

Review Article

Quality of Life and Quality of Dying: Attaining the Optimal Goal

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Abstract

With population ageing worldwide, increasing emphasis is being placed on quality of life at the last stages of various chronic diseases and frailty, such that the principles of palliative care would apply to a large number of older people. In many countries health care policies have not caught up with such needs, although palliative care may be comparatively well developed for those with cancer. This commentary describes the ideal goals articulated by developed countries such as the United States and the United Kingdom, and using Hong Kong as a case study, shows that raising capacity among doctors in death competence, as well as health literacy among the public in these issues, are necessary steps before such goals can be attained.

INTRODUCTION

For many years public health initiatives have been targeted towards prevention and treatment of non-communicable diseases (NCDs) [1], and this strategy has guided health care policies and systems worldwide. In parallel there has been a development in palliative care services accompanying the management of patients with cancer, predominantly in the hospital or hospice setting [2]. In recent years attention has been drawn to the quality of such services using a world-wide ranking format [3]. However with population aging world-wide, life expectancy at birth is in the mid-80s in many developed countries, and the profile of patients now include a high prevalence of geriatric syndromes such as frailty, sarcopenia, falls, various degrees of physical and cognitive functional impairments in addition to co-existence of multiple diseases, shifting the goal of care from cure to maintenance of function or intrinsic capacity [4,5]. Many patients with such profile have entered into a downhill trajectory towards death, which may vary from a few years to a few months. Therefore the principles of palliative care as well as service model first developed for patients with cancer would be equally applicable to older people at the final stage of life. Yet this perspective is largely absent in many countries, as though health care policies and societies have not caught up with the needs of rapidly aging populations.

PERSPECTIVES FROM THE US

This was eloquently illustrated in the book 'Being Mortal', where the author, a surgeon, based on his personal experience with family and patients, reflected on the emotional distress as a result of avoidance of discussion of options of care and informed

choice that patients and families can make, in relation to how the last phase of life could be spent [6]. He suggested that this may be overcome by initiating serious illness conversations at an early stage, and started a training workshop for doctors and other healthcare professionals on how to tackle such conversations. Recently the Institute of Medicine produced the report 'Dying in America', listing out the strategies for improving the quality of life and quality of dying covering five domains: the delivery of person-centered, family-oriented end of life care; clinician patient communication and advance care planning; professional education and development; policies and payment systems to support high quality end-of-life care; and public education and engagement [7].

PERSPECTIVES FROM THE UK

The United Kingdom also drew attention to the need for such quality improvement in a series of studies published by the British Medical Association [8]. To attain the ideal situation described by these reports, the crucial step is achieving a mind-set change among all health and social care professionals, patients and the general public, as well as policy makers, through raising awareness of the medical ethical principle of autonomy, health literacy regarding prognosis and the end of life trajectory for various non cancer conditions, developing enabling policies, pathways and care models, use of advance care plan and advance directives.

Current situation in Hong Kong

Using Hong Kong as a case study, this paper illustrates ongoing attempts to attain the goal of optimizing quality of life

and quality of dying among an ageing population with the highest life expectancy in the world.

Historical perspectives

Palliative care services in Hong Kong were first established for cancer patients during the 1980s following the UK model, led by the Society for the promotion of Hospice care and supported by the Hospital Authority. The latter established Hospice beds in their hospitals, and took over the management of the only dedicated hospice in 1995. The concept of end of life care (EOL) for non-cancer patients dying of chronic diseases was first promoted by the geriatric medicine community, drawing attention to the fact that all professionals who look after such patients should adopt palliative care principles, and with philanthropic support, a pilot continuous quality improvement initiative (CQI) was carried out in all the medical wards of one non acute hospital affiliated with the Faculty of Medicine of the Chinese University of Hong Kong. All ward staff were involved, and the train the trainer approach was adopted together with compiling of guidelines and various learning materials were placed in each ward. Each ward was led by a ward manager working together with the ward physician in charge. The first step documented that patient with various chronic diseases at the end of life suffered from high prevalence of symptoms comparable to those patients with cancer [9]. This was followed by the identification of patients in this phase, where management placed strong emphasis on symptom control and quality of life, avoiding unnecessary investigations. The CQI consisted of education through seminars, ward meetings, and role play aiming at culture change and identification of barriers toward change [10]. An evaluation after one year showed improvement in symptom control, reduction of unnecessary investigations and duration of hospital stay, while increasing the utilization of community support services and improving caregivers' experience [11]. The pilot project demonstrated that awareness of the need to improve quality of care at the end of life for patients with non-cancer conditions as well as those with cancer could be improved among the lay public, health and social care professionals as well as policy makers, so that appropriate services may be developed.

However after the first cycle was completed, with staff rotations, the principles that were promoted were gradually lost, in spite of the availability of guidelines and resource material still being available on each ward. A strong barrier noted was the pre occupation with treatment at all cost that is prevalent among many doctors with little thought of eliciting patient and relatives wishes regarding the end of life, indicating that medical ethical principles did not guide management in this phase [12].

Raising capacity among healthcare professionals

- An opportunity arose to take this initiative further, again with philanthropic support of a territory wide project to develop culturally-sensitive, need-based, integrated and family oriented intervention models of end of life care in hospital, long-term care settings as well as home-based support [<http://foss.hku.hk/jcecc/en/>]. Since the diagnosis of reaching the end of life begins in the hospital setting, and for 90% of the population also ends in hospitals, an important part of the project focused on the hospital setting and building capacity among hospital health

and social care professionals, and raising health literacy among patients with chronic diseases being cared for there and their families. The program consisted of three components-education sessions for hospital staff (doctors, nurses, social workers etc) on the principles of EOL care in the hospital setting; how and when to initiate conversation with patient and family members, with an emphasis on ethical principles such as autonomy, benefit and harm with respect to quality of life rather than life extension as the goal of treatment. Real cases were used as illustration, discussing either current ongoing problems or past cases, especially those that resulted in conflict either between family members, between patient and family, or between hospital staff and family. The program also included communication skills workshops for staff.

- education sessions for family members/patients who were frequently readmitted to the hospital system during the EOL period, regarding treatment regimens that are curative versus palliative, and how choices can be made by patient and family specific to their clinical conditions eg. End stage dementia; end stage organ failure; disseminated cancer etc., using advance directives (AD).

- education sessions in the community so that older people and their families can prepare for the above scenario both materially (enduing power of attorney; other financial arrangements; nominating family decision maker, making ADs and wills etc), as well as psychologically.

A series of talks, case presentations, and group discussions were carried out initially among doctors, nurses, patients and members of the general public. These issues were also the subject of TV programmes. Among the public, there was much interest in being able to make choices at the end of life, and practical enquiries regarding how to execute advance care planning (ACP) and ADs.

Members of the public appeared to take up the idea of AD and ACP much more readily than health care professionals. Doctors seemed reluctant to engage in this topic and avoided agreeing to sign ADs even when asked by patients: 'you are not dying yet'. There was a perception that ADs were for those who had entered the dying phase. Many doctors avoided/refused to sign as they were afraid of subsequent litigation. Yet patients expressed a wish to decide early when they were still of sound mind and not under physical or psychological distress, to be able to talk to their relatives about it. Indeed there were several comments from the public about doctors refusing to sign.

Nurses in general were more receptive and keen to learn about end of life conversations; yet some expressed moral distress because the doctors behaved in a different way and unless the management plan was agreed, the doctors' plan always took precedence, and so they may not be able to practice what they learnt. There was wide variation in knowledge among doctors regarding the management of symptoms, prescribing of drugs, what is end of life care and the diagnosis of the end of life phase, how to initiate end of life conversations, advance directives and advance care plans. Reluctance in engaging in this area was prevalent, with the following reasons being cited: no time; uncertainty in diagnosing end of life; debating about continuing treatment using death avoidance as the main objective without engaging patient

or relatives regarding their wishes about quality of life; not a palliative care specialist.

A common response from management was that EOL care was already being provided. Yet this was contradicted by actual practice in the wards as reported by ward staff, as well as by the absence of any documentation for many cases. For example patients with chronic obstructive pulmonary disease often require non-invasive ventilation, and few patients had been invited to express a choice between ventilation and comfort care.

Avoidance of end of life issues also occurred among final year medical students, with much concern about the legal consequences of signing AD.

At one workshop sharing session, one nurse recounted how she felt guilty for a long time after a patient under her care died in great pain because the doctor could not be contacted to prescribe morphine, and no analgesic drugs on an as needed basis were prescribed. One relative whose husband has cancer with metastasis to the brain and spinal cord affecting walking and urination in a cancer unit, reported that only medical/surgical treatment options were discussed, and not subsequent care or support, other than finding an old age home if home care is not possible. One social worker reported family disagreements about Ryles tube feeding for their 98 year old grandmother with end stage dementia. No healthcare professionals discussed with the family about the 'futility' of this situation. Similarly a relative of a patient with end stage dementia, who had been bedridden for a few years admitted to hospital with fever, requested that antibiotics be withheld. She was told that this was unacceptable practice by the doctors. She was from the US and merely reflected the current attitudes and practice there. Patient died a few days later in spite of the antibiotics. Among residential care home staff, level of knowledge was low.

What needs to be done?

Obstacles that account for 'resistance' to end of life care discourse need to be identified and tackled. All doctors need to be engaged, and not consider such care as the responsibility of palliative care specialists. A change in mindset for all doctors that takes into account end of life care principles is desirable: to be effective this should be incorporated into regular work meetings based on case discussions; videos of case histories and critique of management. Training in initiating end of life care conversations, implementation of advance care plan (ACP) and Advance Directives (AD) is needed. All these initiatives should be supported by top management where quality care may be established as part of regular audits.

A Report into elderly service needs including end of life care commissioned by the Hong Kong government submitted in 2016 recommended the need for changes to current palliative and EOL programmes/models; integration into existing care settings; identification of gaps in current health and social services and devise models of care to overcome them. The report also highlighted the lack of studies and information regarding the quality of dying, such as methods of evaluation, integrated service models between the hospital and community care

settings; patients' health literacy and preferences regarding EOL care; methods and effectiveness of public education initiatives [Yeoh et al, 2016, unpublished report].

Using a locally validated scale [13] to measure competence in working in the area of dying among healthcare staff of hospitals in one region of Hong Kong, not surprisingly competence increased with age, number of years in the profession, and past experience with care of patients at the end of life. Notably higher competence was observed in the dedicated hospice units as well as a non-acute hospital that had developed CQI programmes in EOL [unpublished results]. This finding highlights the importance of incorporating EOL components in undergraduate medical curriculum as well as professional qualifying examinations. Training programmes to acquire skills in initiating serious illness conversations should be a core requirement and started early during medical training.

Concurrent with this effort to raise capacity in EOL care, the Hospital Authority began an initiative to promote the use of advance care planning and advance directives as part of a system wide accreditation process where quality of EOL care has been included. Forms have been designed, and this information maybe uploaded into the computerized clinical management system for each patient.

CONCLUSION

Population ageing has highlighted the need for the palliative care concept to be extended to patients other than those with cancer. While there are many policy documents at international as well as national levels drawing attention to the need for providing and improving the quality of such care, this case study of Hong Kong shows that there is a wide gap between actual and desirable practice. In order to close this gap, initiatives in promoting a mindset change where EOL care perspectives and skills constitute core competencies for any professionals caring for patients, in tandem with the articulation of care standards with regular audit, are needed. Sustained improvements may not be achieved unless both components are addressed at the same time. Merely promoting use of documentation and audits may result in yet another tick box exercise.

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