**Palliative Medicine Doctors’ Meeting**

**Fulfilling patients’ wishes: Dying in the place of choice**

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Abstract:

Dying in peace at home and accompanied by beloved family contribute for a good death. This is supported by the results of a recent survey on preference of home death in Hong Kong. However, limitations exist in current health care setting. We would like to share two cases which we successfully fulfilled patients’ wish to die at home with dedication of doctor and utilization of different health care resources. Factors for considerations, preparation and challenges for home death would be discussed. This article also includes literature review on clinical and socio-demographic predictors of home hospice patients dying at home in Singapore and narrative review on family carers providing support for home death.

**CONTENTS:**

**Two patients who died in place**

1) Catholic sister who died in a convent

Ms. C was an 88-year-old nun who lived in a convent in Shatin. She had diabetes, hypertension and ischemic heart disease. She suffered from cancer of uterus with pelvic radiotherapy done in 2014. Subsequently, she was noted to have lung and liver metastasis in 2017 and she preferred not to have further oncology treatment. She was admitted to St. Teresa’s Hospital in August 2017 for chest infection and was referred to home care team of Bradbury Hospice upon discharge.

For her social background, she was born in mainland China and studied in the United States. Her elder brother was a priest. She had been serving in Hong Kong since 1970s and worked as the principal of a kindergarten until retirement. She lived in the convent next to the kindergarten all along.

**Visiting of home care team and preparation of dying in convent**

Home care team with doctor and nurse visited Ms. C in convent and noted her to be weak and mostly bedridden. She was anorexic and tolerated puree only. She only had mild pelvic pain which was managed with ibuprofen and paracetamol as needed. She was taken care by a part-time helper during daytime and other nuns at night.

Psychospiritually, she showed acceptance to her progressive illness with peace in mind. She showed appreciation for returning to convent from hospital and enjoyed sitting out in garden.

Upon discussion of advance care planning, she was keen on comfort care only and minimisation of hospitalisation. She clearly expressed her wish to die in convent and the nuns were willing to take care of her at terminal state. Advance directive and DNACPR form for non-hospitalized patients were signed.

One week later, she had further decrease in oral intake and was noted to have delirium at night. Regular trazodone was added for nocturnal confusion. Otherwise, she was not in distress from pain or dyspnea. Unfortunately, Ms. C’s part time helper resigned upon recognising that Ms. C was dying. The home care team helped to find a new part time helper, a retired Health Care Assistant of Bradbury Hospice, with experience in looking after terminally ill patients.

She became terminally ill on the second week of returning to convent. Supplemental home oxygen was arranged for dyspnea. Home care team prepared her brother and the nuns for her deterioration. She was noted to be in dying phase a few days later and lowest dosage of fentanyl patch was commenced for pain control.

On the day of death, part time helper noted her to be gasping. Her brother and nuns continued praying on bedside. She stopped breathing in the small hours at night. The helper performed last office for Ms. C and then placed the body in a single room with air conditioner switched to the lowest temperature. Doctor certified death in the convent in early morning on the next day. The nun went to the Death Registry Office to obtain the Certificate of registration of Death on the same day and the funeral parlor took the body to mortuary thereafter. Family and the nun perceived peace during her dying process.
Dying in the place of choice

2) An elderly lady who died at home

Ms. A was an 84-year-old elderly, diagnosed to have cancer of uterus with peritoneal and pleural metastasis since 2007. She was treated in private sector all along and given multiple cycles of chemotherapy until 2016. She was admitted to Prince of Wales Hospital under Department of Clinical Oncology in April 2017 for multiple brain metastases, presented with cognitive decline and repeated vomiting. Whole brain radiotherapy was completed and she was transferred to palliative ward in Shatin Hospital for further care. She remained drowsy with no improvement of mental state after whole brain radiotherapy.

She lived with her elderly husband in Sha Tau Kwok. The couple was taken care of by 2 maids. They had immigrated to Ireland for many years and returned to Hong Kong after retirement. Their children stayed abroad. All children returned to Hong Kong for visiting when patient became terminally ill.

Upon discussion of advance care planning with children, they would like to bring patient back to Ireland for dying at home. Yet, patient was already too frail and medical team escort would be needed. They felt relieved to know that dying at home would also be feasible in Hong Kong and decided to bring her back to Sha Tau Kwok. Children agreed for referral to Jockey Club Home for Hospice (JCHH) for further support of patient at home on weekend.

We subsequently discharged the patient, who was terminally ill, to JCHH on Friday. The doctor in JCHH further discussed with family for the medical support of patient dying at home. Family brought her home on the next day.

Home care nurse from JCHH visited Ms. A daily. Patient further deteriorated 4 days later with desaturation and undetectable blood pressure. Family was prepared that patient was at dying phase and management of body after death was advised. Patient passed away in early morning and doctor from JCHH certified for her death on the same day. Family subsequently got the certificate of registration of death and the body was taken by the funeral parlor. It was consolatory for the children to accompany her at home during her last days.

Discussion

A Local survey on the preference of home death in Hong Kong

A survey organized by The Federation of Medical Societies of Hong Kong (FMSHK) in 2016 analyzed 799 postal questionnaires from medical staff, majority being doctors and dentists, and 775 telephone questionnaires of adult citizen. More than 50% claimed home to be the most suitable place of death while around 30 % prefer hospice. Sixty-seven percent of medical staff in the survey preferred to die at home in future.

Factors for Consideration relating to Home Death in Hong Kong

1) Legal Perspective

According to Coroners Ordinance (Cap. 504),2 certain types of deaths must be reported to the Coroner. Type 2 reportable death is “any death of a person (excluding a person who, before his death, was diagnosed as having a terminal illness) where no registered medical practitioner has attended the person during his last illness within 14 days prior to his death.” In this context, home death of patients with terminal illness, already under ongoing care is not reportable. Deaths in registered nursing Homes are exempted from reporting to the Coroner (unless deaths belong to other types of reportable deaths) while deaths in RCHE (Residential Care Homes for the Elderly) are reportable to the Coroner.

All deaths from natural causes in a house must be registered under the Births and Deaths Registration Ordinance (Cap. 174) within 24 hours after death (exclusive of the time necessary for the journey and of any intervening hours of darkness and of general holidays as defined by the General Holidays Ordinance). Upon death of a patient with terminal illness, the doctor who has attended the patient during his last illness, can personally view the body and sign Form 18 (Certificate of Cause of Death死因證明書) and Form 2 (Medical Certificate (Cremation)). A relative or informant has to bring Form 18 to one of the Death Registry offices and get the Certificate of Registration of Death (Form 12) 死亡登記證明書.

2) Removal of deceased bodies

Upon deaths, deceased bodies cannot be removed immediately to funeral homes or public mortuaries. The Certificate of Registration of Death (form 12), or a permit from the nearest police station, must first be obtained.

Preparation for Home Death

Upon encountering patient with wish of dying at home, we need to further discuss and document the Advance Care Planning (ACP) with the patient and his/her family. An Advance Directive with a refusal of cardiopulmonary resuscitation (CPR) should be signed by a mentally competent patient. The Hospital Authority Do-Not-Attempt CPR (DNACPR) Form for non-hospitalized patients which is signed by two doctors with one as specialist would serve as a DNACPR recommendation to the receiving healthcare team. A medical certificate or document (e.g. discharge note) confirming the diagnosis of terminal illness would be preferred as well.
A registered medical practitioner, either from public / private sector, has to attend the terminally ill patient and be the designated doctor if he/she would certify the death of the patient at home in future. Home care team would visit patient at home, providing information and knowledge to the family about what to expect and how to act. Continued communication and support to the family on management of distressing symptoms and detection of dying phase would be provided by the home care team.

Upon death, the designated doctor would certify death of patient at home. A relative / informrant have to bring the Certificate of Cause of Death (Form 18) to the Death Registry office within 24 hours after death so as to get the Certificate of Registration of Death (Form 12). The body may need to be kept at home for a short period of time before picking up by the funeral parlor with the Form 12. Prior contact with the funeral parlor is required. Doctors from public sector may not be able to attend the patient for certification of death. The police would be involved in this circumstance and the body subsequently be transferred to the public mortuary. The death would be reported to the Coroner. The family needs to be primed that they may face interview by police and forensic pathologist. With the background of terminal illness, autopsy may be waived but it will take more time to obtain the Certificate of Cause of Death and proceed to funeral. Joint support of patient and family with public / NGO / private sector collaboration may fill up this service gap.

Challenges in fulfilling patients' wish of dying at home

Although the local survey by FMSHK found that more than 50% of people perceive home as the most suitable place of death, dying at home is not a common practice in Hong Kong. As compared to a retrospective analysis of patients under home hospice service in Singapore from 2004 to 2013, 55% of a total of 19,721 patients passed away at home. The positive predictors of dying at home in that study included female, older age, living with a caregiver, more doctor and nurse visits, shorter duration of home hospice stays and fewer episodes of acute hospitalizations.4

In Hong Kong, we need to overcome challenges in different aspects to achieve a good death at home. For the physical aspect, it may be difficult to relieve terminal symptoms at home as parental medications may be needed. Use of syringe driver medications for death rattle or terminal restlessness require daily visiting by home care nurse or doctor which may not be feasible in the public sector. As the use of parenteral Dangerous Drugs at home will require careful monitoring, this limits the use of subcutaneous opioid infusion to manage dying patients with distress from pain or dyspnea at home. For patients requiring subcutaneous fluid rehydration, home care nurses need to visit regularly and set up the infusion set. Caregivers have to be competent for monitoring and removal of catheter upon finishing. There is lack of manpower in public sector to provide 24 hours on-call support to patient and family at home.

For the psychological aspect, family may feel incompetent or uneasy to take care of a dying patient at home. Prompt and continuous support from experienced palliative workers would be needed. It is not uncommon for caregivers having guilt feelings or sense of helplessness in witnessing patient’s distress. There is also risk of burnout of caregiver in looking after patient throughout 24 hours.

For the social aspect, it may not be easy to find a helper who is experienced and willing to take care of dying patients. Home death may generate fear and discomfort to neighbour. There is fear of depreciation of property value with home death as well. It also incurs more cost for private home care nurses visit and removal of body by funeral parlor from home.

Among those factors, the availability of dedicated caregivers and a holistic ‘around-the-clock’ medical supportive team play a fundamental role in making a home death possible. In a narrative literature review of family carers providing support to a person dying in the home setting, they require emotional, instrumental and information support from professional home care team. Maintenance of normality and privacy of caregivers, clear and timely information on symptoms management, prognosis as well as practical assistance, acknowledging the significance of the family carers’ role are important factors to overcome burdening of carers. On the other hand, family carers perceive home environment provides a sense of security, peace and dignity to the dying person and facilitate for bond development with family members.5

Conclusion

We still encounter much difficulty to achieve home death in public health care sector. In regards to our patients, we have early discussion with patients or families for their preference of place of death in advance care planning and explored for its acceptance with family members. Timely and continual support for symptom management to caregivers is crucial, which would require dedication of doctors and nurses to attend when in need. Recruitment of helpers with experience on caring for dying patients or liaison with other care providers would fill up the gap out of working hours. Finally, advice on handling of dead body and prior arrangement of funeral parlor are needed.

References: