Peaceful Death in Nursing Home - A Family Perspective

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Death and dying affect more than an individual, and should be considered a family event. Epidemiologically, each year at least 150,000 to 200,000 persons in Hong Kong are affected by death events, assuming a dying person affects 3 to 4 persons on average.

Locally, there have been many discussions on “ageing in place”, but little discussion has been focused on “dying in place”. A survey conducted by the Society for the Promotion of Hospice Care on “Good Death” in 738 subjects sampled from the public in 2004 showed that “dying at home” scored the lowest among 14 items (2.72 out of score from 1 to 10). Another survey conducted by SPHC in 430 subjects among public in 2002 showed that 27.2% preferred dying at home if they were terminally ill. (Table 1) No formal study has been conducted on “Good Death” among the terminally ill in Hong Kong. Nevertheless, responses from the residents of Haven of Hope Nursing Home did show a rising trend and significant proportions (30% of all deaths of nursing home from April 2005 to March 2005) of terminally ill residents had shown a preference of “dying in place” in nursing home (Dr W Chu, personal communication). Factors affecting place of death including patient and family factors, care factors and system factors.

For seniors who moved to a nursing home, albeit the support gained from the care of nursing home, the psychological journey of the family is often a process of saying goodbye to one after the other: to health and independence, to home environment and family, to the state of full recovery and finally to life itself. The seniors and family have to face a new form of relationship in terms of accepting the nursing home as a “surrogate home” and nursing staff as “surrogate caregivers”. To prepare for the smooth transition, certain degree of transfer of responsibility from family to nursing home staff and the formation of trusting relationship between the family and staff of nursing home should occur. The story of my father was shared as an illustration for this journey. He suffered from normal pressure hydrocephalus with progressive mobility impairment and mental decline over two decades. He was admitted into Haven of Hope Nursing Home at late 1999.

The recognition of the progressive losses and the preparation for the anticipatory grief for our loved one with progressive disease are especially important for family during this journey. Planned living in the dual perspectives of present and future is especially helpful. Delivery of tangible care, fulfillment of wishes, communication, being present, life review and reflective writing by family members are possible ways to recapitulate and reorganize relationship with the senior. Reflective writing has become my way to express my personal anticipatory loss. Through reflective writing, I recapitulated past events, reorganized my inner world, expressed emotions, grieved future losses and captured past memories as legacy. Organizing parents’ photo album was taken up by my sister as a mean to address the anticipatory loss. These photos had helped in capturing past memorable moments, organized events, facilitated emotional expressions and integrated relationship internally.

Nevertheless, the most difficult issue concerning last days is to bring about open discussion about it within the family. This process takes courage, sensitivity, opportunity and skill for initiation and conduction, and the realization that dying is a natural process in life. Most seniors are comfortable to discuss about this in the context of advanced life planning. Although issues related to treatment decision such as prolonging life versus quality of life could be a struggle, attitudes towards death and dying, family dynamics and communication will shape the final process.

My elder brother timely returned to Hong Kong to see my father after his health had deteriorated considerably. We decided to let our father stayed in nursing home. He passed way peacefully at one midnight without any distress. No CPR was conducted. His last office was assisted by me. My family said goodbye to him in the room behind the chapel where his body stayed. A memorial album was printed to capture all our memories to our Dad.