you've got a good ward-nursing manager, nursing home manager... it will work here, because they've got the ability ... and passion to drive it forward... it does depend on leadership within individual organisations."* (Palliative Nurse)

In our wider project on Networks in Healthcare<sup>7</sup> we found that 'distributed leadership' was essential for evidence-based changes to happen. Distributed leadership is a systemic approach to leadership, which recognises the inter-relationship between leadership and followership and that people in every part and at every level of an organisation can affect its functioning in practice<sup>11</sup>. Accordingly, distributed leadership in healthcare networks must involve key members of all the important constituencies involved (commonly doctors, nurses and managers and different organisations) who have the clinical and personal credibility to affect practice in every part of the network.

Similarly, the support and "excellent" clinical and personal skills of palliative nurses, nurse clinical directors in homes and GPs were also seen as essential to the success of the GSFCH project. Interviewees commented on "very good relations" between the GP practice, hospice and homes and that the project had been "a team effort". The EOLC project involved networking between independent care homes, a GP practice, and a hospice all operating different systems but interviewees suggested that the GSFCH project had worked due to personal communication:

*"The systems are completely different but they're not a barrier because it's verbal communication."* (GP)

Relations between the two care homes in this study were not so close because they competed both for patients and staff. Consequently, they did not directly share learning about EOLC. However learning was channelled through staff moving between care homes:

*"Some of the nurses actually work in both places... it's really helpful to us because they know what goes on over there and try to bring it over here."* (GP)

*"Before I came here I was working for BUPA... I have worked in different places... before [that] we were using the Gold Standard one and then when I joined BUPA we were using the Liverpool [care pathway]... I bring that."* (Nurse Clinical Director)

Networking around EOLC also provided an important indirect channel for learning between the homes. GPs and palliative nurses took their learning about improving EOLC processes from one home and applied it in the other. A GP commented:

*“With [one home] it was a learning curve for both of us... gradually the systems have evolved, while we’re there we tweak them all the time... you’re always changing systems to improve anyway... that worked well for us and for them. So we’re kind of trying to implement that over there [other home]”*

However in the Networks we examined<sup>7</sup>, shared learning was fragile and could easily be indirectly undermined by commercial considerations. In previous research we have also found that learning can be crowded out by top-down management in networks, such as cancer networks<sup>12-13</sup>. When we had completed our research the EOLC project appeared to be making excellent progress in improving and sharing good EOLC practice. However we subsequently heard that in an attempt to reduce costs, one of the care home had decided to cancel its contract with the GP practice to exclusively provide care for residents, potentially undermining not only patient care but also the networking channelling learning from the other home. The PCT was reportedly considering stepping in to preserve the relationship between the home and practice, and so learning may yet be saved. However, this incident, like others in the wider project, highlights the vulnerability of learning in networks to increasing cost pressures in health and social care.

#### “Where things fall apart”: Handing over care to clinicians who do not know patient

Although communication and relations between the GP surgery, NHS hospice and care homes were “excellent”, problems occurred due to poor communication with temporary agency staff, working at weekends and at night. In the wider Networks project<sup>7</sup> we also found that Networks may function well at their core, due to close personal relationships, but less well at their periphery. So a balance needs to be struck between networks being too tight and too loose. Also, although the NHS talks about having a ‘no blame culture’, we are seeing a rise in professional disciplinary hearings and litigation, which may be leading staff to behave defensively, off-loading risks onto other organisations, rather than in the best interests of patients. Similarly here, agency staff, working out of hours, were reported to feel “vulnerable” dealing with dying patients and were consequently “bouncing” people into hospital unnecessarily:

*“Nursing staff feel very anxious, especially when we’re [GPs]*

*not around. So it’s fine during the week, sort of 8 until 6.30, we’re here ... in the evenings and weekends, often there’s not regular staff on, there’s agency staff or night staff, there’s the out of hours service and sometimes that’s where things fall apart.” (GP)*

*“How can you communicate well? ... care home staff [saying] this patient is dying [to] the GP who’s never met [them] before... it’s a real problem ... [calling an ambulance] it’s a safer way to go, but without understanding the possibility for harm, by sending a frail old person to hospital.” (Palliative Nurse)*

*“The problem... is that the nurses that work in the day... we’ve worked and educated them but the nurses who work nights... only work at weekends, we never see those ones. So unless there’s very good hand over from the nurses... those nurses will more likely call an ambulance. And I don’t think the hand over is particularly good at these nursing homes because when you go round, you ask the nurses... when did this [illness] start? And quite often they say, oh I don’t know, I’ve only come in today or I wasn’t here at the weekend.” (GP)*

*“They do funny shifts and don’t necessarily communicate the fact that they’re going to be off, that drives me mad.” (Palliative Nurse)*

So again here we see the importance of inter-personal contact in order to ensure good patient care, but in its absence better information communication technologies, records and processes may be needed. The handover of dying patients from the hospital to care homes could also be problematic. A GP described hospital discharge notes as:

*“A single page of handwritten, illegible information... you can normally read the drugs the diagnosis may be SCC lung and that’s all you have to go on... you can take a while to try and find the last GP to actually get some information.” (GP)*

GPs also commented on receiving “a very good social services report that doesn’t have medical understanding.”

A Social worker agreed that doctors and social workers saw patients in different terms:

*“We’re coming from two different sort of angles... they’re medical, they focus on the health needs, we [social workers] look at the whole picture... all holistic... we’re organising everything there in the background and just making sure everything is in place.” (Social Worker)*

Palliative nurses leading the EOLC project acknowledged it was important to develop personal relationships across organisational boundaries and had tried to work more closely with social services:

*“[We’ve] done lots of teaching with social workers, again all very, very interested and they are very key people, continuing care is incredibly key... that’s going to be one of the major blocks... we divide health and social care in two.” (Palliative Nurse)*

"[Social services] They're so much an important part of the puzzle... you could have fantastic medical GP support, you could have fantastic nursing support but if your care support falls down, you're stuffed." (Palliative Nurse)

So although EOLC networking was successful in large part due to close working relations between core clinical staff working in primary care, it is important that they reach out and develop links across organisational boundaries at the periphery of existing networking.

## DISCUSSION

This paper reports a number of key issues in relatively successful informal, clinical networking to improve EOLC. Its success can be explained by a balance of factors, which are reflected in our wider study<sup>7</sup>. So why was this EOLC networking successful? First, it was based on policy and guidelines, which were credible with clinicians at local level because they had been developed nationally by respected clinicians. These guidelines are also aligned with incentive structures (GSFCH accreditation, CSCI star ratings and GP QOF points), so people were intrinsically and extrinsically motivated to implement the GSFCH. But policy and process alone cannot improve care. People with clinical and personal skill and credibility must own changes to EOLC at local-level. They may then be more able to convince others at local level to own these changes too. Making such changes through networking depends upon 'distributed leadership' to ensure that key constituencies are enrolled in its purpose.

EOLC can however fall down while handing over care to those who do not know patients. EOLC in weekdays improved due to networking between the homes, hospice and GP practice, but poor communication with 'out of hours' staff, acute care and social services still needs to be improved. And finally, learning through networking appears fragile and can easily be neglected in commercial considerations. As we have seen, making short-term savings in one organisation may have greater inter-organisational costs.

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