

A BREAKTHROUGH IN THE END-OF-LIFE CARE IN A NURSING HOME IN HONG KONG

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Abstract

The first documented case about a 67-year-old lady with terminal illness received End-of-Life Care during the last year of life in a 250-bed nursing home in Hong Kong is reported. There are benefits and difficulties in implementing such service. The clinical, legal and administrative aspects, together with the limitation and progress of the care are also discussed.

Case presentation

Ms C was a 67-year-old housewife with history of carcinoma of left breast (1996) with T12 vertebral metastasis and possible cauda equina as a result of compression to L4 vertebra. She had mastectomy and post-operative radiotherapy performed. On admission to the Haven of Hope Nursing Home in September 1999 she complained mainly of pain in various body parts, anorexia, poor mobility, and low mood. She communicated verbally, walked with a frame, and was able to self-feed.

Various measures such as medication and physiotherapy were directed to control the symptoms. Ms C was also encouraged to join different programmes to improve her psychosocial state. She later developed more complications including bilateral DVT of legs and bony metastasis to ribs. These have caused much distress and she was referred to the CGAT and Palliative Unit of the Haven of Hope Hospital located next to the Home. The geriatric out-reach team has provided support on medical consultation and investigation whereas the hospice team has also provided training and counseling to the staffs in the Nursing Home. Support groups were formed targeting the resident, family, staffs, and other fellow residents. While residing in the Nursing Home, she was frequently visited by her family, chaplain and volunteers who provided comfort and support.

Ms C's condition deteriorated further despite improvement in her mood. During the second admission to hospital in September 2000, Ms C and the family expressed the wish of returning to Haven of Hope Nursing Home for her end of life care. "I want to go home (the Nursing Home)" was her request. After careful discussion and planning among nursing home staffs and hospital palliative care team; together with the support from the management, Ms C was transferred back to the familiar environment in the nursing home for end-of-life care. The hospital Palliative Care continued to provide expert medical advice and support to the nursing home staffs. Pain and symptom control were very satisfactory. Psychosocial and spiritual support were also provided to Ms C and her family. Her condition quickly deteriorated and when she became drowsy, hydration was maintained on Ryle's tube feeding and a brief period of sub-cutaneous fluid infusion for poor gastric emptying. The family was pleased that their loved one was peaceful and showed no signs of distress. Ms C passed away in the morning on 8th Nov 2000 when the nurse proclaimed the death at 0755 hour. The medical officer attended the death and issued the Medical Certificate of the Cause of Death (Form 18) in the Nursing Home. Many of the nursing and personal care staffs who had cared for Ms C in the Home also came to say good-bye. The hospital mortuary supported the last office service and the funeral arrangement was organised smoothly.

After Ms C's death, discussion groups were held among fellow residents on several occasions. They were encouraged to express their feelings and wishes. Five out of ten residents who were close to Ms C actually voiced that Ms C's scenario was the good death and care that they prefer to have. Six months have elapsed since Ms C's death and we have two more residents passed away in the Home.

One of them was a patient with breast carcinoma with liver metastasis and the other had end stage renal failure. They were both cared for in the Home with no hospital admission during last six months of illnesses. This special service programme is also informed to the residents and their families through the Home's Newsletter. Eight other residents and families have so far discussed the issue and decided to join the care programme.

Discussion

There are around 30 000 mainly elderly residents in various residential care homes in Hong Kong (see appendix). They suffered from an array of physical and cognitive impairment¹. Their health status is likely to deteriorate as they grow older. Consequently the homes have to care for sicker and older persons, who will eventually require hospital support. It is a common practice that the terminally ill persons be admitted to hospitals usually via the A&E Departments. The residents and families usually have little choice in this matter. This practice is convenient for the Homes but not cost-effective for the whole care delivery system. It also contradicts with the overriding philosophy of "Ageing in Place" advocated by the Government and the concept of "good dying" for which the persons choose the place of death where they feel at home.

It has been increasingly recognised that principles of good palliative care are universal, and should be applied in many different conditions including Elderly Care^{2,3}. The ultimate goal of palliative care, with which the Home also shares, is the achievement of the best quality of life for the residents and families. Indeed, excellence in terminal care is proclaimed to be a major priority in long-term care⁴. To accomplish the goal the Home tried to look into other's experience and success. Hospice care is commonly provided in the nursing Homes in US^{5,6} and there are reviews and researches reporting the implementation and precautions on the provision of such service. However, published data and experience in the local setting is rather scarce. To start off the service the Home relied on the experience of its staff members as well as receiving professional help and practical support from the Administration and Palliative Care Team of the Haven of Hope Hospital.

The "End-of-Life Care" service in Haven of Hope Nursing Home aims at providing holistic care and good palliative medicine to the terminally-ill residents and their families, who are voluntarily participated and are well-informed. The End-of-Life care service enables and helps them to walk through

the last phase of life in a caring, familiar, and trusting environment. Our model of care addresses the physical, psychosocial, and spiritual needs. The continuing care for the residents in the Home even during the dying phase would also avoid unnecessary hospital transfer.

To successfully implement the care we have to address three particular issues.

1) Patient's and family's factors

1.1) Wish and Autonomy - They should always be observed and respected in all case. The residents and the families should be fully explained on the consideration, planning and the implementing of such care provision. It is only after a thorough understanding and acceptance of the care would the service be meaningful and beneficial to them.

1.2) Advanced Directives - The Do Not Resuscitate (DNR) order and the "Do Not Transfer" agreement - All family members and not just the principle member should agree on the decision. The decision is more likely to be welcomed when the residents are in stable condition before acute crises appears. The discussion on DNR and "End-of-Life Care in Nursing Home" are preferably be made separately with a good period between. This gives the families better psychological preparation and acceptance to their love one's condition and the care.

1.3) Selection of suitable cases - The life expectancy is limited and suitable cases include incurable cancer or end-stage organ failure. The residents should be physically and emotionally stable so that stress to other fellow residents is minimised.

2) Care factors

2.1) Staffs - Sharing sessions and discussions groups are held over different occasions before planning the care. The objectives and views are openly discussed in order to share a common vision with the ultimate goal of maximising resident's benefit. With the guidance given by the experienced and senior members in the Nursing Home, the staffs could explore more innovative and effective ways in provision of care and to meet up different challenges. We are also fortunate to have a senior nurse who has served for many years before in a Hospice to guide and support the staffs in the process. It is through the inter-disciplinary

and collaborative effort of the Home staffs that this could be achieved.

- 2.2) Support from Palliative Care Team - The strong medical and expert nursing support is provided from the palliative care team in the Haven of Hope Hospital. Support and attention is also paid to the families, carers, fellow residents, and staffs. There are active sharing and counseling before, during and after the dying process with the parties involved. Adequate skills, knowledge, and psychological preparation can therefore be provided to the staff members. This is given through teaching sessions, discussion groups, and during clinical intervention. Clinical support is also given to achieve the best possible symptom control.
 - 2.3) Support from Community Geriatric Assessment Team - The CGAT provided on-site comprehensive geriatric assessment and management to selected residents who have more complex health care issues. Early investigation and management of new symptoms enhances speedy symptom control. The CGAT also coordinates different services including Palliative Home Care with the aim of early referral and collaboration between specialties. The CGAT injected expert opinion into the setting up of various Long Term Care Protocols for common geriatric problems in nursing home that would encourage streamlined care planning and its implementation.
- 3) *System factors*
- 3.1) Physical environment - suitable rooms should be available to the dying residents during the terminal phase. This would facilitate the care to the residents and the visit by the family members. At the same time the disturbances to others can be kept minimal. Places for carers to rest are essential, as the dying process may be long and unpredictable. In addition, mortuary should be close-by for ease of transport of the body.
 - 3.2) Fellow residents' acceptance - With the careful selection of cases and a provision of suitable environment the disturbances so caused can be very little. Our experience showed that some residents may show sincere concern and was relieved when they knew that their old friends were in peaceful condition. Sharing with them would ease their worries and gain the acceptance.

- 3.3) Administrative support - The administrations of Haven of Hope Nursing Home and of Haven of Hope Hospital have been working closely together since the early planning of such care. The legal as well as the practical aspects has been carefully worked out. There are procedures agreed on handling of the dead body and the use of the hospital mortuary.
- 3.4) Coroner's Ordinance⁷ - It is lawful for deaths to occur in Nursing Homes in Hong Kong (which is registered under the Hospitals, Nursing Homes and Maternity Homes Registration Ordinance Cap165), provided that the attending medical staff is satisfied with the cause of death. The medical officer should follow guidelines laid down by the new coroners ordinance in completing the Form 18 (Medical Certificate of Cause of Death). When death occurs outside working hours the nurse-in-charge could proclaim the death but the medical attendant must view the body and certify the death in his earliest convenience.

The planning and establishment of the care could not be successful without overcoming difficulties. There are barriers arising mainly from the parties involved (fellow residents, families, and staff members). "Death and Dying" are issues uncommonly, if not rarely, talked about in the Chinese culture, especially among elderly persons. An Advanced Directives is therefore not usually prepared. Asian families tend to request that the elderly not to be told their diagnosis. They may in fact believe that they have the right to decide whether or not to let the elderly relatives know the diagnosis and the right to make decisions on their behalf⁸. The residents and relatives may think that hospital is the only place for dying and reluctant to accept other places which they considered as inappropriate or second-class. It is also necessary to point out that the patients' perspectives on end-of-life care should be addressed in addition to the health care professionals⁹. The patients identified five domains of quality end-of-life care as: receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones. It was also reported that many nursing home residents have severe symptoms and unmet needs for palliative care during the last three months of life¹⁰. The bereaved family members are also concerned with failures in communication and pain control.

Discussions that focus on specific treatment decisions may not satisfy the real needs of dying patients and their families¹¹. There may be fear, verbally or non-verbally, expressed by fellow residents towards the dying persons.

There has been concern about “proclaiming death by nurses” which, though well accepted in hospices overseas, is not a common practice in Hongkong. Administrative and clinical members should clarify the legal and practical feasibility before reassuring the staffs. There may be fear among personal care workers who may not have experience in caring or handling a dead body before. The emotional attachment between staff members and the residents may be profound and has to be addressed.

There is limitation in the nursing Home setting and selection of the cases should be careful. This is because the Home has only limited types and quantity of the medications. For example, Morphine would be available in oral or nebulised preparations but not in syringe driver. Moreover, very distressed resident may provoke fear and stress to other residents as well as straining the man-power in the staff level. The staff members would “need” training, education, and support while they would view improved staffing ratio and teamwork to be more important⁵. All these issues are important and have to be addressed through detailed sharing and discussion guided by trained staffs.

With the recent employment of Minimum Data Set - Home Care (MDS-HC) as an assessment tool in the Standardized Care Need Assessment Mechanism for Elderly Service¹² by the Social Welfare Department of Hong Kong, there may be an additional point to note. There were comments that MDS is insensitive in the domains of palliative care^{6,13}, and staffs working in the long term residential care field in Hong Kong may need to be alert to this.

In conclusion, with appropriate case selection, careful planning, and support from Hospital Geriatric/Palliative Care Team, provision of end-of-life care in the Nursing Home setting in Hong Kong is possible and worthwhile. Counseling, involvement and support to residents, family, and staffs are essential. Last but certainly not the least, the commitment and collaborative effort from every member of the inter-disciplinary team is vital to make the care a success. “Good death” is the desire of all elderly persons in the last journey of their lives. Assess to good palliative care in the nursing homes is the ultimate fulfillment of the concept of “Ageing in Place”. More open discussions and innovative improvement, e.g. mortuary facilities

support on end-of-life care issues would certainly be beneficial in the quality of elderly care provision in Hong Kong.

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Appendix I: Estimation on number of residents in different types of residential placement as in April 2001

Estimated number of residents in hostel / C&A Homes*	26 925
Nursing Home capacity ¹⁴	1 400
Infirmiry bed capacity ¹⁵	1 710
Total estimated number of resident in Residential Homes	30 035

* Verbal communication from the Licensing Office of Residential Care for the Elderly (LORCHE)