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 in stepwise planning for ACP plus personal sharing of end of life scenarios with and without ACP.

Program feedbacks from the participants

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

- 97% elders shown increased understanding of ACP
- 90% elders indicated likelihood to plan for their own ACP
- 91% elders expressed to discuss ACP with their family
- 100% participants were satisfied with the program
- 50% workers believe death taboo is one of the major barriers for ACP
- 9% elders indicated not wanting to talk about death

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-
relationships addressing the seven emerged major themes, and is presented in Figure 1.

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 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 adamant 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**

**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: