HCA HOSPICE CARE SERVICES (B):
THE DESIGN OF HOME HOSPICE WORK

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The multidisciplinary team at HCA Hospice Care (HCA), comprising of doctors, nurses, social workers, counsellors and volunteers, provided home-based hospice care to needy patients with terminal illnesses. The case focuses on the design of hospice home care services by HCA, in particular, the work performed by two groups of professionals (doctors and nurses) in the delivery of palliative care. The key competencies required of such workers and job-specific context of home hospice care are also discussed.
THE PATIENTS

Terminally-ill patients referred to HCA by the government hospitals generally had a prognosis of one year. However, about 75 percent passed away in three months.

Each day, HCA’s multidisciplinary teams comprising of doctors, nurses, social workers, counsellors and volunteers travelled to the homes of these patients who had been discharged from acute care hospitals.

The majority lived in public housing (HDB) in suburban Singapore and a growing number lived alone. As care was delivered at home, patients were generally more at ease and it was possible to make adjustments to personal preferences such as sleeping areas and dietary habits, than was possible in an institutional setting. However, the general state of patients’ home environment varied widely in terms of hygiene and orderliness.

THE CARE DELIVERY TEAM

These teams operated from four satellite centres located in public housing estates (Hougang, Woodlands, Jurong and Bedok) and one centre that was housed in the charity’s headquarters located near the city centre. The aim was to serve patients within the vicinity of the centre.

In 2009, each satellite centre was staffed with one doctor, four to five nurses and one social work assistant. They were supported by some part-time doctors, nurses and volunteers.

THE CARE DELIVERY

The care delivery combined both scientific and humanistic approaches to care as the caring process was facilitated through a combination of science, presence, openness, compassion, attention to detail, and teamwork.

Hence, the teams not only administered medical and nursing care to patients but emotional and psychological support as well. Patients often needed relief not only from physical pain but also the mental and emotional stress.

The delivery of care was nurse-centred and the nurse was the first point of call for the patients. Nurses walked the journey with patients, becoming trusted friends, helping patients and families through their psychosocial and spiritual struggles. Sometimes patients grew so close to the nurse that they would ask for her to be present during their last moments.

Patients on palliative care often presented therapeutic challenges. All of these patients had advanced diseases, most commonly metastatic cancer. Several organ systems were often affected - bones, the lungs, liver and kidneys, which made it more challenging with regard to the drug handling and drug metabolism. The number of symptoms that had to be treated ranged from an average of five at the time of presentation to a palliative care service to nine at the end stage of life. A large proportion of patients in the older age group were also at higher risk of co-morbidities, such as cardiovascular disease, diabetes and impaired renal function.

The patient’s family was also included in the unit of care. Nurses had to be trained to assess fears and anxieties of patients and their family members. This provided insights into family dynamics and helped to console the family when death occurred. The goal was to promote the quality of life as the illness progressed through the relief of suffering, including care of the dying and bereavement follow-up.

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1 The Housing and Development Board (HDB) was the statutory board of the Ministry of National Development responsible for public housing in Singapore.
2 Elderly HDB residents living alone had increased from 14,300 in 2003 to 22,000 in 2008 and was expected to rise further. Retrieved June 15, 2010 from http://www.news.gov.sg/public/sgpc/en/media_releases
THE JOB OF HCA PALLIATIVE CARE DOCTOR

Roles and responsibilities

- Make patients comfortable through symptom control, despite the disease.
- Manage terminally-ill patients in the last phase of life.
- Provide holistic care, including psycho social care to the patient and caregivers.
- Communicate with patient, caregiver and family on medical matters relating to the patient's illness.
- Be medical consultant to nurses to facilitate the performance of their work including endorsing nurse’s treatment plans for the patient.
- Continually upgrade knowledge and practice of palliative medicine.

Work activities

Typically an HCA doctor examined and administered medical care to six patients a day from 8.30 am to 5.30 pm, mostly with a nurse and sometimes alone. Visit duration ranged from 30 minutes to one hour. Coordinating closely with nurses, a typical day for the doctor would include the following activities:

- examine patient and assess present condition including pain and symptoms (vomiting, nausea) management.
- write prescriptions for patients and exchange information with nurses.
- assess patient's awareness of their medical condition and family's attitude on this issue.
- identify caregivers and refer them for training as needed.
- evaluate psychosocial factors related to the patient and, if necessary, refer to HCA social worker.
- co-ordinate with doctors in hospitals to ensure continuity of care between hospital (or inpatient hospice) and hospice home care team.
- record-keeping - write continuation notes to be subsequently keyed into a database.

Organisational and work context

- The patients' homes were the normal place of work for the home care team. Doctors/nurses travelled to patient's home by taxis and on average travelling time accounted for 1 - 1.25 hours per work day. This meant that there was a wide variation in the physical work environment. Also, the usual work systems and process flows of consultation rooms/hospital rooms were not available to support their work.

- The charity provided a 24-hour hotline service and doctors were on call at least once a week. Doctors on call could be required to visit patients at home, possibly two to three calls during one night and usually on weekends. However, close follow-up of patients by nurses helped reduce the number of such calls. In addition, doctors had to be on weekend call once a month from Friday 5.30 pm to Monday 8.30 am.

- The nature of work could be emotionally draining and stressful as the doctor was dealing with death as the inevitable outcome of palliative care. Outcomes were variable while families had a lot of hopes associated with them. Compassion fatigue was common and the challenge was how to draw the line at a personal level so as not to compromise the care of other patients.

- HCA doctors met once a week to learn from each other by (a) making presentations (b) having case discussions and (c) sharing experiences on how to manage patients.
THE JOB OF HCA PALLIATIVE CARE NURSE

Roles and responsibilities

• Categorise patient cases and plan patient home visits by route and/or medical priorities.
• As the first point of contact with the patient, make home visit to:
  - introduce HCA’s services to the patient and family.
  - assess patient’s needs and problems, and coordinate with the doctor on home visit.
  - work with assistant social worker on means testing requirements.
• Ensure patient is comfortable by relieving pain and symptoms through administration of medicines/ painkillers (requisite prescriptions were prepared for doctor’s endorsement before visits if making the home visit alone).
• Assess care available at home including competence of caregivers.
• Assess family dynamics and possible psychosocial issues; coordinate with social workers, volunteer coordinators or others as required.
• Record-keeping of patient visits (using handheld devices).
• Follow-up previous day’s visits with phone calls to check on state of patients.
• Continuous upgrading of knowledge on pain and symptoms relief.

Work activities

Each HCA nurse had a case load of 35-40 patients and typically visited about five to six patients a day. Each visit could range from half an hour to more than an hour depending on the patient’s condition. During these home visits, nurses carried out the following activities:

• Diagnose patient’s symptoms either independently or in consultation with doctor, as required.
• Administer basic nursing care to patients, including medicines and injections.
• Advise family members and caregivers on care of patient and provide caregiver training.
• Interact/communicate with patient, family members and caregivers in regard to:
  - patient’s condition and symptoms
  - possible psychosocial issues
  - means testing requirements
  - HCA activities
• Liaise with other team members and external parties on physical and psychosocial issues associated with patient’s condition, such as patient’s fears and anxieties.
• Console the family upon bereavement.

Organisational and work context

• Nurses worked a five-day week from 8.30 am to 5.30 pm, except for an afternoon shift twice a month and one weekend call every three to four months. In addition, nurses worked one full Saturday per month to enable them to meet family members.
• Delivering care at home, the nurse had to work independently in a wide range of patient home conditions.
• Nurses were witnesses to family grief and at times, negative emotions of family members, especially when they were in denial of the patient’s condition.
HCA DOCTORS AND NURSES: ON DELIVERING HOSPICE HOME CARE

“Palliative care professionals need good communication skills and have to be emotionally stable. They have to be emotionally strong to be able to do this for a long time. They also have to know how to take care of themselves to prevent burnout. Going beyond your working hours and beyond the job is normal for people in our line.”

Dr R. Akhileswaran
CEO and Medical Director, HCA

“The major difference in dealing with patients at home is that at hospitals the complete support services were available, whereas at home the doctors and nurses are on their own. You become a generalist.”

Dr Dennis Dignadice
HCA Jurong Centre

“I derive satisfaction from being able to help patients manage their symptoms in the comfort of their homes; knowing that I have made a difference helping patients to die at home; and also supporting the family. This is the essence of true medicine and I am privileged to do this every day.”

Dr Chong Poh Heng
HCA Woodlands Centre

“Hospice care is not for doctors who want to see results or find satisfaction in curing. It is about giving patients a better quality of life and making a difference. The biggest challenge is to be prudent enough to know how much to do. It is futile to do more in some settings. For example, we know that the patient will not survive beyond a week, then do we send him to the hospital when it is clear that he will not benefit? At the same time the family wants to do whatever they can… so the decision is very hard.”

Dr Do Su Em
HCA Bedok Centre

“Life experience is more important than work experience. We need to pay more attention to the loners who have no relatives as well as younger patients… occasionally such patients are averse and we have to handle their suspicion.”

Gertrude Chia
Senior Nurse and Satellite Manager
HCA Bedok Centre

“One needs passion in this job to tide over difficulties. As time goes on, you learn to detach when the time is right. Sometimes patients or caregivers want to try traditional or complementary medicines and that is acceptable as long as it doesn’t compromise treatment.”

Debbie Low
Senior Nurse and Satellite Manager
HCA Jurong Centre

5 Dr Chong Poh Heng to Authors on 29 October, 2009.
6 Gertrude Chia to Authors on 5 November, 2009.
7 Dr Dennis Dignadice to Authors on 13 October, 2009.
8 Dr Do Su Em to Authors on 5 November, 2009.
9 Debbie Low to Authors on 12 November, 2009.
THE JOB OF THE SOCIAL WORK ASSISTANT

- Accompany the nurse on the first visit.
- Construct the family tree.
- Conduct means testing for the family to determine the subsidy eligibility from MOH.
- Prepare forms for submission to relevant agencies.

ACTIVITIES OF VOLUNTEERS INVOLVED IN HOME CARE DELIVERY

- Perform household chores and general housekeeping for patient.
- Deliver medical equipment, run errands and render specific services such as haircuts.
- Accompany patients for medical appointments.
- Assist in outings organised for ambulatory home care patients.
- Befriend home care patients.

Discussion

1. Analyse the key knowledge, skills, abilities and other attributes needed by:
   (i) HCA home care doctors; and
   (ii) HCA home care nurses to perform their work duties and responsibilities effectively.

2. What are the likely profiles of successful recruits for these positions?

3. Given the roles and responsibilities, work activities and work/organisational contexts, what would be needed for such staff to perform at peak levels? Discuss in terms of performance management, compensation and rewards, and work environment.

4. Analyse HCA home care delivery system with regard to:
   (i) Effectiveness in achieving the aims of the charity – what should be the key performance measures?
   (ii) Efficiency in the use of resources – to what extent can HCA utilise the learning curve of experience/ work redesign to improve productivity?
   (iii) Robustness in reconciling operating capacity with growth in demand.