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The Symposium was held on 3 July 2010 at Meng Wah Complex, The University of Hong Kong. The program began with, on behalf of the organizing committee, Dr. Chan Kin-sang’s warm welcome to all participants. We are honored to have Mr. Thomas Chan, Deputy Secretary for Health, Food and Health Bureau as our Guest of Honor for the opening ceremony. He has made an impressive speech regarding end of life care from the policy maker’s perspective. More than 20 guest speakers were invited for the Symposium.

In the first morning session, Dr. Doris Tse presented “Care standard for the dying in modern hospitals”, Dr. Lau Kam-shing shared “Facilitating patients dying at home”, and Dr. Helen Liang presented “Care management for miscarriage women & family”. The second session began with “Drama on Advance Care Planning: 愛在生命末了時” by SPHC 3G Alumni, followed by Dr. Tse Chun-yan on “Advance Directives: Their role in clinical practice and their difficulties”, Dr. Yvonne Mak on “Advance Care Planning: The client’s perspective”, and Ms. Faye Chan on “Advance Care Planning: Older adults’ perspective”.

There were four concurrent sessions in the afternoon program. In the clinical update & free-papers session, Dr. Annie Kwok shared “Recent advances in symptom management in palliative care”, and followed by four free-paper presenters. In the session on NGOs’ Innovative Programs, Ms. Christine Yick & Ms. Sherisse Tai presented “Mobilizing volunteers & the bereaved to serve people facing death and loss”, Ms. Molin Lin shared “Continuity of care for children with advanced cancer and their families”, Ms. Iris Leung presented “New model of care for cancer patients”, Ms. Wong Kam-fung shared “Psycho-therapeutic group intervention for cancer patients: The way forward”, and Ms. Helina Tsang presented “Remembrance program for the bereaved”.

Another afternoon parallel session is a workshop on “Meaning-making intervention for advanced cancer patients” by Dr. Pamela Leung. In this year’s new addition, “Students’ Session – End-of-life care issues”, Ms. Heidi Wu presented “Communicating with the terminally ill”, and Ms. Camila Li on “Professional carer’s grief in caring for the dying”.

More than 300 participants attended with much enthusiasm.
In our last issue of newsletter, we have discussed about Advance Directives (AD) in response to the release of the consultative paper on advance directives (AD) by the Food and Health Bureau HKSAR in 2009. The discussion about care for the dying has recently generated more interest in the medical field as “care for the dying” is among one of the criteria to fulfill in the Hospital Accreditation process piloted in public hospitals. As the pilot hospitals are acute regional hospitals, the assessment is not confined to death and dying in palliative care units, but rather, the care for the dying in various clinical settings in an acute hospital.

In the Hong Kong Palliative Care Symposium held in July 2010, both advance care planning and care for the dying in modern hospitals were presented and discussed. It was most encouraging to have Mr. Thomas Chan, the Deputy Secretary for Food and Health Bureau with us, who has been involved in the consultation process of the paper on AD. The encouragement did not just come from his physical presence, but also from his opening speech, which demonstrated his genuine interest in reflecting on death and dying. The development of palliative and EOL care for the dying in various places of the world is most facilitated when this essential part of health care is addressed at the policy level.

Nonetheless, this is not all in the promotion of care for the dying, and a lot of work has to be done at community and hospital levels. Various NGOs have shared their experiences and programs in the Symposium. We hope that every effort we spend and every encounter in death and dying we experience contribute to a better EOL care in the future.

It is also important that palliative care workers keep abreast of the advances in medicine that could make a difference in palliation, including the targeted therapies that are rapidly developing. Dr. Roland Leung, specialist in Medical Oncology, has written a succinct and yet extremely practical article on what palliative care specialists need to know in caring for these patients, including the important parts on the side effects and drug interactions.

Last but not least, please reserve your date for our coming Annual Scientific Meeting. The discussion on ACP and AD continues, and we have invited Dr. B Hammes, the expert in this area, to come to Hong Kong again. Please do not miss the valuable opportunity of meeting a very experienced expert not just at home, but also instrumental in assisting other countries in policy making.

Dr. Tse Man Wah, Doris, Editor-in-Chief.
Opening Speech by Mr. Thomas Chan JP,
Deputy Secretary for Food and Health Bureau, Hong Kong SAR.

Mr. Thomas Chan has been with the Food and Health Bureau since October 2006 and his responsibilities include healthcare financing policies, healthcare reform initiatives, primary care, electronic health record system, tobacco control and other health-related policy matters. He joined the Government as an Administrative Officer in 1991 and has served in a number of positions in various bureaux and departments since before joining the Food and Health Bureau. Most recently he had served as the Deputy Representative of the Hong Kong Special Administrative Region to the World Trade Organization in Geneva from 2001 to 2006.

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It is my great honour to be here today at the Symposium with all the people who have their hearts and minds in the field of palliative care. I should declare interest that I am a civil servant having worked for four years in the Food and Health Bureau, which is often half-jokingly called the Cradle to Grave Bureau. Take two hot topics we handled in recent years, maternity beds and columbarium, and you will understand why. But I am not a doctor myself. I am not even a health specialist.

So I felt utterly unqualified when Dr. Doris Tse from the Organizing Committee asked if I could address the opening of the Symposium. I could not really say no. First, I happen to be responsible for the policy, or rather the non-existence of a policy (yet), on the subjects of advance directive and advance care planning. Second, I happen to have a recent encounter with death when my father was diagnosed with liver cancer a year ago and Dr. Tse showed me first hand what palliative care was about when my father spent his last few days peacefully in her hospital.

Confronting death is and will always be a very personal experience, and I do not think the experts here need to hear another anecdote. I guess what I can contribute today to the symposium is the policy-worker’s perspective, i.e. how someone working in a policy bureau would contemplate any policy for end-of-life care. I am still far from understanding palliative care, let alone qualified to speak about a policy for such. But I hope by setting the scene for deliberation in the broader policy context, we could escalate the level of the policy debate and turn it into a meaningful and fruitful one, and hopefully getting it into the health policy agenda for action.

First of all, we always start by looking at the scale of the problem. Right now we are seeing about 41 000 deaths each year, 80% of which aged 65 or above. Give our demographic profile, it has been projected that the number of deaths will rise to about 76 700 per year by 2036, over 90% of which aged 65 or above. Most of the deaths happen in hospitals and it is often quoted that near three quarters of the healthcare costs
over a person’s lifetime are spent in the last two years. So at least theoretically we can say end-of-life care occupies a major chunk of our healthcare system, even if we may not be able to separately account for it in reality. Simply looking at the numbers, I cannot help but wonder why end-of-life care does not get more often onto the headlines, at least more often than the medical incidents.

Second, we have to contemplate the nature of the problem we are dealing with. Benjamin Franklin once said death and tax are the only two certain things in life. What he did not know was that death today including how much it costs is a lot less certain than your tax bill that comes in through the mail every year at the same time. Yes we will all die some day. But when it will happen, how it will come, what to do when it does, and perhaps the more philosophical question of what comes after, contribute to the numerous uncertainties surrounding our certain deaths. And when facing uncertainties people do many things, both rational and irrational. I do not pretend to understand what end-of-life care encompasses, but I do believe that it has something to do with alleviating some of these uncertainties or the pain they cause. Has that value been well recognized by the community yet? I am not too sure.

Third, any policy deliberation would need to take into account societal values and acceptance. It has always been said that death is a taboo in Chinese culture. And it does not help when end-of-life care often gets mixed up with emotional topics like euthanasia, passive or active. But the society’s mood seems changing, partly due to the ageing problem that everyone talks about these days, and partly a result of increasing demand for quality of life, even while ageing or facing death. I believe the window of opportunity is beginning to open for a more candid and probably long overdue discussion on what to do about end-of-life within our healthcare system, on how we care for “dying with dignity”.

Do not get me wrong, I am not suggesting we should try to proactively change our societal values. Quite on the contrary, I think what we should do is to recognize the diverse and changing societal values, and focus our discussion on how best to care for end-of-life fully respecting these values.

Finally, we need to look at how the existing healthcare system is organized to deal with the problem. On this count, I am afraid it does not seem to be doing well for end-of-life care, which is often characterised, perhaps wrongly, as only care for the dying, and usually does not get as high priority as say disease-curing and life-saving care, especially when it comes to resource allocation or even getting public attention. It is of course always difficult to assess and quantify quality of life, and it is even more difficult to talk about quality of death. But shouldn’t we pay more attention to the part of our healthcare system where the care and the caring actually make probably the most difference to a person’s quality of life? Shouldn’t we all be entitled to quality of life even when we are on our last journey?

On this, I must commend our colleagues in public hospitals and non-government organizations like the Society for the Promotion of Hospice Care and many others which I fail to mention here, for pressing on with palliative care with perhaps disproportionately little resources and support. I believe this is possible only through the devotion and altruism of the many healthcare professionals and other workers involved. What they have been able to achieve with that little support makes a great deal of difference and is most invaluable to those concerned, even if they work ever so quietly beneath the radar screen and do not often get the public attention and credits that they deserve.

So how are we to start a policy debate to put end-of-life care in its rightful place? It is a cliché to say that we start with the low-hanging fruits. But I think we have made not too bad a start on the deliberations of advance directive, thanks to the good ground work done by colleagues in the Hospital Authority, when we started the policy consultation late last year. We have made a small, cautious but sure step of putting advance directive squarely on the policy agenda and in the public arena.
Next, I suppose it would only be logical to extend the discussion to advance care planning, and in that conjunction promote better understanding of palliative care in the community. Advance care planning, much as advance directive, is still a very alien concept to people in Hong Kong. But I am hoping that by starting with something practical that people would encounter in the healthcare process, the public would start to realize the need for a proper policy for palliative care.

Providing end-of-life care within the community rather than in hospital settings is another such opportunity. Whether we can provide end-of-life care in elderly homes or even at homes would require new thinking in delivery care and possible substantial changes to the existing legislation. It is likely to be a complex issue requiring coordination on many fronts. But it would be worth doing if this is something that can instill a positive change in the mindset of people towards end-of-life care and death.

Above all, we need the help of healthcare professionals involved including all of you present today to bring the subject matter to the forefront, to make it known to members of the public, and to educate the community including our media the proper concepts and notions of palliative care. Hopefully, through a gradual infusion of practical matters relating to end-of-life care, we can slowly but surely build an increasing momentum in support for mainstreaming palliative care within our healthcare system, while avoiding many of the pitfalls of embarking upon an open-ended discussion surrounding death.

As a policy worker, I consider myself always on the learning curve. I share these immature thoughts about end-of-life care today in the hope of prompting for more and better ideas and suggestions on how to take a meaningful cause forward.

With these words, I wish the Symposium a success and you all have a meaningful and fruitful discussion today. I myself certainly look forward to being educated. Thank you.
Care Standard for Dying in Modern Hospitals

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Background

Dying remains highly institutionalized in Hong Kong and yet marginalized in the hospital setting. High expectations of modern health care, alienation of the dying process, death as a taboo are possible factors in shaping the dying phase of our patients. The needs for end-of-life (EOL) care in hospitals will increase appreciably as the population continues to age. Mortality of the population increases with age; so is the use of hospital beds. By 2030, one in four citizens will be of age 65 and above. By then, the number of deaths in Hong Kong will increase by 2-fold as compared with that in early 2000s.

Palliative care for cancer has been established in Hong Kong since 1982. Albeit the development of a comprehensive service in terms of care types and geographical coverage, a review of the cancer deaths in 2009 in Hospital Authority conducted by the Central Committee in Palliative Care has shown that 56% of all cancer deaths did receive palliative care service, with 71% of all cancer deaths occurred in non-palliative care settings. Furthermore, around 90% of non-cancer deaths did not receive any palliative care in their last year of life.

Although cancer is the leading cause of death in Hong Kong, multiple chronic diseases are prevalent in Hong Kong. While deaths from cancer peaked at age 70’s, deaths from chronic non-cancer diseases rise sharply after age 80 years. From the vital statistics of past years, there is a trend, though subtle, that the deaths from cancer are decreasing and that from chronic diseases increasing. [1]

Another challenge in care for the dying is to overcome barriers to provision of end-of-life (EOL) care in non palliative care settings. Interfacing palliative care with acute care has been addressed in various places of the world with variable degree of accomplishment, and evidence suggested that a lot more have to be improved. In 2009, the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) published the survey on 4,571 patients who died within 4 days of admission in various hospitals in UK. [2] Two-thirds of the patients admitted were either moribund or suffering from incapacitated systemic diseases. In 21.8% of cases the Do-not-resuscitate (DNR) orders were signed by very junior trainee doctors. Palliative care team was only involved in 12.5% of deaths.

Half of all patients were expected to die. Among patients who were not expected to survive, only one-third had EOL care pathway implemented; near 30% had no DNR order in place; 16.9% had no discussion between the health care team and either the patient or relatives on treatment limitation.

Recurrent themes arising from the results include: (1) poor communication (2) lack of multidisciplinary support (3) poor EOL care planning and (4) lack of palliative care team involvement. Four out of 10 patients admitted to hospital close to EOL received poor care. Staffing arrangements and shift working have also been shown to be disruptive and effective team working, which is fundamental to EOL care, has to be restored.

Hospital accreditation of modern hospitals

Care for the dying and its quality has been described as the ‘litmus paper’ of a modern health care system. With globalization of health-care standards, more and more modern hospitals underwent accreditation, which is a process of external peer review for determining compliance with a set of standards (WHO 2003). The hospital accreditation process is one focusing on continuous improvement with reference to the established standards for rating.

In Hong Kong, the Hospital Authority has embarked on the hospital accreditation process in five pilot public hospitals in 2009. The process is being conducted by the Australian Council on Healthcare Standards (ACHS), based on the fourth edition of the Evaluation and Quality Improvement Program (EQuIP) Standards. The Care for the dying is among the 45 standards that have to be addressed: Criterion 1.1.7 Systems exist to ensure that the care of the dying and deceased consumers/patients is managed with dignity and comfort. Assessors will look for documented evidences of pain management, access to palliative care, patients with advance care planning, withholding and withdrawal of life sustaining treatment, responding to the psychosocial and cultural concerns of patients and families, and training for staff involved in caring for the dying.

Similar criteria can be identified in the Joint Commission International Accreditation Standards for Hospitals adopted by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), including Care of Patient (COP) COP.7 The organization addresses end-of-life care; COP.7.1 As appropriate to the care and services provided, assessments and reassessments of the dying patient and their family are designed to meet individualized needs; COP.7.2 Care of the dying patient optimizes his or her comfort and dignity. Each criterion has its own elaboration of the standards that should be attended to. For example, in assessment and reassessment of the dying patient and their family for meeting individualized needs, the assessor will look for evidence and documentation of symptoms such as nausea and respiratory distress; factors that alleviate or exacerbate physical symptoms; current symptom management and the patient’s response; patient and family spiritual orientation; patient and family spiritual concerns such as despair, suffering; patient and family psychosocial status, coping & reaction to illness; the need for respite services; the need for an alternative setting or level of care; and survivor risk factors such as family coping & risk for pathological grief.

Accreditation: Does it work?

At this point, health care professionals might anticipate that undergoing through such an assessment will involve collection of voluminous data and evidences. Moreover, in the practical sense, professionals would wish to know whether the exercise will be transcribed into improvement in patient care and other aspects of health care. This question is especially relevant in care for the dying when goals to achieve are qualitative than quantitative.

In a systematic review of 66 studies on evaluation of the effectiveness of the hospital accreditation process, results show that promoting changes and professional development are two areas with plausible positive impact, while evidence on its relationship with quality indicators and its credibility remain inconsistent, and there is insufficient data to support its impact on patient’s satisfaction. [3] Consistently, changes are least in doctors, and doctors are more likely to have little awareness of the accreditation process, find it irrelevant or being skeptical.

On the other hand, some leading hospital-based EOL palliative care programs have been established in US with the implementation of hospital accreditation, and features that may contribute to their success include:

1. Healthcare executives / leadership assume a critical role
2. Recruitment of trained / qualified staff and specialists
3. Effort to modify the environment or atmosphere in the areas occupied by dying patients
4. Dedicate specific beds and hospital rooms for the provision of palliative care
5. Patients not limited to any particular diagnosis
6. Involvement of patients and families in the course of care
Among all, there are two factors that are constantly associated with the success in improving EOL care in hospitals, namely the leadership and the organisational culture.

**While the hospital accreditation process will look for establishment of systems and documentations as supporting evidence for continuous improvement, the key to success is PEOPLE, PEOPLE, PEOPLE…**

Local programs to improve EOL care in an acute hospital

In Caritas Medical Centre, an acute regional hospital with a palliative care unit in place, various projects have been implemented in past 6 years to improve care for the dying. These include the “Care for the Bereaved Project” targeting staff in the acute wards; enhancing EOL care in intensive care unit (ICU); piloting palliative care for patients with end stage renal failure; implementing the integrated EOL care pathway. Engagement of staff is a pre-requisite in promoting changes.

**Care for the bereaved Project**

This was launched with the objective to raise the awareness of the health care professionals to grief reactions of the families when patients are dying in acute wards. A survey was conducted on 210 nurses and 30 doctors in the acute wards to study their attitude in handling the dying scene and the bereaved. [4] Staff found it most difficult to handle relatives with great emotional upset or non acceptance of patient’s death. Training needs were also identified. The bereaved relatives were also interviewed to explore their experience of the dying scene. Educations on understanding grief emotions and conflict resolution were provided to the nurses and doctors. The procedures related to patient’s death were reviewed and information provision on the burial procedures was reviewed and enhanced. The project would not be possible without the collaborative effort of various disciplines and departments in the hospital, including doctors, nurses, social workers, clinical psychologists, hospital administrators, mortuary staff.

**EOL care in intensive care unit**

Another challenge that we have embarked on is to raise the awareness of staff in end-of-life care in the intensive care unit, where potential barriers to EOL care are no less than the acute wards, including short time frame of disease course, younger patients, unrealistic expectation of family and staff, family or staff discordance, shifting medical care decisions made and lack of training in communication skills and palliation. [5]

Data from Hospital Authority show that around 5% of all deaths in public hospitals occur in intensive care units. Half of the ICU deaths were above age 70 years; half of the ICU deaths occurred in the first 2 days of admission. A rapid transition from the phase of intense life saving interventions to the point of no return poses more difficulties both for staff and the families. We provided education seminars to the ICU team, incorporated EOL care into the clinical care pathway and defined outcomes measures. Information including withholding or withdrawing life sustaining treatment, do-not-resuscitate orders, patient’s preferences, relatives’ acceptance and the parent team’s opinion are documented and provide trails for audit. In one such audit on 70 ICU deaths, near 66% involved discussions on withholding or withdrawing life-sustaining treatments and this occurred at a mean of 23 hours before death. In all patients, family members were present by bedside at time of death. [6]
**Renal Palliative Care Program**

The pilot of the Renal Palliative Care Program in Caritas Medical Centre is in response to the needs of an ageing population and the contemporary and anticipated epidemiology of dying. World wide and also in Hong Kong, there is an increasing incidence of diabetes mellitus and a potential demand for renal replacement therapy. A local study on the end-stage renal disease (ESRD) patients showed that patients, irrespective whether they were on dialysis or not, reported similar symptom burden and impaired quality of life. [7] Patients who declined dialysis were significantly older and had higher Modified Charlson Comorbidity Index scores. The results showed that ESRD patients do have considerable palliative care needs, and patient’s factors are affecting their decisions.

Albeit being more sophisticated with medical advances, dialysis is not one size treatment that fits all. The decision process is one that involves consideration and balancing of benefits, risks, prognosis and choices based on personal values and preferences and available options. The Renal Palliative Care Program provides an option to patients who prefer palliative care for dialysis or patients who are unlikely to benefit from dialysis. The salient features of the program includes [8]:

1. ACP takes place when patients are mentally competent and families are also involved.
2. Given a choice of palliative care and not just withholding of dialysis
3. Prognostic telling empowers the informed decision making process
4. Provide care appropriate to patient’s preference and goal of treatment

Patients enrolled into the program shall receive a comprehensive range of services including inpatient, outpatient, home care and bereavement care. In 2010, this program has been successful in soliciting support from the Hong Kong Government and the Hospital Authority in building up the capacity for provision of palliative care for ESRD and to other non-cancer diseases.

**Integrated EOL care pathway**

A multidisciplinary EOL clinical care pathway was piloted in the Palliative Care Unit of Caritas Medical Centre in July 2010. The pathway consists of 5 parts:

A. Review symptoms / medications / procedures
B. Review of nursing care
C. Communication and information support
D. Psychological and spiritual needs
E. Dying scene, aftermath, bereavement

Review shall be conducted in due course to evaluate achievement of defined goals, feedback from families and staff.

**Care for the Dying: Whose business?**

Studies have shown that dying patients and their families reported higher levels of satisfaction after receiving evidence-based, patient-centered EOL care. The Hospital Accreditation Project serves as an opportunity to review and improve EOL in hospital setting, only if we stop alienating of death and dying. Care for the dying should be a core service in health care. Organisation support, committed leadership, recruitment of expertise, staff training and support, cultivating an interdisciplinary approach and development of quality indicators are pertinent factors for a successful EOL care program. Providing “documentation” for hospital accreditation can become an end in itself if there is no instillation of key elements for continuous quality improvement in EOL care.

**References**

8. DMW Tse. Experience of a Renal Palliative Care Program in a Hong Kong Center: Characteristics of patients who prefer palliative care to dialysis. Hong Kong J of Nephrol 2009; 11(2):50-8
**Definition**

Advance care planning [ACP] is a process of discussion among the patient, care providers and relatives regarding the patient’s wishes, preferences, values and beliefs about future care to guide future best interests decisions in the event the patient has lost capacity to make decisions [1]. The discussion may lead to an advance statement (a statement of wishes and preferences), an advance decision to refuse treatment (an advance directive) in a pre-defined potential future situation, or the appointment of a surrogate to make decisions on the patient’s behalf.

**Traditional versus developing model of ACP**

The traditional model of ACP focused on completing an advance directive which allowed patients to prepare for incapacity and to have autonomy over what life sustaining treatments they would refuse when they lost capacity to make decisions. This would prevent doctors from imposing life-sustaining treatments on patients who might not want them. The ACP was usually discussed with the doctors or lawyers. However, the model of ACP has changed over the years. A study on the patients’ perspective regarding ACP showed that the patients’ purpose of ACP was to prepare for death and dying, and their underlying goals included the exercise of control and an attempt to relieve burdens placed on loved ones [2]. The process helped to strengthen relationships as it facilitated communication with their loved ones and so it was viewed more of a social process than just documenting an advance directive. The context usually involved close loved ones and doctors were involved only infrequently.

**Facilitated ACP: The Respecting Choices Programme**

Dr. Hammes quoted, “The Respecting Choices approach is not focused on the value of autonomy, forgoing treatment or the need for a specific document… It is focused on helping persons, in the context of their relationships, to explore and to discuss what it would mean to care about each other if a life-changing medical problem occurred.”
The programme is coordinated and systematic involving all healthcare providers within its district. Non-medical facilitators are trained to guide the patients and their relatives in the discussion process, such as nurses, social workers, chaplains and volunteers. The discussions are patient-centred and the family is usually involved. Their documentation is correctly filed and there is systematic staff education. They do not focus on death and dying which can be threatening for many but they talk about facilitating others to live well near the end of life.

During the process of ACP discussion, the patients need to understand what options and decisions that might be faced. They must be given ample time to reflect, discuss and communicate their issues, concerns and decisions with their care providers and family members. Their preferences must be clearly reflected in the documentation. The document needs to be retrievable and available when needed.

**The Clients’ Perspective**

**Reflection on Personal Experience**

As a cancer patient, I was offered some years ago to sign an advance directive. To this day, I still have not decided. In the AD form, what should I tick? There are so many hypothetical scenarios. I would have to discuss and decide on every possibility of how I might die which can be an emotionally draining exercise. Each circumstance is complex which would change over time. I anticipate my values and perceptions would also change. As life is full of uncertainties, it would be difficult to predict what I would want or would not want at a particular time and in a specific circumstance. There would be many variables in my decision-making process, for example, my physical and functional status at the time when I write my AD; my level of social support and psycho-spiritual status would determine my will to live or die, which would in turn affect my decision to want or refuse life-sustaining treatments. In addition, I would not only consider my wishes but my concept of self would also include the wishes of my loved ones. I would prefer my significant others and healthcare providers to know me as a person, to give me the opportunity to express my needs and share my wishes according to my pace, so when the time comes, I can be assured that they would act in my best interests, but perhaps this would be too unrealistic an expectation. Having experienced cancer, I have to embrace uncertainty and surrender to the reality that nothing ever goes as planned. Rather I need to focus on living in the here and now. I would prefer to think about my AD later when I am ready, and even when I am ready, I have to consider whether my loved ones are ready to discuss such death plans.

**How do patients respond to ACP?**

Some patients are not interested in ACP; some would discuss some but not specific aspects of future care [1]. The process may help them to focus their thoughts but it does not change their thinking. Their decision-making is based more on personal experiences with illness or witnessing of death and dying with preset beliefs rather than on information from healthcare professionals [4]. Some patients perceive ACP as a personal matter and would prefer to involve their loved ones rather than professionals in their discussion. The most significant factor revolves around the issue of not being a physical or emotional burden other than autonomy and control. Some may make a verbal statement only whereas others might document their wishes as an advance statement and AD to refuse life-sustaining treatments. They may appoint a surrogate to represent them who would act on their behalf in the event they have lost capacity to communicate or make decisions [1]. Some will review their wishes. One third of the patients will change their advance care plan over time, influenced by changes in diagnosis, hospitalization, health and functional status, social circumstances and mood [1].
Evidence-base data

Although previous research studies on the value of ACP and AD have been inconclusive, more recent studies have been more promising. Simon and Murray conducted a grounded theory study to explore the experience of end-stage renal failure patients who had completed facilitated ACP programme, adopted from the Respecting Choices Programme [4]. One must take into account that only six out of 18 patients agreed to participate in the study. Nevertheless, the participants viewed the process of ACP as a positive thing. Witnessing illness in self and others was a major factor which led them to think that they do not want to live in a state with physical or cognitive impairment. They perceived this quality of life as poor and that it would cause burden for themselves and their loved ones. The process of ACP gave them a peace of mind as it allowed them to address their concerns about living in a burdensome state for themselves and their families.

A recent Australian prospective randomized controlled trial studied the impact of ACP on end-of-life care in 309 elderly patients who were randomised to receive either usual care or facilitated ACP. Their reasons for hospital admission were mainly cardiac and respiratory diseases or falls rather than cancer. They were followed for six months or until death. Among the 56 patients who had died by six months, end of life wishes were much more likely to be known and respected in the patients who had been randomly assigned to receive ACP. They were more likely to be involved in EOL discussion. They were more satisfied with their hospital care in general as they felt they had received adequate information. They felt they were being listened to and were involved in decision-making. The surviving relatives’ stress level, anxiety or depression scores were less. 83% family in the ACP group was satisfied with the quality of death of the patients and 86% of them perceived that the patients would have been satisfied with their own death.

A recent American study looked at the association between preferences documented in advance directives and the outcomes of surrogate decision-making [6]. The medical records of 3746 descendants aged 60 years-old or above who had died during the period of 2000 – 2006 were reviewed. Of those patients, 42.5% required decision making, of whom 70.3% lacked decision-making capacity and 67.6% of those patients, in turn, had advance directives. Those who had prepared advance directives received care that was strongly associated with their preferences. Patients who had assigned a surrogate for health care were less likely to die in a hospital than those who had not surrogate to make decisions on their behalf. Another study showed that end-of-life discussions were associated with less aggressive medical care near death and earlier hospice referrals [7]. Aggressive care was associated with worse patient quality of life and worse bereavement adjustment.

Potential Benefits, Harms and Risks of ACP

Existing data suggests that ACP is beneficial as it would allow the clients to prepare for death, have more realistic goal setting, have greater control over their dying process, and have their wishes documented and respected. Family members can participate in the process and be better informed of the disease, patient’s preferences and treatment options so that their burden of decision-making would be lessened, and their bereavement would be associated with less stress, anxiety and depression. The participation in the ACP would also strengthen family relationship as ACP is a social process. However, Randall has also pointed out the potential harms and risks of ACP [8].

Potential Risks

- The patient changes his mind but not the ACP. He may have updated his ACP form at home but not at the hospital.
- The patient may have misinformed choices or unrealistic expectations regarding his dying process.
- The Government has not estimated the resources needed to implement ACP. For example, if most patients prefer to die in a palliative care unit, there would be pressure to achieve the preferred place of death for these patients that there would be fewer beds available for other patients requiring symptom control. This would lead to ethically unjust allocation of resources.
Potential Harms

- The discussion can be emotionally traumatic as it can be distressing to have to contemplate one’s dying in such detail. It is also difficult as the situations are only hypothetical. It may not be what the patient would want to hear.
- There can be conflict between the patient and relatives’ wishes, especially if the patient becomes mentally incompetent before the conflict has not been resolved.
- Relatives may not understand that the ACP is to record the patient’s wishes and preferences and not their perspective.
- The process is operator dependent and it must be led by a competent case manager.
- There can be political drive and doctors’ ideals to initiate the ACP which might not actually be in the patients’ best interests.
- There can be confidentiality issues as one cannot assume that the ACP / AD is open to all healthcare involved. Patient consent must be respected.
- There can be misapplication when the ACP is applied when the patient is still mentally competent.

Appropriateness in Initialing ACP

The potential harms and risks highlight the need for a coordinated programme and also trained facilitators who have the expertise in knowing where and when and how to initiate the discussion. Otherwise, one could turn a process which can potentially facilitate better communication, promote autonomy, control and peace of mind into an emotionally distressing experience with loss of hope, false promises and continual rumination on death.

Appropriate Setting

ACP discussion is not a single event but a process [1]. The surrounding should be comfortable and the consultation unhurried. It is better to take place during routine practice such as primary care or out-patient setting rather than in hospitals as patients tend to be more ill with pain, delirium or tiredness when hospitalized, and the hospital environment might cause undue influence on the patients to discuss ACP.

Appropriate Timing

Although most patients welcome the opportunity to discuss ACP and expect their doctors to initiate the discussion, ACP facilitators must exercise their professional judgment to gauge the appropriate timing to initiate the discussion, depending on the patients’ pattern of disease, prognosis, willingness and readiness to engage in such discussion. It should never be forced upon them [1]. Similarly, ACP discussions should not be continued if they are causing the patient excessive distress or anxiety.

Appropriate Client

ACP should be initiated in patients with long-term conditions or receiving end-of-life care. However, some patients with terminal disease or serious illness requiring hospitalization may not feel ready or able to do so [9]. ACP can also be initiated with clients who are stable but will anticipate future ill-health. ACP should not be initiated immediately after a move into a care home but only after the clients are more settled [1]. The clients must be mentally competent, and also have the time and energy to discuss and reflect on their wishes and preferences.
Art and Skills of a Facilitator

The ACP discussion is not a tick box exercise or a chart but an art. Not only must the ACP facilitators have the expertise and training in communication skills and how to discuss ACP, they must also know how to connect with their clients and come across as being trustworthy, and be empathetic and intuitive to know when to initiate the discussion. Not only should they have knowledge about the disease trajectory, treatment options and prognosis, but they should also know their clients in their personal context, their preset beliefs and personal experiences. While it is important to inform, explain and clarify issues during the discussion, facilitators should also be aware of their coping mechanisms and the complex emotions that clients might be going through at the time. While helping the clients to set realistic goals and summarize their wishes and preferences, one must be aware of their psychosocial status and the possible QOL response shift. Facilitators must be sensitive to clients’ cues who may not want to discuss the ACP further; they should sensitively close the conversation so that the clients would not go home ruminating on death and dying.

Conclusion

In order for the process of ACP to be of value, a coordinated and systematic approach must be adopted with trained facilitators. The discussion is a social process that is patient-centred and includes family participation. Documentation is important, which can be in the form of a personal narrative to record the client’s wishes and preferences or an advance directive to refuse specific life sustaining treatment, the latter which is legally binding.

ACP is an art and facilitators must be aware of the clients’ personal context, their psychosocial status and personal beliefs. They require intuition to know the appropriateness of when and with whom to initiate the discussion and also be aware that the clients’ preferences would change over time, requiring regular review. Public education is important to ensure that clients are introduced to the concept early when they have the time, energy and feel non-threatened to think about such death plans according to their own pace.

References:

1. Concise guidance to good practice – advance care planning. www.rcplondon.ac.uk
Advance care planning (ACP) is considered a useful process in improving a person’s end of life care. It is a process of communication among the person, the health care providers, and the significant others (Lynn & Harrold, 1999). ACP is a process of improved understanding, reflection, and discussion to create a clear plan, formulated in advance to guide medical and health care decisions if the ill person is unable to make decisions. This process takes into account the person’s health condition, culture, relationships as well as his or her goals and values (Hammes & Ronney, 1998). The decision regarding ACP will be respected and executed to guide end-of-life care (EOLC) when the person no longer has the decision-making capacity.

This paper will describe SPHC’s community life & death education (LDE) program on ACP as well as our observations, and the feedbacks from participants.

Benefits of ACP

From overseas experience, advanced cancer patients with ACP tend to have less aggressive medical care near death and earlier hospice referrals, better mental health and quality of life, and better bereavement outcomes (Ray et al, 2006; Wright et al, 2008). ACP also improves end of life care, and promotes elderly patient and family satisfaction, as well as reduces stress, anxiety, and depression in surviving relatives (Detering et al, 2010). From local palliative care experience, ACP enhances a patient’s autonomy in decision-making (Kwok, 2008). Moreover, ACP in the early stage of an incurable illness can alleviate caregivers’ burden in decision-making and reinforce the relationship with the loved ones. It could also improve both the patients and their family’s satisfaction in end of life care.

Lessons from the US

The discussion and promotion of advance directives (AD) have been initiated in the US in the 70’s. (AD is a legal document and often considered as an integral part of ACP.) However, it is not widely utilized by the more recent ACP program called “Respecting Choices” in La Crosse, Wisconsin has proven successful in engaging community in establishing ACP (Hammes & Ronney, 1998). The program’s successful factors include ACP process facilitated by trained volunteers at outpatient settings, and a system that honours the person’s wishes. SPHC is endeavouring to provide the earlier part of the ACP process, that is early education and discussion of ACP with psychosocial support and facilitation. The latter part will rely on the local development of honouring ACP among the service providers.

SPHC’s ACP program for older adults in the community

Although ACP may not address specific details of treatment options of specific diseases when an individual is healthy, it lays a good foundation for future needs in a more concrete ACP. It also makes known of a person’s general directions or values about life & living, and death & dying. Older adults in the community are considered as an appropriate target for ACP. Although they are relatively healthy compared to patients admitted to hospitals, they are likely to
have some morbidity. This is one of the reasons considered as an appropriate target for ACP. From SPHC previous experience with community education programs, we have identified that older adults are eager to express their wishes on arranging the final journey of their life but lacking skills or tools to communicate their thoughts to their families. As such, we have developed this ACP program to facilitate the older adults to plan for and communicate their own wishes to other parties concerned. SPHC aims to support older adults in the community to actualise ACP in a systematic manner and territory-wide outreach. By doing so, we hope to honour the wish of many older adults by acknowledging their autonomy in their end of life care, which is considered an important aspect of dying well for contemporary older adults.

The program consists of three parts. First, the photo taking serves as a quick and effective introduction. The venue is primed with 2 to 3 backdrops for photography. Participants walked into the venue, and followed by an invitation to choose a backdrop for his/her portrait. The immediate task of choosing a backdrop for photo taking sets the stage for decision-making, which is a key element for ACP. We make decisions by ourselves all throughout our lives, why should we left important end-of-life decisions to others? Photos are developed on-site for putting into the provided ACP album. This helps to visualize a personalized ACP album. The second part is a talk with basic information on ACP, followed by a skid of a deathbed scene intertwined with discussion on the dilemma challenging each parties involved. The third part is small group discussion on the dilemma challenging each parties involved. The program has commenced since July 2008, and has reached more than 1,700 elders and family members in nearly all districts in the territory. The training workshops for elderly care workers have involved over 300 workers. The program has also trained over 200 volunteers in ACP facilitation.

Feedbacks are gathered from the participants, and are highlighted in Table 1.

Table 1: Feedback from ACP Program participants

<table>
<thead>
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<th>Feedback</th>
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<tr>
<td>97% elders shown increased understanding of ACP</td>
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<tr>
<td>90% elders indicated likelihood to plan for their own ACP</td>
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<tr>
<td>91% elders expressed to discuss ACP with their family</td>
</tr>
<tr>
<td>100% participants were satisfied with the program</td>
</tr>
<tr>
<td>50% workers believe death taboo is one of the major barriers for ACP</td>
</tr>
<tr>
<td>9% elders indicated not wanting to talk about death</td>
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</tbody>
</table>

Observed ACP process of the older adults through grounded theory approach

A qualitative study was conducted to get in-depth data on the elders’ ACP process. A grounded theory approach with purposive sampling of six older adults (age: 72-86; 3 males; marital status: single, separated & married; 0-10 years education; subjective health status: poor, fair & good) was used to explore issues important to the informants in considering ACP (Chan, 2009). These participants had participated in the ACP program less than 4 weeks before the interview for this study, and were recruited via elderly care centres and elderly care homes. The audio-taped interviews were transcribed and analysed for themes and patterns. The resultant core theme, “preparations for end of life”, was identified in the course of the data analysis. This core construct was grounded in complex inter-

- A booklet with information about ACP and a video of stepwise planning for ACP plus personal sharing of end of life scenarios with and without ACP.
- An ACP Album with simple instructions and suggested preparations, which serves as a guide to consider possible issues or scenarios pertinent to the individual.
- A training manual for volunteers
- A training manual for the elderly care workers.
relationships addressing the seven emerged major themes, and is presented in Figure 1.

![Diagram of ACP process]

Figure 1: The conceptual framework of ACP

The conceptual framework presented can be viewed as a way to conceptualise the ACP process for older adults to make preparations for their end of life. The direction of the process (1 to 7) is grounded in the data. The general direction towards completing ACP is moving from the inner to the outer zones. For example, the older adult has to acknowledge death & dying, and then assess his life values in the current and past contexts. He will ponder his own end-of-life care needs. He realizes the need to get assistance from alliance that will support him in his wishes, and to entrust that person to execute his wishes when he is incapacitated at the end of life. Then he will tackle the ACP factors. Identified ACP barriers have to be addressed with follow-up actions. The boundary between zones are proposed to be semi-permeable that allows movements back and forth. In order to proceed to the next outer zone, one has to partially resolve the issues within the inner zone(s). The concepts of zones may appear to occur in sequential, going from one zone to the next. Although the general direction is from the centre zone moving towards the outer zones, the zones are inter-related, interactive and dynamic in nature. Thus, it is possible to travel back and forth during the ACP process. For instance, an alliance is not available anymore, and the process needs to be reactivated until equilibrium is reached.

In the current sample, enhancing and inhibiting factors are identified, and are listed in Table 2.

### Discussions

In order to proceed with ACP, older adults must acknowledge death and tackle their own death anxiety. Addressing death is not a taboo to the majority of the elders who participated in our program. This is adamantly expressed by one elder, “At my age, there is only one thing left- death… it is good to be able to plan ahead and… get a peace of mind.”

The participants conveyed the perception of uncertainties of one’s end of life, and the need to have family’s involvement. Nevertheless, participants of this study were extremely cautious in making decision regarding their end of life lest to cause disturbance to the family harmony. This is likely related to the cultural context of Hong Kong Chinese that the family harmony takes a higher priority than individual’s concern (Tse & Pang, 2006). Individuals

![Table 2: The ACP enhancers and ACP barriers]

**Table 2: The ACP enhancers and ACP barriers**

**ACP enhancers:**
- Old age
- Personal encounter with poor death qualities of significant others
- Valuing individual autonomy
- Perceived as a priority (such as failing health)
- Death not a taboo
- Available support (family & community)
- Higher education level

**ACP barriers:**
- Lack of knowledge & skills
- Poor relationship with family
- Lack of support
- No faith in autonomy
- Death as a taboo
would try to assess secretly, sometimes by hinting and checking, to see if their EOL wishes or decision-making would be acceptable to other family members. This conveyed the cultural practice of family autonomy (Hsu, O'Connor & Lee, 2009) so as to preserve the family accord. As a result, older adults take on a more passive role.

For elders who would like to actualise their ACP, there are a number of difficulties encountered. For example, not many medical doctors are willing to be the witness for an AD while others may find EOL discussions too time consuming in busy clinical settings.

The response of the family members was found to be a crucial factor for the advancement of the ACP process. With the support of family members or alliance, the elders could address the ACP process and overcome the barriers, and actualise their ACP process as preparations for their end of life.

As suggested by this present study, the ACP process for older adults in preparation for end of life is a complex course of actions, involving the appraisal of personal values, as well as issues relating to the significant others, health care system, and societal values relating to death, dying, life and living. The appreciation of this complex process would be helpful for the helping professionals to be sensitive to the concerns of the older adults.

Policies with clear guidelines in support of end of life care including ACP for older adults as well as comprehensive protocol regarding ACP could facilitate frontline workers and professionals to address elders’ EOLC needs in a systematic manner.

Conclusion

From our experience working with older adults, ACP is relevant to elders in the community. It is believed that in a supportive environment, older adults can explore their needs at the end of life. ACP enables older adults to express their preferences in end-of-life care, and to plan proactively according to their own values and wishes. Family support is crucial to facilitate the ACP process. Family members’ readiness to explore this issue could enhance the process. This reaffirms the need to have life & death education in the community.

Acknowledgement

A note of thanks to the participants, participating organizations, volunteers, and Lee Hysan Foundation.

References:

Facilitating Home Death
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Time with loved ones is precious especially in the case of patients with limited life expectancy due to terminal illness. These patients may prefer to stay with their family members in their familiar home environment as near to death as possible or die at home. A survey conducted by the British Medical Journal in 2003 showed that 30% of the 692 respondents (including 521 healthcare professionals and 171 nonhealthcare professionals) regarded the choice of place of death was an important characteristic of good death, and 74% preferred to die at home. [1] In Hong Kong, a local survey on lay persons was conducted by Society for the Promotion of Hospice Care in 2002. Among the 430 respondents, 27.2% of them preferred home deaths. [2]

Home deaths are uncommon in Hong Kong. Various factors may account for that, including existing system barriers, cultural taboos, congested home environments, gaps in community support. However, it is highly relevant to palliative care workers that patients who wish so should be facilitated.

Managing symptoms at end-of-life is challenging and providing care in home setting for the patients when death is near requires a close collaboration between the palliative care team and the family members. It is of paramount importance the family members are given adequate support and education. They also have to be prepared for handling the processes at time of death or immediately after death, including calling ambulance for transport of dead body, process of certification of death in Accident and Emergency Department, followed by transport of the dead body to the mortuary.

During the above process, there are possibilities that events disturbing and unpleasant to the family members who are in grief could occur. For example, performance of cardiopulmonary resuscitation by paramedics or medical personnel; investigation by police officers to rule out foul play; transport of the dead body to the public mortuary and referral to Coroner.

In this article, a local program involving the collaboration of the Palliative Care Team, Department of Accident and Emergency (AED) and the mortuary of Ruttonjee and Tang Shiu Kin Hospitals will be shared. The target patients are patients known to our Palliative Care Unit, whose end-of-life care plan has been discussed thoroughly. The objective of the program is to streamline the process when the patient, who has stayed at home till death is imminent, is brought to the AED by the ambulance. Patients with terminal illness are exempted from the
14-day rule in the Coroner Ordinance i.e. the doctor certifying death should attend the patient within 14 days prior to patient’s death. Our AED colleagues shall certify death after exclusion of foul play. The clinical status and the advance care plan of these patients are readily retrievable from the electronic Clinical Management System of the Hong Kong Hospital Authority. This will obviate the need for transporting the dead body further to the public mortuary. The palliative care doctor would be informed during office hours, who will sign the Certificate of Cause of Death and issue to the family. In case of any doubt or dispute, the case would be referred to coroner instead.

From March 2007 to April 2010, a total of 33 patients (constituted around 2.7% of all palliative care deaths during the period) underwent the pathway of our program. There were 21 male and 12 female patients, of age ranging from 52 to 101 years (mean 77.4 +/- 10.3). The three most common sites of the primary tumour were lung in 10 patients, colon in 5 patients and liver in 3 patients; while the common sites of metastases were lung in 8 patients, the skeletal system and the lymph nodes in 7 patients respectively. These 33 patients received palliative care service for a mean duration of 189.5 +/- 321.7 days (median 56 days; interquartile range 24 – 206.5). They were last seen from 1 to 48 days before death with a mean of 12.1 days and median of 9 days, and 30.3% of all were last seen more than 14 days prior to death. For the functional status, they are mostly dependent; 18 patients were bedbound, 12 patients were chairbound, and 3 patients required assistance in walking.

Concerning their socioeconomic status, 15 patients lived at home and 18 patients were old age home residents. Ten patients were on Comprehensive Social Security Assistance (CSSA) recipients, among which nine were old age home residents. The main caregivers were spouse in 9 patients, children in 14 patients, old age home staff in 7 patients, and others in 3 patients. For those patients who lived at home, 5 patients lived with family (spouse & children), 4 patients with spouse, 3 patients with children, and in 3 patients, each lived with girlfriend, parent & maid respectively.

We contacted the caregivers for their feedback and they rated the overall helpfulness of the program with a mean score of 3.82 using a numerical rating scale of 1 to 4, with 1 being least helpful and 4 most helpful. The caregivers appreciated the following service elements and found them most helpful. (Table 1)

Table 1: Service elements that family members found most helpful
1. Being able to stay with loved one during last moment of life
2. Prompt issue of the Certificate of Cause of Death
3. No need for coroner inquest or public mortuary
4. Adequate psychological preparation and reduced apprehension
5. Adequate education on how to deal with the procedures related to patients’ death
6. The support and the accompaniment provided by palliative care nurse in AED

Concerning the performance of CPR, it was not performed in 27 patients as reported by caregivers. Five patients had CPR performed during transport while in one patient, the caregivers were not certain. While the figure on CPR deserves further review for improvement, we can still maximize our support and help to facilitate good death of our patients within current limits.

References
Disease specific treatment for malignancy during the palliative phase in the era of targeted biological therapies: What is new and what does one need to know?

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Abstract:
In the past decade, there has been an explosion of therapeutics made available for treatment of cancer. These are largely developed through our much improved understanding of the biology of the malignant transformation process. The majority of these medication act through inhibition of critical molecular signaling pathways which are important in cancer cell growth or survival at the tyrosine kinase level. Many of these Tyrosine Kinase Inhibitors (TKIs) are oral and have relatively non-toxic side-effect profiles. They are often continued whilst patients receive palliative care. Because of their unique mechanism of action, they also have novel and otherwise uncommon side-effects. This review will focus on the literature supporting their use and indication in oncology, their potential side-effects and the strategies to manage their toxicity in clinical practice.

Introduction
Over the past decade, there has been a revolution in the treatment of cancer. This is the result of advances made in diagnostics, increased patient awareness, early screening and a quantum leap in medical therapeutics and supportive care. As a result, advanced cancer is no longer a lethal disease with limited treatment options but a chronic disease with some patients able to live with the disease for many years and in selected cases even beyond a decade. This is in part due to the increased incidence of early diagnosis of cancer through public education. The major advances made in treatment utilise all modalities of medicine including diagnostics, surgery, radiation therapy and medical therapeutics which together contribute to the longevity of patients.

Palliative care is increasingly important in the modern treatment of cancer because alleviating symptoms is a critical part of delivering quality cancer care. Patients may present with advanced disease with multiple complaints. They can have many years of disease control but when the treatments eventually fails, it is crucial that their quality of life is maintained at the later and terminal stages of their disease. Due to the advances of drug development, there is an explosion of new orally active medication made available to treat advanced cancers. Due to their convenience and simple ease of use, patients who are required to be managed by palliative care physicians for symptom control or rehabilitation are continued on these medications. A solid knowledge of the mechanism of action, critical drug to drug interaction and potential side-effects is essential for palliative care physicians.

Molecular targeted therapy
At the cellular level, the fate of a cell is governed by signals it receives from itself (autocrine), the surrounding cells (paracrine) and the environment (stromal). These signals are transmitted from the surface of the cell through an orchestrated network of switches known as tyrosine kinases. Signals which can be transmitted include cell survival, cell growth, cell migration and cell death. Although the individual processes of how this intricate process is well beyond the scope of this review, the concept of molecular switches involved in cell signaling is essential to further appreciate how molecular targeted therapy exerts their effect.
There are potentially tens of thousands of pathways which can be targeted for the treatment of cancer. One of the earliest targeted therapies used in the clinic is tamoxifen for the treatment of hormone receptor positive breast cancer. The fact that tamoxifen can also be used to treat endometrial cancer by the virtue of the presence of estrogen receptor on the tumor is a very important one. This forms the basis for targeted therapy. For targeted therapy to succeed, we should be able to demonstrate the dependence or activation of the targeted pathway in the tumors being treated. This had been repeatedly demonstrated in the past decade in the many failed clinical trials of new anti-cancer drugs. If we subject unselected patients to these specific new targeted therapies, the benefit is modest at best for the population being treated as a whole. However for those patients whose cancer depends heavily on the targeted pathway, the response to treatment is nothing short of spectacular. The best examples are gastrointestinal stromal cell tumors (GIST) which are heavily dependent on the stimulation of the receptor c-kit. Imatinib (Glivec) and Sunitinib (Sutent) both processing highly potent inhibition of the c-kit receptor has a treatment response rate into the 80% level. Figure 1 shows the molecular pathways where drugs are available and approved in clinical use to treat cancers with such pathway aberrations.

**Fig. 1** This cartoon illustrates the signaling pathways from the cell surface being transduced into the cell nucleus through various molecular pathways. It also highlights the targets of some of the currently available and investigational agents used in the treatment of cancer.
Review of current treatments for cancers with molecular targeted therapy

In the current era of designing targeted therapy for treating aberrant signaling pathways, it is more useful to understand the biology of the disease process and ask therapeutic questions regarding whether a therapy is in fact useful. Table 1 summarises all the currently orally available targeted therapies and their FDA approvals.

Biologically, renal cell carcinoma (RCC) and GIST share little in common, the reason Sunitinib is approved in both diseases is because of the wide spectrum of signaling pathways which are successfully inhibited by Sunitinib. In GIST, c-kit and platelet derived growth factor receptor (PDGF) are the major targets whereas in RCC, the HIF-mTOR pathway dysregulation lead to over activation of vasculoendothelial growth factor (VEGF) signaling and PDGF signaling which are both effectively blocked by Sunitinib. In fact, Sorafenib also has significant activity in Imatinib refractory GIST by the virtue of its inhibition on c-kit and PDGF.

In the future, it is likely that treatment for different cancers will be based on the individual tumor biology where the pathway leading to tumourgenesis will be probed and then the over-activated pathways will be inhibited using selective targeted therapies available to oncologists. This is the essence of personalized medicine where each patient will have their treatment selected based on their unique tumor biological profile using predictive biological and response markers. Whilst this is not standard practice for all cancers, there is clearly good rationale to follow this approach. Time and time again, we have seen clinical trials involving targeted therapies fail when patients are not subjected to biological selection. The best example is HER2 targeted therapy for breast cancer [1]. Whilst there is no overall difference in response when standard hormone therapy is compared to hormonal therapy combined with HER2 targeting agent lapatanib, there is a striking improvement when patients showing HER2 amplification are analysed separately.

Another proof of principle in patient selection is the improvement in response seen in HER2 amplified adenocarcinoma of the stomach being treated with chemotherapy or chemotherapy combined with anti-HER2 targeting agent Herceptin [2].

Instead of reviewing specific indications for different drugs for different cancers, it is more useful to review the drugs, explaining the clinically significant side-effects and interactions so their use can be safely handled.

Drug Metabolism of oral targeted therapies

All the currently used compounds are metabolized by the liver cytochrome P450 system. In particular, they are all substrate of the CYP 3A4 oxidative system. Because of this, a clear and well documented list of the CYP 3A4 substrate, inducers and inhibitors is crucial in managing this class of compounds. This is listed in Table 2.  

Whilst there is no specific dose adjustment trials done with the concurrent use of TKIs with other medications metabolized or affecting the CYP 3A4 system, it is generally recommended to avoid the concomitant administration of such medications and use of alternatives is crucial in managing this class of compounds. This is listed in Table 2.

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Disease specific treatment for malignancy during the palliative phase

Table 1 Currently orally available targeted therapies, their FDA approvals and indications

<table>
<thead>
<tr>
<th>Drug</th>
<th>Disease</th>
<th>FDA</th>
<th>Indication</th>
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<tbody>
<tr>
<td>Imatinib</td>
<td>GIST</td>
<td>2001, 2008</td>
<td>1st line vs BSC, adjuvant</td>
</tr>
<tr>
<td>Erlotinib</td>
<td>NSCLC</td>
<td>2004</td>
<td>2nd,3rd line setting vs placebo</td>
</tr>
<tr>
<td>Erlotinib</td>
<td>Ca Pancreas</td>
<td>2005</td>
<td>Gemcitabine vs Gem/Erlotinib</td>
</tr>
<tr>
<td>Sorafenib</td>
<td>RCC</td>
<td>2005</td>
<td>1st line versus BSC</td>
</tr>
<tr>
<td>Lapatinib</td>
<td>HER2 + Ca breast</td>
<td>2006</td>
<td>3rd line after 2 Trastuzumab containing regimen</td>
</tr>
<tr>
<td>Sunitinib</td>
<td>RCC</td>
<td>2006</td>
<td>1st line versus Interferon</td>
</tr>
<tr>
<td>Sunitinib</td>
<td>GIST</td>
<td>2006</td>
<td>2nd line vs best supported care (BSC)</td>
</tr>
<tr>
<td>Sorafenib</td>
<td>HCC</td>
<td>2007</td>
<td>1st line vs BSC</td>
</tr>
<tr>
<td>Everolimus</td>
<td>RCC</td>
<td>2009</td>
<td>2nd after TKI failure</td>
</tr>
<tr>
<td>Pazopanib</td>
<td>RCC</td>
<td>2009</td>
<td>1st line vs BSC</td>
</tr>
<tr>
<td>Gefitinib</td>
<td>NSCLC with EGFR mut.</td>
<td>EMEA 2009</td>
<td>All lines of therapy with EGFR mutation</td>
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Abbreviations:
GIST = gastrointestinal stromal cell tumor,
RCC = renal cell cancer,
HCC = hepatocellular cancer,
NSCLC = non small cell lung cancer,
EGFR = epidermal growth factor receptor
Because the current crop of oral targeted therapies share the same pathway of metabolism, future development of combination treatments with two TKIs are particularly challenging. There are multiple phase 1 dose finding trials currently recruiting to address the interaction between these new compounds. The results will be both instructive and revealing about the efficacy and safety of multiple TKI dosing in cancer patients.

For the EGFR TKIs erlotinib and gefitinib, the recommended dose is based on the maximal tolerated taken on a specific relation with food intake. The correct administration of these 2 TKIs is on an empty stomach either one hour before or two hours after food intake. It is imperative that this guidance is strictly adhered to because the co-commitant administration of these TKIs with food increases the absorption in a variable manner and often leads to significant and dose interrupting side-effects.

**Side-effects of oral targeted therapies**

The systemic side-effects of this new class of compound pose a therapeutic challenge since some of them are novel to the field of oncology and medicine. The explanation of why the side-effects of these TKIs are so varied lies in the spectrum of tyrosine kinases that they target. For example, both sunitinib and sorafenib, TKIs which mainly target VEGFR signaling cause significant hypothyroidism because of their off-target inhibition of the kinase Ret [3]. This off-target effect however has been translated to clinical benefit because both agents show significant efficacy in refractory thyroid cancer where the Ret is crucial to the signaling pathway. The real impact of inhibition of some of these signaling molecules are only beginning to emerge from the increase wealth of data available to us as the molecules gain a wide-ranging patient exposure.

The management of most of the mentioned side-effects has been expertly reviewed by Schwandt [4] and Burtness [5]. The product inserts of the various compounds also contain a wealth of information documenting how to manage the side-effects of the current list of molecular targeted therapies. From a practical point of view, it is easier to summarise the different organ systems and the potential side-effects since the management is similar regardless of the causative agent. This is summarized in Table 3.

In general, this group of therapy is well-tolerated. The novel and previous rare side-effects are manageable with experience. In the current standard of multi-disciplinary care for oncology patients, it is likely that the palliative care team will encounter these medications in their practice. In order to best manage the patients, a good dialogue between the oncologist and the palliative care physician is essential for successful and safe outcome.

Whilst these drugs are convenient and are given orally, the patient receiving treatment does need to be reviewed regularly for development of side-effects. In general, a full set of laboratory tests including a full complete blood count with differential, liver and renal function with glucose are checked every 4 weeks. For those patients taking Sorafenib and Sunitinib, TSH should also be checked monthly for the first 2 months on therapy to exclude development of hypothyroidism which can be difficult to distinguish from asthenia, another well documented side-effect of these TKIs. Although this is usually taken care of by the prescribing oncologist, if the patients happen to be in the rehabilitation and respite setting under the

<table>
<thead>
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<th>Substrate</th>
<th>Inducers</th>
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<td>major:</td>
<td></td>
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<tr>
<td>- immunosuppressants</td>
<td>- protease inhibitors</td>
</tr>
<tr>
<td>■ cyclosporin</td>
<td>■ macrolide antibiotics</td>
</tr>
<tr>
<td>■ sirolimus</td>
<td>■ azole antifungals</td>
</tr>
<tr>
<td>■ tacrolimus</td>
<td>■ nefazodone (psychoactive &amp; antidepressant)</td>
</tr>
<tr>
<td>- Chemotherapeutic</td>
<td>■ bergamottin (constituent of grapefruit juice)</td>
</tr>
<tr>
<td>■ erlotinib</td>
<td>■ verapamil (calcium channel blocker)</td>
</tr>
<tr>
<td>■ gefitinib</td>
<td>■ chloramphenicol (antibiotic)</td>
</tr>
<tr>
<td>- azole antifungals</td>
<td></td>
</tr>
<tr>
<td>- tricyclic antidepressants</td>
<td></td>
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<tr>
<td>- SSRI</td>
<td></td>
</tr>
<tr>
<td>- buspirone (anxiolytic)</td>
<td></td>
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<tr>
<td>- venlafaxine (SNRI)</td>
<td></td>
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<tr>
<td>- antipsychotics</td>
<td></td>
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<tr>
<td>- opiate analgesics</td>
<td></td>
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<tr>
<td>- benzodiazepines</td>
<td></td>
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<tr>
<td>- statins</td>
<td></td>
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<tr>
<td>- calcium channel blockers</td>
<td></td>
</tr>
<tr>
<td>- amiodarone(antiarrhythmic)</td>
<td></td>
</tr>
<tr>
<td>- warfarin (anticoagulant)</td>
<td></td>
</tr>
</tbody>
</table>

**Table 2 List of substrate, inducers and inhibitors of the CYP 3A4 oxidative system**

**Inducers**

- strong:          
  - anticonvulsants, mood stabilizers
  - barbiturates
  - non-nucleoside reverse transcriptase inhibitors
  - rifampin(bactericidal)
  - modafinil (stimulant)
  - hyperforin (constituent of St Johns Wort)
  - cyproterone (antiandrogen, progestin)

- strong / moderate:
  - protease inhibitors
  - macrolide antibiotics
  - azole antifungals
  - nefazodone (psychoactive & antidepressant)
  - bergamottin (constituent of grapefruit juice)
  - verapamil (calcium channel blocker)
  - chloramphenicol (antibiotic)

**Inhibitors**

- strong:          
  - anticonvulsants, mood stabilizers
  - barbiturates
  - non-nucleoside reverse transcriptase inhibitors
  - rifampin(bactericidal)
  - modafinil (stimulant)
  - hyperforin (constituent of St Johns Wort)
  - cyproterone (antiandrogen, progestin)
palliative care team, these routine but important follow-up can be managed by the palliative team with input from the oncology team.

**Conclusion**

In this exciting era of molecular targeted therapy, treatment of cancer patients has been transformed. Even the most chemotherapy insensitive malignancies like RCC, GIST and anaplastic thyroid cancers now have treatments which offer a respectable period of disease control with easy to manage toxicities and side-effects. In addition, with the second generation of TKIs entering advanced clinical development, there will be second line and beyond options for these illnesses like in the case of GIST.

These advances also brought a good deal of clinical convenience in the form of oral therapy where patients can minimize clinic visits and enjoy the relatively good quality of life at their place of abode. Whilst these novel therapies have their unique and previously seldom seen side-effects and toxicities, as long as good communication occurs between the oncology and the palliative care team, most of the toxicities can be managed safely and satisfactorily by the palliative team. This allows palliative respite and rehabilitation to be delivered at the specialised centers whilst the patients continue to receive life-saving anti-cancer therapy, a previous unthinkable arrangement in the era of cytotoxic chemotherapy.

**References**


**Table 3 Side-effects and their management of oral targeted therapies**

<table>
<thead>
<tr>
<th>System</th>
<th>Side-effects</th>
<th>Treatment options</th>
<th>Common causative agent</th>
</tr>
</thead>
<tbody>
<tr>
<td>GI</td>
<td>Diarrhoea</td>
<td>Loperamide po, check compliance with food, dose interruption and restart</td>
<td>All agents in Table 1</td>
</tr>
<tr>
<td></td>
<td>Stomatitis</td>
<td>Oral hygiene with antiseptic mouth wash, topical Bonjela, dose interruption and restart</td>
<td>All agents in Table 1</td>
</tr>
<tr>
<td>Respiratory</td>
<td>Interstitial lung disease</td>
<td>Stop medication, po steroids, no further rechallenge with the causative TKI</td>
<td>Er, Ge</td>
</tr>
<tr>
<td></td>
<td>Non-infectious pneumonitis</td>
<td>Stop medication, po steroids, can consider dose reduction with caution</td>
<td>Ev</td>
</tr>
<tr>
<td>General</td>
<td>Asthenia</td>
<td>Dose reduction and/or treatment breaks</td>
<td>Ev, Im, Pa, So, Su</td>
</tr>
<tr>
<td>Dermatological</td>
<td>PPE</td>
<td>Topical moisturisers, treatment breaks</td>
<td>La, So, Su</td>
</tr>
<tr>
<td></td>
<td>Alopecia</td>
<td>Dose reduction and/or treatment breaks</td>
<td>So, Su</td>
</tr>
<tr>
<td></td>
<td>Drug rash</td>
<td>Stop medication, antihistamines, po steroids restart with anti-histamine coverage</td>
<td>All agents in Table 2</td>
</tr>
<tr>
<td></td>
<td>Acniform rash</td>
<td>Topical e.g. minocyclin or metronidazole and oral antibiotics e.g. minocyclin, topical steroids, 1% hydrocortisone for face stronger strength steroid for the rest of body</td>
<td>Er, Ge most likely</td>
</tr>
<tr>
<td></td>
<td>Nail bed deformities</td>
<td>Podiatry, stop medication, topical antibiotics e.g. Mupirocin</td>
<td>Er, Ge</td>
</tr>
<tr>
<td></td>
<td>Trichomegaly</td>
<td>Artificial tears, ophthalmologist referral</td>
<td>Er</td>
</tr>
<tr>
<td>Endocrine</td>
<td>Hypothyroidism</td>
<td>Monitor TSH levels, T4 replacements to correct TSH back to normal range</td>
<td>So, Su</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>Reduced EF</td>
<td>Monitor EF function periodically, cardiology referral for medication optimisation</td>
<td>La, Su</td>
</tr>
<tr>
<td></td>
<td>Hypertension</td>
<td>Treat as normal hypertension with multiple drugs until BP falls within normal range</td>
<td>Pa, So, Su</td>
</tr>
<tr>
<td>CNS</td>
<td>RPLS</td>
<td>Stop medication, optimise blood pressure</td>
<td>So, Su</td>
</tr>
<tr>
<td>Haematological</td>
<td>Various cytopenias</td>
<td>Stop drug, transfusion, growth factor support in cases which are refractory to other supportive measures</td>
<td>Ev, Im, Pa, So, Su</td>
</tr>
</tbody>
</table>

Key: Er=Erlotinib, Ev=Everolimus, Ge=Gefitinib, Im=Imatinib, La=Lapatinib, Pa=Panzopanib, So=Sorafenib, Su=Sunitinib

RPLS=Reversible Posterior Leukoencephalopathy, PPE=Syndrome Palmar-Plantar Erythrodysesthesia

Disease specific treatment for malignancy during the palliative phase
Advance Directives: their role in clinical practice and their difficulties

Dr. TSE Chun Yan
Honorary Advisor, Hong Kong Society of Palliative Medicine.

In the Hong Kong context, an “advance directive” (AD) with legal status refers to an advance refusal of life sustaining treatment (LST). Under the common law framework, a valid and applicable AD refusing LST is legally binding. In 2006, the Law Reform Commission published a report on AD recommending promotion of the concept of AD via non-legislative means in Hong Kong. However, there are different views on this in the community. AD as a legally binding tool in advance care planning (ACP) has its role in clinical practice, but there are practical difficulties as well as legal uncertainties. Hong Kong may have to work towards legislation for AD to clarify its relationship to the best interests principle. At this moment, AD may be promoted in selected patients as part of ACP in advanced incurable illnesses. Regardless of whether AD is promoted in Hong Kong or not, it should be noted that AD is not a panacea for the difficulties faced by dying patients. In patients faced with an advanced incurable disease, AD should be part of ACP, and ACP should be part of the full spectrum of palliative care for a terminally ill patient.

Family Care for Miscarriage

Dr. Helen Liang,
Associate Consultant, Department of Obstetrics and Gynaecology, United Christian Hospital.

To medical staff, pregnancy loss is a commonly encountered event in their practice. However, to the suffering family, it is not only the loss of a baby, but also a loss of (parental) identity, and possibly a loss of self-esteem. It may have great impact in the marital relationship and future planning of a family.

The aim of bereavement counseling is to facilitate expression of feelings and normalize grief emotions, to meet tangible needs and to listen to special requests. There is great difference in the needs of women with spontaneous miscarriage and patients with abnormal baby requesting termination of pregnancy. In a later grief phase, we aim at restoring family daily functioning, helping couples review the loss process, and finding new meaning in life.

There are different reactions to loss at different stage in different people, which are affected by their life experience and beliefs. For example, parents’ age, parity, family supports will affect their recovery greatly. The reactions are also different in women and men.

There are some coping skills may help couples overcome the difficult time including: honor the baby by giving her/ him a name, keep a journal, find a support group, take time off, pick up a new hobby, etc. We also need to help couples face some difficult situations, like how to break the news to friends, relatives, and coworkers, how to talk to children about pregnancy loss.
The prevalence of childhood cancer in Hong Kong is approximately 150 per 1,000,000 children. Nearly 45 children die from cancer every year. Similar to Western countries, childhood cancer is the leading cause of death amongst children between the ages of 1 and 14 years in Hong Kong.

Since its inception in 1989, the Children’s Cancer Foundation (CCF) has been providing comprehensive psychosocial services for children cancer patients and their families on a territory-wide basis. The CCF team consists of experienced professionals including family counselors, clinical psychologists, hospital play specialists, nurse specialists, and occupational therapist. The team, in combination with the hospital staff, provides a range of community-based and family-oriented support services.

CCF first initiated its Palliative and Home Care Service in November 1999, caring for 70% of children with advanced cancer in Hong Kong every year. Our goal is to provide specialized palliative nursing care for children with incurable cancer, enhancing the quality of their remaining life. The three nurses in our team work in collaboration with fellow CCF professionals and the parent teams of five attending hospitals where patients will be referred to us. After a child’s death, bereavement care is provided for the family during this difficult time of emotional upheaval.

Simplification of the procedures related to death of children at home and the issuing of the Certificate of Cause of Death was implemented in April 2005. CCF played an important role in negotiation with the Hospital Authority (HA) to make this possible. Since then, the Certificate of Cause of Death of the child can be issued by the doctor in Accident and Emergency Department in HA hospitals. The body will be kept in the mortuary of said hospital. This removes the nuisance of going through police investigation and therefore avoid adding stress and burden to family members who are already facing grief at such a tragic time.

Respite care service was instituted in August 2009 at the Respite Care and Rehabilitation Center. The service aims at providing respite for parents who have been shouldering the burden of caring for the sick child chronically.

A new private but not-for-profit hospital, the Hong Kong Anti-Cancer Society Jockey Club Cancer Rehabilitation Centre, was opened in October 2008. In this new centre, the HKACS has adopted a novel one-stop 360 degree cancer rehabilitation model for cancer care. Cancer patients and their families are provided care to meet physical, psychological, social and spiritual needs.

Our target patients include cancer patients at various stages of disease, including before, during and post cancer treatment phases. Patients are referred from both public and private sectors. It is the objective of HKACS to help cancer patients in a way convenient and practicable to them during the battle against cancer. With the comprehensive care and rehabilitation, cancer patients could maximize their functional recovery, regain control over many aspects of their lives, and remain as independent and productive as possible.
Among the services for the bereaved provided by Comfort Care Concern Group (CCCG), volunteer-orientation is an important element. The CCCG bereavement services consist of counselling provided and the warm, caring, friendly and continuous support provided by the trained volunteers. Volunteers, with or without experience of losing their loved ones, are valuable human resources coming from the community, and beneficiary to both the bereaved and the volunteers. The potential of volunteer services have been widely used in the CCCG services for years, including individual or family counseling, bereavement therapeutic group, mutual help group, orientation for the newly bereaved, funeral support service and community education. Nowadays, volunteer service in palliative care is well received by patients, families and hospital staff. Some volunteers also contributed further by publishing their experience in books and participating in bereavement training.
7th Hong Kong Palliative Care Symposium: Workshops and Student’s presentations

Dr. Pamela Leung conducted the workshop on “Meaning-making intervention for advanced cancer patients”.

Heidi Wu presented “Communication with terminally ill”.

Camila S.Y. Li presented “Professional carer’s grief in caring for the dying”.