Palliative care: do all patients now have a choice about where they die?

Despite palliative care being a government priority with numerous tools and guidelines, patient choice is still limited and service provision is patchy.

INTRODUCTION

Quality end of life care has been established as a priority in healthcare provision with a series of guidance reports, outlined below. An integral part of palliative care is everyone’s right to choose where they die. However, across the country, patient choice is found to be variable and this fundamental right is being denied.

The Calman Hine report, which was focused on cancer services, identified the need for a patient-centred approach to care and that all patients should have access to uniformly high quality care (Department of Health, 1995). Following this report, the government recognised the need for a strategic approach to cancer and palliative care.

The national cancer plan (DH, 2000) set out a comprehensive strategy linking prevention, diagnosis, treatment, care and research. It highlighted the inadequate resources and inequality of services in communities, and pledged to invest significantly in staff training and support for carers to enable patients who wish to deal at home to achieve this.

NICE (2004) guidance aimed to “define service models likely to ensure patients with cancer, their families and carers, receive support and care to help them cope”. This guidance came as a direct result of national patient surveys on cancer care (DH, 2002), which showed a wide variation in the quality of care delivered across the country. The NHS end of life care programme (DH, 2004) suggested using the Gold Standards Framework programme (Thomas, 2001), Liverpool Care Pathway (Marie Curie Palliative Care Institute Liverpool, 2001) and the Preferred Place of Care plan (Lancashire and South Cumbria Cancer Network, 2000), to standardise care provision. Although these specialist palliative care assessment tools were developed nearly a decade ago and are also recognised by the government, they are still not implemented countrywide.

PRACTICE POINTS

- A patient-centred approach to palliative care must be established, with access to consistently high quality care.
- Service models must be defined to ensure people with a terminal illness, along with their families and carers, receive support and care to help them cope.
- The Gold Standards Framework (GSF) (Thomas, 2001) should be implemented.
- When using the GSF, primary care teams should identify patients in the last year of life and put together a management plan to enable them to have a choice about the care they receive and where.
- GPs should be encouraged to complete a community palliative care management form.
- PCTs should consider engaging a GSF facilitator to help practices develop the skills needed to use it effectively.

GOLD STANDARDS FRAMEWORK

The GSF is a systematic, evidence-based approach to optimising care for people nearing the end of life in the community. It requires primary care teams to identify those in the last year of life and put together a management plan to enable them to have a choice about the care they receive and where.

Riley (2005) suggested it should be mandatory for GPs to complete a community palliative care management form. Cooper (2006) reiterated that the GSF was developed as a means to improve care during working hours for people nearing the end of life to stop an out of hours crisis preventing them from dying at home if they wished to do so.

Many primary care trusts (including Sandwell PCT and Solihull PCT) have chosen to engage a GSF facilitator to actively encourage GPs to sign up to the programme and help practices develop the skills needed to use it effectively, but some GPs seem to use it effectively, but some GPs seem...
restrained. Mitchell (2002) observed that some express discomfort about their competence to provide palliative care adequately. Research suggests that the GSFs is the key to thinking through and implementing high-quality patient-centred care (British Medical Association, 2006).

One of the quality markers defined in a consultation document (DH, 2008) on the end of life care strategy is that GPs must demonstrate they have mechanisms in place to document patients' needs and preferences. I believe that, if GPs are to prove they provide quality services and obtain the financial rewards that go with this, adopting the GSF should be mandatory.

VARIABLE SERVICES

Documenting patients' needs and preferences implies they have a choice about the level of care and where that care is delivered.

NICE (2004) highlighted that palliative care services varied and recommended that commissioners and providers ensure an appropriate range and volume of specialist services to meet the needs of their local populations. Yet this has still not been achieved.

Some PCTs have been proactive and have developed services in line with government recommendations. One PCT in the Midlands embarked on the GSF programme five years ago, engaging a project manager to champion it. As a result, the trust has a robust palliative care service. In contrast, a neighbouring PCT has had to become reactive because of the quality markers consultation (DH, 2008), but is spending money with no structure.

Is it possible to have equity in services when different areas have diverse needs? Nigel Edwards, director of policy at the NHS Confederation, commented in The Daily Telegraph (Hall, 2006) that variation in the delivery of health services – the "postcode lottery" – is seen as a problem by politicians and the public who, at the same time, want more decisions to be taken locally.

In another interview with The Daily Telegraph (Smith, 2008), Baroness Young stated: "The Great British Public has got to make its mind up – either they have to want local flexibility or else they have to accept that priorities would be determined on a national basis."

Decisions made by PCTs at local levels based on local need determine the level and type of service delivered but may not mirror what is happening elsewhere. This could affect patients' experience of services being "good" or "bad", depending on whether the services they felt they needed were available.

Some people may not wish to die at home but may not want to be in hospital either. The role of the hospice or specialist palliative care unit is to provide an environment for palliative care patients away from the acute sector. Working as a team to treat the whole person in terms of symptom management – the philosophy developed by Dame Cicely Saunders – has become the foundation of the hospice movement (Connor, 1997).

However, not every area has access to a hospice. Commenting on a Commons Health Committee (2004) report, chairman David Hinchliffe said: "The right to a good death should be fundamental" (BBC News, 2004). The report commented on variations in accessing palliative care and pointed out that affluent areas were much better served by hospices than less affluent ones.

Hospice care is expensive, and some believe the money would be better spent commissioning nursing home beds with palliative care trained staff at a much lower cost. However, as long as 80% of hospices remain charitably funded, differences in opinion over how best to spend the funds available are likely to remain.

MINORITY GROUPS

When commissioning palliative care services, PCTs must consider the needs of minority groups, including those with dementia, learning disabilities and HIV, and older people.

Research has indicated that older people and those with dementia have similar symptoms and health needs to those with cancer but for a longer period (McCarthy et al, 1997).

Similarly, people with learning disabilities may struggle to access information about cancer. A study involving paid carers who used a pictorial cancer information book to support those with learning disabilities and cancer concluded that carers struggled with the task (Jones et al, 2007). Carers felt unsupported by professional staff and their own organisation, and the study recommended educational programmes to enhance carers' skills (Jones et al, 2007).

Another challenge facing specialist palliative care services over the past decade has been HIV and AIDS, which has seen growing numbers of predominantly young terminal patients with specific needs (Payne et al, 2008). Initially, money was ringfenced to provide specialist care beds for this group, but now generic services tend to be used. Although the number of terminal patients has now declined because of triple therapy, the AIDS Education and Training Centers National Resource Center (2006) suggested that, because of the lack of disease specific palliative care services, palliative care and disease specific care should be integrated to promote quality of life and relieve suffering. This may provide more equitable services for all terminal patients.

RESOURCES VERSUS CHOICE

The Prefered Place of Care plan, now Prefered Priorities for Care (Lancashire and South Cumbria Cancer Network, 2000), is intended to be a patient held record that follows them into a variety of care settings, detailing their choices and preferences. However, Storey et al (2003) observed that the place of final care for people with terminal illness is influenced more by resource availability than patient choice.

Grande (1998) found that people with informal carer support were more likely to die at home and to access palliative home care. Therefore, reassuring lay carers is an integral part of professional carers' role (Clark and Seymour, 1998).

Storey et al (2003) concluded continuity of care and availability of 24 hour care are important issues. Changes in options relating to place of death often occur because the "regular" healthcare professional in charge is not available when needs change. Patients are still being admitted to hospital or hospices because GPs are not aware of their wishes or carers feel vulnerable. Storey et al's (2003) conclusion would support the government's drive for access to palliative care 24 hours a day, seven days a week, to prevent inappropriate hospital admissions.

REFUSING TREATMENT

Incorporated in the GSF is a document covering patients' wishes regarding resuscitation – the do not resuscitate (DNR) document. They may have a living will, which includes details of withdrawal of treatment or perhaps even euthanasia. Patients clearly have a right to refuse treatment that prolongs life (Clark et al, 1997).

However, their "right to die" does not extend to the "right to be killed". The Human Rights Act 1998 (Office of Public Sector Information, 1998) regards the protection of innocent human life as the central principle to morality.

If we accept that all people have equal
moral status, then we have to accept our obligation to one another, specifically to do no harm (Payne et al, 2008). Those who argue against legalising euthanasia suggest there will inevitably be abuse of the law and vulnerable people will be put at risk. These arguments are collectively known as the "slippery slope". Payne et al (2008) observed that many hospices reject euthanasia as it may be seen as an easy alternative to the challenge of addressing care delivery. However, Twycross (2002) argued there is a level of existence where most if not all people would not want to be kept alive; this creates powerful images that must be acknowledged by those who oppose euthanasia. The National Council for Palliative Care (2004), in response to the Assisted Dying for the Terminally Ill bill, said "the issue of where limits should be set is one for society to decide through its legislators in parliament". For this reason, euthanasia is a highly contested subject. The Mental Capacity Act 2005 (Office of Public Sector Information, 2005) seeks to protect vulnerable people and relates to people who lack capacity to make appropriate decisions for themselves. If euthanasia is legalised in the UK, as well as all the legislation that will surround its introduction, it would undoubtedly be used in conjunction with the Mental Capacity Act to avoid the "slippery slope".

CONCLUSION

The government has recognised palliative care as a priority in health policy. Although strategic direction for policy is driven by the government, implementation is generally local, leading to variations in services. These variations may affect quality of services depending on resources available and how they have been allocated, resulting in a so called "postcode lottery". Does choice depend on what PCTs and other organisations that commission services see as priorities within government policy? Whatever the argument about resources and allocation, research has shown that people do not always have a choice about where they die even if they have documented that choice.

Choices about euthanasia are also prominent in the media, and many people would like to see it legalised in this country. People with special and specific needs, although acknowledged, generally receive non-specific services. The introduction of the GSF has helped to focus community services around the needs of palliative care patients and, although slow to be implemented, it is beginning to gain momentum. This will help to address inequity in services across the country.

REFERENCES


Lancashire and South Cumbria Cancer Network (2000) Preferred Place of Care. Updated in 2007 as Preferred Priorities for Care(2007). Lancashire and South Cumbria Cancer Network. tinyurl.com/PlaceOfCare