

A Descriptive Study of the Demography, Symptomology, Management and Outcome of the First 300 Patients Admitted to an Independent Hospice in Singapore

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Abstract

The aims of this study were: 1) to describe the demography, symptomology, investigations conducted, non-pharmacological interventions and outcome of patients admitted to an inpatient hospice and 2) to identify the nursing and medical needs of terminally ill patients. Case-notes of the first 300 patients admitted to Dover Park Hospice were studied retrospectively. There were 159 men and 141 women making up 325 admissions. The racial distribution was: Chinese 95.0%, Malays 3.0%, Indians 1.3% and Others 0.6%. Two-thirds of the men (64.2%) had spouses while 44.7% of the women were widowed. The mean age was 64.7 years. The 3 most common cancers were lung (21.7%), colorectal (14.6%) and hepatobiliary (12.5%). A proportion of patients (39.5%) were not known to have any metastases. Most patients were referred from hospitals and the home-care based Hospice Care Association. The commonest reason for admission was for "terminal care" (57.2%). At admission, only 38% of the patients were aware of their diagnoses and prognosis while 30% did not know either.

The average length of stay was 25 days with 7.7% of patients having more than one admission. The most common symptoms were pain, anorexia, breathlessness, insomnia, constipation and dry skin. Non-pharmacological interventions ranged from manual evacuation of the rectum to transfers to tertiary hospitals for surgery and other more invasive interventions. Many patients also attended day-care activities (23.1%). Outcome of the 325 admissions were as follows: went home 20%, died in the hospice 73.2%, went home to die 4.9% and others 1.8%.

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Introduction

Modern society views death as an aberration which has to be postponed and, if possible, prevented at all cost. Death is just unacceptable and cannot be regarded as a natural process of life. It should be kept out of sight and no one should be allowed to see it as it is. This treatment of death was aptly described by Gorer as the "pornography of death", i.e. "something inherently shameful or abhorrent so that it can never be discussed or referred to openly and the experience of it tends to be clandestine and accompanied by feelings of guilt and unworthiness".¹ Consonant with this negative view of death is the misconception of what a hospice really is and what it stands for. Many in the lay public and some within the medical profession view hospices as places where terminally ill patients are sent to die. They are even regarded as "death houses" or holding places between life here and the life thereafter where treatment is minimal, passive and fatalistic.

Planning for Dover Park Hospice (DPH) as a charitable organisation began in 1992 and the hospice started functioning only in late 1995. It is a 40-bedded purpose-built residential hospice managed by a team of 4 administrators, a medical director, a senior registrar, a medical officer, a nursing director, a nursing officer, 5 staff nurses, 16 nursing aides, 7 health attendants, a social worker and a volunteer co-ordinator. Its mission is to provide comfort, relief of symptoms and palliative care for the terminally ill regardless of age, race or religion and to support grieving families. Management is holistic, encompassing physical as well as psychosocial aspects of patient care. A multidisciplinary team approach is the guiding principle and the hospice functions in close collaboration with the Hospice Care Association (HCA), a charitable organisation providing home-care and day-care for the terminally ill and with which it shares the building complex known as the Hospice Centre.

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The primary aims of this study were: 1) to describe the characteristics of patients admitted to Dover Park Hospice in terms of demography, symptomology, investigations conducted, selected non-pharmacological therapies and the final outcome of each admission and 2) to identify the nursing and medical needs of terminally ill patients. The secondary aim was to show that the hospice is not purely a “death house” but a place where treatment is active, holistic and multidisciplinary in nature, involving physicians from the various specialties, nurses, social workers, physiotherapists, and administrators.

Materials and Methods

Case records and charts of the first 300 patients admitted to DPH between 19 September 1995 when it first started taking patients, and 15 October 1996 were studied retrospectively by a single observer. Data were collected under the following groupings: (1) demographic characteristics (2) details of the terminal illness at admission (3) symptomology at admission (4) selected non-pharmacological interventions in the course of admission and in the last 3 days of life and (5) the outcome of all admissions. These data were entered into a database programme (Foxpro) and statistical analysis performed using the SPSS software.

Results

Demographic Characteristics

Table I shows the distribution of sex, age, race, marital status and primary care-giver of the study population. The 300 patients comprising 159 (53%) men and 141 (47%) women accounted for 325 admissions to DPH. Their ages ranged from 27 to 92 years. The mean age was 64.7 years with no significant difference between the sexes. The median age for men and women were 66 and 70 years respectively. Two-thirds (66%) were 60 years and older and 15% were 80 years and above.

The racial composition of this group consisted of 95.0% Chinese, 3.0% Malays, 1.3% Indians and 0.6% Others. There were relatively more Chinese compared with the most recent population census.² Of the Chinese patients studied, 44.6% were Hokkiens, 17.7% Teochews, 24.6% Cantonese, 8.1% Hainanese, 3.5% Hakkas while Others constituted 0.7%.

The distribution of the religious background of the study population is as follows: Buddhism 37.3%, Taoism 30.0%, Christianity 16.0%, Catholicism 2.7%, Hinduism 1.0%, Islam 3.3%, Others 0.3% and 9.3% had no religion (Fig. 1). It is important to note that the line dividing Taoism and Buddhism is blurred as many Singaporeans practice elements of both religions simultaneously. Nonetheless it is the dominant practice that is recorded.

Men were more likely to be married (64.2%) compared to women (37.6%) with an odds ratio of 2.971 (CI 1.856,

TABLE I: DISTRIBUTION BY AGE, RACE, MARITAL STATUS AND PRIMARY CARE PERSON

	Male	Female	All
Number of cases	159 (53)	141 (47)	300 (100)
Age range	27-90	33-92	27-92
Mean age	63.7	65.7	64.7
Median age	66	70	66.5
Race			
Chinese	152 (95.6)	133 (94.3)	285 (95.0)
Malay	3 (1.9)	6 (4.3)	9 (3.0)
Indian	2 (1.3)	2 (1.4)	4 (1.3)
Others	2 (1.3)	0 (0)	2 (0.6)
Marital status			
Married	102 (64.2)	53 (37.6)	155 (51.7)
Single	22 (13.8)	12 (8.5)	34 (11.3)
Separated/divorced	9 (5.7)	13 (9.2)	22 (7.3)
Widowed	26 (16.4)	63 (44.7)	89 (29.7)
Primary care person			
Spouse	71 (44.6)	30 (21.3)	101 (43.7)
Daughter	16 (10.1)	32 (22.7)	48 (16.0)
Son	29 (18.2)	35 (24.8)	64 (21.3)
Mother	3 (1.9)	5 (3.5)	8 (2.7)
Brother	3 (1.9)	2 (1.4)	5 (1.7)
Sister	6 (3.8)	3 (2.1)	9 (3.0)
Self	17 (10.7)	8 (5.7)	25 (8.3)
Maid	0 (0)	3 (2.1)	3 (1.0)
Daughter-in-law	2 (1.3)	9 (6.4)	11 (3.7)
Others	11 (6.9)	14 (9.9)	25 (8.3)
Unknown	1 (0.6)	0 (0)	1 (0.3)

Numbers in brackets are percentages.

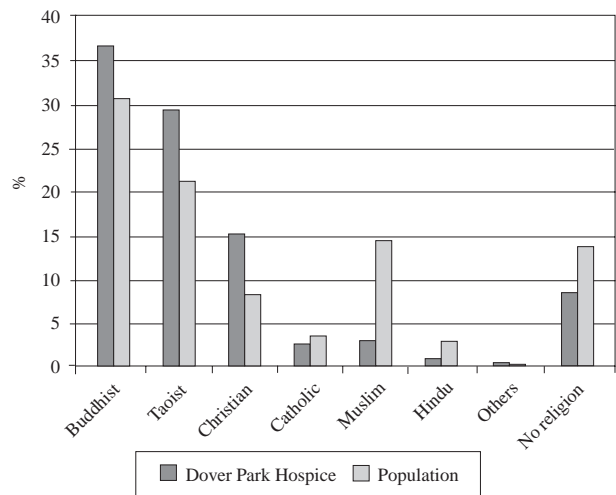


Fig. 1. Distribution of religious beliefs in DPH patients and the general population.

4.755). Women tended to be widowed (44.7% vs.16.4%, OR 4.132; CI 2.418, 7.059). Of the 159 males, 71 (44.6%) of them had their spouses as the main care-giver while the corresponding figure in females was 30 (21.3%). Put in a different way, of the 102 married men, 71 or 69.6% of them had their wives as the primary care-giver while of the 53 married females, 30 or 56.6% of them had their

husbands as the primary care-giver. Other main care-givers were sons (21.3%), daughters (16.0%), daughters-in-law (3.7%), sisters (3.0%), mothers (2.7%), brothers (1.7%), maids (1.0%) and others (8.3%). About 8% of patients were self-caring at the time of referral.

We also studied the number of offspring that each patient had. The results are as follows: no children 16.3%, 1 to 3 children 41.3%, 4 to 6 children 29.7% and more than 6 children 12.7%.

Disease and Admission Details

From Table II it can be seen that the 5 commonest cancers were carcinoma of the lung (21.6%), colorectal carcinoma (9.8%), carcinoma of the hepatobiliary system (9.4%), carcinoma of the stomach (7.1%) and carcinoma of the breast (4.1%). Five (1.7%) patients did not have terminal cancer. This group consisted of 2 patients with chronic renal failure, 2 patients with chronic obstructive airway disease and 1 with diabetic gangrene of the foot.

Of the patients with terminal cancers, 60.5% were documented to have metastases. This included metastases to bones (20.7%), liver (22.0%), lungs (14.6%), brain (12.6%), regional lymph nodes (10.2%) and others (19.4%).

The proportion of the specific cancers without metastasis was as follows: the hepatobiliary system/pancreas 81.1%, lungs 40.6%, colon and rectum 34.9%, head and neck 38.5% and cervix/uterus 53.3%.

Most of the patients were referred from restructured hospitals (50.7%) and Hospice Care Association (41.7%). The remainder of the admissions were from government hospitals, private hospitals and nursing homes.

Terminal care was the most common reason for admission (57.2%) while other reasons for admission were symptom control (22.2%) and "carer distress" (20.6%).

TABLE II: DEATHS FROM THE TEN MOST COMMON CANCERS IN THE GENERAL POPULATION IN 1996 COMPARED WITH TYPES OF CANCERS IN PATIENTS ADMITTED TO DPH

Ten most common cancers	Deaths in general population in 1996		Cases admitted to DPH	
	Numbers	%*	Numbers	%**
Lung, bronchus	897	22	64	21.6
Colorectal	536	13.3	29	9.8
Hepatobiliary	428	10.6	28	9.4
Stomach	373	9.2	21	7.1
Breast	221	5.4	12	4.1
Nasopharynx	190	4.7	20	6.8
Pancreas	140	3.4	9	3.1
Leukaemia	127	3.1	1	0.4
Lymphoma	107	2.6	4	1.4
Oesophagus	105	2.6	4	1.4

* Percentage of 4034 deaths from neoplasms in 1996

** Percentage of all patients with cancer admitted to DPH (295 cases)

The last term implies a breakdown in the carer system of the patient resulting from carer exhaustion, inability to cope or other social problems causing a disruption in the care arrangement of the patient.

We also studied the types of lines, catheters, stomas and tubes that came with patients at admission. The results are shown in Table III.

At the time of first admission, 30.0% of the patients were not aware of their diagnosis and prognosis; 30.3% knew the diagnosis but not the prognosis while 38.0% knew both the diagnosis and prognosis. This means that almost two-thirds of all the patients never knew that their days were short and that death was imminent.

The length of each admission ranged from 1 to 205 days. The average length of stay was 25 days. Median length of stay was 12 days. Most patients stayed between 2 to 10 days. The majority of patients (92.3%) had only 1 admission, while 7.0% had 2 admissions and 0.7% had 3 admissions.

Symptomology

The findings are outlined in Table IV. The 6 commonest symptoms were pain (70.5%), anorexia (46.5%), breathlessness (35.4%), insomnia (34.2%), constipation (33.8%) and dry skin (27.4%).

Investigations and Selected Non-pharmacological Interventions

The findings are summarised in Table V. The therapies under "others" included 2 colostomies, a tarsorrhaphy, a cystoscopy cum insertion of percutaneous nephrostomy, a blood transfusion, an intra-abdominal Cope loop insertion and an intra-rectal application of formalin for a bleeding proctitis which were all performed at tertiary referral hospitals. Of the whole cohort of patients, only 1 patient underwent insertion of a nasogastric tube. Syringe drivers for subcutaneous delivery of drugs were required in 16.3% of patients. Of these, 54.7% were

TABLE III: LINES, STOMAS AND CATHETERS AT ADMISSION

	Number	% of 325 admissions
None	245	75.4
Urinary catheter	37	11.4
Colostomy/ileostomy	16	4.9
Gastrostomy	2	0.6
Suprapubic catheter	1	0.3
Nasogastric tube	24	7.4
Syringe driver	5	1.5
Tracheostomy	10	3.1
Nephrostomy	3	0.9
Porta-catheter	3	0.9
Intravenous line	3	0.9
Others	7	2.2

TABLE IV: SYMPTOMOLOGY AT ADMISSION

Symptom	Number	%
Pain	229	70.8
Anorexia	151	46.5
Breathlessness	115	35.4
Insomnia	111	34.2
Constipation	110	33.8
Dry skin	89	27.4
Abdominal distension	80	24.6
Cough	70	21.5
Nausea	62	19.1
Dysphagia	61	18.8
Vomiting	58	17.8
Dry mouth	35	10.8
Urinary problems	17	5.2
Confusion	17	5.2
Paraplegia	16	4.9
Faecal incontinence	14	4.3
Diarrhoea	12	3.7
Per rectal bleeding	9	2.8
Fever	7	2.2
Restlessness	6	1.8
Pruritus	5	1.5
Haemoptysis	3	0.9
Others	70	21.5

initiated in the last three days prior to death. The duration of usage ranged from 1 to 11 days with an average of 2.9 days.

The specialties to which the patients were referred were ophthalmology (4), general surgery (3), geriatrics (2), radiotherapy (2), dermatology (2), urology (2), neurology (1), radiology (1) and colorectal surgery (1). Two patients were referred to dental surgeons.

We also looked at the proportion of therapeutic interventions initiated in the last 3 days of life. The findings were as follows: syringe drivers for drug delivery 54.7%, oxygen therapy 51.4%, hydration with subcutaneous infusions 17.8% and urinary catheterisation 11.1%. The patient mentioned earlier, who required insertion of a nasogastric tube, received it in the last 3 days of her life.

The number of patients who attended the Day Care Centre in the adjoining Hospice Care Association building was 75 (23.1%). The mean number of attendances per admission was 10.6 with a range of 1 to 66.

In 10.5% of admissions the patients went on home leave for an average of 3.1 days per admission (range 1 to 17 days). Home leave here refers to the number of days the patients spent away from the hospice during each admission. It does not include periods between admissions.

Outcome

Of the 325 admissions, 65 (20%) were discharged home, 16 (4.9%) went home to die, 3 (0.9%) were transferred to another hospital while 238 (73.2%) died in the

TABLE V: INVESTIGATIONS AND SELECTED NON-PHARMACOLOGICAL INTERVENTIONS

Investigations/therapies	Number of patients	%
Laboratory investigations	34	10.5
X-rays	8	2.5
Manual evacuation (rectum)	32	9.8
Oxygen therapy	107	32.9
Nasogastric tube insertion	1	0.3
Urinary catheterisation	27	8.3
Syringe driver	53	16.3
Intravenous drip	6	1.8
Subcutaneous drip	28	8.6
Abdominal tap	16	4.9
Pleural tap	2	0.6
Referral to other specialist	20	6.2
Transfer to other hospital for further management	14	4.3
Others*	7	2.2

*1 tarsorrhaphy, 1 cystoscopy and bilateral percutaneous nephrostomies, 1 blood transfusion, 2 colostomy, 1 formalin application to rectum, 1 Cope's loop insertion (abdomen)

Hospice (Fig. 2). Three patients whose prognoses were deemed to be better than expected and whose life expectancies were assessed to be longer were transferred to nursing homes.

Discussion

As in all case-record studies, data may be influenced by observer and subject variables which can occur at the time of referral, first assessment by the doctors or in subsequent assessments in the wards. Patients may have different perceptions of what a symptom might be while the doctor assessing may record symptoms according to his own interpretations. Subjective symptoms can vary according to a patient's beliefs and personal experiences. There is also the language and cultural variation in interpreting the various symptoms. These problems were minimised with the use of formatted assessment protocols that were already incorporated into the clerking sheets.

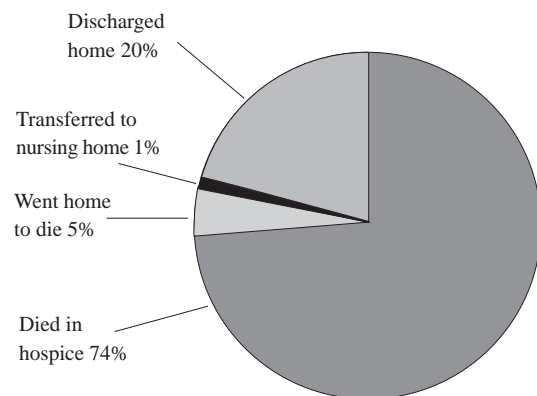


Fig. 2. Outcomes of 325 admissions to DPH.

Demographic Characteristics

There were more males than females in this cohort. This is contrary to what some other researchers have found.^{3,4} As expected most patients admitted were in the older age group, reflecting the higher incidence of cancer in this group. A small but important number of patients (16.7%) were below the age of 50. Younger patients generally have difficult psychosocial problems as most of them are in the prime of their lives and careers and some might still be in the process of raising families which depend on them as sole breadwinners.

Chinese were over-represented in this study. Possible reasons for this could be due to the higher incidence of cancers in this racial group⁵ or other racial groups may be more willing to care for their dying at home and more able to accept the death of a loved one in the home.

The multi-religious facet of the Dover Park Hospice is reflected in the figures given earlier. It can be seen that the Hindu and Islamic religions are somewhat under-represented (OR 0.3 and 0.2 respectively) while the Christian religion is somewhat over-represented (OR 1.98) compared to the population figures (Buddhism 31.9%, Taoism 22.0%, Islam 14.9%, Catholicism 4.1%, other Christian denominations 8.8% and Hinduism 3.3%).⁶ The proportion of patients who profess no religion was 9.3% which is lower than the national figure (14.5%).

It was interesting, though not unexpected, to find that most of the men admitted were married while the women tended to be widowed. Cancer is a disease of the elderly and, since the women tended to be older as reflected by the higher median age, it can be presumed that they would have outlived their older husbands and would be widowed by the time they contracted the cancers.

From the results it is observed that, in those who were married, wives were more likely to be primary care-givers than husbands (OR 1.625; CI 0.815, 3.242). This could be postulated to be due to the fact that their older husbands were too frail or incapacitated themselves to care for their spouses or, in the younger age group, because of the fact that they were working to support the family. There were relatively few patients whose primary care-givers were maids possibly because those with maids were less likely to require admission.

Disease and Admission Details

The 5 most common cancers in this study group corresponded to the figures of the Singapore Registry of Births and Deaths.⁷ Haematological cancers however appear to be fewer in the study group compared to the population. It is likely that many of the patients with these malignancies who usually fall into the younger age group may be receiving treatment in oncology units in the acute hospitals where treatment may be aggressive right until the end. It is more difficult to “let go” of these younger patients.

The 1.7% of patients who were admitted for non-cancers were admitted mainly for end-stage organ failure. None of the patients were admitted for advanced AIDS or advanced neurological conditions such as motor neurone disease or dementia which some hospices in the UK would accept for palliative care.^{4,8}

A major proportion of patients were admitted from HCA, while all patients who are discharged from DPH are referred to HCA for continuation of care at home. This reflects the symbiotic relationship between the two institutions. There were no referrals from general practitioners, an observation which contrasts sharply with that of the UK where 54% of referrals came from this group.⁸ This can be attributed to the difference in the system of health care delivery between the 2 countries. In the UK, the family physician acts as the primary care physician coordinating referrals to the various specialties for the patient, whereas in Singapore the main specialist diagnosing the primary condition takes over this role.

Nearly one-quarter of patients (24.6%) were admitted with lines, stomas, catheters or tubes requiring some form of maintenance and nursing care. Hence nurses who are to be trained in palliative care should have some grounding in the management of these lines and catheters.

There is some suggestion that the principal doctors who diagnosed the patients' conditions were not educating the patients about their illnesses. In an earlier study by Tay et al⁹ of patients at home who were under the care of the HCA, 41% did not know their diagnoses at the time of referral. In this study, only 69.7% knew their diagnosis and only 39.7% were aware that their lives would come to an end soon. A higher proportion of patients who were referred from HCA were likely to know their diagnoses, 76.0% (OR 1.769; CI 1.057, 2.960) and prognoses 47.2% (OR 1.836; CI 1.142, 2.951) compared to the rest of the referral sources. These figures imply that some of these patients were told of their diagnoses by the home care team. Possible reasons for the reluctance of doctors to reveal information to patients could be due to the families' wishes or perhaps some doctors may feel that they are inadequately trained to break bad news to patients and thus are reluctant to discuss such issues.¹⁰

There were 23 (7.7%) patients who were admitted more than once to DPH. These patients were either admitted for symptom control or as a result of carer distress. The fact that they usually went back home once the symptom came under control or the care situation became more satisfactory reinforces the fact that the hospice is not only for the dying.

Symptomology

The symptom profile of the patients in our study is similar to other studies.^{4,8,11} Pain remains the most com-

mon symptom and was present in 70.5% of patients. The control of pain has come to be almost synonymous with palliative care. It is such an important symptom because it gives rise to many of the other symptoms that are common in palliative medicine, e.g. insomnia, constipation, bedsores, anorexia and depression.

Investigations and Selected Non-pharmacological Therapies

A hospice is not a place where terminally ill patients are merely nursed until they die. This part of the study seeks to demonstrate that palliative care really is “the active total care of patients whose disease is not responsive to curative treatment”.¹² It is in fact an active process requiring frequent assessments and aggressive pursuit of appropriate therapies to control pain and other symptoms.¹³ Hospice care is sometimes referred to as “intensive terminal care” where laboratory investigations and various pharmacological and non-pharmacological interventions are instituted, including referrals to other specialists for more appropriate management. Medications are closely titrated against the patient’s symptoms and are added or discontinued depending on the patient’s condition. This is unlike the practice in nursing homes to which hospices are often compared.

An important modality for symptom control in palliative care is the use of the syringe driver to deliver drugs such as morphine, hyoscine, metoclopramide and midazolam. A number of our patients (16.3%) required the use of a syringe driver for an average of 2.9 days. A study from Hong Kong found that 42% of their patients were put on a syringe driver for an average of 9.1 days.¹⁴

A hospice day care centre is important for promoting a sense of well-being in ambulant patients. The patients in our study frequently used the day care centre where they were able not only to interact with the outpatients but also to have meals cooked by volunteers. There, they also received physiotherapy, massages and dental treatment and participated in the various activities organised for them such as group exercises, art and craftwork and other activities.

Outcome

About a quarter of the admissions to DPH ended with the patients going home. This once again reinforces the fact that a hospice is not solely a place of death or a “death-house”. Concomitantly, death occurring in the hospice is inevitable and when it does occur, the hospice’s role is to make the dying process easier for the patient as well as the family.

Conclusion

In this study we have briefly described the profile of patients admitted to an inpatient hospice in Singapore. We have also outlined the scope of patient care in a hospice and consequent to that, the nursing and medical

needs of terminally ill patients.

It is abundantly clear that the needs of a dying patient can be very different from that of a patient in an acute care setting. The former requires comfort and palliation, making effective symptom control and intensive nursing care the cornerstone of treatment.

Finally, the hospice is not a “death house” where patients with terminal diseases are sent to die. On the contrary it is a place where the art of palliative care is practised to its finest, utilising the principles of active symptom control while incorporating a holistic and multidisciplinary team approach, where psychosocial support is given to the patient and his relatives and where there is active participation of the relatives as well as volunteers in the care of the patient.

The practice of palliative medicine changes the priorities of treatment from cure to comfort, quantity of life to quality of life and the reduction of suffering.¹³ This is in keeping with the well-known 16th century aphorism which says that the physician’s aim should be “to cure sometimes, to relieve often and to comfort always”.

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