Improving integrated team working to support people to die in the place of their choice

Although many people express a wish to die at home, few do so. A team of community nurses and GPs changed working practices to address this

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ABSTRACT Bowers B et al (2010) Improving integrated team working to support people to die in the place of their choice. Nursing Times; 106: 32, 14-16.

Dying in a place of one’s choice is considered to be a quantifiable measure of the effectiveness of end of life services in primary care. Although most people say they would prefer to die in their own home, very few actually do so.

This article looks at how a team of community nurses and GPs changed their practice by using recognised end of life care tools. These helped practitioners in supporting adults with terminal illnesses to die in a place of their choice.

A subsequent audit of patients’ actual place of death against their preferred place demonstrates how working in more integrated ways has helped.

INTRODUCTION

Helping someone to die in the place of their choice is widely considered to be a quantifiable measure of the effectiveness of end of life services in primary care (Agar et al, 2008; Department of Health, 2008). Some 56-74% of the population express a desire to die at home (National Audit Office, 2008).

However, as death approaches, people often change their mind and the preference for dying at home sharply declines. The reasons for this include no longer believing their symptoms can be suitably controlled at home or feeling that they are putting too much of a burden on their family (Agar et al, 2008; McCall and Rice, 2005).

Nonetheless, while the majority express a wish not to die in hospital, over half still do so (see Background box).

This article shows how a team of community nurses and GPs have changed their practice to identify adults with palliative care needs at an earlier stage and support them in dying in the place of their choice.

The patients discussed are registered with a GP practice with two surgeries, one covering several rural villages and the other a busy urban area in Cambridge.

Practitioners’ previous experiences were that end of life care could be well planned, or unpredictable and reactive. There were several instances where community nurses first met patients in the last few days of their life. In these cases, last minute crisis management led to people dying in hospital or at a hospice when they had wanted to die at home.

An audit of the 21 patients who died in the six months following the changes, and with whom the community nurses were involved, demonstrates how effective the multidisciplinary team is now in supporting patients to die in the place of their choice.

GOLD STANDARDS FRAMEWORK

The Gold Standards Framework offers a practical structure for primary care practitioners to coordinate and support care pathways centred on the needs of patients and their carers (Pellett, 2009; Thomas, 2003).

This means GPS, community nurses, Macmillan nurses and other professionals involved in end of life care meeting together. Through liaison and discussions, practitioners are prompted to look at the seven Cs of care provision (Box 1).

From November 2009, we increased the frequency of the practice’s GSF multidisciplinary team meetings from every three months to every eight weeks. Although the number of patients on the GSF register and hence the related workload increased, practitioners were still able to identify people with complex needs before they had a crisis in the last few weeks of life.

Community nurses, practice nurses and GPs were empowered to add patients with any illness requiring palliative care who were likely to be in the last year of life to the register.

Previously, the register had focused on people with a cancer diagnosis believed to be in the last six months of life. With structured meetings being held every eight weeks, clinicians are now better able to monitor individualised care pathways before the person dies and adjust care coordination to meet changing needs (DH, 2009; Grande et al, 1997).

As practitioners experienced in coordinating end of life care, the community nurses maintain a lead role in organising the care of patients who want their involvement. However, being a busy practice covering two sites, patients would often see the allocated duty GP on the day they requested a visit.

Now, through the GSF meetings, a lead GP who knows the patient well is identified, and makes any medical visits to add further continuity to care.

BACKGROUND

- Mortality statistics show that only 18% of people die at home (Department of Health, 2008).

- The majority of people with terminal illnesses express a preference not to die in hospital, yet 58% do so.

- If care is planned in an individualised and coordinated way, more people can be supported to die in the place of their choice (DH, 2009).
The GSF meetings are jointly chaired by the GP lead for end of life care and the community charge nurse. The meetings act as a dynamic forum for identifying care issues and group problem solving (DH, 2009). The chairs identify action plans from the discussions. The most appropriate clinician is then nominated to work alongside patients and carers, supporting them in exploring and meeting their needs (Eyershaw and Ward, 2003). Recent deaths are reflected on to facilitate constructive practical learning (Thomas, 2003).

OUT OF HOURS SERVICES
Carers and patients take reassurance from knowing that they will receive skilled support quickly if they need help out of hours (DH, 2009; Ellershaw and Ward, 2003).

In Cambridgeshire, there is a night community nursing service and an out of hours doctor service. However, neither of these can automatically access information on patients’ situations and care needs. Once a patient has been identified as having deteriorating health at or before the GSF meetings, the relevant GP or the community nurses fax information to the out of hours doctor and nursing services. This information letter is based on the nationally advocated GSF out of hours front sheet (tinyurl.com/front-sheet). It contains information on diagnosis, anticipated needs, preferred priorities for care, medications, next of kin information, current care input and any risks identified.

Since November 2009, this letter has been accessed through the patient’s electronic notes. A substantial amount of information is automatically filled in when the clinician opens the document, which has speeded up the process of completing the letter and concordance among busy practitioners. The surgery’s receptionists then fax the letter to both out of hours services. Out of hours letters were sent for 18 of the 21 patients in the audit. Two who did not have letters were being cared for and died either in hospital or in the hospice. The third deteriorated unexpectedly and died at home.

At the front of patient notes in the home service, Macmillan nurses have identified needing “unwanted” physical help from relatives, such as with incontinence, as a precursor for needing to be cared for somewhere else (McCull and Rice, 2005). Now that people are being placed on the GSF register earlier, the community nurses are meeting and getting to know patients and their families earlier. By building up trusting relationships before symptoms become problematic, patients and their families can be offered access to appropriate and timely support (Agar et al, 2008).

The community nurses can support patients in rapidly accessing integrated care services to help them stay at home. Locally, we have a well established hospice with a hospice at home nursing service and Macmillan specialist nurses attached to it. Community nurses work as part of an established integrated team comprised of an NHS integrated care team, physiotherapists, occupational therapists and social workers, which means it is possible to refer to other services quickly. Wherever possible, they will assess patients with deteriorating health on the same day.

A wide range of appropriate services is invaluable in maintaining patients’ quality of life at home (Agar et al, 2008; Ellershaw and Ward, 2003). Fig 1 shows the frequency and range of services accessed by patients and families in the audit. Not everyone wanted care input but, by respecting patients’ views and needs, community nurses helped them identify the services available to plan future care (McCull and Rice, 2005).

INTEGRATED SERVICES
Often, it is the fatigue of providing constant emotional or physical care to loved ones which can cause a breakdown in relatives’ abilities to cope (Grande et al, 1997). Similarly, patients have identified needing “unwanted” physical help from relatives, such as with incontinence, as a precursor for needing to be cared for somewhere else (McCull and Rice, 2005).

Just in case drugs
Commonly, these are drugs that can be administered subcutaneously by practitioners for nausea, sickness, pain, respiratory secretions and agitation (Pellett, 2009). The GP fills in a prescription chart for the house, which enables community nurses to administer these drugs when needed. Thirteen of the 21 patients audited had just in case drugs prescribed.

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in case drugs at home; of these, 11 needed to use them.

Not everything has gone smoothly with just in case medication. In one case, the drugs were put in the house during the day, but there was no prescription chart for the out of hours nurses to use when they were called that evening to administer pain relief. This was filled in by the out of hours doctor, but added to the delay in the patient receiving pain relief. Education was subsequently provided to the prescribing GPs so they were aware of what paperwork would be needed in the future.

**PREFERRED PRIORITIES FOR CARE**

Evidence that healthcare professionals often assume where patients would like to die without discussing it directly with them or their families (McCall and Rice, 2005). A significant change in practice has involved community nurses and GPs now explicitly asking people where they would like to be cared for when they die. As part of these conversations, discussions are facilitated between patients and their families (Agar et al, 2008).

To aid open discussions, patients are asked to explore the questions in the nationally recognised Preferred Priorities for Care (PPC) document (www.ppcdocument.com). The community nursing team has also been provided with training from Macmillan nurses to help them explore these subjects with patients at the right time.

Some patients chose not to discuss issues in depth, while others found that discussions enabled them to have open conversations with their families. Moreover, when questions were broached at the right time or returned to later, patients were able to discuss the realistic future care options available with practitioners (Agar et al, 2008; Grande et al, 1997).

On several occasions, practitioners found that although patients were willing to discuss where they would like to be cared for when they die, they did not want this information written down formally in the PPC. One reason a patient gave for not wanting to complete the PPC was that writing down these wishes, make it feel like the choice was “set in stone”. As an alternative, with consent, patients’ wishes were made clearly visible in their home notes and electronic notes at the surgery. It was made clear to them all that they could change their mind at any point about where they wished to die.

Of the 21 patients audited, 90% (n=19) were able to die in the place of their choice (Fig 2). Both those who died in a setting not of their choice did so in a hospice where they were receiving symptom control. Indeed, both were due to come home on the day they died.

Five people changed their preferred place of death from home as their illnesses progressed. There were a number of reasons for this, including not wanting to die alone or needing more complex clinical care than it was possible to provide at home. Originally, 16 of the 21 wanted to die at home and, by the time of their death, 11 maintained this wish. Every suitable integrated care resource was put into place to enable them to do so. Notably, with this extra care, 43% (n=9) of patients could stay at home compared with the national average of 18% (DH, 2008).

**CONCLUSION**

The changes in practice have enabled the whole multidisciplinary team to better support people in achieving their wish to die in the place of their choice. The number of situations requiring crisis management has also been dramatically reduced. Practitioners continue to build on the existing strong communication systems and partnerships between colleagues and with patients.

Having a team suitably equipped with a variety of palliative care skills is fundamental in providing meaningful end of life care (DH, 2009). Within this particular team, several community nurses had a variety of specialist and generalist palliative care experience and interests. Access to this collective experience stimulated the whole team to question how pre-existing good practice could be improved and built on.

There were already strong working relationships between community nurses and GPs. The GPs at the practice were both open to change and had ample partner experience to implement the GSF and prescribethe most suitable anticipatory drugs to enable each patient’s care to be planned ahead of time. Without such a highly experienced team, the changes in practice may have taken longer to implement.

Although this article demonstrates practice in just one small area, it highlights what can be achieved with strong leadership, patient centred care and integrated practice (DH, 2009). Feedback from patients and families shows that practitioners are enabling them to openly plan their care and make the most of their remaining time together.

The multidisciplinary team is now working to ensure that evidence based practice is delivered in the last few days of life. Community nurses and GPs are piloting the Liverpool Care Pathway in the community to ensure communication and clinical decisions remain focused. This includes appropriately withdrawing unnecessary care, and supporting patients and their families in the last day of life and in bereavement (Eyre, 2010; Ellershaw and Ward, 2003).

Encouraged by the achievements of the practice’s GSF meetings, one of the GPs has now established separate regular GSF meetings in a large residential and nursing home to aid continuity of end of life care.

For more information, contact Ben Bowers at bbowers@nhs.net

**REFERENCES**


Department of Health (2008) End of Life Care Strategy – Promoting High Quality Care for All Adults at the End of Life. London: DH; tinyurl.com/end-strategy


