After-Hour Home Care Service Provided by a Hospice in Singapore

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Summary
A home care Hospice programme was set up to provide care to the patients with advanced diseases and their families in Singapore. After office-hour, the service is managed by a doctor on weekdays, with the assistance of a nurse during daytime on Saturdays, Sundays and public holidays. The doctor on-call made an average of 3.1 phone calls and 1.3 visits each weekday evening. Over the weekends and public holidays, there were a mean of 16.7 phone calls and 6 visits each day. More than half of the visits (50.3%) were made for certification of death. The commonest symptoms that prompted visits were dyspnoea (20%) and pain (12.2%). The busiest period during weekdays was between 6.00 pm and 11.00 pm, when our doctors did most of their visits. The workload of the hospice home care service is likely to increase and resources such as family health physicians can be explored to help to meet this increasing demand. This can be achieved through the provision of comprehensive training and easy accessibility to medical records which are kept with patients.

Key Words: Phone calls, Home visit, Death, Symptom

Introduction
Patients with advanced diseases need a continuum of care that covers them from specialised institution through home care. Caring for dying patients at home is a stressful burden for the family members who require constant support12. When the patients develop problems in the helpless hours late in the nights and weekends, there can be no better relief than a visit, or even just a phone call, by the familiar doctors and nurses.

Our home care programme is carried out by a team of doctors and nurses during office-hours, i.e. 8.30 am to 5.30 pm, from Monday to Friday. After 5.30 pm, there will be only one doctor on standby throughout the night. As the regular staff do not work on weekends, Saturdays, Sundays and public holidays will similarly be covered by one doctor. Starting from four years ago when the workload became too heavy for a single doctor to handle, a staff nurse was put on roster to help the doctor between 8.30 am to 5.30 pm of Saturdays, Sundays and public holidays.

To maintain a high standard of such an after-hour service is very difficult. It is very stressful for the person on-call to attempt to solve problems over the phone after being woken up in the middle of night. The entire family of the doctor can be disturbed by the pager and phone calls.
Moreover, a vast majority of our population lives in high-rise apartments. Navigating through the concrete jungle in the dark is no easy task. Therefore it is not surprising that these after-hour duties have been cited as a major reason why doctors and nurses shun away from hospice and palliative work. We reviewed the after-hour service to identify its magnitude, and attempted to tackle some difficulties in the system.

Materials and Methods

A retrospective review of phone calls made to patients and carers and visits carried out by the on-call team after office-hours between July 1997 and June 1999 was carried out. Our home care programme looked after 1,896 patients in 1997, and 2,158 in 1998. During that period, daily mean census was 329 patients. Vast majority of our patients suffered from advanced cancer. A small handful of patients had end-stage renal failure, liver cirrhosis and motor neurone disease. The mean duration of survival under hospice care was slightly more than 30 days.

The records of the team on-call from July 1997 to June 1999 were reviewed. The information obtained included number and indications of phone-calls made to patients or their carers as well as the frequency of home visits made. For the purpose of analysis, the phone-calls and visits were divided into two groups: weekdays evenings (5.30 pm to 8.30 am the morning after), weekends and public holidays. For each phone-call and visit, the record entry made by doctors and nurses in the patients medical record were retrieved and studied. Further information collected included the reason for each phone-call or each visit made. These reasons include symptom distress such as dyspnoea, uncontrolled pain, insufficient medications, reporting death of a patient on the home-care programme and social distress.

Our record only showed the time of arrival at the patients' home. It was not possible to determine the duration taken for the team to respond after receiving the distress call.

Results

Frequency

A total of 5,408 phone calls were made in the 2 years. One thousand five hundred and forty-one phone calls were made after office-hours during weekdays, giving a mean number of 3.1 phone calls each weekday evening. Over weekends and public holidays in the two years, 3,867 phone calls were made. That gave a mean number of 16.7 phone calls on each of weekend day and public holiday.

In 1997, the hospice home care service made a total of 13,182 visits to patients' home, and in 1998, 15,747 visits. Among these visits, 2,051 were carried out by the on-call team after office-hours: 658 (32%) occurred in weekday evenings, while 1,393 (68%) visits were made during weekends and public holidays. During weekdays, the mean number of home-visit made by the doctor on-call was 1.3 visits per night. On public holidays, Saturday and Sunday, the mean number of visits made to patients' home increased to 6.0.

The home hospice care programme is affiliated to a 40-bed in-patient hospice, which is covered by the same team after office hours. Over the two-year study period, 308 (15%) of the visits were made to our in-patient hospice after office-hour.

Indications

Two thousand one hundred and eighty-three (40.4%) of 5,408 phone calls received were to notify patients' death. Symptom distress accounted for 2,506 (46.3%) phone-calls received. Among the symptoms, 951 (17.6%) were complaints about dyspnoea. A smaller proportion (14.9%) were enquiries about pain management. Other problems especially gastrointestinal symptoms and fever accounted for 12.2% of phone calls. Some family members called to ask about dosage of medications (1.5%). About one in seven calls (13.3%) were made for social distress. (Table 1)
One thousand and thirty-three (50.3%) of the 2,051 visits were made for certification of death in home or in-patient hospice. For the non-death related visits, the commonest symptoms were dyspnoea (20%), and pain (12.2%). Other symptoms included gastrointestinal problems like constipation, vomiting, diarrhoea, blocked nasogastric tube (13.4%). Less frequently encountered problems like fever, urinary retention or complication of catheter, convulsions, bleeding etc accounted for other visits. (Table II)

Death certificates were issued by doctors when the patients died at home. All were certified to have died from natural causes and did not require coroner’s enquiry. Some families agreed to wait for the Inspector of Death who would come the next morning, instead of insisting for the certificate in the night. The Inspector of Death is a trained lay officer who examines the corpse and certifies death. Family members of patients who died in the in-patient hospice usually would wait for the morning doctor and did not insist on a visit by doctors at night.

Discussion

In recent years, cancer therapy has shifted to the domiciliary setting. Patients at the last stage of life prefer to be managed at home where they feel comfortable among the chosen company. Greater responsibilities have been delegated from the healthcare professionals to families. The home care programme gave us great opportunity to study the complex patterns of family dynamics in their coping with the physical, social and emotional burden. Our understanding of the concept of patient-family unit, a basic unit of care, has expanded after years of providing a service at home. Family members frequently develop a bond of sharing with the home care team, to the extent of identifying them as part of the family.

One must not forget that caregivers at home are vulnerable to the emotional, psychological and physical burden of caring for the patients. The potential for serious co-morbidity in the caregivers must be recognised. When a patient is dying or groaning at home, many bereaved families are torn between parties who want aggressive professional help and others who prefer a conservative approach. The conflict among family members can rapidly escalate to become a detrimental confrontation. It is not unusual to see the extension of such conflicts onto the relationship between family members and the healthcare professional. While it is acknowledged that our service is a vital support when they are helpless, lay carers and members of the public appeared to misunderstand the role of a hospice hotline or
emergency service. Difficulties were frequently encountered when family members insisted on doctors' visit for what sounded like trivial consultations. This is especially likely to happen when a member of the family who had not met the hospice home care team visited their ailing relative in the evening. More clarity in explaining the role to patients and lay carers may enable better understanding.

Good communication is the key to overall care of patient. Our home care team maintains a set of records in the patients' home, and that serves as a tremendous help for doctors and nurses who visit patients for the very first time. This allows the factual information and previous discussion with the family members to be transferred without causing confusion.

The focus of palliative care is gradually moving away from treatment towards prevention of symptoms. Good home care prepares the family members to handle deterioration of the patient's health and to react calmly. However, unexpected downturn and death still occur, and logically more likely to happen during the 75% of living time which is outside office-hours.

Our records could not tell us the qualitative aspect of the service, such as response time and patient satisfaction. Feedback from family members and patients seems to suggest that a good home care team with responsive after-hour service reduces hospital admissions. Many families feel assured and comforted that such a service is available. We could at least allow a large number of our patients (48% in 1997, 45.1% in 1998) to die at home over the two years.

Institutional practice takes the availability of expertise and access to resources for granted. The situation in the community level is entirely different. Albeit our home care service and logistics have greatly improved, we are surrounded by health care providers and a lay public whose traditional thinking seems to label home care as unreliable and unprofessional. Without a change in mindset, such service can never acquire the participation and support of other community-based health care agencies.

Family physicians should be encouraged to play an active role in the decision-making and treatment at home. From our experience, the busiest period during weekdays is between 6.00 pm to 11.00 pm, when the doctors on-call do most of the visits. This is the time when family members gathered around after work before retiring. Perhaps we should make use of family physicians who still operate during those hours. The primary health care scene in Singapore is changing with a growing number of 24-hour group practices in residential estates. With appropriate training to handle the unique ethical issues and dilemmas of terminal illness, these family physicians can become a valuable resources to enhance the empathic care. Our detailed records kept in the patients' home will also help the reluctant family physicians to certify death. With an average annual number cancer deaths close to 4,000 in Singapore, and an increasing awareness that non-cancer patients are also entitled to good palliative care, we are likely to receive more referrals than our present team can handle at this moment. We hope that the involvement of general practitioners could help us to strengthen care by our community instead of care in the community, and to continue the service because of, rather than despite of, the action of the community.


