

The continuing challenge of palliative care

Palliative care, unlike many other specialties, has many of its roots in primary and community care. Cicely Saunders' original vision on her pioneering journey to establish hospices and hospice care worldwide, was primarily to ensure that excellent care relieved patients' suffering as they approached death. She coined the term 'total pain' to express the overwhelming feelings of pain and despair that occur when physical pain is compounded by emotional anguish, social concerns and isolation, and spiritual turmoil. She also drew attention to a patient's need to feel confident that the professionals are committed to providing care, valuing the individual patient, and above all, not abandoning the patient in their hour of greatest need, whenever that is. Such a personal relationship was seen in the traditional family doctor role, but the establishment of the hospice movement brought the science of palliative care into the frame.

Now the new GP contract has radically altered the work-patterns of GPs, and hence the service that the patients can expect. There are advantages and disadvantages for both parties in the new relationship. However, for terminally ill patients, the disadvantages are thrust into view. A recent study by the Parkinson's Disease Society, *Just Invisible: the Advanced Parkinson's Project*, makes stark reading.¹ For so many patients with advanced disease, their carers bear the brunt at nights and weekends, becoming exasperated and exhausted, with the patient dependent and feeling ashamed but helpless in the face of bladder and bowel problems. Sleep deprived relatives struggle, with limited carer input. Few have been properly taught to lift and turn the person they love. As death approaches, so fears increase, yet relatives providing care at home hesitate to call for help. When they do call, inappropriate emergency hospital admission occurs all too often.

Recent Parliamentary debates² and the report from the House of Commons Select Committee³ have emphasised the need for ubiquitous good palliative care. We know what to do for patients but we are not doing it. The knowledge exists, as do staff with the necessary skills and there are 24-hour telephone advisory services from many major hospices. Almost 1000 doctors, many of

whom are GPs, have done the Diploma in Palliative Medicine course at Cardiff; some have gone on to MSc level. Year on year more enrol to improve their palliative care skills for the benefit of their patients. But the challenges remain: providing continuity of care, responsive at times of need, that can shoulder the burden to make a tragic situation bearable and eventually create a satisfying memory for all who are left behind after the death. Yet such attitudes have been sacrificed in the political drive for targets, for tick-box outcomes and financial expediency. Commissioning of palliative care services remains inadequate, with about two-thirds of the cost nationally borne by the charitable sector. Much of that fundraising has traditionally been around end-stage cancer, yet other diseases — especially neurological and cardiac — have huge unmet needs.⁴ The NHS frameworks are now in place to change that, but some hard rationing decisions will have to be taken.

Worth *et al* highlight the crises that suddenly arise out of hours.⁵ They report the stark reality from those patients and carers who did not have their care needs met by the new service, which is designed more for acute interventions and triage than for the complex physical and psychosocial needs of the terminally ill. Carers describe uncertainty about when to call, feeling their request for help is blocked, and experience an insensitivity that should be absent from a system claiming to provide care to those with greatest need. Although handover sheets can improve continuity and help carers navigate the system, the descriptions make salutary reading — patients fear being a nuisance, sense the doctor's reluctance to come out and fear being 'bounced back' into hospital, threatening their wishes to remain at home.

Deschepper *et al* in Belgium⁶ have attempted to ensure patients' wishes to remain at home can be met, by developing a resource book for GPs to guide them through decision making and the pitfalls that can occur in trying to provide continuity of home care. They highlight the sea-change that the Belgium euthanasia law has imposed on GPs, who were ill-prepared for this and who find discussions with patients about euthanasia both emotionally and practically

difficult to deal with. Decisions over hydration and nutrition at home exemplify that continuity of care and communicating the issues behind decisions is a major challenge when the patient's own GP is not available. Borgsteede *et al* from the Netherlands⁷ confirm one's gut feeling — patients need their GP to be available when they are in greatest need, to be professionally competent in end-of-life care and to coordinate care to ensure continuity.

That patients usually wish to die at home cannot be in doubt; in Britain two-thirds of those dying wish to end their days at home, but less than a quarter achieve this. But if patients do end up in hospital, they fare no better. The National Audit Office report on hospital care also makes salutary reading.⁸ It catalogues that half of hospital patients experience moderate to severe pain, with over a quarter of these feeling hospital staff did not do all they could to try to relieve it. One in three cancer patients felt so anxious and/or depressed that they needed help to cope, but one-fifth of those reported that hospital staff did not do all they could. So when home care failed, the hospital sector often also seems to fail these patients.

Help the Aged report that the needs of older people who are dying are often ignored. They are, in the words of the report *Dying in Older Age*:⁹

'... more likely than younger people to experience multiple medical conditions, repeated hospital admissions, lack of preventative planning, under-recognition of symptoms and physical or mental impairment. They are more likely to experience social isolation and economic hardship. Despite this, they are less likely than younger people to receive support at home, in hospital or in a hospice, or to receive attention from GPs or district nurses during the last year of their lives. Older people are often described as the "disadvantaged dying".'

Wherever the patient is, the process of care must work; measuring outcomes at one point or another is not enough. Care is a continuum — an iterative process. Like an intimate conversation, it cannot just be picked up by a

stranger when the most difficult, sensitive and personal aspects of the story are being played out. Bad care does not die with the patient; it lives on in the memories of those deeply affected by the death, often across several generations in a family, altering their view of the future they want for themselves, reinforcing fears and fuelling anger with a service perceived as having let them down.

All patients who are dying need to have a GP lead in care at home, with clear care plans and instructions about 'what to do if ...'; respite care — both planned and acute — must be potentially available; specialist palliative care advice must be easily accessible at all times. District nursing out-of-hours is probably the most important factor in maintaining patients at home — in some areas additional out-of-hours support from community hospice services has increased the proportion of deaths at home.¹⁰ While generic nursing skills should include competence in palliative care, there will always be complex clinical problems for which district nurses do not have the training, time or experience to cope adequately on their own and they need additional help. One answer would be for specialist nurses in a district to come together in a pooled out-of-hours rota to

provide advice, additional input and education of the generic nurses across a whole population, covering home, hospital and nursing home beds. After all, when someone is dying, the specialist knowledge needed is applicable wherever they are — pain, distress, constipation do not vary from home to hospital; children and relatives need help to understand what is happening and particularly distraught family members need support around the deathbed, wherever that bed is.

The End of Life Care initiatives may help, but cannot substitute for personalised care.¹¹ I have never known a GP's personal number be abused by the family of a dying patient, but I have seen the comfort provided from just having that phone number available. For we must all think of what we would want and 'do as we would be done by'.

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Counting the cost of fast access: using discrete choice experiments to elicit preferences in general practice

In publicly provided healthcare systems, when limited resources are coupled with unlimited demand, decisions have to be made about the efficient allocation of scarce resources. This raises questions of how services should be provided (for example, should breast cancer patients be prescribed Trastuzumab®? Should there be an increased role for pharmacists in prescribing?) through to the optimal provision and financing of health care (for example, how can we encourage doctors to provide out-of-hours care or work in remote and rural areas?). Trade-offs inevitably have to be made. A technique gaining popularity in health economics to identify trade-offs is the discrete choice experiment approach,¹ used by Longo *et al*² in this Journal to consider patients' preferences for shared

decision-making. Within general practice the technique has been used to elicit patient and community preferences,^{2–6} as well as to explore GP preferences for job characteristics.^{7–9}

Discrete choice experiments are based on the assumptions that interventions, services or policies can be described by characteristics, and that value depends on the levels of these characteristics. Responders are presented with a number of choices that involve different levels of attributes. For each choice they are asked which option they would choose. Making choices involves trade-offs between attribute levels. Responses are analysed using regression techniques and from this it is possible to estimate the relative importance of attributes, as well as the trade-offs

between attributes; for example, how much longer individuals are willing to wait for a consultation with their preferred doctor. If a price proxy is included as a characteristic then willingness to pay, a monetary measure of benefit, can be estimated,¹ that is, willingness to pay to see a doctor. The paper by Longo *et al*² describes the stages involved in conducting a discrete choice experiment. For further information see Ryan and Gerard.¹

Longo *et al*² use the approach to look at the relative importance of attributes of shared decision-making. While this is a useful output, one of the favoured outputs of the technique by economists is estimation of trade-offs between attributes. In economics something is only of value if we are willing to give something up for it. Thus, the value of one attribute can be defined in terms of the