

# Two decades of palliative care

## Medicine and dying patients

The decoding of the human genomic sequence at the turn of the millennium marked the historical success of science in unfolding the secret of the human body. Nevertheless, man is facing the destiny of ageing and death. Suffering, a common experience for our patients, remains underdiagnosed.<sup>1</sup>

Western anthropology, based on the belief of dualism of body and mind, has unconsciously but profoundly influenced the basic approach to medicine for centuries. This separation of body and mind has become greater since the day of Descartes. Medical care has thus focused more on disease than illness, pain rather than suffering. New medical technologies bring new hopes of cure, but fail to alleviate the distresses of patients with incurable disease, as expected by patients. Illich<sup>2</sup> and Clark<sup>3</sup> vividly described the scenario of death and dying during the 1970s as “medicalisation of the dying”. Every effort is made to combat death, rather than to come to terms with dying. Dying is often perceived as medical failure. The SUPPORT study published in 1995 revealed that half of the 9105 terminally ill patients spent at least 8 days in coma, in intensive care, or in pain before they died.<sup>4</sup> Many patients’ needs were unmet. Moreover, when considering disease burden, end-of-life care should be seen as a global public health issue. If we estimate that each death affects four persons who are closely related to the dying person, with an annual death incidence of 30 000 in Hong Kong, 2.5% of our population will be affected by issues of end-of-life each year. Can doctors rise to the challenges of care for the dying?

## The era of palliative care

The rise of the modern hospice or palliative care movement in the late 1960s was one response to the call to preserve dignity at the end of life. Palliative care can be defined as the care of patients and their families with active, progressive, far-advanced diseases and a short life expectancy for whom the focus of care is the relief and prevention of suffering and improvement of quality of life. Affirmation of the remaining life, person-centred holistic care, active palliation of symptoms, and alleviation of psychospiritual distress are the pillars of palliative care. Thus, palliative care is more than tender loving care. Patients and health care professionals are not passively waiting for the final moment. With the recent advances in pain medicine,<sup>5</sup> increased awareness and knowledge of cancer pain, and the availability of effective drugs and clinical guidelines, cancer-related pain is often relieved for more than 90% of patients.<sup>6,7</sup> Palliative care physicians have moved beyond pain control to recognising and elucidating other common coexisting symptoms such as dyspnoea and adopting a better treatment approach.<sup>8</sup> Depression is no longer regarded as a normal companion of

incurable illness, or as a ‘normal’ grief reaction, and therefore requires more recognition and treatment. What is considered to be refractory such as cancer cachexia may not be so with the discovery of its pathogenic mediator, the transcription factor nuclear factor- $\kappa$   $\beta$ . Moreover, palliative care is more than symptom control. Recent studies on ‘will to live’,<sup>9</sup> ‘good death’,<sup>10</sup> and ‘dignity in the terminally ill’,<sup>11</sup> have illuminated the complexity of psychospiritual issues when one faces the paradoxes of living and dying. Hope can be instilled amidst the process of dying.<sup>12</sup> In the era of evidence-based medicine, systematic reviews show palliative care improves the outcome and satisfaction of patients and families.<sup>13</sup>

Hospice palliative care is now established in every continent and almost every developed country. The first hospice service in Hong Kong was pioneered by a team at Our Lady of Maryknoll Hospital in 1982. A voluntary organisation dedicated to the promotion of the hospice, the Society for the Promotion of Hospice Care, was established in 1985. The Society started the first hospice home care service in 1988 and the first independent hospice in 1992. Another four hospices were established at the Ruttonjee Sanatorium, Haven of Hope Hospital, United Christian Hospital, and Nam Long Hospital between 1986 and 1988. Since the era of the Hospital Authority, there has been a steady growth of hospice services in the form of 13 palliative care units/teams and 11 home care teams within the public-funded hospitals. There are now 40 hospice beds per million population. Hospice palliative care serves approximately 50% of the patients with terminal cancer. The service features a holistic and multidisciplinary approach. By adopting a total pain concept, pain is controlled in 93% of patients within the first week of admission.<sup>7</sup> Significant improvement in quality of life has been shown by outcome audit programmes, that are periodically performed across all units.<sup>14</sup> Professional societies, namely the Hong Kong Society of Palliative Medicine and the Hong Kong Hospice Nurses Association, were both established in 1997. With the establishment of the specialty of Palliative Medicine within the Hong Kong College of Physicians in 1998 and the Hong Kong College of Radiologists in 2002, a structured training pathway for doctors is available.

## Challenges ahead

Palliative care in Hong Kong has made great progress during the past 2 decades, from a few involved people to well-developed teams and organised professional development. This development can, however, only be sustainable if the basic paradigm shift,<sup>15</sup> so intrinsic to palliative care, occurs in medical care. This paradigm shift entails a change from the biomedical model to the biopsychospiritual approach, from a disease-centred approach

**Box<sup>16</sup>****Existential/spiritual distress at the end of life**

1. Death anxiety
2. Meaninglessness, demoralisation
3. Powerlessness, loss of control
4. Undignified death
5. Existential aloneness
6. Guilt, regret
7. Life after death issues

to person-centred care, from 'doing care' to 'being care', and from prolongation of survival to enhancement of meaningfulness in the last journey. The challenges ahead for the medical profession are many. The cultural and person-specific concept of a 'good death' should be better understood. The ever-present refractory symptoms require more research into pathogenesis and new therapeutics. An indigenous model of communication is urgently needed to improve psychosocial care. Ethical issues such as autonomy, advanced life-care planning, forgoing life-sustaining treatment, euthanasia, and physician-assisted suicide should be studied within the local cultural context. With better control of symptoms, more attention may be given to the crucial issues of existential or spiritual distress (Box),<sup>16</sup> which often triggers the quest for euthanasia. A bereavement model that is applicable to local people can be further explored. The success of care for the dying does not rest on a small group of specialists, but the concerted efforts of all doctors and health care professionals.<sup>17,18</sup>

Encountering death and dying challenges the nature and limits of medicine, not only its science but also its art, and our being as doctors.

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