

Caring for the frail, demented and dying

Prolonging life at the expense of its quality can rob elderly people of peaceful, meaningful years, Muriel Gillick tells Les Olson.

Q: Ageing populations in developed countries are often mentioned as a problem, but is this an issue that developing countries need to be concerned about?

A: Very much. Today, there are about 50 million very old people – aged 80 and over – in developed countries and about 50 million in developing countries. In 40 years there will be about 120 million very old people in developed countries but 300 million in developing countries. The elderly population is growing faster than the population as a whole: at present in low- and middle-income countries there are roughly 10 people of working age (20 to 64 years) for every person aged 65 or over. By 2040 there will only be four or five.

Q: The World Health Organization (WHO) has promoted a model of ageing in which older people remain active and robust. This sounds like something everyone would think was a good idea, but you have expressed some misgivings about it. Why?

A: We must certainly do what we can to prevent illness and disability, but we must be careful that a focus on robust ageing does not lead us to neglect the frail, the demented and the dying.

Q: What are the reasons for your concerns?

A: The first is that I do not think it is possible to prevent all illness and disability. The frail elderly often suffer from a combination of multiple chronic diseases that jointly produce disability and predispose them to vulnerability in the face of acute illness. The proportion of those who are limited in their ability to care for themselves has been rising.

Even if we can make elderly people generally healthier, we will never eliminate all their health problems. In particular, we currently have no prospect of being able to alleviate or prevent one of the biggest causes of disability in the very old: dementia. The number of people living with dementia is expected to double in high-income countries over the next 40 years, and to increase



Courtesy of Muriel Gillick

Dr Muriel Gillick

helping them to obtain medical care that makes most sense to them.

Dr Muriel Gillick is professor of population medicine at Harvard Medical School in the United States of America (USA). She studied history at Swarthmore College, medicine at Harvard Medical School and later completed a residency in internal medicine at Boston City Hospital. She also sees patients at Harvard Vanguard Medical Associates, a multispecialty group practice in the Boston area, and at the Brigham and Women's Hospital. The major focus of her work is caring for patients near the end of their lives, in particular

fourfold in low- and middle-income countries. And even if we can keep most people healthy for most of their lives, we are all going to die. For most people that means a period of very poor health and dependency leading up to death.

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My second concern is that talking about “successful ageing” – meaning robust and active old age – implies that old people who are not robust and active are “unsuccessful”. While everyone would like to be active and robust in old age, there is a risk that people who don't achieve that will be regarded as failures and blamed for their disability. Sooner or later we will all stop being healthy, and we need to plan for that so that we can deal with it when it happens.

Q: What should care of elderly people involve?

A: In the USA it tends to mean looking for technological means to prolong life. I think that care should, instead, focus on helping people re-

tain meaning in their lives. Treatment should be targeted at controlling symptoms, not on prolonging life, and on helping patients to maintain human relationships and personal dignity.

Q: Do you think care will differ in developing countries?

A: My fear is that as developing countries have more resources to spend on health care, they will follow the American model of technological medicine. I think that would be unfortunate. It is possible to provide, with very limited resources, care that is technically excellent and compassionate and that helps old or dying people keep meaning in their lives.

Q: Some communities appear to feel that it is important not to give up on curative treatment.

A: Yes. But there is evidence that when people everywhere understand what frailty and dementia mean as a lived experience, they have a common view of what appropriate care in those conditions involves: treatment directed primarily at controlling symptoms and maintaining relationships and personal dignity. The medical profession is one of those communities: its goal is to preserve and prolong life, and it is very difficult for doctors to accept that not all life-prolonging measures are desirable from the point of view of the patient.

One issue I get worked up about is the use of feeding tubes (tubes surgically inserted into the stomach) for patients

who have difficulty eating because of advanced dementia. The evidence is overwhelming that this does no good for the patient; it neither prolongs life nor improves the quality of life by preventing pneumonia or healing pressure ulcers, for example. But it is very hard to get doctors and families to trust the evidence, because it goes against the instinct not to feed the people who depend on you.

I believe that we should not provide treatments unless they bring real benefits to patients. The choice is not between curative treatment and neglect. We can offer treatment that deals with the need for families to provide care but does not cause suffering and does not cost a lot.

Q: How important is care provided by families as opposed to professional care?

A: In the USA about 80% of all care for disabled elderly and dying people is provided by family. The figures may be higher in poorer countries. However much care families provide, they cannot provide optimal care without some professional help in certain domains such as symptom management.

Q: Are drugs for pain control an issue?

A: Certainly. Easy access to opioids – morphine and related drugs – is essential for control of pain. A lot of progress has been made in the USA by showing people that these medications do not kill patients and, when properly used near the end of life, they do not cause addiction.

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Q: How do we teach people about these things?

A: Stories of real patients provide the key. Here is one. A 66 year-old engineer could no longer do complicated mathematical calculations in his head.

He saw a doctor, and tests showed that he had a highly malignant brain tumour. He had weeks to live. His doctor suggested surgery and chemotherapy, although there was little chance that this would prolong his life outside hospital. He and his family chose not to have curative treatment. What mattered to him was to control symptoms, to be able to talk to his family and to leave a positive legacy. Skilfully prescribed drugs controlled his pain and prevented most of his seizures, so that he was able to spend his last weeks at home with his family and friends. He was able to die well because – and only because – he had access to good palliative care. Good palliative care is not complicated or expensive: it simply means that his care was managed by professionals who were skilled in using opioids and who appreciated the value he placed on his autonomy and legacy.

Muriel Gillick was interviewed as a guest speaker of the World Health Organization's global health history seminar series. Access the seminars online at: http://www.who.int/global_health_histories/seminars/en/ ■

Recent news from WHO

- By 12 August, more than 14 million people had been affected by **Pakistan's** worst floods on record, according to the United Nations' Office for the Coordination of Humanitarian Affairs. More than 1200 people have died and at least 2 million left homeless by the disaster which has also destroyed homes, farmland and major infrastructure in large parts of the country, most notably the north-west province of Khyber Pakhtunkhwa. United Nations aid agencies, including WHO, have requested almost US\$ 460 million to help Pakistan address the needs of flood-affected families, including by providing food, clean drinking water, tents and other shelter and non-food items, as well as medical supplies.
- WHO is calling for increased access to **infant diagnosis of HIV** within four to six weeks after birth. Without treatment, an estimated one-third of HIV-infected infants will die before their first birthday, and about half will die before reaching two years of age. By the end of 2009, 355 000 children were receiving life-saving HIV treatment, compared to 276 000 at the end of 2008; but many more lives could be saved if more infants started on medication earlier.
- On 19 July at the **XVIII International AIDS Conference** in Vienna, WHO announced that an estimated 5.2 million people in low- and middle-income countries were receiving life-saving HIV treatment at the end of 2009. WHO estimates that 1.2 million people started treatment in 2009, which is the largest increase in people accessing treatment in a single year.
- The **maximum amount of melamine** allowed in powdered infant formula is 1 mg/kg and in other foods and animal feed is 2.5 mg/kg, according to new rulings decided in July at the 33rd Session of the United Nations' food standards body, Codex Alimentarius Commission. Melamine is a chemical used in a variety of industrial processes and traces of it unavoidably get into food without causing health problems. However, the substance is toxic at high levels.
- **WHO and the International Olympic Committee (IOC)** signed a memorandum of understanding on 21 July in Lausanne to promote healthy lifestyle choices, including physical activity, sports for all, tobacco-free Olympic Games and the prevention of childhood obesity. The WHO and IOC will work at both the international and country level to promote activities and policy choices to help people reduce their risk of noncommunicable diseases such as cardiovascular disease, cancers and diabetes.

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