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Cover Picture:

Johannes Evangelista Purkinje (1787-1869):
19th century's foremost phenomenologist
(Refer to pages 208-209)

Care of the dying – whose job is it anyway?

C R Goh

Currently in Singapore, over 16,000 people die each year. In 2003, 75% of deaths occurred in people aged 60 years and older, and 57% aged 70 years and older⁽¹⁾. In this issue of the Singapore Medical Journal, Seah et al described the characteristics of elderly patients who die in an acute care hospital in Singapore, and the care they received. Their retrospective study population comprised all patients who died under the care of the Department of Geriatric Medicine, and all hospital deaths above the age of 75 years over a one-year period. Of the 189 patients studied, the age range was 70 to 102 years, and only four (2.1%) were below the age of 75 years. They looked at the symptom profile of these patients, whether they had palliative care input, and what difference that made in terms of symptom treatment and the incidence of cardiopulmonary resuscitation at the point of collapse⁽²⁾.

The study population was sick and frail, with 20% of them having contractures and 17% pressure sores at the point of admission. Common co-morbid conditions included dementia in 47%, hypertension in 43%, cerebrovascular disease in 42% and ischaemic heart disease in 39%. Those known to have terminal disease comprised 17%, three-quarters of whom had cancer. The deaths were expected in 88% of cases, and of these, 31.1% received palliative care input, while none of the patients who died unexpectedly received palliative care⁽²⁾.

The patients under palliative care were more likely to have their symptoms treated, for example, 100% vs 61% for pain; and 81% vs 27% for breathlessness. They were also less likely to receive cardiopulmonary resuscitation at the point of collapse (9.6% vs 39.4%), which the authors attributed to greater awareness of the futility of such intervention in this group of patients. Neither of these findings were surprising⁽²⁾.

What this study did not aim to do was to look at outcomes in terms of effectiveness of symptom control, and whether palliative care input in hospital patients influenced the place of death. Over the past decades, a growing proportion of people are dying in hospitals, the trend rising from 53% in 1985 to 58% in 2003. There was a proportionate decline in deaths at home, from 38% in 1985 to 30% in 2003⁽¹⁾. This not only contributes to the escalating healthcare costs, but goes against patients' preferences as to place of death^(3,4).

The Singapore hospice movement was started as a grassroots movement in 1985 in response to a need. Patients with cancer were dying at home with little support. Pain and symptoms were inadequately relieved. Care in hospitals, being geared towards cure, gave low priority to those whose disease was incurable and who would inevitably die from their disease. Because of these roots, hospice care in Singapore developed first as

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home care, providing symptom relief and support for families of patients at home. Before adequate in-patient hospice beds became available, hospice home care services managed to achieve a home death rate of 70% in 1994⁽⁵⁾. This proportion of home deaths among patients under hospice home care has since decreased, in 2003 to 49%, with a concomitant rise in deaths at in-patient hospices of 11%. Deaths in hospitals for patients under hospice home care have been consistently below the national figure, 27% in 1994 with hospice home care versus the national average of 56%, and 39% in 2003 under hospice home care versus the national average of 58%^(1,5,6).

The fall in the proportion of patients dying at home while under hospice home care may be partially related to changing demographical factors, such as the availability of home care providers. But it is of concern to the service providers, as the home death rate is one of the audit tools of the efficacy of such services. Indeed, the justification for government funding of such services, first achieved in 1996, was largely based on the ability of hospice home care to prevent unnecessary hospitalisation. Deaths in hospital for patients under hospice home care has crept up, from 27% in 1994 to 39% in 2003. Does this mean that the quality of home care is falling? How good the services are depends on whether they can attract good health professionals to work in those services. Is the quality of hospice home care falling because of a lack of doctors qualified to provide such care?

Medical manpower has always been the greatest concern for hospice and palliative care services in Singapore. From the earliest times since 1986, doctors working in hospices were mainly foreign talent, first as volunteers, and later as paid staff. This continues to be the case today. In addition, there is no accredited training pathway in Singapore to train doctors to work in this field. Most doctors currently working in hospice and palliative care in Singapore are either self-taught from the early days of pioneering for hospice, or apprenticed while working in an established hospice service.

Among the eight community hospice service providers which together were estimated to have received a total 2,802 new referrals in 2004, which represents 74.9% of cancer deaths or 19.4% of total deaths, there are only a total of 13 doctors. Only one of these is a consultant with an overseas accreditation in palliative medicine recognised by the Singapore Medical Council (SMC), while the other two consultant level staff have overseas qualifications which are not recognised by the SMC. The rest of the doctors are at medical officer level. So the quality of care is a real concern.

Like the community hospice services, palliative care services for hospital patients were started because of a need. Inevitably, terminally ill patients do end up in hospital from time to time. By the mid-1990s, an anomalous situation had arisen in Singapore where the only place patients were unable to receive palliative care was when they were admitted to hospital. The first hospital palliative care service was started at Tan Tock Seng Hospital under the auspices of the Department of Geriatric Medicine in 1996. In 1999, a dedicated Department of Palliative Medicine was established at the National Cancer Centre, providing specialist outpatient services and consultative in-patient services at Singapore General Hospital and KK Women's and Children's Hospital. These plugged a gap in the palliative care services available to patients. But apart from providing service, these

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hospital departments also aimed at providing training for doctors, for both the specialist and non-specialist in palliative care.

There is ongoing debate as to who should look after the dying, and where they should be looked after. The hospice and palliative care community has always advocated that the patient should be cared for in the place of their choice. Very often, this is in their own homes^(3,4). Hence, palliative care should be provided for patients at home. As mentioned above, hospital services are also needed, and these should form a continuum with home care, a situation often achieved by hospital specialist palliative care services.

But is not the care of the dying the job of all doctors, regardless of their field? Undoubtedly so, and especially in the fields of oncology, neurology, infectious disease, and all who look after patients with end-stage organ failure. It is also the domain of the family physician. But if all doctors need to be trained in palliative medicine, do we need specialists?

There needs to be a distinction between the training of specialists in palliative medicine and non-specialists. The latter is for all doctors who need to look after dying patients. The palliative care approach of interdisciplinary care addressing each patient's physical, emotional, social and spiritual needs has been advocated for all dying patients. But who is to train the non-specialist in palliative medicine? Is it good enough for the non-specialist to train other non-specialists, for example, in pain management, or care of fungating wounds and fistulae, or the delirious patient with existential distress?

As in all fields, most cases may be straightforward, and manageable by a non-specialist with the relevant training. But who can be consulted in the more complex and difficult cases? When a non-specialist gets out of his depth, what other resources are there to call upon? Without specialist palliative care, we would go back to the bad old days when staff would get stressed out and patients had to be ignored because no one knew how to deal with them when the problems got really bad.

Finally, medical care does not stand still. Continuous progress has to be made to improve services, improve care delivery and improve outcomes. Every field needs its champions. Dying patients, sometimes described as those without a voice, also deserve the best care, for themselves and for their families, for their present reality and for the future of those bereaved. The mission for specialist palliative care is to push back those frontiers of knowledge and skills, so that people in our community can benefit from the best care available within our knowledge and resources. The role of specialist palliative care units in audit and research is crucial if improvements in care is to be achieved.

Singapore still has not recognised palliative medicine as a specialty in its own right. The recent recognition of palliative medicine as a subspecialty of internal medicine, geriatric medicine and medical oncology is a setback to the development of the field. Unnecessary obstacles are placed before young doctors who wish to obtain proper training and work in the field. It is a disincentive to have to complete advanced specialist training in another medical specialty before commencing to train in palliative medicine as a sub-specialty. Also, attitudes and approaches to problems are formed during advanced specialist training, and it is inappropriate that these have to be unlearned during sub-specialty training.

Unlike many specialties, palliative medicine is not an exclusive field, where the specialist excluded all others from practising in his field unless they have the requisite training. Instead, palliative medicine is an inclusive field which welcomes all doctors to practise the craft. But it still needs to be a specialty in order to champion standards of care, teaching and research. Taking an analogy from the well-established specialty of cardiology, we do not all have to do cardiac catheterisations and angioplasties, but we do all as doctors have to treat heart failure and hypertension. But if complicated situations arise, and I have a sudden coronary artery occlusion, I would prefer to be in a specialist unit in the hands of a cardiologist than with my family physician.

It is a simplistic view that establishment of a new specialty necessarily means further fragmentation of care and increased health care costs. On the contrary, establishment of palliative medicine as a specialty would mean better coordination of care between acute care facilities and the community, and better quality community services for the increasing numbers of people dying in Singapore. **SMJ**

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