Resources, the family and voluntary euthanasia

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SUMMARY. Ethnological studies show that the care which societies are able to provide for their old people depends largely on available resources. However, the concept of resource depends on contemporary requirements and expectations. Modern families still try to look after their old people, but increasing longevity is making this more difficult. There is a finite ability of populations, however wealthy, to support dependent members. Resources provided to look after old people must necessarily be subtracted from those available for the other, still more important dependent group, the children, with potentially disastrous results in underfunding of social support and education. The sociobiological theory of inclusive fitness emphasizes the importance of the ways in which family members interact to help each other and try to ensure their genetic survival, even if this involves sacrificing their own interests and occasionally, their lives. Many old people do not wish for further longevity after they have become too disabled to be of service to their families, and would prefer to see limited resources being used for the young. In the USA, loss of autonomy of patients and their families owing to the practice of defensive medicine has resulted in the development of the 'living will', a legal document in which people can specify in advance what treatment they wish to accept in the event of life threatening illness. It is to be hoped that improved understanding of family relationships will make this generally unnecessary in the future and that, unless specified to the contrary, families will be allowed to decide about treatment for members who are unable to decide for themselves. This should include withholding or withdrawing life support and even in certain circumstances, active euthanasia.

Resources

ETHNOLOGICAL and historical studies show that the extent to which societies practise euthanasia depends largely on resources. De Beauvoir,[1] in her exhaustive study of old age, concludes that the treatment of old people by their children is determined mainly by three factors: the way of life of the tribe, particularly whether nomadic or settled, the availability of food, and the behaviour of parents towards their children. All three are interrelated; thus the Yakuts in north eastern Siberia may depend for their survival on behaving with extreme harshness towards rebellious sons or unwanted daughters, and to their old parents who have formerly meted out similar treatment to them. She quotes travellers to this region who describe how 'the old were either expelled from their homes and reduced to beggary, or turned into slaves by their sons who beat them and compelled them to work very hard. Even in well to do homes, I have seen living skeletons, wrinkled, half naked or completely naked human beings, who hid in the corners, only emerging when there were no strangers there to come near to the fire and fight with the children for the remaining scraps of food'. She discusses other tribes living under almost equally harsh conditions, who contrive to behave much better to their children and in turn to their old parents. But most of these still have to practise infanticide for excessive numbers of births, and to leave incurable and old people to die in times of stress, such as war or famine.

As societies become more settled and prosperous, families behave differently in order to maximize their numbers and influence. They may exploit less fortunate families in the same or other societies on a slave, feudal or industrial class basis. The privileged classes can now afford to do their best to promote the survival of all their children and to strive for their successful placement in society. They also honour their old fathers and mothers who now frequently preside over the family's wealth. Life among the less fortunate families in these societies, however, is often little better than that of the Yakuts.

Gradually, as man learned to exploit minerals, coal and eventually oil, countries became so well off that most, not just a few, families were able to benefit from the increased supply of food and opportunities for self-advancement. In western counties, self-advancement is now the principal method of ensuring a good living. Modern conscientious parents put their maximum effort into providing their children with the best education they can afford and then expect them to leave home and make the best use of it that they can. This policy often involves many years of loving self-sacrifice by parents for their children. According to de Beauvoir, this should be reciprocated by the care with which children are prepared to repay their parents when they are old and, in our present day society in the UK, it usually is.

Carers

Health workers agree that there is no truth in the frequently stated belief that families do not look after their old people like they used to do.[2-4] Sentimentalists who make these assertions usually go on to deplore the decline of the three tiered family and the good old values of filial respect. De Beauvoir's comments should make us wary of such illusions. In fact, far more children, especially daughters, are providing far more care now than ever before.[5]

Only a tiny minority of the population in the UK aged over 75 years, about 8%, live in old peoples' homes or hospitals. Of the remainder, 85% require help with shopping and housekeeping, 50% of those over the age of 85 years need help with bathing, and 10% with going to the toilet. Half of this general care and 70–100% of the personal care is provided by the family, mainly daughters.[6,7] There has been much discussion in recent years about the strain this amount of help is imposing on carers, especially women.[8-10] Many are trying to do a full time job and run a young family as well as caring for their ageing parents. Furthermore, removing the failing old person to live in the son's or daughter's home is seldom a sensible plan.[7] Such moves are frequently unhappy, even necessitating a return to the old person's original home, when this is possible. At this point most families begin to look round for some alternative placement, and this is where the state should be able to step in. By this time many old people themselves have come to realize that they no longer want to live alone.

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Submitted: 23 March 1989; accepted: 19 September 1989.

In an adequately funded, well run home, the elderly resident has a chance of being reasonably comfortable, if not always happy. The care and concern shown by families usually continues in the new setting. A study carried out in the long stay wards in my department in 1981 showed that 84% of the patients had regular visitors, 20% of them daily, and that this continued even after they had been in hospital for years.[11]

But will these options continue to be available to old people and their families in the future?

Demographic changes

Bryan Thwaites has shown how, between 1957 and 1987, expenditure on the NHS had grown by about 4.5% per year, but that from 1977 the rate had dropped progressively.[12] His projected growth rate for 1983–93 was 0.5%. Even if resources rose at the best conceivable rate of 2.5% per annum for the next 20 years, he was able to demonstrate that it would have no hope of keeping up with demand, which was increasing twice as fast. In 10 years, expectation would exceed supply by 27% and in 20 years by 62%. Thwaites discussed the causes of this exponential increase in demand more fully in a lecture (Thwaites B, Health care into the twenty first century, keynote lecture, Nuffield Institute for Health Service Studies, University of Leeds, 1988), but although he recognized that the principal problem is that 'we are all no longer dying sufficiently quickly of the ailments of which the NHS has cured us', he did not specifically address the effects of the ageing population. The Americans have generally been more alert to this than the British for reasons which a consideration of the population structures of the two countries should make clear.

Life expectancy at birth in the UK and the USA today is 74 years. The tremendous improvement in survival which has occurred in the last century has been largely due to a reduction in infant mortality (Figure 1). Increases after middle age have been far smaller, but recent figures show that life expectancy even in old age is now increasing, for men as well as women.[6,7] As there is no reliable evidence yet for either diminution or postponement of the principal degenerative diseases, this means that the duration of physical and mental disability is also likely to be becoming longer.[9,13]

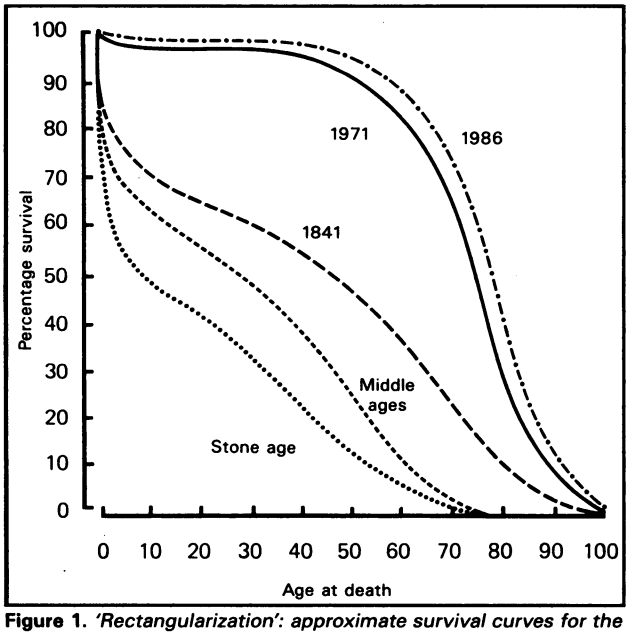

Figure 1. *'Rectangularization': approximate survival curves for the UK population.*

Figure 2 shows the 'squaring of the pyramid', or the effect of the increase in life expectancy on population structure. The blocks of the pyramids represent the percentage of people of different ages. The bottom blocks show the proportion of children under 20 years of age, and the top blocks elderly people over retirement age of 65 years. The two intermediate blocks represent young and middle aged adults, or the working population.

In the UK in 1901,[14] when the average length of life was 50 years, the pyramid was broad based, with large numbers of children and young adults and relatively few people, only 9%, aged over 60 years. Today, 15% of people are aged over 65 years. The last UK diagram shows a projection of what the population will look like in the year 2025 if life expectancy continues to increase at its present rate to an average of 78 years:[15] 19% of people will then be aged over 65 years, and a higher proportion of those will be very old, in their 80s and 90s, than at present.[6]

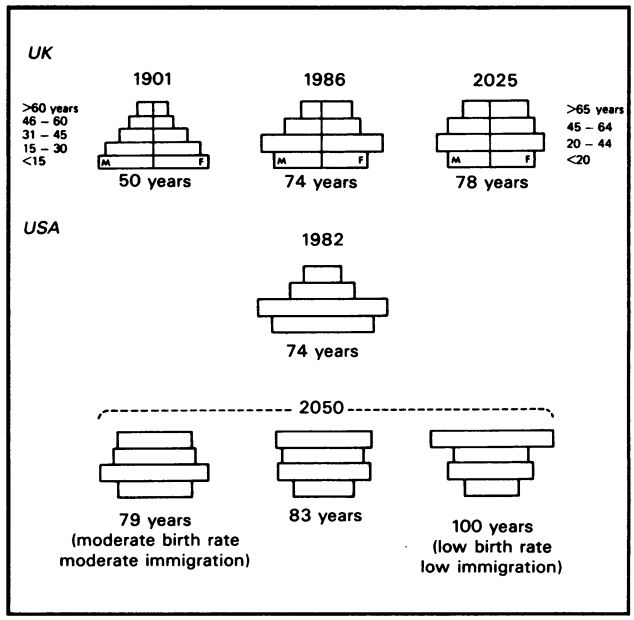

Figure 2. *'The squaring of the pyramid': actual and projected population structures according to expectation of life at birth (shown as percentages of total population).*

Turning to the USA,[4] the centre diagram shows the structure of the population today. Owing to recent high immigration and birth rates, it looks superficially more healthy than the British equivalent, with a wide base indicating large numbers of children and young adults supporting a relatively small elderly population, only 12%. But what will happen by 2050, when today's teenagers will be approaching 80 years of age? Three projections based on average life expectancies of 79, 83 and 100 years are shown. Politicians and doctors talk as if a life expectancy of 100 years was the desirable norm, even the 'right', of people living today. If this were to happen in the USA, 36%, or one third of the population, could then be aged over 65 years, more than double the proportion in the UK today.

Can we begin to envisage such a state? Figure 3 shows a comparison of the present average annual cost per capita in the USA of patients under and over the age of 65 years.[16] The Americans already spend more than 1% of their gross national product on the care of old people in the last year of their

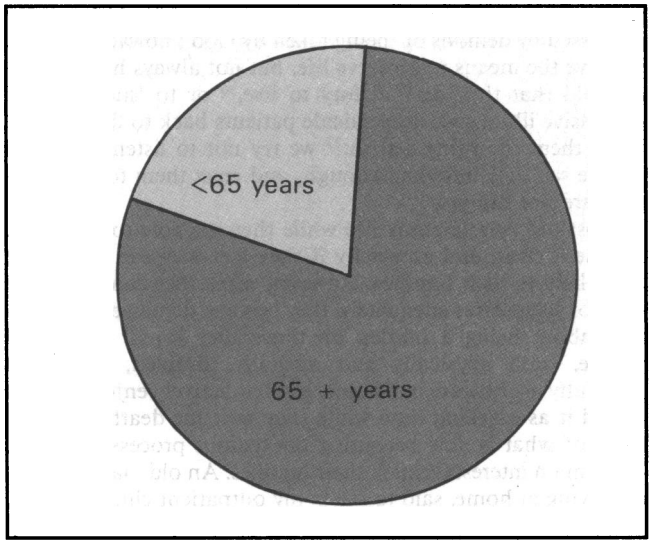

Figure 3. *United States of America: proportion of health care expenditure per capita spent on younger and older people in 1981.*

lives.[17] The UK spends less, but our system of health care seems likely to draw closer to that of the USA in the future. If we consider the relatively small proportion of old people in the USA today, 12% compared with 15% in the UK, it may help us to comprehend the enormity of the problem facing, not just the USA, but all developed countries, and, indirectly, underdeveloped countries[18] in the world.

The real anxiety is not competition for resources among old people themselves, but between old people and other dependent sections of society, principally children.[7,19-21] Both the USA and the UK have shown evidence of serious underfunding of education in the past decade. Which is most important for the future of society: unlimited health care for the old, or a really good primary and secondary education for our children? To whom should we pay more: geriatricians or teachers?

We should now be in a better position to understand what Thwaites meant by a 5% annual increase in public expectations for health care; and we should remember that we have all this time been talking only about old people, not about disabled, mentally handicapped or chronically sick young people whose numbers are also likely to increase with improved medical care. What does the shortfall Thwaites predicts mean in practice?

Future patterns of care

It is widely feared that the present reorganization of the National Health Service by the government will result in a decline in services for old and disabled people.[22,23] The current shortage of nurses is still more serious. The 'black hole' report (Conroy M, Stidson M, South West Thames and Oxford Regional Hospital Boards, 1989) shows that there will be a 25% reduction in the number of school leavers in Britain between now and 1993. The NHS has virtually no hope of competing with industry for young people who have the necessary qualifications. One proposal put forward in the London area is to relocate 'support departments' in the Midlands or the north of England where recruitment may be easier. In the geriatric unit of the City and Hackney health district, we have already had to close one ward owing to lack of nurses, and we are due to lose at least another 40% of our longstay beds in the 1990s. Meanwhile, local authority residential homes have been closed to new applicants for long periods owing to shortages of staff.

To expect that we can pay proper wages to sufficient nurses to look after thousands of patients with Alzheimer's or cerebrovascular disease in the future is a dream. Nor will we be able to continue to import cheap labour for this purpose as we have done in the past. Families are going to have to do it themselves, and they are likely to find it impossible. The Alzheimer's Disease Society say that carers of present day sufferers do not want their children to go through what they are suffering now, and that if they themselves become demented in the future they want to be 'put in a home'. The government response to the Griffiths report emphasizes community care for elderly people as the major element in its strategy.[24] However, 'community care' is unlikely to be either realistic or cheaper for many frail elderly people and depends on our ability to pay suitably trained and responsible workers. In my health district in the last few years, five out of eight of our borough occupational therapy posts have remained unfilled and the service has been intermittently closed to new applicants. I can still only get bath aids for my patients by bringing them to the day hospital (at about £40 an attendance).[25] Attempts to bypass the block by allowing borough engineers to install aids at the request of patients or their doctors is prevented by threats of industrial action.

Caring for a very physically or mentally frail person in their own home requires more imagination, organization and integrity than looking after them in an institution. The reality of a service in the community is all too likely to be 'no service', or a return to the Sairy Gamp days of unprofessional, poorly paid sitters-in,[9] who slumber or tipple by the fire having dosed their charges to keep them quiet. For old people for whom even this form of care is impossible, the only recourse is to a local authority home. It is significant that this is the only institution for elderly people which has remained virtually unchanged since its establishment by part 3 of the national assistance act in 1946. Despite the fact that local authority homes care for 3–4% of the elderly population,[8] and that the average age of residents has risen from the low seventies in 1950 to the mid eighties today, and that admission criteria depend now more on applicants' unfitness rather than fitness,[8] these homes still need not have nurses on the staff, and are less likely to have a qualified nurse manager today than they were 40 years ago.

Unless local authority homes become part of an integrated service before it is too late, they seem set to become the workhouses, if not the madhouses,[26-28] of the future.

'Inclusive fitness'

Resource is a subject which is often dismissed by doctors, either owing to ignorance or fear, or because they believe it is their business to ignore it.[29]

Until now, the greatest benefit of the National Health Service has been its ability to apportion resources fairly among the whole population. We should do everything we can to see that this system continues, but we cannot do it without being realistic and without making sacrifices. It may seem ludicrous to compare our society with that of the Yakuts, but ironically, our very success is recreating the battle for resources which determines the behaviour of primitive tribes, and which may demand similar solutions. We cannot expect to enjoy unnatural life unless we are also prepared to accept unnatural death.

This may not be so difficult as it sounds if we allow ourselves to understand the progress which has been made in biology as well as in medicine in the last 30 years, in particular the theory of 'inclusive fitness', or the importance of the family, in explaining our emotions and behaviour.[30] It is becoming increasingly clear from animal — and plant — studies that the pivot of selection is not, as has been assumed from Darwin's time, the individual, but the gene. This may sound an even more restricted

unit, until it is remembered that genes are not solitary; they are not even confined to one individual, but shared among many members of a family, tribe, race and even different races. The theory is that genes interact with other genes in order to try to maximize their numbers. They do this by programming their bearer to behave in ways which are likely to contribute to the success, not just of that individual, but of other related members of his or her family who tend to contain the same genes.

'Fitness' in the biological sense means reproductive success, that is the number of viable offspring produced by an individual.[31] However, for the survival of a gene, the fitness of an individual is less important than the 'inclusive fitness' of all the individuals of contemporary and future generations who share copies of that gene. 'Kin selection' is the process by which an individual may promote the survival of its genes, and hence its 'inclusive fitness', without necessarily reproducing itself at all. Parents and their children and full siblings share 50% of the same genes; grandparents and grandchildren and uncles and aunts and their nephews and nieces share 25%; cousins 12.5% and so on. Hence, an altruistic action by an individual which prevents it from reproducing itself, but which assists the reproduction of siblings, or other close relatives, could result in the survival of a greater number of copies of its genes than if it had reproduced itself.[32] The likely success of such altruistic behaviour will depend on the degree of relatedness of the participants and on their reproductive potential. Thus as Essock and Vitale[31] observed in their paper discussing the relevance of kin selection to psychiatry, 'an individual past his or her reproductive prime [is especially well placed] to assist a close relative who is just entering the peak years of reproduction, with very little cost in terms of individual fitness and a good chance of ... gain in inclusive fitness. Conversely, individuals in their reproductive prime [may] be ... less willing to invest in the well-being of their kin because the potential loss in decreased personal reproduction may be relatively great.'

We may find it difficult to think of ourselves in these terms just as a century ago people found it difficult to believe that they had descended from animals; but, as the concept of evolution and genetics unleashed development in the biological sciences including medicine, so the theory of kin selection is likely to revolutionize our understanding of our behaviour and social organization. The drive for inclusive fitness helps to explain the anguish of family tensions,[32] and cooperation and war between races and nations.[33,34] Together with 'reciprocal altruism',[32] a form of symbiosis, inclusive fitness probably motivates most of the actions of love and heroism which we most admire. In essence, it means that we should not think solely of elderly people as individuals but should also consider the set of genetic shadows which exist in the family and society. Attempting to help individuals in a way which makes people really happy without trying to help their families is unlikely to be successful.

Once we have grasped this concept, we should find it easier to respect the concerns of parents of handicapped babies,[35] and to understand why some old people may no longer wish to live. It should also help us to decide how we can redeploy our limited resources to provide the maximum benefit and happiness to the whole population. The two most important principles to be derived from this new concept is that families, not the law or the state or the medical profession, should be allowed to make decisions for individuals who are unable to decide for themselves, and that the autonomy of individuals should include the right to decide whether they wish to continue to live or not. Both of these are important in the care of old people.

The feelings of older people

What about the feelings of old people? To some extent, these are imposed by society. Thus in the past, when people had to succumb to dreadful diseases, they believed that they were possessed by demons or 'being taken by God'; nowadays, when we have the means to preserve life, but not always health, they are told that they have a duty to live,[36] or to 'snap out' of depressive illness; we drag suicide patients back to life and upbraid them for being selfish;[37] we try not to listen when old people say they have had enough, and coax them to eat when they are not hungry.

Most old people enjoy life while they are able to do things for themselves, and especially if they feel they can still be of some help to their families. However, when they can no longer care for themselves adequately, they become depressed and anxious about being a burden on those they love.[38] Many old people, both physically and mentally disabled, eventually gratefully accept care in a home, but few actively enjoy it. Most regard it as marking time while they wait for death to relieve them of what is now becoming the tedious process of living. Their main interests remain their families. An old man who was still living at home, said to me in my outpatient clinic recently, 'I wouldn't mind if I went tomorrow. I only live to see my nephews, but even so, I wouldn't mind'.

Other old people worry about the money being spent on nursing home fees which they would prefer to see going to their grandchildren. Their families worry about this also. This is not unnatural. As we have seen, the common desire of families is to help, not hinder, their members, and old people are particularly likely to resent seeing money being spent on them which could be supporting the younger generation.

So why do we spend huge sums carrying out medical procedures on old people so that they must continue to live lives which they do not enjoy? Would it not be more humane as well as more honest to allow patients and their families to make their own judgements about the value of their lives and what they want done with them?

'Living wills'

The system of medical care in the USA, where many intensive resuscitative procedures are carried out on old people, mainly because of the fear of litigation, has had one beneficial result: the introduction of 'living wills'.[39] These are now legal in 38 of the 50 states.[40] In a 'living will' a person can specify in advance what type of medical care he does or does not wish to receive in the event of a life threatening or terminal illness. A medico-legal working party is at present discussing whether similar measures should be adopted in this country. Some doctors are worried that this might increase the risk of legal interference with medical practice here.[41] Nevertheless, people do need to be given the right to decide for themselves about what they wish to accept in the way of medical intervention in their lives, in the full knowledge both of the limitations of the benefits of the procedure itself and of resources for subsequent care, if this is likely to be necessary. Naturally most young people will want to avail themselves of any treatment which may preserve their lives, but many old people will not. For patients who are unable to think for themselves, their relatives should be allowed to decide for them. The importance of families helping to make decisions on behalf of very ill or old people is already becoming better recognized.[7,40] If no relative is available, or willing to act for a patient, then a court similar to the court of protection should be invoked to act as a proxy. Obviously, a 'living will' should be able to be altered at any time by the testator. This should be accepted even if he or she becomes demented, but appears to be unhappy about the existance of such a will. In general, however, families or other proxies should accept the responsibility of acting for old people and be prepared to carry out their wishes as sympathetically as they can.

Euthanasia

I hope that in future the rights of children to make decisions for their parents who are incapacitated by age or dementia will be so well recognized that 'living wills' will only need to be made by people who wish particular family members, or persons outside the family, to represent them; or if they wish for treatment which they feel their natural proxy might find difficult to support, for example, euthanasia.

Any discussion of euthanasia inevitably evokes fears about a society determined to purge itself of what it perceives as imperfect members, or concern about greedy relatives anxious to get their hands on an inheritance.[39] However, a proper understanding of the theory of 'inclusive fitness' should allay these fears. There is a fundamental difference between a state deciding that it wishes to rid itself of Jews or of mentally deranged people, and families deciding among themselves what is best for their various members. 'Gerontocide' would be impossible if decisions were confined to patients' close relatives or, in a few cases, to friends or professional representatives. Religious views and practices would be upheld. Some critics fear that poorer families might feel impelled to ask for euthanasia because they were unable to afford as high a standard of care for their old people as those who are better off, but in fact patients and families of all social classes tend to react similarly to depression caused by pain or disability in old age. Requests for euthanasia might even be more likely to come from better educated patients, who have more to lose from the deprivation of their faculties. Whatever the results, nothing could be more bizarre than the present situation in which many weary, or unhappily demented, old people have to live unwanted lives at the cost of enormous distress to their children and to the detriment of the education and welfare of their grandchildren.

Regarding the danger of old people being exploited by their children, we should remember de Beauvoir's unspoken warning: 'Do as you would be done by'. Not all authorities caring for old people feel that we should necessarily interfere with families who appear to be trying to expropriate patients' funds or property.[21] At least exploitation by relatives would mean that benefits would be likely to remain in the family. In practice, I find that most children love their old parents far too dearly to want to do other than their best for them, at almost any cost to themselves. And, as one mother, a member of the Voluntary Euthanasia Society, declared, 'If my daughter wanted to get rid of me, I shouldn't want to go on living anyway!' I am less concerned about the abuse of legalized euthanasia by relatives than by doctors. The brutalizing effects of Nazi policies in encouraging doctors to carry out experiments on human beings and to participate in extermination exercises[42] are all too well known. However, present medico-legal practice can also cause doctors and nurses to behave cruelly, for example 'non-volitional' feeding,[43,44] or tying up old people throughout the 24 hours to prevent the possibility of an accident, often causing severe pressure sores.[45-47] We need a reaffirmation rather than abandonment of the essential compassion of the Hippocratic oath.

I think that doctors' ability to help their patients should extend to providing euthanasia if necessary. Many geriatricians admit that they practise 'passive euthanasia' or 'letting die' for very old or ill patients who request it, or who are unlikely to recover.[39,41] However, philosophers and theologians[18,48] agree that there is no real difference between passive and active euthanasia, and the former can be unsatisfactory or even cruel.[21] I have reasons for being particularly concerned about this. My major interest has been trying to find ways of preventing pressure sores in elderly patients. With our district nursing officer,[49] I have tried to improve the use of alternating pressure air mattresses in hospitals and in the community. Most of our sick old people are now being nursed on these and other pressure relieving mattresses, with the result that the incidence of pressure sores has fallen from 25% in 1976 to 5% this year, with necrotic sores less than 2%. This would be very gratifying were it not for the fact that, during the same period of time, the length of stay in our geriatric wards has increased to double that of most other departments in the country.[50] There are various possible reasons for this, but the most worrying is that it may be partly associated with the reduced incidence of pressure sores. Pressure sores are a 'pre-death'[39] condition which usually only occurs in patients who are extremely ill or who have gross neurological disease. By helping to prevent them, therefore, I may be even more guilty than my colleagues in the intensive care unit of preserving the lives of very ill or old people who do not want it.

I hope that before much longer, patients and their relatives may be allowed to decide at what point in life euthanasia should be possible. And I hope that some of the money which is at present being spent on resuscitating dying patients may be able to be used for providing a high standard of care in private and local authority homes for all physically and mentally dependent old people who need it. Perhaps it is not even too much to hope that in the future the success of the NHS may be able to be measured in terms of a decreasing, rather than the present monotonously cited, increasing life expectancy?

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Acknowledgements

I am indebted to the Office of Population Censuses and Surveys (Medical Statistics Division) for the population and mortality statistics for England and Wales; to Ms J Thomas, statistician, St Bartholomew's Hospital Medical College, for constructing the survival curve for 1986; and to the Editor of the *Journal of the Royal College of Physicians of London* for allowing me to reproduce Figure 1.

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