

Market failure and care at the end of life in the NHS.

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Abstract

Care at the end of life, like all health care, is an economic good and is traded in a market. To date there exists no published model of how the market for this good operates. As with all health care, the market for end of life care is subject to market failure. Although widely accepted sources of market failure are present, these are manifested in end of life care in a distinct fashion. A primary characteristic of the provision of end of life care is the degree to which care is provided informally and through charitable organisations. This makes it difficult for the market to reveal the true value of such care. It may also lead to indirect costs to the labour market, as individuals remove themselves from employment to provide care. Other factors that affect the market are the range of illnesses experienced by individuals at the end of life and the historical development of the field as specialist care for cancer patients. The socio-demographic characteristics of patients may also have an impact, as care provision may be influenced by income and wealth to a greater degree than in other areas of healthcare. The objectives of this paper are to build a conceptual model of the market for end of life care, to highlight where the market fails and to discuss the ways in which intervention may lead to a more efficient market.

Introduction

At present in England, the care that an individual receives at the end of their life, no matter the setting, is likely to involve a complex system of agents. Care is provided by both specialist and generalist healthcare practitioners and in a variety of settings, ranging from the patient's home to intensive care units in hospitals. A person who dies after a period of illness may have contact during the last stages of life with primary care services (GPs, district nurses), secondary and tertiary care services (hospitals, specialist care services), emergency care services (A&E, ambulance services) for-profit care services (care homes, home care), non-profit and charitable services (hospices, home care) and informal care (family, friends). Care at this stage in an individual's life may be more focused on improving the quality of life, rather than extending life. Indeed, in the USA patients are required to forego any further curative treatment in order to receive hospice care through Medicare, the state funded system for individuals over 65 years of age.

This study of the system for providing end of life care in England explores how the market for care operates and the ways in which the market fails uniquely among healthcare provision. In order to fully explore this, a brief description of how markets operate is provided and the justifications for intervention by the state in any given market. The nature of end of life and palliative care is then outlined. Finally, the ways in which this particular market does not operate efficiently are discussed, with reference to how current intervention by the state fails to address the unmet demand for care.

End of life and palliative care

High quality end of life and palliative care attends in close detail to the physical, emotional, spiritual and social care needs of those with advanced progressive life limiting illness as death approaches. It is difficult to predict with any certainty when an individual's life will end. This is recognised in the Department of Health End of Life Care Strategy¹, where the end of life phase is necessarily vaguely defined and dependent on diagnosis and prognosis – for some patients, this period may constitute a matter of hours, days or weeks, for others it may mean months or even years of remaining life. In any case, the Department strategy places an emphasis on attending to the needs of both the patient and their family or carers throughout life and into the bereavement period¹.

Historically people have been born and have died in the home. Over time, and with the increasing availability of medical technology – and its success in keeping people alive longer during periods of illness - a significant shift took place, with increasing numbers of people dying in hospital². At present most people (59%) in England die in NHS acute hospitals, with fewer dying at home (19%), care homes (15%) and hospices (4%)³. Recent estimates suggest that more people would, given the choice, prefer to die outside of hospital, with 65% of people expressing a preference to die at home according to one survey⁴. This difference between preferred and actual place of death indicates a degree of unmet demand in the provision of care at the end of life. It also suggests that the market for this care is not operating effectively.

The market for end of life care shares many of the characteristics of market failure experienced in nearly all other domains of health care and intervention in the market can be justified on the same grounds. There are however particular aspects of the care people require at the end of their life that

give rise to unique manifestations of market failure and in some cases serve to reinforce existing failures of the market. Economic analysis of the market for end of life care can contribute to an understanding of the rationale for government intervention in the market; it can improve knowledge of the market structure, particularly in relation to the voluntary and charity sectors and household voluntary contributions; and the use of cost-effectiveness analysis can aid in the identification of appropriate policies.

The provision of end of life care is characterised by complexity. The care individuals require and receive may be related to factors such as their diagnosis, length of illness, personal preferences, mix of health and social care needs, psychological status, the availability of informal care, family factors and advance care plans. The system in which end of life care is delivered is no less complex. Care can be delivered as primary, secondary or specialist care, in NHS or social service run facilities, in the patient’s home or in privately owned facilities. It may be delivered by government, private sector, voluntary or charity providers as well as informally by family and friends. People may eventually die at home or in hospitals, care homes, nursing homes or hospices. Figure 1 illustrates the complexity of the system for delivering end of life care. Not only do each of the care services potentially interact with the patient, there is a great deal of interaction amongst themselves. Figure 2 illustrates the pathway a patient will follow once it has been agreed that they are in the terminal phase of life. At stage in the pathway, the patient may receive care from any number of the services illustrated in Figure 1.

Figure 1: The delivery of end of life care in England

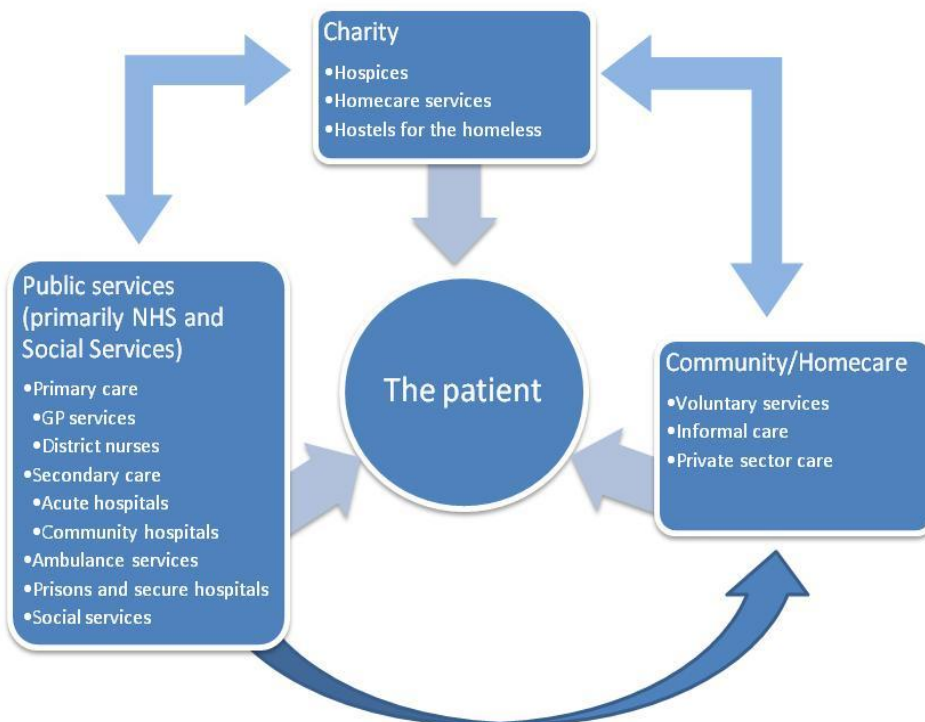
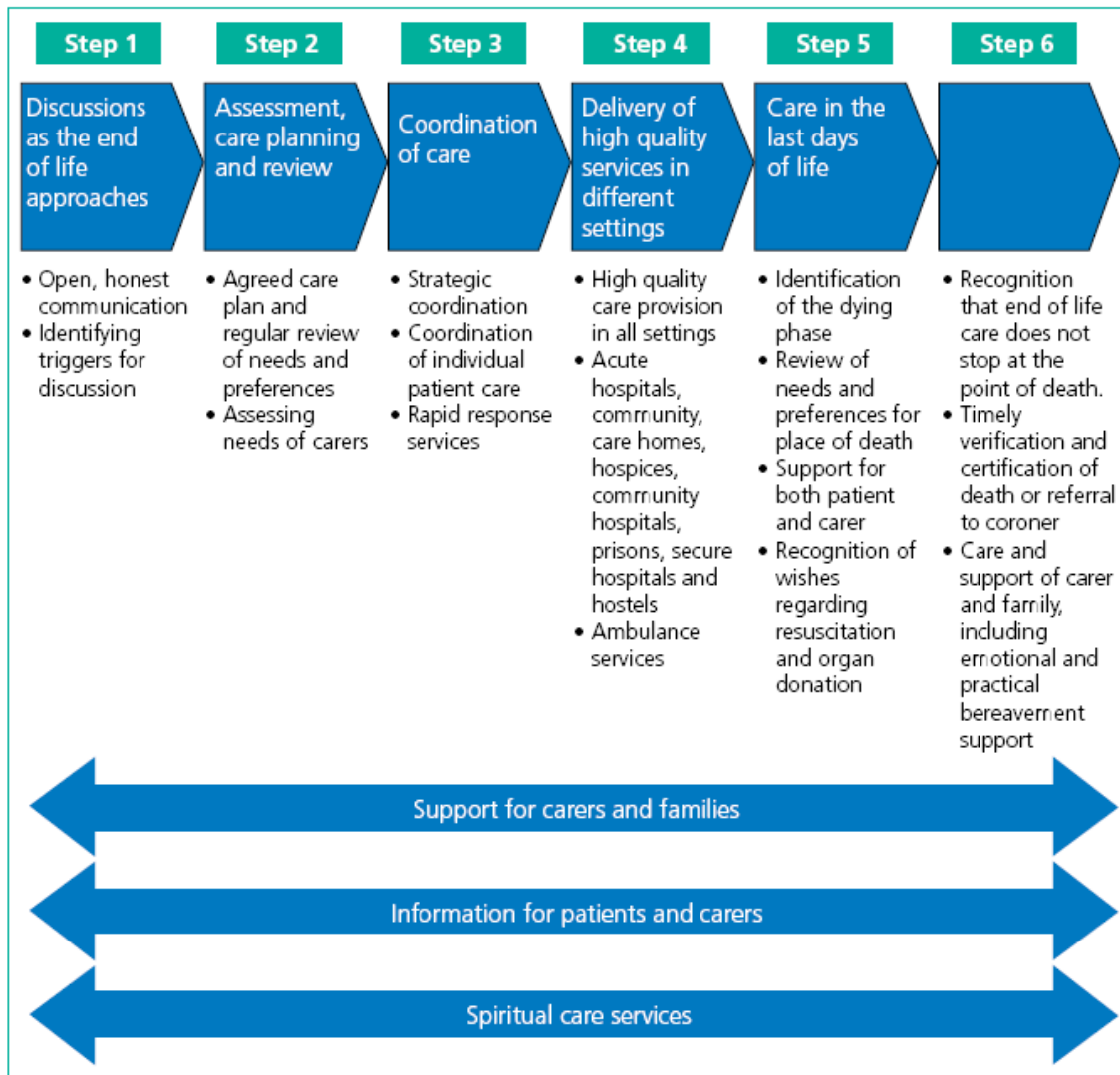


Figure 2: The End of Life Care Pathway (Reproduced from the End of Life Care Strategy¹)



Rationale for Government intervention

The provision of healthcare frequently violates the assumptions required for the formation of a perfectly competitive market. The care that is sold is unlikely to be homogeneous, consumers are unlikely to have perfect information, licensing restrictions on healthcare professionals and treatments restrict entry to and from the marketplace and individual producers often have sufficient market power to set prices rather than act as price takers. Arrow (1968) identified uncertainty as a key characteristic of healthcare that differentiates it from many - though not all - other goods and in part leads to the failure of the market to be perfectly competitive.

These sources of uncertainty are as relevant in end of life care as it is in other areas of healthcare. While all individuals can expect, ultimately, to die, any given individual cannot know exactly when or if they will need end of life or palliative care. Nor can they predict with certainty what care they would require. And given the shifting priorities people experience as the end of life approaches, individuals may be uncertain over what type of care they would even prefer. This uncertainty makes

healthcare distinct from many other goods, though it does not necessarily distinguish end of life care from other forms of healthcare.

Previous research has shown that the care a person receives is not always related to their clinical need. Factors that affect the access to health and health outcomes for individuals include income⁵, family background⁶ and education⁷. Geographical proximity to health care services as well as service density has also been shown to affect the use of health services and influence health outcomes^{8;9}. Illness or disease severity may also play a role in predicting health outcomes, though the evidence is less robust in this area¹⁰. Government intervention to address inequalities arising from such factors as described may be appropriate in end of life care.

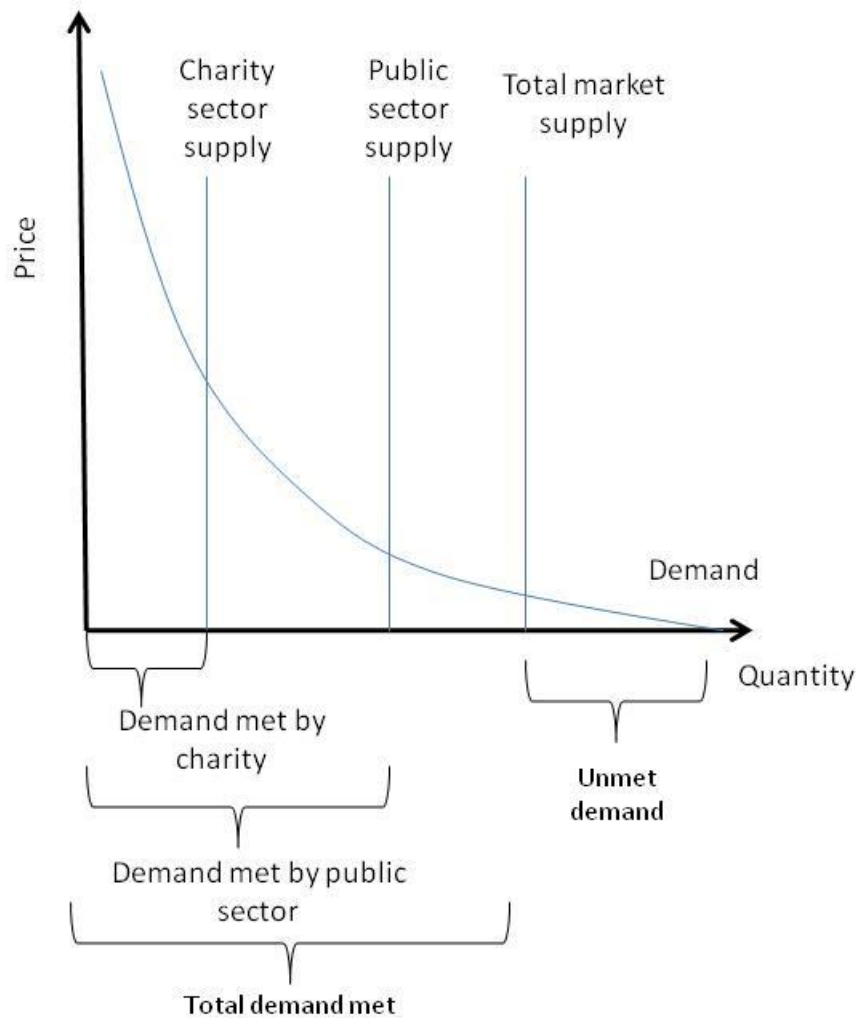
Intervention may also be justified where a market provides a sub-optimal level of certain goods. Some forms of healthcare can be considered merit goods; that is, care can often be considered socially desirable owing to the positive externalities it generates. If providing care to one individual generates benefits for a second individual then it may be the interest of the state to provide that care. In the case of end of life care, providing greater levels care at the end of a person's life may reduce the amount of time an informal carer is away from work. Providing care to the dying may even reduce the amount of care the carers themselves require – for example, Walsh and colleagues highlight how the carers of those with terminal cancer are themselves at risk of psychological and physical ill-health[REF]. Reducing the burden on these carers can in turn reduce future burden on the health service. As the state providers of health and social care have effective monopolies on the production of care, it is in their interests (as well as those of the patient and their carers) to provide care.

The care an individual receives at the end of their life is the last form of healthcare they will ever receive and the principle of enabling people to experience the best possible death is fundamental to the Department of Health End of Life Care Strategy¹. Not all individuals will be able to experience the death envisaged by the strategy. In the absence of government intervention, many individuals may die without access to formal care for reasons related to income or illness, among others, but may be supported by family or friends in an informal care role. Other individuals may not have access to informal resources. In either case, there is a clear justification for government intervention in the market place in order to support individuals in experiencing death in a manner commensurate with that described in the End of Life Care Strategy.

Market failure in end of life care

There is clearly a role for government intervention in the market for healthcare, and end of life care is no different in that respect. Figure 3 illustrates how the market for end of life care operates. In this diagram, healthcare services are the main provider of services. Services are resource constrained and fixed, and so government provision is inelastic. Charity and voluntary sector producers also provide services. These services are again resource constrained and in the short run are also inelastic. Public and charitable provision together still do not meet the entire demand for care. So individuals/households become involved in the supply of care in order to meet additional demand. In practice, households are likely to supplement care, particularly informally, regardless of the level of service provision from other sources¹¹.

Figure 3 – Supply of care from government and charity providers



The relationship between the price of care, the costs and benefits of caring and the supply of care are complex. People care for a variety of reasons, ranging from feelings of altruism through to a sense of obligation. While many carers are not in paid employment, many may have to give up paid employment to provide care. Informal carers are less likely to be in paid employment than non-carers¹². The burden of caring falls largely on women (more women are carers than men, and on average women care for more hours per week than men) and on older women in particular¹². For those in employment, caring can only be carried out when individuals are not otherwise employed; yet evidence suggests that caring does not significantly decrease time in employment¹³. However, carers are more likely to work fewer hours per week than non-carers¹², which may help explain why time spent caring does not significantly reduce time at work. A large proportion of informal end of life care is provided by family members¹⁴, many of whom are not in employment¹² and therefore the cost of providing care, measured in lost income, is low. The supply of this care is thus likely to be highly elastic in relation to the price faced by other suppliers of providing care.

As a result of this complexity, the supply curve for informal care differs from the supply curve for most goods. A review of the literature for this study did not uncover any previous estimates of how a supply curve for informal care might function. Figure 4 is an initial proposal to map the supply curve of informal carers where carers can choose to spend their time either caring or working. In Figure 4a, care is provided by those who are not in employment nor seeking employment. This care is likely to be inelastic, and not change in relation to the wage rate (the assumed cost of providing informal care). The amount of care that can be provided through this route is, in the short run, relatively fixed. Additional care is supplied by those in employment, shown in Figure 4b. This care is assumed to be a function of the wage rate. In the simplest case, as the wage rate increases, care is likely to decrease, as the cost of providing care increases – this is supported by the evidence that those who forego the least are more likely to provide care¹². This leads to a supply curve that is downward sloping. Evidence suggests that the supply of care is somewhat inelastic in this group as well, as “...the effect of care hours on labour supply is not significant for the probability of leaving the labour market.”¹³

Figure 4a: The supply of informal care from those not in employment

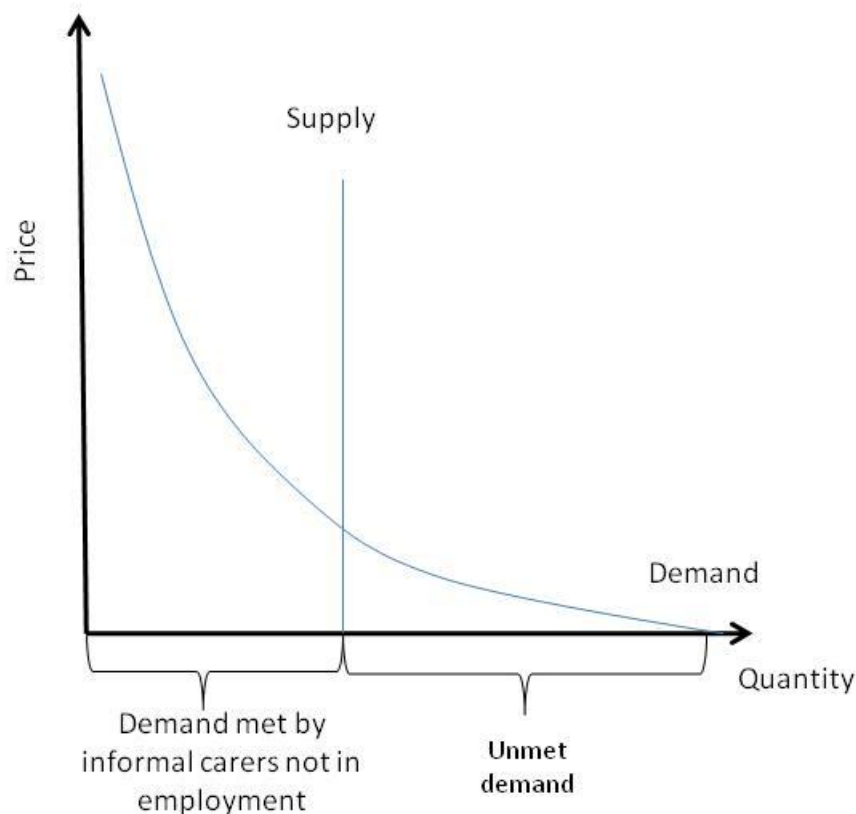
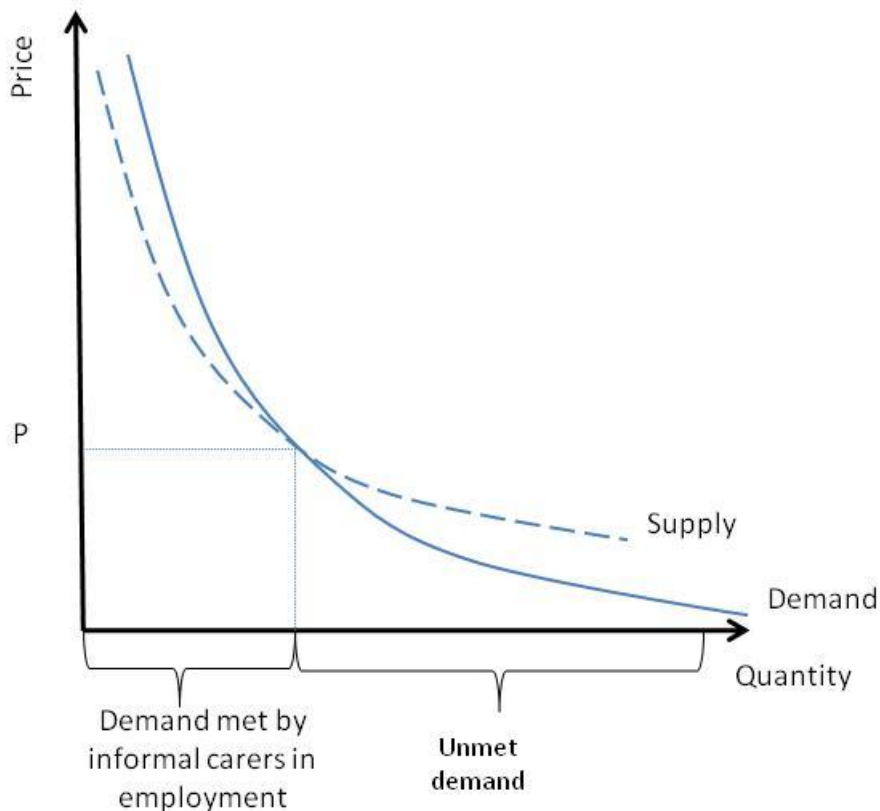


Figure 4b: The supply of informal care from those in employment



The actual estimation of the supply curve must account for other factors that affect the production of informal care, typically through changing the effective income foregone by leaving employment. Government policies have often been implemented in an effort to reduce the burden on carers. Such interventions often take the form of subsidies or tax credits, the effect of which would be to lower the effective income that carers must forego from withdrawing from employment thereby increasing the level of informal care¹². This would have the effect of shifting the supply curve to the right, as a greater quantity of care would be provided at any given wage rate. Additionally, it is possible that once wages reach a certain level, individuals will be able to switch from employment to care, as the marginal gain from additional income will be offset by the marginal gain provided by caring. This would result in a kinked supply curve that is downward sloping to a point, then upward sloping beyond this pivotal wage rate.

Although end of life care is not unique in that it requires government intervention, it does raise a number of problems for decision makers when determining how best to intervene. An important source of market failure in end of life care is the presence of imperfect information. This is particularly the case when trying to measure the benefits of care or treatment. In most other areas of healthcare provision, benefits of treatment can be measured (if not perfectly) by evaluating the outcomes for the patient. These measurements may be made directly or indirectly, subjectively or objectively, but are ultimately post-hoc measurement. When the aim of care is to provide a good death, it is often not possible to know the effects of the care, as a post-hoc assessment is not possible.

This difficulty is exemplified by disagreement over what would be an appropriate measure of benefit in end of life care. The ultimate outcome for all people receiving end of life care is death, and the aim of the care is, in many respects, to provide a good death. It is possible to measure many aspects of the process of care, such as access to pain relieving medication. It is also possible to measure a range of clinical outcomes, such as the severity of pain. However, such outcome measures are of limited use in economic evaluation¹⁵ as they do not enable decision makers to choose between alternative courses of action with reference to the opportunity cost of that decision.

The alternative measure of outcome used widely in economic evaluation to allow comparison of a range of alternative courses of action is the quality adjusted life year (QALY). Arguments have been raised that suggest the QALY is not an appropriate measure of outcome for use with individuals at the end of their life^{16;17}. Even if these arguments were rejected and the QALY agreed to be the best expression of outcomes, the post-hoc problem would still be present. No matter what measure is used to quantify the benefits of treatment, it will never be possible to know if the patient experienced a good death. It will always be the case that some level of uncertainty will accompany the measurement of end of life care treatment and the problem of imperfect information with regards to the benefits of is likely to remain intractable in this patient group in a way that it is not in most other areas of care.

Much end of life care may be concerned with the management of chronic diseases and as such may share similar characteristics of market failure. Watts and Segal outline how market failure and government intervention distort markets in chronic care¹⁸, including distortion arising from public subsidies for medical services and inconsistent preferences for health over time amongst consumers. These two aspects of market failure and distortion are evident and important in end of life care. The health service provides public subsidy for healthcare through government intervention. In end of life care, much of this subsidy is directed towards paying for acute medical care. This type of care typically takes place in hospitals, where the majority of deaths occur. By contrast, much of the care required at the end of life is not acute medical care but rather social and nursing care. Resource constrained individuals or third party payers, when working to a model of technical rather than allocative efficiency, may not direct appropriate resources to preventing the need for acute medical care through the provision of nursing and social care¹⁸.

It is argued that the time preferences of individuals at the end of life may differ from those at other stages of life¹⁶. Watts and Segal identify the differential in time preference as a source of market failure; where there is "a discrepancy between an individual's future time preference and the social intertemporal preference rate for health" it may be that goods are provided at a sub-optimal level¹⁸. There is high probability that any given individual nearing the end of their life would be unlikely to benefit directly from resources spent (ie health deferred) in the future. As a result, that individual may excessively discount future benefits relative to the socially optimal level of benefit for the same resource used elsewhere. Policy guidance from the Department of Health, such as the end of life criteria applied to some NICE technical appraisals, suggest that decision makers are being asked to discount health gain at this time of life differentially from health gain at other times of life.

While informal care may be required as a result of market failure in end of life care, it may also be a cause. As a cause of market failure, it generates externalities, both positive and negative, meaning its true value is difficult to estimate and therefore it is difficult to arrive at the socially optimal level

of informal care to be provided. Positive externalities of providing informal care arise through altruistic or paternalistic means¹¹. Altruistic externalities accrue to caregivers through the benefit they feel themselves through the act of providing care. Paternalistic benefits arise as a result of the improved welfare of the individual being treated. Negative externalities arise through increased carer burden and illness resulting from having to provide care, as well as time lost from work or other activities¹⁹. The existence of positive externalities suggest that intervention in the market should not go so far as to replace all informal care while the presence of negative externalities suggests that government intervention is warranted to some degree; finding the appropriate balance will continue to challenge policy makers.

Care provision where market intervention fails

Market failure can still exist following government intervention. In the case in end of life care, this continuing market failure is manifested in such a way that the market failure has become self-reinforcing. Governments are resource constrained, and cannot meet the full demand for care. This does not distinguish end of life care from other areas of care. However, given the historical development of the market for end of life care in England as described above, government care represents a smaller proportion of the total spent on care than in many other areas. In the case of end of life care, government provision is largely supplemented, and in some cases wholly replaced, by voluntary, charitable, informal and private sector provision.

A key way in which market failure in end of life care in the UK and other publicly funded health systems is manifested is through an unmet demand for care. Unmet demand may exist in any market. In competitive markets, the level of this unmet demand will be unknown at the equilibrium. It is not possible to know what the demand for a good is below the equilibrium price because there are no producers willing to supply the good. But in non-competitive markets this may not be the case. For example, one important indication of unmet demand within the NHS is the presence of waiting lists²⁰. Waiting lists represent a demand for a particular good (say hip replacements) that the producer cannot immediately satisfy. In end of life care, this approach may not reveal the true unmet demand – by the time the producer can satisfy the unmet demand the patient may no longer require the care. An alternative measure of unmet demand therefore needs to be considered.

Another potential measure of unmet demand in health and social services at the end of life is the degree to which care is provided outside of the normal structures of the state system of provision. This is reflected in the presence of a private market for healthcare in England. This market is not large relative to the market for publicly provided care; the purchase of private healthcare is costly and beyond the means of most individuals in England. However, for care at the end of life, non-public suppliers produce a significant amount of care – for example, roughly two-thirds of hospice funding comes from non-public sources²¹. That this care is provided outside the public system (particularly through charitable organisations) is a reflection of a high degree of unmet demand.

End of life care is not unique within health in having otherwise unmet demand provided through charitable organisations. The provision of informal care is also an important means of meeting patient needs across the health sector. However these sources of care are particularly important in supporting patients to experience a good death. The way in which the market for end of life care in England has developed has created an environment in which state providers free-ride on the

contributions of informal carers and charitable organisations in providing care. With care having not been provided by the state historically, the market is now subject to a form of moral hazard, with state providers treating the charitable sector as a form of insurance against unmet demand. The charitable sector therefore, having come into existence to meet a perceived need for care, sustains the ability of the state to under-invest in care.

It is a useful thought experiment to consider the provision of end of life and palliative care within England if the current levels of informal and charity provision of care were no longer available. If it is accepted that it is a duty of the state to provide clinically- and cost-effective care to individuals on the basis of their clinical need then there is a clear moral argument that such care should be provided at the end of life as well as at all other times. In the absence of charitable and informal care, the state would necessarily have to increase its provision of end of life care. It has been estimated that primary care trusts spend £245 million on end of life care annually, though more is spent by other organisations²¹. The same report estimates that £1.2 billion is spent on the care of cancer patients in the last 12 months of their life. Though not all of this will directly involve end of life or palliative care, it still represents roughly 1% of the entire NHS budget. Patients that die from cancer represent just over a quarter of all deaths in England; it is clear that the costs of providing end of life care would not be inconsequential.

At present, 19% of people in England die in their own home³. A further 9% die in a nursing home and 7% in an old people's home³. Much of the care that takes place in these environments is provided by private organisations, whether run for-profit or otherwise. When care is provided by agents acting outwith the state system of care provision, these costs must be met by non-state payers. In some instances, these producers of care may be charitable. For example, Marie Curie Cancer Care is involved in some capacity with the deaths of between 4% and 5% of the population in the UK (from Marie Curie data) – in England alone this is over 23,000 deaths per year based on over 500,000 deaths per annum³. Other charitable organisations provide similar types of care, though it is unclear to how many patients. To replace this unmet demand with state provision of care would be a considerable undertaking. Charitable and voluntary organisations provide just a small (though high profile) proportion of care that people receive at the end of their life.

In the absence of publicly or charity provided services, individuals frequently access other sources of care, primarily from the private sector or through informal care. While some care in nursing and old people's homes is provided by the state, in England such care is means tested as it is considered social, not health, care. Given the often complex care needs of patients at this time in their lives, it is difficult to argue that such an artificial distinction between health and social care needs can be sustained. As a consequence of this distinction however, the nursing and health care needs required by some patients towards the end of their life is paid for directly by patients and their families. This gives rise to a situation where patients with potentially identical care needs will not have access to equivalent levels of care, whether that care takes place in the patient's own home or some other setting. If an aim of state intervention in the market is to provide care based on clinical need rather than ability to pay, then the market intervention has failed to achieve that objective.

Hospices all also provide an important contribution to end of life and palliative care. Approximately 5% of patients will die in a hospice and each year over 100,000 patients are cared for by hospices as outpatients or in the community²¹. The NAO report that in 2006-07 PCTs provided roughly one third

of the expenditure of independent hospices, totalling £130million. The remaining cost of providing hospice services are met largely by charitable organisations and other independent providers of care. Of the 208 inpatient hospices in England for adults in 2002, just 56 were provided directly by the NHS with the remainder operated by independent providers¹⁹. Were the NHS and social services required to provide this hospice care in its entirety, this would require a further £260million approximately. With evidence from a YouGov survey suggesting that 23% of people would choose to die in a hospice if possible, to meet the unmet demand for these service would perhaps bring the cost of providing hospice care to four to five times as much as currently spent by the NHS and independent providers. Though this would be offset by savings achieved from not providing the same care in other settings, it is still likely to represent a significant burden to state providers of care. The conclusion to be drawn is that the state providers of care are again able to free-ride on the care provide by other organisations. The existing market for services in England is failing to meet the demand for care.

Much of the additional care that individuals receive at the end of their life takes place in the last few weeks and months of living, during the period immediately prior to death. While there is clearly still an important role for the NHS and social services in the provision of much of this care, a great deal of it is performed by others on an informal basis. If all informal care - for all conditions - were replaced with paid for care, it has been estimated that this would have an annual value of £71 billion²¹. There are no published estimates of the value of informal care across end of life and palliative care. The NAO report on end of life care cites a study by the Motor Neurone Disease Society that the informal care a patient receives in their last year of life would have a value of over £100,000, though such patients are likely to have high care needs and may not be representative of the typical patient. Although the evidence does not currently exist to accurately value the care that patients receive informally at the end of their life, it is clear is that the sums involved are significant. If this care were not provided informally, the demand would still exist and the burden of providing the care would fall on government providers. The undervaluation of informal care can lead to the sub-optimal allocation of societal resources²², and this is arguably the case in end of life care.

The historical development of the market for end of life care has also influenced which patients have traditionally had greater access to care. Palliative care developed largely within the field of cancer care. Many charitable providers of end of life and palliative care have a focus on cancer patients. Although many such providers now make their services available to patients with a wider range of illnesses, more patients with cancer will die in hospice than with other illnesses. Only patients whose underlying cause of death was cardiovascular disease outnumbered cancer patients in dying in their own home, though the difference is slight and when viewed as a proportion of deaths from a particular illness, cancer patients were still more likely to die in their own home³. Many palliative care interventions are still largely based on models developed with cancer patients, even if they are not appropriate in non-cancer patients²³. Other illnesses commonly identified as having similar care needs at the end of life include dementia, chronic obstructive pulmonary disease, chronic kidney disease and heart disease²⁴⁻²⁷. The degree to which there is unmet demand for care amongst these patients is indicative of a failure of the market. That there exists unmet demand that is provided outside the publicly provided system of care is indicative of care not being produced at socially desirable levels.

Discussion

The failure of markets is as evident in end of life care as it is in any other area of health provided by the state and in many ways end of life care is not unique. Government intervention in markets for health is widespread – even in countries where most healthcare is provided through private markets, a large state market for care often exists. Government provision exists to correct the failure of the market to provide a socially desirable level of private and societal health. Perhaps what is unique about end of life care is the degree to which government intervention fails to deliver desired levels of care. In order to improve the use of public resources and increase societal welfare, the application of health economic analysis methods to end of life care is warranted. The use of such methods would enable decision makers to improve the way care is delivered, from the viewpoints of both technical and allocative efficiency.

It is clear that there is a large unmet demand for end of life care. The evidence for this unmet demand is provided by the large contribution to care provided by the charitable sector, the large market for privately provided care and the degree to which care is provided informally. It remains unknown however to what degree societal preferences would recommend a shift towards providing greater public provision of end of life care at the expense of providing some other forms of care. Greater understanding of the market place, the level of resource currently directed towards end of life care and societal preferences for care is required in order to improve resource allocation.

Economic evaluation is also crucial in achieving technical efficiency when choosing between individual courses of treatment. Cost-effectiveness analysis is increasingly used to help achieve this end and is mandatory for treatments being considered as part of the NICE technology appraisal process. But to date few economic evaluations have taken place in end of life care and those that have often have methodological shortcomings (Hulme, manuscript in development).

One of the key obstacles in conducting economic evaluations in end of life care is choosing a measurement of benefit that permits comparison of both technical and allocative efficiency. As highlighted above, the measurement of outcomes in end of life care is difficult. For certain interventions, such as the Liverpool Care Pathway, it is not simply not possible to ask patients about the care they received. Increasingly researchers are considering options that move beyond the framework of QALYs^{16;17} that is considered the gold standard in health economic analyses. And if the QALY framework were to be retained, further work is necessary in the measurement and valuation of health states, as current methods lack validity in the end of life population (Round, manuscript in preparation).

Other restrictions in conducting economic evaluations end of life care exist. Although these may not be unique to end of life care, they still present methodological challenges that must be addressed before economic evaluations can be used to help allocate resources. Estimating costs is complex and difficult, particularly in relation to informal care. Additionally, study designs that are used in other areas of care may not be appropriate in end of life care. Much of the care people receive falls within complex interventions for which it is difficult to isolate the effective component. Studies also suffer high rates of attrition due to the death of patients during the study period.

The efficient supply of end of life care is not only affected by a lack of economic evaluations and analysis. Supply side problems exist such that even if interventions were found to be cost-effective, it is often difficult to provide staff or other resources to implement them. And the supply of care

provided by charities exists not just to supplement demand that is unmet by other providers. Many individuals experience high levels of motivation to commemorate the deceased through charitable giving, in some cases founding hospices or providing substantial donations to existing charities. Although such charitable action might decrease as a result of increased public care provision, it is unlikely to cease altogether.

Conclusions

The market for end of life care is, in most ways, no different from the market for any other form of healthcare. However, two aspects of this market distinguish it from other healthcare markets in important ways. First is the degree to which unmet demand from public providers of care is met by charity and household supply. The causality of this first situation is unclear. To a certain degree, end of life and palliative care developed as a response to the shift of death being considered a natural part of life that occurred at home or in the community to something to be staved off for as long as possible in hospital. The increase in care outside the public sector could initially be considered part of a response to unmet demand for certain forms of care. However, the current public care system has come, to an extent, to rely on the care provided by charities and households and therefore free rides on this care – the evidence is clear that the public system does not meet the demand for care.

The second important and unique element of end of life care is the difficulty in measuring outcomes in a way that allows for comparisons of allocative and technical efficiency. For economists, this is perhaps the most pressing issue in the analysis of end of life care. Other methodological issues relating to estimating costs or in relation to study design are important, but without an appropriate measure of outcome, decision makers cannot make informed choices about which care to fund and what resources would be required to provide that care. Alternatives to the QALY framework are currently being explored and further work should be undertaken to improve the measurement and valuation of health states in people at the end of their life.

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