

## Medical Ethical Principles may Drive Improvement of Quality of Dying in Hong Kong

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### Abstract

Population ageing raises concern regarding the quality of end of life care (EOLC), not only for people with cancer but for all dying of end stage chronic diseases, particularly for dementia. Medical ethical principles, legal and cultural factors affect the quality of end of life care. This article discusses how these three factors currently contribute to EOLC in Hong Kong, in the context of differing trajectories of development in China, other Asian countries, and the USA.

EOLC for non cancer patients has only recently been highlighted, where ethical, legal, and cultural issues are being debated. Although there is no statute or case law that directly govern the legal status of advance directives in Hong Kong, a validly made advance directive is generally recognized at common law. However, there is a range of other legal barriers to providing EOLC according to medical ethical principles. There is little discussion among health care providers or the public regarding advance directives, euthanasia, physician assisted suicide, or withdrawal of life support, particularly for those with dementia. It is hoped that a continuing medical ethics discourse regarding EOLC issues may provide momentum to overcome current inertia or avoidance of EOLC issues, such that population aging may not be accompanied by increasingly poor quality of care in the dying process.

**Keywords:** Medical ethics; End-of-Life care; Quality of dying

### Dying well as a Goal

With population ageing and the increasing prevalence of chronic diseases, there is growing concern regarding the quality of care for people reaching the end of life with various chronic disabling diseases. Traditionally in Hong Kong, End-of-Life (EOL) healthcare has focused on cancer patients and tends to be underdeveloped for non-cancer patients, particularly for those with long trajectory of dying. In many countries such care is of low priority compared with the development of curative or diagnostic medical technology. Nevertheless, non-cancer patients should receive the same quality of palliative care as for cancer patients. In fact, with longer number of years lived with long-term, chronic diseases for non-cancer patients, it has been argued that they may suffer greater burden of disease than cancer patients using the principles of disability-adjusted life years (DALYs) and quality-adjusted life years (QALYs). In drawing attention to this underdeveloped area of healthcare, the Lien Foundation of Singapore commissioned the Economist Intelligence unit to examine the quality of dying, or end of life care, across the world [1]. The report highlighted various obstacles for the development of end of life care, including stigma surrounding dying, insufficient funds, lack of knowledge and training, low recognition by policy makers, lack of drugs or knowledge in using them for palliative care, and distractions by debates relating to euthanasia or physician-assisted suicides (PAS)

which only affect a very small percentage of people who are dying. It has been famously argued that attention to strengthening palliative care should precede those regarding euthanasia and PAS according to the notion that there is still a lack of much needed effort in the direction of medical and social reform to promote major initiatives in medical and public education regarding pain control, sensitization to issues of quality of dying as well as laws that may hinder access to pain relieving medications [2].

In the report, the quality of death index is a composite index covering basic end of life healthcare environment (20% weighting), availability of end of life care (25% weighting), cost (to patient) of end of life care (15% weighting) and quality of end of life care (40% weighting). The report also included views across the world from 22 experts who were palliative care specialists, physicians, healthcare economists and sociologists. Factors influencing good end of life care include differing cultural attitudes to death, levels of awareness of end of life care, differing legal framework, funding models, and government policy [1].

Out of the 40 countries surveyed around the world, Hong Kong was ranked 20 for the overall score, 31 for basic end of life care environment, 24 for availability and cost, and 8 for quality. The relatively high rank for quality is largely due to the development of palliative care for cancer patients, resulting in the provision of hospice beds in public hospitals, specialist societies and inclusion of palliative medicine in the higher specialty training programme for physicians.

## Ethical Principles: Theory versus Ethnic and Cultural Variations

While many would agree with the sentiments underlying the production of the Report, dying well has seldom been discussed as an ethical issue in the healthcare or public arena in Hong Kong, other than in the context of euthanasia or physician assisted suicide (PAS) and very limitedly in the context of advance directives and advance care planning. The ethical principles relating to end of life care may be considered in the context of those in geriatrics and long term care, which in turn are basic principles of medical ethics. These cover beneficence and non-maleficence, futility of treatment, confidentiality, autonomy and informed consent, physician-patient relationship, veracity (truth telling), distributive justice, non-abandonment, non-discriminatory decisions in the context of limited health care resources. There have been few studies in Hong Kong examining end of life care in the context of medical ethics.

### Euthanasia, physician-assisted suicides, advance directives, and other legal considerations

**Euthanasia:** Currently euthanasia has been legalized in the states of the Netherlands, Belgium, and Luxembourg under strict conditions to ensure valid consents, and the practice appears to have found acceptance in many Western European countries [3]. In Hong Kong, euthanasia has not been legalized, the conduct of which could constitute a criminal offence under Offences Against the Personal Ordinance (Cap. 212). The Medical Council of Hong Kong's Code of Professional Conduct defines euthanasia as 'direct intentional killing of a person as part of the medical care being offered'. It further states that euthanasia is 'illegal and unethical' (MCHK 2009, para 34.2).

Euthanasia may be considered an ultimate act of autonomy, with the patients choosing death over suffering from their terminal, irreversible diseases. There are safeguards to ensure that available known methods and services to minimize suffering have been exhausted, and that the decision is reviewed by more than one doctor before the administration of the lethal drug. Although there has been intense debate in recent years regarding euthanasia, particularly in Europe, the topic has seldom been raised in the public domain in Hong Kong. The only study addressing this issue was carried out over 10 years ago, where the attitudes of 618 members of the public from a general household survey and 1,197 physicians towards different types of euthanasia were surveyed. Over 60% of the public were supportive of active euthanasia, or wish to discuss this, while physicians were generally against it [4]. The general public's support for active euthanasia may not be related to any ethical consideration of autonomy, but more guided by practical considerations, such as old age, and being a burden on families. Furthermore, more support for euthanasia was found with increasing age. A follow-up study through two focus group meetings with members of community centres for elders found that the main reason was fear of pain and suffering, fear of being a burden to the family, and the feeling of uselessness with old age [5]. These findings suggest that the support for active euthanasia was more related to cultural stereotypes in Hong Kong where being old equates with burden to family and society. Furthermore, knowledge of and provision of palliative care services were limited. The topic seldom appear in the media; yet there have been occurrences of older people suffering from debilitating chronic diseases committing suicide, as well as requests to doctors to administer an injection to end life (and suffering).

This may be a reflection of inadequate care provision, thereby raising the issue of possible inequity of healthcare resource prioritization in the context of limitation. It is notable that end of life care is ranked very low (10/12 items) in a general population survey in Hong Kong, in contrast to the United Kingdom where it was ranked second, among the same 12 items [6]. Prioritization of services in the context of resource limitation has not been acknowledged explicitly, or implicitly denied, so that these issues have not been debated either by professionals or the lay public.

**Physician assisted suicide (PAS):** On the other hand, there is another practice that is part of the same debate – physician-assisted suicides (PAS). It is defined as means of ending life prescribed by a doctor to the patient usually in the form of a lethal dose of drugs, to which the patient has autonomy over taking. In Hong Kong, a person who knowingly and intentionally aids another's suicide commits a criminal offence that is punishable with imprisonment of up to 14 years. The secretary for justice must approve such prosecutions, although there is no publicly available policy guidance regarding this approval process and criteria. However, while PAS has been vigorously debated in recent years around the world, it has not been mentioned much among healthcare professionals in Hong Kong, although the media reported on PAS proposals in other countries. For example in 2014 in the UK, Lord Falconer proposed the Assisted Dying Bill, which if passed into law would allow adults who are expected to live six months or less to be provided with assistance to end their lives, when they are fully aware of all the palliative care options and make a fully informed decision in the presence of two doctors. A survey carried out in 2010 in the UK showed that 82% of people were in favour of a change in law on assisted dying [7]. The cardinal medical ethical principle underpinning the proposal is the respect for autonomy [8]. Eminent doctors argued for both sides, the debates being widely reported in medical journals. Although it was supported by the majority of peers, it fell due to lack of time before reaching the House of Commons. However the Bill will have a second reading debate in the House of Commons on 11th September 2015. The bill proposes to allow someone judged to have no more than six months to live, and has a 'clear and settled intention' to die, to be prescribed a lethal dose of drugs on the authority of two doctors and approval by a High Court Judge [9].

It is unclear why there is little discussion among healthcare professionals or the public about euthanasia or PAS in Hong Kong, in contrast to other countries. Possible reasons include avoidance of talking about dying, and the implied family obligation to take care of the sick or senile relatives, a feature of the Chinese culture, low level of awareness of medical ethical principles, and distorted perceptions of the curable nature of illnesses with overemphasis on technology and pharmacological solutions.

**Advance directives and other legal issues:** After a long gestation period, Advance Directives have been introduced (but not promoted) mainly in public hospitals. At the time of writing, there continues to be no statute or case law in Hong Kong governing the legal status Advance Directives. As the English common law is a key source of Hong Kong's legal system, Common law has recognized that a dying adult person may refuse life-sustaining treatment and that a clear and validly made advance directive refusing such treatment to be legally binding. An Advance Directive is generally considered valid unless it can be challenged on the grounds of incapacity or undue influence. It should be noted that legislation on Advance Directives has been

introduced in other countries such as the US, Canada, England, Australia, and Singapore.

In 2006, the Law Reform Commission released a report on 'Substitute Decision-making and Advance directives in Relation to Medical Treatment'. The Commission concluded that 'it would be premature to legislate on advance directives' at that point in time 'when the concept is still new to the community and is one on which most people have little knowledge'. The report recommended that the Government should work with other stakeholders such as the Medical Council and Hospital Authority to promote public awareness of advance directives, and should review the situation (of whether or not to legislate) once the community has become familiar with the concept. Subsequently the Food and Health Bureau undertook public consultation on Advance Directives in 2009/2010. Generally from the consultation, there did not appear to be a clear consensus among the respondents or public support for promoting the concept of advance directives by legislative means in Hong Kong [10].

The Hospital Authority took up Advance Directives from July 2010 onwards and issued a specific guidance on Advance Directives for its clinicians [11]. A model form was designed, based on the one developed by the Law Reform Commission, which allowed patients to choose or decline various types of life-sustaining treatment under three specific conditions: terminally ill, persistent vegetative status or a state of irreversible coma, and end-stage irreversible life-limiting conditions. The Hospital Authority has designed on form for Advance Directives, which covers the following three categories of treatment: cardiopulmonary resuscitation, artificial ventilation, artificial hydration and nutrition. The patient retains the option to change choices at a future date. The information is entered into the electronic medical record, and accessible by staff responsible for care of the patient. However the form is not legally binding, and in practice, not many patients have been asked to complete the form. There are no guidelines that require completion of this form. Many professionals, patients and carers are not aware of this form. Requests to complete this form by members of the public are met with uncertainty of what steps to take to make an advance directive, since the form requires a physician as a witness and is only available in public hospitals.

The wishes of the patient expressed in the Advance Directives may not necessarily be respected by the professionals providing care, or overridden by family members because it may be formulated without much discussion and deliberation.

In some cases certain laws and regulations may prevent wishes expressed by advance directives to be implemented. For example the ordinance governing the Fire Services Department (under which the Ambulance Command falls within) states that the duties of the Department to include assisting 'any person who appears to need prompt or immediate medical attention by... resuscitating or sustaining his life' (Fire Services Ordinance, Cap. 95). There is no provision in the ordinance regarding dying patients who do not wish to be resuscitated. This runs against the medical ethical principles of autonomy and futility of treatment. A similar situation applies to the Coroner's Ordinance (CAP 504), which states that if a person residing in residential care homes for the elderly (except nursing homes) dies, the police must be notified. For these 'reportable deaths', the Ordinance also requires persons within a stipulated list (including medical practitioners, hospital officials and police officers), who become aware of the death to make a report of it as soon as reasonably practical. Failure to discharge this duty imposed upon him under the Ordinance renders him liable for conviction punishable by a fine

and/or imprisonment for 14 days. It has been shown in a survey that up to 33% of residents expressed a wish to 'die in place' rather than be admitted to hospitals at the end of life [12,13]. Currently many residents living in such homes are under the care of Hospital Authority Geriatric outreach teams, who are able to provide much of the end of life care, even for those who expressed a wish to die in the care home. However, effectively the law is depriving residents of old age homes (and their relatives) of the choice in the place of dying, as well as depriving them of dignity and creating much discomfort as well as distress in their relatives during the process of dying. We suggest that an amendment of the above ordinances would enable such wishes to be respected, especially given the legally ambiguous status of Advance Directives in Hong Kong at this point in time.

Without a chance to elicit the patient's end-of-life care wishes and realize their right to self-determination, their voices are often being ignored by the professionals providing care or family members in the medical decision-making process. US experience has showed that advance directives are only a means to document the patient's wishes and the advance care planning process that engages individuals, their family members and health care providers in an open communication about the end-of-life care goal would be more important. To support this notion, an advance care planning programme was developed for the local socio-cultural context. The programme was entitled Let Me Talk that highlights the importance of frank communication and included components to elicit individual personal values underpinning end-of-life care wishes [14]. The programme was initially tested among old age home residents with multiple morbidity. Although they generally perceived the medical paternalistic culture, the programme significantly empowered the residents to indicate their end-of-life care wishes and the commonest preferred goal of care was comfort care. Establishment of a dedicated pathway to allow the implementation of advance care planning has been piloted and hopefully can contribute to improving the quality of the dying process. While it is possible to engage frail older people living in residential care homes to implement advance care planning [14], much education of staff working in long term care settings needs to be carried out. A recent survey showed that among the staff working in these homes, knowledge gaps exist in the areas of mortality relating to chronic diseases, pain and use of analgesics, feeding tubes, dysphagia, sputum management, and attitudes towards end of life care issues. Staff highlighted lack of knowledge in dealing with refusal to eat, management of feeding tubes, managing the dying process, advance directives and advance care planning [15].

The medical ethics of end of life care for those who have dementia have largely been neglected, since few would discuss advance directives early on in the disease. It is uncertain what role medical ethical principles play in the making of decisions regarding care for patients in the late stage of dementia. A major ethical dilemma in the care of people with dementia in Hong Kong is the widespread use of tube feeding for poor feeding and aspiration risk at the advanced stage of dementia. While it is clear that most non-demented older people do not wish to have tube feeding when they have advanced disease [12], and that tube feeding is poorly tolerated by older people with dementia, tube feeding is routinely used and enforced by physical restraints in hospitals and nursing homes in Hong Kong.

The predominant view by health professionals and the lay public in Hong Kong is that life-sustaining treatments should be standard practice, unless they are refused by the patients. As people with dementia are mentally incapable, they cannot refuse life-sustaining



treatments. The beneficence and futility principles do not necessarily support the withholding or withdrawal of tube feeding in advanced dementia if one believes that preservation of life per se is of paramount importance. Consistent with this view, in a survey of primary family caregivers of older people with advanced dementia in nursing homes in Hong Kong, 45% of the respondents would still opt to have tube feeding for their loved one in the extreme hypothetical scenario of irreversible coma, even after having been told that the poor outcomes of tube feeding [16].

A counter-argument against tube feeding in advanced dementia is the lack of evidence that it prolongs life [17,18]. Careful hand feeding has been suggested to be an effective alternative [19]. But few would dismiss tube feeding as a life saving measure of the last resort even if they accept that the practice is not evidence based. Moreover, careful hand feeding is often dismissed by health professionals as impractical because of its resource implication and the risks of complaints and litigation.

The limitations of the contemporary focus on autonomy in medical ethics in the care of people with dementia have been recognized. Some have proposed to consider the personhood of people with dementia within the social context of the individuals. When one considers life sustaining interventions, beneficence should be the guiding principle, and the burden experienced by the person with dementia should be taken seriously. The negative responses to the intervention e.g. repeated attempt to withdraw nasogastric tube, should be interpreted at face value as an indication of refusal by the body of the person. Such form of "bodily autonomy" should be respected [20]. Without this alternative vision of personhood, it is not almost impossible to deliver palliative care for people with advanced dementia.

Alongside public education in palliative care in Hong Kong, there has been some shift in the public and professional opinion on the use of tube feeding in advanced dementia. But the shift has not been enough to ensure a consensus among the health professionals and the families in the great majority of cases. In reality, it only takes one person in either party to shift the decision towards tube feeding.

Therefore, it is clear that much more work needs to be done to shift the emphasis on the preservation of life to the preservation of quality of life and personhood of people with incurable diseases in Hong Kong. In addition, care professionals should be proactive in discussing end of life issues with people with early dementia or mild cognitive impairment, as advanced directive may still be feasible. This is undoubtedly a challenging exercise as people with early dementia are often in the state of denial and uncertainty. Moreover, it is uncertain if their advanced directives will be honored in the years ahead. But this kind of discussion, preferably with their family members, and probably in conjunction with advanced planning of other caring issue, may influence the attitudes of family members when end of life care decisions are called for.

Advance care planning is recommended for patients with early signs of cognitive impairments, including patients with Mild Cognitive Impairment. A recent qualitative study with 7 older people in Hong Kong that assessed older people's readiness for advance care planning in dementia care found that the majority of them agreed with the need for advance care planning. But they also entertained some common concerns: such as the worry that no one understood their care wishes or needs, no or not enough number of health proxy and the fear of no family consensus [21].

## Soliciting patients' views

Recently a research project promoting and evaluating advance care planning to improve end of life care in patients with advanced disease supported by the government had started, with the primary outcome of whether the patients' end of life care preferences were known, documented and respected [22]. This is the first study to engage both patients and their family members in the advance care planning process. Patients with a wide range of diseases are included. With the experience of repeated hospitalization and increased severity in symptoms, they are generally aware that their conditions are deteriorating irreversibly and thus many of them have some forethoughts about their end-of-life care. However, rarely have they shared their thoughts with their family members. As aforementioned that end-of-life issues are deemed as complicated, the concepts of advance directives and advance care planning have not been promoted much in the society and thus nearly all participants have not heard about them. Despite this, during the study, many of them clearly indicated that they would opt for comfort care at the end of life. What they fear is the suffering induced by futile treatments, especially if they have witnessed patient being placed on these treatments in the hospital setting previously, rather than death itself as they accept it as a natural part of life. Qualitative interviews with the patients found that they value the chance to share their care wishes with their families and that brought peace in mind. Though some family members may be distressed by discussing these issues, many family members agreed that open discussion can help to prepare them for the difficult decision and they will respect the patient's wishes.

## Withdrawal of Life Support

In the absence of advance directives, family caregivers are often asked to make surrogate decisions when their elderly relatives are critically ill. A study showed that most caregivers had poor knowledge relating to life-sustaining treatments and decisions tend to be made from their own, rather than the patient's preferences [16]. This is in spite of the drawing up of a document by the Hospital Authority of guidelines on life-sustaining treatment in the terminally ill in 2002, by a working group on clinical ethics convened by the Authority. The Working Group consisted of doctors, policy makers and philosophers. The document was a response to Section 26 on 'care of the terminally ill' in the Professional Code and Conduct of the Medical Council of Hong Kong, and delineates the ethical principles and communication pathways in making decisions on withholding or withdrawing life-sustaining treatment. It emphasizes the importance of consensus-building process, and recommends approaches to handle disagreement. The document also applies to other seriously ill patients who do not fall into the category of terminally ill. The document highlights two ethical principles underpinning the guidelines: respect for wishes of a mentally competent and properly informed patient to refuse life-sustaining treatment, and the concept of futility, which takes into account the balance between burden and benefits of the treatment towards the patient. It states that there is no ethical difference between withholding and withdrawing. However, it clearly states that except when the treatment is physiologically futile, the decision-making process is basically a consensus-building process among the healthcare team, the patient, and the family. While drawing on principles in the UK and USA, it emphasizes that the ethical principles should be interpreted in the local Chinese cultural context, where the concept of self may differ from the West, in being more of a relational one [23], and where the role of family in decision making

may be more important than in Western cultures [24]. At the same time it advocates respecting advance directives, patient's wishes, and for mentally incapacitated persons without an appointed guardian, for the medical team to take a dominant role in considering what is best for the patient. It also recommends the setting up of Clinical Ethics Committees to deal with any conflicts arising.

This commendable development within the public hospital community had not received widespread promotion and reinforcement, nor had the contents been promoted to the public nor discussed by the media. Hospital Ethics Committees which deal with medical ethics tend to have a low profile, overshadowed by the development of the Clinical Research Ethics committees, which focuses on research ethics instead. Furthermore, the guidelines merely state principles, without describing clinical service structure or pathways. In contrast, Taiwan had enacted the Hospice Palliative Care Act, amended in January 2013, which legalizes the compassionate extubation (CE) procedure. The Palliative Care team, in consultation with the Ethics Committee, receives consultations for CE according to a defined protocol [25].

Nevertheless, guidelines may have played an important role in guiding practice in the intensive care setting with respect to withholding and withdrawing life-sustaining treatments. A recent survey of such practices in 16 Asian countries show that Hong Kong and Singapore, both being previous British colonies, have practices similar to the West, in terms of not making a distinction between withholding and withdrawal of life sustaining treatment, attributing this to strong British influence in integrating palliative care into public hospitals [26,27].

In contrast to the situation in Hong Kong, it is the public that is spearheading the demand for a good death with dignity in mainland China. A group from the younger generation of the elite who have had bad personal experiences of their parents who have suffered from the use of tubes and ventilators to prolong death (rather than life), have been formed recently, while only recently the official view was that it is too early to have a public discussion in China on the promotion of dying with dignity 'because doctor-patient relations are tense, medical reforms are entering deep waters, wealth gap is wide and legal reforms face formidable tasks'[28]. The 'tense' relationship refers to the not infrequent physical attacks on doctors and nurse by relatives when a patient dies, which in some cases have resulted in deaths of healthcare workers.

## Development and Provision of End of Life Care Services

The past thirty years or so have been taken up with the development of palliative care services for cancer patients, as well as professional training for healthcare workers, such that the specialty of palliative medicine has been firmly established. However the needs of end of life care have increased at a very fast rate as a result of population aging, so that in addition to cancer, the number of people dying from other chronic diseases, in particular dementia, have received relatively little attention at all levels from policy makers, hospital administrators, doctors and nurses. At the same time there is an increasing number of elderly people who present to the Accident and Emergency Department with widely disseminated cancer, at a late stage. Existing cancer palliative services are unable to keep up with the demand and provide good end of life care.

The situation had only been highlighted in the recent 5 years by a quality improvement initiative started at the Shatin Hospital using a bottom up approach where the needs, deficiencies in knowledge among health care workers, service adaptation and improvement, and evaluation were documented in a series of publications drawing attention to this issue [29-32]. These principles were also disseminated to the public through a Press conference ([http://www.cadenza.hk/index.php?option=com\\_content&view=article&id=3&lang=en](http://www.cadenza.hk/index.php?option=com_content&view=article&id=3&lang=en); [http://www.cadenza.hk/pdf/latestnews/261010/ppt\\_EoL\\_26Oct2010\\_final.pdf](http://www.cadenza.hk/pdf/latestnews/261010/ppt_EoL_26Oct2010_final.pdf)) and various media interviews. An indication of how these topics resonated with the public was reflected by the fact that Shatin Hospital was inundated with phone calls from people who wanted to receive such care in the Hospital.

What is required is that good end of life care should be integrated into all care levels and settings, and receive a prominent place in resource allocation and professional training. The current situation would appear to contravene the medical ethical principles of equity and distributive justice, when this sector of the population appears to be largely invisible to many professionals, administrators and policy makers.

## Facilitators and Barriers to an Ethical Approach

It can be seen that there has been progress in providing end of life care along medical ethic principles in Hong Kong; however the demands as a result of population aging has outpaced existing infrastructure, with the result that it may be difficult to provide care following ethical principles unless a major initiative involving all sectors (healthcare professionals, administrators, policy makers, legal professionals and bioethicists) is undertaken. Currently there are scattered advocates for the need to improve end of life care, but a concerted effort underpinned by ethical principles is lacking. It has been shown that aligning care with patients' needs and preferences in order to improve the quality of the dying process is not easy, the situation in the USA showing that improvement occurs in phases over forty years from 1976 to the present, from securing rights, to facing clinical realities, to end-of life care systems reform [33]. The barriers and what still needs to be done are similar to the situation in Hong Kong, particularly with respect to the large gulf between the theory and practice of end of life care. Similarly for Hong Kong, improvement is likely to be a continuing process consisting of many steps over a period of years; nevertheless it is important that the momentum should be sustained by medical ethical principles taking a prominent position constantly in the collective consciousness of professionals and the public alike. The Inauguration of the Chinese University Centre for Bioethics launch conference highlighted the call for health to match wealth, which include a better way for the elderly to die [34].

## Future Tasks

Clearly medical ethics education covering end of life care issues need to be included in the training of all health and social care professionals. Public education is also warranted as public opinion may also be needed to form a critical mass in order to drive policy change as well as service provisions. However research in collecting evidence to inform such activities is essential. On a more theoretical perspective, is it still true that the Chinese concept of self still exist, unchanged by globalization and economic development? In other words is autonomy still taking a secondary role to the family as a whole? This would have an important influence on many end of life situations.

We need to understand why there is such inertia in amending the ordinances that govern dying in residential care homes as well as resuscitation in ambulances. Much work needs to be done relating to advance directives: awareness among the public, legal and health and social care professional; how to make an advance directive in institutions as well as the community; how this fits in with the power of attorney; and its implementation in special groups such as those with dementia or in persistent vegetative states.

## Conclusion

In attaining the goal of dying well in our society according to the four domains of the Lien Foundation of the quality of death, we need to move forwards now by taking a big step consisting of all the above activities. In the absence of such an effort, population aging in Hong Kong will be accompanied by increasingly poor quality of care in the dying process. Hopefully a continuing medical ethics discourse regarding end of life care issues may provide a suitable momentum to drive these changes.

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