

“Please, I want to go home”: ethical issues raised when considering choice of place of care in palliative care

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Many palliative care patients would prefer to receive care, and to die, at home. Despite this many die in institutions. In response to this, politicians and charities have adopted policies aimed at increasing the opportunities for care and death at home. The need to discuss plans for discharge with most inpatients reinforces expectations of a choice of place of care. However, many palliative patients do not have a choice of care at home. This article will explore the circumstances in which patients are unable to choose home care and consider changes in clinical practice that can help to maximise choice. We shall argue that there is a distinction between the preferences of patients and the choices actually available to them. In attempting to make this distinction we advocate consideration of the balance between the ethical principles relevant to each case.

from home, after which it may not be possible to arrange discharge. Reasons for admission often reflect a change in the patient's condition, which may not necessitate inpatient care, but for which alternative arrangements cannot be made rapidly enough.^{5 20 21} Even if the patient's condition remains stable informal carers may become exhausted, precipitating emergency admission.

POLICIES

In response to the fact that many cancer patients are not dying in their preferred location, government and voluntary sector bodies have recently developed policies promoting choice of place of death.

Marie Curie Cancer Care has a campaign entitled “Supporting the choice to die at home”.¹⁶ This campaign is “about ensuring the choice of home or hospice care is available to all—and known to all”.¹⁶ A report on the health economics of increased numbers of home deaths, commissioned by Marie Curie Cancer Care suggested that if more people were able to die at home, the costs of their care would be reduced.¹⁶ However, savings would only become apparent once considerable numbers of admissions were avoided, and this might require significant initial investment.¹⁶

Government bodies have also been promoting choice of place of death. This started in 2000 with the National Cancer Plan which recognised that patients should have choice about where they are cared for.¹⁹ *Building on the best: choice, responsiveness and equity in the NHS* was published by John Reid, the Secretary of State for Health in 2003.²² This report pledged “to ensure that in time all people at the end of life, regardless of their diagnosis, will be given a choice of where they wish to die”.²² In 2004 the *House of Commons Health Committee report on palliative care* publicly backed Marie Curie Cancer Care's campaign.¹⁸ However, it questioned the feasibility of providing such choices at the time and recommended changes that might make it more realistic to do so.¹⁸ More recently an Early Day Motion has been tabled by MP Tony Wright: “That this House believes that every terminally ill patient who chooses to die at home should be given the opportunity to do so”.²³

PATIENT EXPECTATIONS

Given the publicity surrounding these policies it is not surprising that patients and relatives expect such choices to be available. Hospitals and specialist palliative care units provide facilities for short term admissions only. Few units in the UK provide longer term admission. Patients with more

Many patients with advanced cancer would prefer to be cared for and to die at home.^{1–3} Studies have questioned patients early in their disease and later on, and longitudinal studies have followed patients through the course of their disease.^{4–6} There are also data from relatives about their loved ones' wishes, obtained both before and after the patient's death.^{4 5 7} The opinions of proxies can be useful because they provide data about those who would otherwise be unrepresented.^{2 8} There will always be a cohort of patients unable to participate in studies, either because of their frailty or because of difficulties gaining consent for participation.^{9 10} There is also under-representation of the views of those with non-malignant terminal diseases and of other groups who tend not to access specialist palliative care services, including minority ethnic communities.^{11–14}

PLACE OF DEATH

A patient's place of care may become her place of death. For some patients this is a strong preference and a significant reason for wanting to be cared for at home.⁵

Although about 90% of those with terminal cancer spend much of their last year at home, and 50–70% of those with a terminal illness would prefer to be cared for and die at home, only about 25% of UK patients have a home death.^{1 3 15–17} More than 50% die in hospital, 20% in care homes, and 4% in specialist palliative care units.^{16 18}

Many patients, including those discharged after an admission, do not manage to stay at home and instead die as inpatients.^{3 6 19} A significant proportion of patients experience an emergency admission

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than the shortest prognosis must be transferred elsewhere, and discussions about alternative places of care reinforce the expectation that patients will have a choice of where they go.

Despite the expectations of patients, relatives and professionals, offering a choice about place of care can be problematic. In circumstances where others would experience significant burdens or risk by caring for a patient at home, it can be argued that offering a choice of home care is inappropriate. The same may be true where limited resources in community care cannot stretch to home care for highly dependent individuals without being stripped from other people in need.

ETHICAL DECISION MAKING

Moral theory

A professional duty of care underpins the relationship between healthcare professionals and patients. Four principles often cited as the central duties of those working in healthcare are non-maleficence, beneficence, respect for autonomy, and justice.^{24 25} These four together provide a framework in which to consider ethical dilemmas, enabling clear thinking about the emotive issues involved and helping to ensure that important factors are not overlooked. There is no universal agreement around the use of this set of principles but we shall use them here as an approach conforming reasonably to most important accounts of what it means to act ethically.

Non-maleficence

The sense of common morality shared by most people, and most doctors, includes the idea that we should *avoid doing harm*. Although it is not really an absolute ethical principle, it is true that we should strive to minimise any harm to patients and others and ensure that it is proportionate to the benefits of our actions.

Beneficence

We could see *doing good* as our professional *raison d'être* and therefore the pre-eminent moral duty. If not seeking to do good, then what would we be doing? But beneficent acts can be wrong if they violate other moral principles—for example, if great harm were also caused—so we need to be proportionate in considering our duty to act beneficently.

Respect for autonomy

Autonomy is the capacity to make and express (and perhaps act on) choices. It is a characteristic of (some) persons. It requires that they should be free from external constraints such as coercion, and from internal ones such as coma, so some people lack autonomy for some choices.

The moral principle at stake here is that we should respect this characteristic of our patients; *respect the choices* they make about their lives and their bodies. There are excellent moral reasons from many kinds of theoretical perspectives to think that this is important. This is not because people's choices necessarily tend to be good ones; rather, the importance lies in people exercising the freedom to make those choices, good or bad. However, this does not mean that we should always do precisely what a patient wants, regardless of requirements arising from the other principles. Relying too heavily on respect for autonomy exposes a major difficulty—that the autonomy of so many patients, particularly patients nearing death, has been diminished or lost entirely. These persons must still be respected even though their autonomy cannot, and in this framework it is the other principles that must do the work.

Justice

All of us have to make decisions about which patients get our time and other resources in health care. Justice is the moral principle by which we should act in making such decisions. It

requires of us that we act in *fairness*, give equality of consideration, that we use only morally relevant criteria in deciding on treating different people differently, and never morally arbitrary ones.

In any such framework, principles sometimes conflict. We then need to use pragmatism in balancing them, remembering that none is absolute and that any one may have to trump others. This approach has a particular role to play when practical limitations make it hard to achieve a person's preferences about place of care.

We could take any of the four and always regard it as the most important, but not without problems. Trying above all to do no harm can constrain us from doing all sorts of useful things. Trying above all to do good can get us into all kinds of trouble with unintended harmful consequences. Trying above all to respect autonomy has various problems attached: we can end up causing harm; it gives us no guidance at all on dealing with the non-autonomous (a majority of people at some time in their final illness); and it is hard to do well while acting justly because people make competing demands, some louder than others, and justice requires that we ignore the volume of the voice and pay attention to the voiceless.

Why is patient choice desirable?

Choice for patients is considered to be ethically desirable. Supporting the exercise of choices about healthcare provision is fundamental to respecting a patient's autonomy.²⁶ Promoting choices about how and where healthcare is received enhances patients' quality of life; this is partly through retaining an element of control over their lives which is often compromised by illness.

Despite the benefits that follow from offering choice, there are times when patients have fewer choices than they have preferences. (Patients would *prefer* not have a terminal illness, but do not have any *choice* about this.) If professionals are not clear in their thinking as to this distinction then they may be left feeling uncomfortable when what are perceived to be choices (but are actually only preferences) about place of care are not achieved. The role of healthcare professionals is to facilitate those choices that do exist, and to help patients understand why other preferences are unachievable.

DISCHARGE PLANNING

When planning discharge for patients with life-limiting illnesses, whether in a palliative care setting or elsewhere, professionals must consider whether the patient in question has the mental capacity required to make a decision about place of care. Further considerations include the risks a home discharge would pose to those providing care, the views of these individuals, and issues of resource allocation. Evaluation of these factors can aid the team in their interactions with patients and carers and guide the process of discharge planning. This will ensure that patient choice is facilitated wherever possible, but that harm is prevented where it is not possible or not right to facilitate a patient's choice. In this way, teams will take account of patient autonomy, and will also consider the best interests of the patient, those involved in providing care and other patients.

The process of planning a complex discharge can take several weeks; it is therefore imperative that this is initiated as early as possible following the patient's admission. Unnecessary delays may risk the patient missing any window of opportunity for care at home, and will also limit the time available for decision making.

Patient autonomy and mental capacity

The first step in discharge planning is to ascertain a patient's preferences with respect to place of care.

Patients without capacity for this decision

By the time this issue is addressed, some patients will not have the mental capacity for this decision and decisions about place of care must be made in the patient's best interests. Some patients may have made their preferences clear in advance of the need to make a decision. The preferred place of care plan is a tool developed for this purpose.¹⁵ Teams using this tool are reminded to ask about preferences for place of care, and to continue checking whether these have changed.

Preferences expressed before loss of mental capacity do not guarantee that the patient was informed about and understood her choice, that she expressed it voluntarily or that she would not have changed her mind, and some ethicists raise theoretical objections to the moral significance of a person's former view in any case.²⁷ The concept of best interests, however, has evolved to encompass more than physiology and pharmacology, and properly interpreted prior preferences are useful.

Risk taking: patients with capacity for this decision

Other patients will clearly have the mental capacity needed to make a valid decision about place of care. A competent patient who is aware of the risks of a premature unsupported discharge, and who is prepared to accept these for the sake of being at home, has made a valid decision about his place of care that should be respected. In the absence of harm to others it may be unethical to prevent such discharges.²⁸ However, professionals may find this difficult in view of the requirements of the NHS and Community Care Act (1990) that they make a "full assessment of their [the patient's] needs and demonstrate...that a care plan is in place to meet those needs".²⁸ If we stick to the letter of the law, the only way for the patient to go home is for him to self-discharge.²⁸ Even though this is technically easy to do (it involves signing a form accepting responsibility for any subsequent adverse events), it requires the patient to have determination and persistence beyond what many can achieve given their poor physical condition and the asymmetry of power within the patient-professional relationship.²⁹

In clinical practice, it is only in extreme circumstances that a patient is prevented from going home due to the risks involved. In general, it is preferable to support the competent patient as much as possible, while ensuring that he has understood the risks of going home and is prepared to accept these. This collaborative approach respects patient autonomy and maximises beneficence by ensuring the supportive relationship between patient and professionals continues. Premature termination of this relationship and associated support might occur following the conflict associated with a patient discharging against medical advice.

Enhancing patient decision making: patients who are competent but appear unrealistic

It is when dealing with a third group of patients that professionals often face challenges. There are occasions when a patient who appears to be competent, seems so unrealistic about the future that the team may doubt that the decision is fully autonomous.^{30 31}

We should remember that many decisions cannot be made immediately. Rather, patients require time to begin to accept their situation. Even in the best circumstances it is difficult to make important decisions—for example, whether to get married. We all know that these should not be rushed because we have seen the consequences when they are. It is hard to give patients the time they need to make important decisions about place of care because of the relentless pressure on inpatient beds. Specialist palliative care units have an advantage in that support while hard choices are made is an integral part of an admission rather than something seen as delaying discharge.

The patient's short prognosis or expected brief period of stability may also make it difficult to provide sufficient time to make decisions about place of care. Specialist palliative care teams can often see that if a patient does not go home soon, he will not be able to go at all. In such cases it may be that patients who delay reaching a decision are less confident about the risks involved, so the duty to follow a particular preference is less strong. Ultimately we cannot be held to have a duty to respect a suggestion that is too inconsistent for us to know that it constitutes a true preference.

Facilitating an "unsafe" discharge

Even when patients have had sufficient time to make decisions, some still appear worryingly unrealistic about their ability to manage at home. There is evidence to suggest that patients find it difficult to assimilate new information, in particular about risks.^{30 32}

It may be helpful to assist the patient to gain experience in a safe environment, in the hope that this will enhance his or her ability to make decisions.³³ With respect to decisions about place of care, many patients seem to want to go home in part because they have unfinished business or because they have not had an opportunity to "say goodbye" to their home. (Few patients are aware at the time of admission that they may not go home, and even if aware of this possibility many hope that this will not be the case.)

If discharge home for such patients is fraught with difficulty and risks, it may be possible to organise a short home visit (lasting between a few hours and 3 days). This is likely to be safer than actual discharge, as the inpatient bed is available for the patient to return to at any time, and all those involved in care can pull out the stops for a clearly defined and short period to provide as much care as possible. Even a short period at home can help patients say goodbye and provide experience of how things would actually be after discharge. This may help those who are initially unrealistic to see how hard it would be to manage without 24 h care, and to discover that the safety and security previously associated with "home" is no longer there. This strategy is not without its challenges. The resources required from inpatient and community staff and the ambulance service could be utilised in the care of other patients. There is also the risk that patients or relatives will feel as if they have failed if it becomes apparent that care at home is not sustainable. The possibility of emotional distress is one of the risks inherent in allowing people to make what could be considered to be unwise choices. Professionals must therefore balance respect for autonomy against non-maleficence and justice when considering whether to organise a period of home leave for a patient.

Risks to others

Providing care for palliative patients in the community is usually the responsibility of the primary healthcare team. District nurses and general practitioners provide the majority of care. They are supported in their roles by the specialist palliative care team who may offer advice to members of the primary care team, and/or may visit the patient at home. Pastoral services to address spiritual concerns come either from the relevant religious organisation in the community, or from faith leaders affiliated to the specialist palliative care team. Departments of social services may also be involved in caring for the patient, and supporting relatives.^{31 34 35}

Protection of professionals

There are several reasons why it would be unethical to expose professional carers to unnecessary risks. The opportunity costs incurred by using resources to train a professional are justified if the individual concerned goes on to care for many patients in

the future. The premature retirement of a team member following physical injury denies patients the care that he or she would have provided, and necessitates the use of further resources to train a replacement. Provision of substandard care by a professional as a result of psychological stress may also be inefficient, with tasks taking longer or needing to be repeated. Those who choose to become professional carers would prefer not to suffer pain and the limitations caused by physical injuries. They would also choose to enjoy their work, rather than experience stress.³⁶

In addition to these issues of autonomy and justice, employers have an obligation to protect professional carers from unnecessary harm while at work. This obligation is recognised legally in the contract of employment, and is morally valid where an employer requires that an employee's activities are restricted and directed. (When painting the outside of my house I may choose freely to take risks when climbing a ladder, but if a professional painter were asked to take the same, unnecessary risks he might feel coerced by his employer and not make a free decision.)

Physical injury to carers

The greatest risk of physical injury relates to the manual handling of patients. Many patients receiving care at home have mobility problems, but this is a particular issue for palliative patients. Because of the progressive nature of their diseases, those patients who are mobile at the time of discharge or assessment will only remain so for a limited period. All palliative care patients will develop mobility problems at some stage, and the rate at which and manner in which they do so is difficult to predict. In contrast to many others the mobility problems of most palliative care patients will not improve, so admission for rehabilitation is usually inappropriate.

Society's view of the end of life as an important time, and the particular weight given to emotional needs, also make palliative care patients a special case with respect to care at home. This attitude on the part of society means these patients are often the most dependent patients receiving care at home. Despite their extreme frailty and significant mobility problems, palliative care patients can be managed at home without unnecessary risk of physical injury to those undertaking manual handling if appropriate equipment is in place. Unfortunately, there can be significant delays while waiting for equipment to be delivered to the home (often in the order of weeks). During this period of waiting, the patient and relatives will often ask for discharge. As it would be inappropriate to expose professionals to the risks of caring for a patient without equipment, patients and their relatives should be made aware of the limitations to care that could be provided in the absence of equipment. Ideally, patients would be able to make a choice about whether to go home and receive restricted care, or whether to remain as an inpatient in the interim. However, the difficulties with decision making that have been outlined above may be relevant and professionals need to weigh up the conflicting considerations of respect for autonomy, non-maleficence and justice.

Multiprofessional teams have a duty to minimise delays arising in systems for purchasing, ordering and delivering equipment to prevent unnecessary delays in discharge.

Psychological stress to carers

In the literature, "stress" is the term most commonly used to denote adverse psychological outcomes for carers, and much effort has gone in to elucidating the particular factors that cause such stress. The following factors in palliative care patients are particularly likely to cause stress in district nurses: complex needs requiring multiple visits, insufficient time to undertake all tasks, challenging symptoms, lack of open

communication about disease and prognosis, a young patient, and the presence of young children in the family.^{34 36-39}

Despite the difficulties of quantifying the consequences of the psychological stress that results from caring for palliative patients in the community, it is reasonable to conclude that it can contribute to poor job satisfaction, lack of motivation and enthusiasm, poor self-esteem and burnout.^{34 37} Those who experience burnout may leave the profession, or continue to work but provide substandard care.

Although this risk of psychological stress is not limited to those providing community palliative care, there are reasons why it may be more likely. As discussed above, palliative patients are often significantly frailer than other patients receiving care in the community, with more complex needs, including the need for emotional support. These patients are therefore more likely to engender stress in district nurses than others whose needs are simpler and involve less psychosocial support. District nurses often work alone with limited opportunity for support from colleagues during the working day.^{36 38} In contrast, nurses caring for inpatients have much greater opportunities for support from colleagues within the environment of a ward.

It may not be harmful for an individual to experience some limited degree of stress in their working day.⁴⁰ However, it is the responsibility of those managing a team of carers to ensure that workload is not consistently so great that the team is exposed to sustained unsafe levels of stress.^{34 40} There is also a duty to ensure appropriate training for team members, as those who feel inadequately prepared to provide palliative care are more likely to find this experience difficult.^{6 19 41}

One of the difficulties in attempting to minimise the stress associated with providing community palliative care is that it can be difficult to foresee whether the discharge of a particular patient will lead to harmful stress in any individual carer. It may be that caring for a new patient exacerbates difficulties already present within the team, particularly if care of the new patient is added to an already busy schedule, or to a caseload that is too great for the personnel available. In such cases it is not the new patient in isolation that causes problems, but care of this patient in addition to ongoing problems.

If stress is a recurring problem for staff, managers must review the organisation and working patterns of the team. This may involve the use of practices such as waiting lists, imposing a maximum caseload or restricting the number of visits to a patient per day, to limit the potential for excessive stress in team members. In some circumstances such measures could be used to attempt a just distribution of resources; all patients (whether palliative care or not) would have similar opportunities (or similar lack of opportunities) for care at home.

It is not the nature of the harm to professional carers that creates the difference between physical injury and psychological stress. Any injury is directly linked to the particular patient and the provision of equipment will significantly reduce the risk. This enables teams to predict which patients pose an unacceptable risk of physical injury, and only their discharges are delayed. In contrast, when considering psychological burdens, it is harder to link the occurrence of stress in a professional solely with the care of a particular patient, as there will be other contributing factors in the background; it is managerial interventions and training that will reduce this risk. These measures to minimise stress are ongoing, and there is no clear point at which they are absent or present, and thus no clear point to signal that a discharge that previously carried unacceptable risk no longer does so.

The views of relatives

Ethical dilemmas arise when a patient, in the expectation of a choice of place of care, asks to go home, but the relatives who

will have to provide care are opposed to this. In view of the asymmetry of power in the relationship between professionals and patients/relatives, it is important that teams are clear in their decision making when the choices of a patient and her relatives conflict.

The first point to consider is the practical one that it is likely to be harder to support a patient at home if his relatives do not wish him to be there. This may not be an insurmountable problem, but in some cases such a discharge may fail, with the patient being readmitted. In assessing this difficult balance, it may be useful to consider the following framework for decision making.

A patient who could be discharged home if living alone should not place significant additional demands for care on a relative who lives with him. Any emotional demands resulting from such a discharge will be within the context of a longstanding relationship, and although complicated by the presence of terminal illness and physical decline, would not necessarily constitute a burden on the relative significant enough to warrant ignoring the patient's choice to be at home. In addition, the relative's experience of home care may demonstrate that caring is less of a burden than originally anticipated. In these circumstances, the arguments in favour of a trial of discharge may well outweigh those against.

In contrast, a patient whose physical condition and need for care would preclude a safe discharge home if living alone is unlikely to be able to go to a home shared with relatives without them incurring significant additional burdens. If the relatives are unwilling carers they will experience none of the psychological benefits associated with caring,^{35 42 43} and are more likely to be adversely affected. In these circumstances discharge is more likely to fail, and the associated burdens and risks of such a failure for the patient may tip the balance against facilitating a period of home care. In short, the professional team should not feel ethically obliged to attempt—in fact, should not attempt—a discharge home which cannot succeed because the carers are unable to undertake the necessary tasks of caring.

CONCLUSIONS

Decisions on place of care for and with patients with life limiting disease are often ethically challenging. Considerations of beneficence and non-maleficence must be balanced against the duty to respect patient autonomy, and the need to ensure that scarce resources are distributed fairly. By referring to these principles when facing dilemmas around discharge planning, clinicians can ensure that no important factors have been overlooked. A solution that respects and even enhances patient autonomy, as well as accruing benefits to the patient and minimising harms, will be ethically desirable. Considerations of justice can help to ensure that duties to others are not neglected.

The liberty to make choices is at the heart of autonomy. The duty of healthcare professionals to respect patients' autonomy relates to the value that we place on our ability to make choices as well as the beneficial effects that such choices may bring. It is the responsibility of those involved in the care of patients to ensure the widest possible range of choices. Patient autonomy is best respected and enhanced by allowing sufficient time and experience for decision making as described earlier. Such practice is also likely to produce better patient outcomes, and reduce adverse events.

There are times when a patient's expectation of being able to choose care at home is unrealistic because of the risks and burdens to themselves and others. Professionals must be clear that this is actually the case before opposing discharge and some of the techniques suggested earlier may be of use. Once it

Summary points

- Up to 70% of palliative care patients wish to be cared for and to die at home
- Only about 25% of deaths in the UK occur at home
- Patients should be offered as many choices as possible about place of care
- Where home care places disproportionate burdens or risks on others, the preferences of patients wishing to receive care at home do not constitute available choices

Key references

- Beauchamp TL, Childress JF. *Principles of biomedical ethics*, 5th ed. Oxford: Oxford University Press, 2001.
- Randall F, Downie RS. *Palliative care ethics. A companion for all specialities*, 2nd ed. Oxford: Oxford University Press, 1999.
- Storey L, Pemberton C, Howard A, *et al.* Place of death: Hobson's choice or patient choice? *Cancer Nursing Practice* 2003;2(4):33–8.
- Lancashire and South Cumbria Cancer Network. The Preferred Place of Care Plan and why it was developed. www.cancerlancashire.org.uk/ppc.html [accessed 3 February 2007]
- Higginson IJ. *Priorities and preferences for end of life care in England, Wales and Scotland*. London: National Council for Hospice and Specialist Palliative Care Services, The Cicely Saunders Foundation and Scottish Partnership for Palliative Care, 2003.

is clear that the burdens and risks associated with discharge make this unethical, the role of healthcare professionals is to explain to patients why their preferences cannot be facilitated.

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REFERENCES

- 1 Higginson IJ, Astin P, Dolan S. Where do cancer patients die? Ten-year trends in the place of death of cancer patients in England. *Palliat Med* 1998;12:353–63.
- 2 Higginson IJ, Sen-Gupta GJA. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *J Palliat Med* 2000;3:287–300.
- 3 Wilkinson S. Fulfilling patients' wishes: palliative care at home. *Int J Palliat Nurs* 2000;6:212.

- 4 Hinton J. Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? *Palliat Med* 1994;**8**:183–96.
- 5 Townsend J, Frank AO, Fermont D, et al. Terminal cancer care and patients' preference for place of death: a prospective study. *BMJ* 1990;**301**:415–17.
- 6 Storey L, Pemberton C, Howard A, et al. Place of death: Hobson's choice or patient choice? *Cancer Nursing Practice* 2003;**2**:33–8.
- 7 Higginson IJ. *Priorities and preferences for end of life care in England, Wales and Scotland*. London: National Council for Hospice and Specialist Palliative Care Services, The Cicely Saunders Foundation and Scottish Partnership for Palliative Care, 2003:8.
- 8 Koffman J, Higginson IJ, Donaldson N. Symptom severity in advanced cancer, assessed in two ethnic groups by interviews with bereaved family members and friends. *J R Soc Med* 2003;**96**:10–16.
- 9 Mazzocato C, Sweeney C, Bruera E. Clinical research in palliative care: patient populations, symptoms, interventions and endpoints. *Palliat Med* 2001;**15**:163–8.
- 10 Randall F, Downie RS. *Palliative care ethics. A companion for all specialities*, 2nd ed. Oxford: Oxford University Press, 1999:247.
- 11 Addington-Hall J, Fakhoury W, McCarthy M. Specialist palliative care in nonmalignant disease. *Palliat Med* 1998;**12**:417–27.
- 12 Anderson H, Ward C, Eardley A, et al. The concerns of patients under palliative care and a heart failure clinic are not being met. *Palliat Med* 2001;**15**:279–86.
- 13 Luddington L, Cox S, Higginson I, et al. The need for palliative care for patients with non-cancer diseases: a review of the evidence. *Int J Palliat Nurs* 2001;**7**:221–6.
- 14 Gatrad AR, Brown E, Notta H, et al. Palliative care needs of minorities. *BMJ* 2003;**327**:176–7.
- 15 Lancashire and South Cumbria Cancer Network. The Preferred Place of Care Plan and why it was developed. www.cancerlancashire.org.uk/ppc.html [accessed 3 February 2007].
- 16 Marie Curie Cancer Care. *Supporting the Choice to Die at Home Campaign Briefing*. London: Marie Curie Cancer Care, 2004.
- 17 National Institute for Clinical Excellence. *Guidance on cancer services – improving supportive and palliative care for adults with cancer – the manual*. London: NICE, 2004:117.
- 18 House of Commons Health Committee. *Palliative care. Fourth report of session 2003–04, volume 1*. London: The Stationery Office Ltd, 2004:3–15.
- 19 National Health Service. *The NHS Cancer Plan. A plan for investment. A plan for reform*. London: NHS, 2000:11–45.
- 20 Bowling A. The hospitalisation of death: should more people die at home? *J Med Ethics* 1983;**9**:158–61.
- 21 Storey L, Pemberton C, Howard A. The Preferred Place of Care. www.modern.nhs.uk/cancer [accessed 26 February 2005].
- 22 Department of Health, NHS. *Building on the best. Choice, responsiveness and equity in the NHS*. London: Department of Health, 2003:9.
- 23 UK Parliament. EDM470, edm.ais.co.uk/cache/printable/edm470.html [Accessed 15 February 2005].
- 24 Beauchamp TL, Childress JF. *Principles of biomedical ethics*, 5th ed. Oxford: Oxford University Press, 2001:12–13.
- 25 Gillon R. Ethics needs principles – four can encompass the rest – and respect for autonomy should be “first among equals”. *J Med Ethics* 2003;**29**:307–10.
- 26 Beauchamp TL, Childress JF. *Principles of biomedical ethics*, 5th ed. Oxford: Oxford University Press, 2001:63–4.
- 27 Beauchamp TL, Childress JF. *Principles of biomedical ethics*, 5th ed. Oxford: Oxford University Press, 2001:68–9.
- 28 Randall F, Downie RS. *Palliative care ethics. a companion for all specialities*, 2nd ed. Oxford: Oxford University Press, 1999:206–8.
- 29 Coulter A. Patients' views of the good doctor. *BMJ* 2002;**325**:668–9.
- 30 Beauchamp TL, Childress JF. *Principles of biomedical ethics*, 5th ed. Oxford: Oxford University Press, 2001:88–9.
- 31 Beaver K, Luker KA, Woods S. Primary care services received during terminal illness. *Int J Palliat Nurs* 2000;**6**:220–7.
- 32 Thornton H. Patients' understanding of risk. *BMJ* 2003;**327**:693–4.
- 33 McCall K, Rice AM. What influences decisions around the place of care for terminally ill cancer patients? *Int J Palliat Nurs* 2005;**11**:541–7.
- 34 James V, Field D. Who has the power? Some problems and issues affecting the nursing care of dying patients. *Eur J Cancer Care* 1996;**5**:73–80.
- 35 Jarrett NJ, Payne SA, Wiles RA. Terminally ill patients' and lay-carers' perceptions and experiences of community-based services. *J Adv Nurs* 1999;**29**:476–83.
- 36 MacDonald L, Macnair R. Your views on terminal care. *Journal of District Nursing*, 1986;March, 11–14.
- 37 Bergen A. Nurses caring for the terminally ill in the community: a review of the literature. *Int J Nurs Stud* 1991;**28**:89–101.
- 38 Field D. 'I never interfere with what they want': nursing terminally ill people at home. In: Field D, eds. *Nursing the dying*. London: Routledge, 1989:94–109.
- 39 Hatcliffe S, Smith P, Daw R. District nurses' perceptions of palliative care at home. *Nurs Times* 1996;**92**:36–7.
- 40 Randall F, Downie RS. *Palliative care ethics. A companion for all specialities*, 2nd ed. Oxford: Oxford University Press, 1999:84–5.
- 41 Burke K. Palliative care at home to get further funds if it saves money. *BMJ* 2004;**328**:544.
- 42 Karlsen S, Addington-Hall J. How do cancer patients who die at home differ from those who die elsewhere? *Palliat Med* 1998;**12**:279–86.
- 43 Singer Y, Bachner YG, Shvartzman P, et al. Home death – the caregiver's experiences. *J Pain Symptom Manage* 2005;**30**:70–4.

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