Promoting quality end-of-life care: an elderly woman with visual impairment

CASE REPORT

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INTRODUCTION

Chinese people consider being able to die in the presence of one's family the greatest fortune. Unfortunately, constraints on living space and medical advances mean people in Hong Kong usually die in hospitals after medical technology fails to save their lives. Recently some advocates have begun promoting allowing people to die at home, be it a natural home or a residential care home. It is beyond doubt that the majority of elderly people would prefer not to die in hospitals, surrounded by four white walls, with only professionals accompanying them on their final journey on this earth. The concept of dying at home will definitely gain support from and be popular with old people.

Recently a case illustrating this need happened in the Tung Wah Group of Hospitals (TWGHs) Jockey Club Yee Lok Care and Attention Home for the Aged Blind. A terminally ill frail resident insisted on leaving hospital even when her illness reached a very critical stage. Although the Home staff were able to anticipate the difficulties likely to occur if she returned to die in the Home, they were brave and committed enough to accept the challenge. As a result, this dying woman felt at ease during her end-of-life stage. Both her family and all the staff who worked with her felt gratified as this elderly lady's last wish was fulfilled. There is certainly a lot of work that needs to be done to accommodate a dying person in a residential home. But the dying person's peace of mind, something that can be seen and felt by all around her is priceless. All professionals working in residential homes should try all means to have such a mission materialised. Below is a brief description and analysis of this case.

CASE REPORT

The patient, aged 81, had been a resident of the TWGHs Jockey Club Yee Lok Care and Attention Home (hereafter called the Home) for 8 years and had a long history of diabetes mellitus. In late 2005, her health deteriorated and she was sent to hospital for treatment after Christmas. The Home staff kept in close contact with her daughter, who was the patient's principal carer. The patient's condition did not improve after hospitalisation and her mood changed significantly. She was very uncooperative with the medical staff, shouting and cursing at them all the time, behaviour she had never manifested in the Home before. More significantly, she refused to eat while in the hospital. After learning this, the Home Manager arranged for some staff and residents who were friendly with the patient to visit her and sent along some audio tapes with get well messages from other staff and residents to help her achieve a speedy recovery.

According to her daughter, the patient's mood showed a remarkably positive change on the day of the visit. But the situation reversed itself a few days afterwards. The daughter was very worried and distressed. She cried bitterly whenever she called the Home Manager and told the Manager that her mother was demanding to return to the Home.

Now that they were aware of what the patient wanted, the Home management seriously considered the request. Although there was no precedent for admitting a resident for end-of-life care, the Home staff were willing to take this challenge as the Home's mission was to provide quality care for elderly people in need. Death and dying are inevitable last tasks that elderly people must accomplish at the end of their lives. The Home was prepared to find any means to meet the needs of the patient. Bearing such a mission in mind, the Home staff visited the patient once more and explored further her wish to return. The discussion was held in the presence of the ward's nursing officer who was surprised by the very calm and peaceful dialogue between the Home staff and the patient as the discharge plan was discussed. The nursing officer revealed that she had never seen her so gentle as at that meeting. However, the discharge idea was beyond the comprehension of the medical officer-in-charge who had many reservations about the proposal. After lengthy persuasion, the medical officer-in-charge finally compromised and signed a 3-day home leave for the patient, on condition that she had to be sent back to the hospital immediately if any abnormality was detected. Three days afterwards, the patient returned to the hospital and the medical officer-in-charge was pleased with her condition after a thorough examination. Because there had been a noticeable improvement in her physical condition, she was formally discharged and returned to the Home after the 3-day trial.

Although the patient's physical and emotional condition improved after the 3-day home leave, her medical condition remained poor. All the staff understood very clearly that they were going to take care of a dying resident. On the afternoon of February 10, after the patient had spent 2 weeks in the Home, her blood pressure dropped drastically and she became confused. After consulting her daughter, she was admitted to hospital and passed away peacefully at noon on February 11.

All the Home staff treasured the opportunity to be with this patient as she took her final journey on earth. There was much learned and insight gained from working with this patient. An analysis of this valuable work experience is elaborated below.

THE THREE PRINCIPLES OF QUALITY END-OF-LIFE CARE

Katz[1] has listed three inter-related principles for good end-of-life care. The first is to enable the dying person to die with dignity. The second is to retain the dying person in his/her familiar surroundings till death[2] if at all possible, and the third is that the dying person is entitled to good pain control and nursing care.

It has never been an easy task to adopt the first principle since physical deterioration and decline, such as immobility and bedsores do create a loss of dignity for dying people.[3] So we tend to define dying with dignity more in terms of "being treated and respected as a person". With this patient, we tried to work with her using a person-centred approach where personal choices and decisions are always respected.

With regard to the second principle—retaining the dying person in his/her familiar surroundings till death—successfully convincing the hospital staff to discharge the patient is evidence that this principle was achieved, even though she did not ultimately die at the Home. Considering the constraints of the Home, the arrangement made was the best one.

In relation to the third principle of good pain control and nursing care, the Home staff made every effort to help the patient with this. As mentioned above, she refused to eat while in hospital so a nasogastric tube was applied which further irritated her and made her try to pull out the tube. During her 3 days of home leave, the Home staff not only took away the tube, but also spoke to her tenderly, persuading her of the importance of food, even some drinks. Each day the staff asked her what she preferred to eat, in order to stimulate her appetite. Fluid supplements were also added to her meals every day. As a result her condition improved after the 3-day home leave enabling the medical officer-in-charge to witness the effect of the quality care provided to her.

To help ease the patient's pain, the Home staff worked closely with the Visiting Medical Officer to manage nursing tasks. The Home staff tried as far as possible not to use a urinary catheter, to minimise her discomfort. She was frequently given body massage for further comfort.

Froggatt[4] mentioned that the provision of general comfort to a dying person is very much based on the carers' personal relationships with the dying person and their experience of working with people with chronic, long-term conditions. That experience should enable them to perceive the person's needs even when the latter is unable to articulate. The Home staff, who had developed good relationships with the patient, were able to perform the caring tasks smoothly.

ADDRESSING DIFFERENT NEEDS OF THE DYING RESIDENT

Death in a residential home is often characterised by psychological suffering.[5] The dying resident, like this patient, very often needs 'individualised' care to compensate for her social isolation and psychological suffering. The Home staff devoted much time and manpower to this aspect; for example, staff would take turns to talk to her during her wakeful periods. Whenever she expressed any desire to eat, whether it be food that could be cooked in the Home, or purchased outside the Home, her wish was fulfilled. As Jeffrey[6] mentioned, "Here, care is concerned with the whole person."

FACTORS CONTRIBUTING TO QUALITY END-OF-LIFE CARE

This case highlights several elements that are central to the successful implementation of quality end-of-life care. First of all, the commitment of senior management to the provision of quality care is vital. Equally, a flexible and responsive approach from the middle level and frontline staff, working in the best interests of the dying resident, counts too. Moreover, inter-disciplinary co-operation, centring on the needs of the dying person is also significant.

The practical implications of dealing with death in a home are time consuming and the whole experience can be emotionally draining.[1] Peace and Katz[7] contend that fundamentally, quality end-of-life care in homes is concerned with two factors: relationships and resources.

The relationships with other health care professionals as well as informal carers is a very important factor contributing to quality end-of-life care.[8] Peace and Katz wrote, "There are many relationships in care homes: between care staff and residents: residents and family and friends; care staff and family; between residents themselves; managerial and care staff at all levels; care home staff and external health workers, and each of these relationships may have an impact on the person who is dying and their death."[7] The Home had an advantage in this area since all these complex relationships were managed well all along, creating a peaceful and loving environment for the dying resident.

The relationship between the patient and her family is particularly worthy of mention. During her hospitalisation, when the patient demanded to return to the Home, her daughter once tried to trick her by driving her out of the hospital for a short while, then returning her to the hospital, saying she was back in the Home. Despite the patient's visual problem, she realised that she was still in the hospital. The mother-daughter relationship became very poor then. It was only when the patient returned to the Home and her daughter could stay longer with her that her anger towards the daughter was resolved. The daughter realised that the Home, which was more flexible about routines, could provide more time and space for her to be with her mother. Hence, she was very grateful to the Home staff for all the humane arrangements made for her mother.

All quality work requires resources, the difference is only the extent of those requirements. Training home staff about palliative care is essential for improving end-of-life care for people dying in residential homes. Very often, staff lack the skills to address the different needs of dying residents.[9] Froggatt[4,10] found that not only nursing staff, but also ancillary staff could benefit from training. So staff training is another area that determines whether good end-of-life care can be delivered.

FUTURE DIRECTION

At present, a large proportion of people in Hong Kong die in hospitals, rather than at home or in residential settings. But if we view the issue within the changing context of demography and policy, i.e. the rapidly ageing population, the promotion of community care, the concept of ageing in place and dying at home promoted by the government, there will potentially be more frail elderly people spending shorter times in residential homes. As in

other developed countries, the residential home will be the place of death for many elderly persons in the future.[11,12] The issues of quality end-of-life care will become increasingly central.

Lynn[13] concluded, "Living with serious illness through to death can be an extraordinarily important phase of life for patient and loved ones, but only if the dying person is comfortable, assured of the resources needed for daily living, and respected. We need to build the skills, attitudes, and patterns of care that allow us to make promises of good care to dying patients."

Seeing the growing significance of this issue, it is hoped that partnerships between different stakeholders can be formed to create a dynamic resource able to consider how policy, practices and research can be pulled together to work on different quality end-of-life care models for the diverse needs of the people of Hong Kong.

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