(versus 30% during the non-epidemic period), particularly within family, suggesting person-to-person transmission. Stool cultures are seldom done in general practice (only in 2% of cases) for common acute diarrhoea; however, cultures in 101 cases showed salmonella was significantly more rarely isolated (8% vs 28%) and rotavirus significantly more frequently (22% vs 7%) compared with the non-epidemic period.

We thank the Sentinelle GPs who collected these data. The Sentinelles network is a part of the French Communicable Diseases Network (FCDN), which is developed at INSERM U263 in collaboration with the Réseau National de Santé Publique (Public Health Network) and the Direction Générale de la Santé (Ministry of Health).

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## Decisions and care at the end of life

Michael Gordon, Peter A Singer

Successful public health and social policies and apparently inexorable medical advances are now compelling physicians and others who care for the elderly to confront clinical issues and ethical dilemmas that hardly existed fifty years ago. In North America and Europe more than 12% of the population are now over 65 years of age and all are facing decisions at the end of life which will affect their families and society.<sup>1,2</sup> Older people deserve to be cared for with respect and dignity.3 They have more years of function and potential life fulfilment than any previous generation.<sup>2,3</sup> Indeed, so compelling is this positive image that some old people, when they become ill, question their bad luck or wonder what they did wrong. Despite the call for massive programmes of health promotion, many age-related conditions that cause disability (eg, Alzheimer's and Parkinson's diseases) and many malignancies and musculoskeletal syndromes have no identified pathophysiological process for which preventive measures are beneficial.<sup>4</sup> Although treatments for the underlying disease vary in efficacy, old people who become unwell will often benefit from interventions targeted at improving function even when no cure can be offered. Virtually all countries find that they cannot afford all that medicine has to offer and are looking at ways to decrease health care costs.<sup>3,5</sup> The elderly population, especially when life is drawing to a close, often become the focus of such efforts at cost control.<sup>6,7</sup>

Many issues arise at the end of life—where should one's last days be spent, consent to treatment, advance directives, aspects of clinical care such as resuscitation and palliation, and the controversies of euthanasia and assisted suicide—and this review cannot cover all of them in detail.

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### The ties that bind

The modern family is mobile and dispersed in many western countries, especially the USA and Canada. On retirement many people go to warmer climates while children move away from their parents and grandparents because of educational, work, and social opportunities. While family members remain well and independent this geographical separation is of limited consequence since visits and communication by telephone and letter remain possible. The impact on families of prolonged illness and disability can be profound because a son's or daughter's ties and obligations of kinship to parents may conflict with their responsibilities to their own families and their jobs.

Old people usually want to live independently for as long as they can and many struggle with their own financial and living arrangements and with how best to spend the rest of their lives. Governments are grappling with the same issues as expenditure on social services and residential care mounts. Many government-supported options seem costly and attempts are being made to transfer the expense to old people themselves and their families. Although attractive conceptually, communitybased systems of care may not always be cheaper than comparable facility care, and much of the burden of socalled community care is borne by families, usually the women.<sup>8,9</sup>

When the level of care required or a lack of community support means that admission long-term to a nursing home or the like is unavoidable the important question for the family is how to ensure that the care provided will be of high quality. For government the challenge is to maintain sufficient places without embarrassing the agencies appointed to oversee standards. And for those who run such long-term care facilities the goal is to provide a standard of service that is both acceptable to their clients and affordable.<sup>8</sup>

## **Consent to treatment**

During the past two decades there has been a major shift in the relation between doctor and patient. "The doctor proposes, the patient disposes" is an aphorism that accurately encapsulates a large body of bioethics

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## Panel: Reminders for physicians caring for the elderly

Quality health care for senior citizens, should include attention to end-of-life issues, especially consent to treatment, advance directives, and palliative care.

As educators, physicians must provide geriatric medicine training that equips young doctors to tackle end-of-life issues. As advocates for the older population, physicians must help define criteria for success in health care delivery, develop and promote good practices for patients at the end of life, critically evaluate legislation that affects health care delivery for old people, and challenge any initiative that threatens their dignity.

The scope of medical practice must include knowledge of "how to care", in addition to "how to cure".

The ultimate goal should be to ensure a good and dignified death for older patients, no less than the medical profession's objective of a good and dignified life.

literature, policy guidelines, and health law. Capable (competent) people have the right to make their own health care decisions, a right based on the ethical principle of respect for autonomy and the legal doctrine of informed consent.<sup>10</sup>

How can physicians determine that a patient is competent? This question is becoming increasingly important as medical decisions have to be made for more and more individuals whose mental function is undermined by age-related conditions such as delirium, dementia, or depression. Capacity-the ability to understand the information needed to make a treatment decision and to appreciate the reasonably foreseeable consequences of that decision—is specific to the particular situation and may vary over time. We do not yet have any reliable clinical measure of capacity to consent to treatment.10,11 Physicians must rely on questions that attempt to establish a patient's understanding of what he or she is being told.12 The doctor might, for example ask "What is your medical problem?", "What treatment has been proposed?", "What will happen if you receive the treatment and what will happen if you do not?", and "What have you decided about receiving treatment and why?" Such questions can serve as a screening tool to help healthcare providers to assess the capacity of the patient to make important clinical decisions. In certain cases, the physician may want to consult an expert in the assessment of capacity, such as a geriatrician, neurologist or psychiatrist well versed in the subject.

An incapable person retains in theory the right to make treatment decisions but that right must be exercised by someone else on the patient's behalf. Who should make the decision for the incapable person, and how? The goal is to reach the decision the person would have made, if capable, and that can often be achieved through an advance directive or, if one is not available, on the basis of the patient's earlier, verbally expressed wishes, or their known values and beliefs, or, failing those pointers, on what the substitute decision maker sees as the patient's "best interests".

## **Advance directives**

An advance directive or "living will" is completed by a capable person to guide future health-care decisions when the person becomes incapable. It has two parts: one names the substitute (proxy) decision maker, the other states what decisions a person wants. While many people include both components, either may exist separately.

Advance directives have gained wide endorsement in Canada and the USA. All American state laws support

directives and the federal Patient Selfadvance Determination Act requires health care facilities to advise patients of their statutory right to complete one.13 In Canada five provinces have passed legislation on advance directives and the momentum is growing. In the UK, the Bland case and the House of Lords Select Committee on Medical Ethics both supported advance directives. of patients and providers show strong Surveys endorsement of advance directives.14,15 However, their use has been disappointing. One study found that only onequarter of Americans had completed a directive.<sup>16</sup> The barriers include lack of information, a fatalistic attitude towards death, cultural beliefs, and non-support of loved ones. Some of these obstacles may be amenable to sensitive counselling by physicians and other caregivers. Perhaps the completion of written documents is the wrong endpoint. Discussion of and publicity about advance directives could stimulate a discussion between patient and family or friends about end-of-life care that is useful in itself.

Most advance directives are generic (ie, not disease specific) and contain many choices that may be irrelevant to the affected person. Disease-specific documents, tailored to specific conditions, have been recommended.<sup>17</sup> For example, a person with early Alzheimer's disease might focus on scenarios of mild, moderate, and severe dementia, and on the treatment of intercurrent illnesses, such as pneumonia, pressure ulcers, and inability to eat, that arise as the dementia worsens. The best advance directive is one developed for an individual and drawn up on the basis of that person's health situation and prognosis in consultation with his or her personal physician. Communication between health provider and patient is an important element of planning for future care.

The influence of culture on advance directives has only recently received attention. Some societies favour family decision making over the individualistic approach inherent in the directives devised to date; others may regard the completion of such a document as inviting bad luck and challenging fate. In view of western societies' increasing multiculturalism, the role of culture requires clarification, especially for elderly people who may cling to old traditions.

Astonishingly, little is known about how advance directives affect the care of incapable persons.<sup>18,19</sup> Nowadays no drug or medical device is introduced into practice without rigorous evaluation of safety and efficacy—yet that is exactly what has occurred with advance directives. These directives are being widely recommended and used and their impact on care must be carefully examined.

## **Cardiopulmonary resuscitation**

successful The development of closed chest cardiopulmonary resuscitation (CPR) held out the possibility of averting death from cardiac arrest but with time the limited chance of success in certain groups of aged individuals emerged. It is difficult to avoid being subjected to CPR in a hospital setting unless a "do not resuscitate" (DNR) order is in place. The clinical and legal climate in Canada and the USA has meant that CPR will be attempted unless there is a DNR order whereas in other western countries there is a lesser emphasis on this form of therapy.<sup>20,21</sup> The benefits, especially to older people, became a special focus of the CPR debate in the

early 1980s when reports indicated that although age in itself was not the major determinant of outcome with CPR success strongly correlated with previous functional status and disease burden.<sup>22</sup> For community dwelling elderly people who are not disabled the success rate is not very different from that in younger patients.<sup>23,24</sup>

During the past decade the focus has been on whether the frail, highly dependent old people who live in longterm care facilities benefit from CPR.<sup>25</sup> Evidence thus far indicates that for this population CPR is not very successful and that in some situations it may be futile.<sup>22,25</sup> When the dismal results are combined with the emotional consequences of an unsuccessful attempt perhaps CPR should not be provided in certain long-term care settings except under carefully defined circumstances.<sup>22,25</sup> For some, this position is extreme, but there is general agreement that only for those arrests that are witnessed, that have a rhythm (when obtainable) of ventricular fibrillation or tachycardia, and for which CPR can be tried promptly should resuscitation be attempted.<sup>23,25-27</sup>

## **Palliative care**

"It is not death, but dying which is terrible" wrote Henry Fielding in his novel Amelia (1751). Palliative care is, ethically, a mandatory part of the care of the dying. A byproduct of the success of modern medicine is that the dying process is prolonged. With chronic, debilitating diseases and cancer, the terminal phase is often predictable once interventions directed at the underlying disease have been exhausted—and what is then required is palliative care, aimed at providing comfort, and symptom relief, and meeting psychosocial and spiritual needs.28,29 The hospice movement and palliative care programmes have developed in many countries, yet it is still common for patients to be deprived of palliative care in advanced malignant and other end-stage disease states when they are in hospital or at home. Contrasting with contemporary technological advances in medical care, good palliative care is often an elusive goal.<sup>29</sup>

Despite apparent commitment to the principles of palliative care, necessary medical attention such as continuous analgesia is often not provided or investigations and therapies may be continued beyond the point when they can do any good. The philosophical acceptance of dying combined with support for what valuable life remains have to be incorporated into clinical practice if unnecessary suffering at life's end is to be avoided.

The distinction between palliative care and euthanasia causes conflict and confusion. If a physician's actions meet the following criteria they constitute palliative care and not euthanasia: the patient is suffering, the doctor's therapeutic response is commensurate with the degree of that suffering and there is a feedback loop between the suffering and the continuing therapy; and the actions are not intended to lead directly and deliberately to death.

## **Euthanasia and assisted suicide**

"Just as I shall select my ship when I am about to go on a voyage, or my house when I propose to take a residence, so I shall choose my death when I am about to depart from life", wrote the Roman philosopher Seneca (in his *Epistulae ad Lucilium*). Euthanasia is a deliberate action that leads directly to death (eg, the injection of a lethal dose of potassium chloride). Assisted suicide is the provision to patients of the medical means to commit Euthanasia and assisted suicide are legally prohibited in almost every jurisdiction in the world<sup>30</sup> but since the late 1980s they have been gaining increasing prominence in debates on public policy. In 1994, by referendum, the voters of the US State of Oregon approved regulated assisted suicide, this approval being overturned by the courts subsequently. In the Netherlands euthanasia is allowed under defined circumstances. Court decisions (eg, the Sue Rodriguez case in Canada) and the high profile actions of individual physician advocates in the United States have heightened interest.

Proponents argue that euthanasia and assisted suicide in response to a competent patient's voluntary request should be permitted, the principle here being respect for autonomy and the right of self-determination. Supporters also quote the principle of beneficence; such acts relieve the suffering of patients and are thus legitimate responsibilites of physicians. Legalising the process would avoid the surreptitious actions that already exist and that so often result in pitiful and unsuccessful suicide attempts. Opponents argue that such interventions should not be permitted because human life is sacred, the societal risk of abuse outweighs the potential for individual benefit, and vulnerable persons, especially the frail elderly, require protection. They also argue that assisted suicide and euthanasia are anathema to the traditional healing role of physicians.

Proponents and opponents have reached stalemate. One can sympathise when a terminally ill patient requests euthanasia yet be concerned about the risk of abuse were the practice to be legalised. This is the paradox: although euthanasia appears ethically defensible in individual cases, it may represent a perilous direction for social policy. While the euthanasia debate rages, physicians should provide the best care available within the framework of the law. They should not abandon patients for whom a request for euthanasia cannot legally, morally, or professionally be complied with but continue to provide sensitive care and attention.<sup>31,32</sup>

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# A physician with endocarditis

#### John Feehally

When I became feverish I knew it couldn't be serious. After all, I was a fit 43-year-old and a consultant physician to boot-a guarantee of immunity from illness of consequence. But in the second week the night sweats began and our charge nurse increasingly looked askance at me as I raided the ward drug cupboard for the paracetamol which briefly staved off some of my febrile symptoms. The vagaries of our on-call rota meant I was in the middle of a particularly busy stretch of ward work and I was not going to admit weakness to my colleagues by seeking respite. I found myself sitting down on patients' beds on the ward round, not because I like talking to them on the level but because I simply had to rest before I could resume. In the third week I thought I detected some improvement so resumed my regular weekly lunchtime squash game: I lost by only a little more than usual but had no choice but to go home to bed for the rest of the day. I met my wife's concerns with the conviction that I would be better after the imminent Christmas break and failed to glimpse the fear mixed with exasperation in her eyes. At last on Boxing Day I admitted defeat when on our country walk my young sons had to wait at the end of every field as I panted to catch them up.

"You must see a cardiologist today" said my GP after listening to my story and to my heart. "Thanks for the offer but I'm too busy; we've got tickets for Stratford tonight. I'll pop along after the weekend." She changed

Lancet 1995; **346:** 166–168 Department of Nephrology, Leicester General Hospital, Leicester LE5 4PW, UK (J Feehally FRCP) her tone: "You misunderstand; this is not negotiable". An hour later I was trying the "Stratford" ploy on my cardiologist friend—but I capitulated when he got me on the couch in the echo room and showed me my severe aortic regurgitation and the large vegetation on my aortic valve.

Had I thought I had endocarditis? Of course not. Since I knew I had never had heart disease it had not crossed my stubborn mind and I certainly had not bothered to listen to my heart. At least I hadn't dabbled in selfmedication with antibiotics, so the *Streptococcus viridans* was grown without difficulty. I tried hard not to think about what might have happened if some vegetation had become dislodged as I charged self-destructively around the squash court a couple of weeks earlier. And then I remembered the visit I had made to the dentist for a crown a week or two before the fever started.

So I never left the hospital that day and never got to Stratford. It was seven weeks later that I emerged into the world after six weeks of intravenous antibiotics and an aortic valve replacement.

## The other side of the tracks

I had always presumed that any physician charged with my care would have a hard time convincing me his decisions were right and defending his actions with chapter and verse. When the time came it was not so. I felt an immediate sense of relief that I didn't have to struggle any more and could hand over the responsibility to someone else. But I felt sympathy for the consultant and friend who cared for me—a thankless task to look