

## THE NEEDS OF ELDERLY WITH ADVANCED INCURABLE CANCER IN AGED HOME

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### Summary

*We studied the prevalence of advanced incurable cancer in aged home residents and assessed their palliative care needs. A cross-sectional survey was conducted in all government licensed aged homes in a local district. All residents with diagnosis of advanced incurable cancer were identified and interviewed by an experienced nurse or a geriatrician using a common assessment form. A total of 49 seniors, including 20 males (41%) and 29 females (59%), with mean age 79.1 ± 8.2 years were identified from 2042 residents of the 23 aged homes. Prevalence of advanced cancer was 2.4%. Despite continued care by various healthcare sectors, 46.9% suffered from either physical or psychological symptoms and 14.3% suffered both. 8.2% were clinically depressed. Pain was the most common complaint, followed by fatigue and anorexia. Overall, 22.4% had poor to fair symptom control, and majority of them (57.1%) expressed need for extra psycho-socio-spiritual support. Less than one third received care from hospice service. It is important for doctors and nursing staff to incorporate good palliative philosophy of care into their practice. There is also a strong need to develop palliative care in aged homes locally for both cancer and non-cancer terminal cases. Further research is needed to determine optimum care strategies to deliver palliative care to this group of patients.*

**Keywords:** Palliative Care, Nursing Home

### Introduction

Cancer has a higher incidence among older people. In fact, cancer is still the leading cause of death for patients aged 65 or above in Hong Kong<sup>1</sup>. To provide holistic care to these patients, a paradigm shift from the biomedical model to the bio-psycho-socio-spiritual approach is required. As the nursing home is considered an important setting for the provision of hospice care, palliative care for seniors in nursing home has been

developing rapidly in the West and in Australia since the last decade<sup>2-6</sup>. Hospice funding was also extended to include persons living in nursing homes in the U.S.<sup>6</sup>. The hospice movement in Hong Kong officially started in 1982, with hospice services developed in the form of hospital-based palliative care teams and hospice beds within acute or chronic wards and hospitals<sup>7</sup>. However, many elderly patients suffering from terminal cancer are living in aged homes. Although provision of ambulatory geriatric care by Community Geriatric Assessment Services (CGAS) since 1995 greatly improve nursing and medical care, we yet do not have information on whether the needs of this group of elderly patients are met. A survey was done to study the (d)-5 l5 (t)5 (u)52 TD [ (g(d)-5 (y))-5( )-5 yor1ne tdy100 (ie)-5 Tong District. These comprised all government licensed aged homes in the district. All residents aged 65 or above with diagnosis of advanced incurable cancer were identified from the medical records of the aged homes. The inclusion criteria were those who satisfied 1) a firm diagnosis of progressive malignant disease, and 2 a) the exhaustion of all therapeutic alternatives offered by conventional anti-cancer therapy, or 2 b) the goal of treatment shifts from treatment aimed at the control of tumour to treatment primarily prescribed for symptom control<sup>8</sup>. Residents with diagnoses of malignancy that had already been treated with a curative intent by any anti-cancer therapy, without evidence of relapse or recurrence, were excluded. Those screened were then interviewed by a community nurse with more than 2 years of experience in geriatrics or by one of the 2

specialists in community geriatric care using an assessment form primarily developed for this survey. For those who had communication deficits because of aphasia or deafness, non-verbal means of communication were attempted. For those who had severely impaired cognition or failed both verbal and non-verbal means of communication, the assessment would then be directed to the next of kin or care assistant who was directly responsible for the patient. For any subject, information on a) demographic data, b) hospice team involvement, c) co-morbid conditions, d) type of physical or psychological symptoms and their control, e) use of morphine or other analgesics (including NSAIDs, paracetamol and weak opioid), f) activities of daily living (Barthel Index) and mental state assessment (Abbreviated Mental Test) was collected. The analysis used descriptive statistics to summarize the quantitative data. For satisfaction with symptom palliation, the Verbal Descriptor Scale (VDS) was used; i.e. the patient was asked to choose the most appropriate word that could describe the satisfaction with his/her symptom control: good, satisfactory, fair, poor.

## Results

A total of 49 (2.4%) seniors, including 20 males (41%) and 29 females (59%) were identified among 2042 residents in 23 aged homes. Their mean age was at  $79.1 \pm 8.2$  year. 39 seniors were able to complete the assessment themselves, while 6 assessments were directed to the care assistants and 4 assessments were directed to the next of kin. No patient or proxy refused the assessment. Among these 49 seniors, 37 (75.5%) were staying in private nursing homes and 12 (24.5%) in subvented aged homes. 36 seniors (73.5%) were ambulant and 27 seniors (55%) had 2 or more co-morbid medical conditions. Eight seniors (16.3%) were documented to have dementia as well. The mean Barthel Index was  $69.8/100 \pm SD30.6$  and Abbreviated Mental Test was  $6.5/10 \pm 3.1$ . Thirty three patients (67.3%) were followed up geriatric (including CGAT clinic) or other specialist clinics. Eleven patients (22.4%) were followed up by oncology clinic. Fifteen patients (30.6%) were cared by hospice professionals.

23 patients (46.9%) suffered from either physical or psychological symptoms and 7 patients (14.3%) suffered from both. 9 patients (18.4%) had psychological symptom, among which 5 (10.2%) were anxious and 4 patients (8.2%) had diagnosis of clinical depression before the survey. Pain was the most common complaint ( $n=12$ , 24.5%),

followed by fatigue ( $n=8$ , 16.3%) and anorexia ( $n=5$ , 10.2%) (Figure 1). The commonest drug prescribed for symptom control was non-morphine analgesic, including paracetamol, NSAIDs and weak opioid ( $n=12$ , 24.5%). 5 patients (10.2%) were prescribed morphine for symptom control (Figure 2). Overall, 11 patients (22.4%) had poor to fair symptom control. 38 patients (78%) had good / satisfactory symptom control though 28 patients (57.1%) still expressed need for extra psychosocial support.

Figure 1. Types and Prevalence of physical symptoms

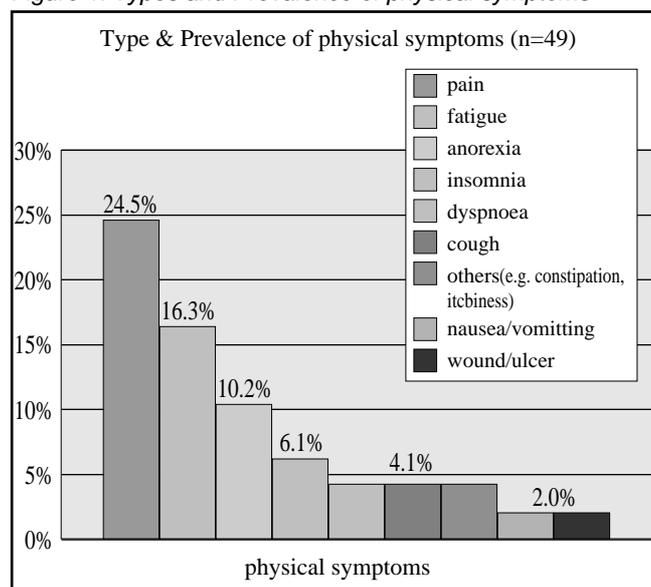
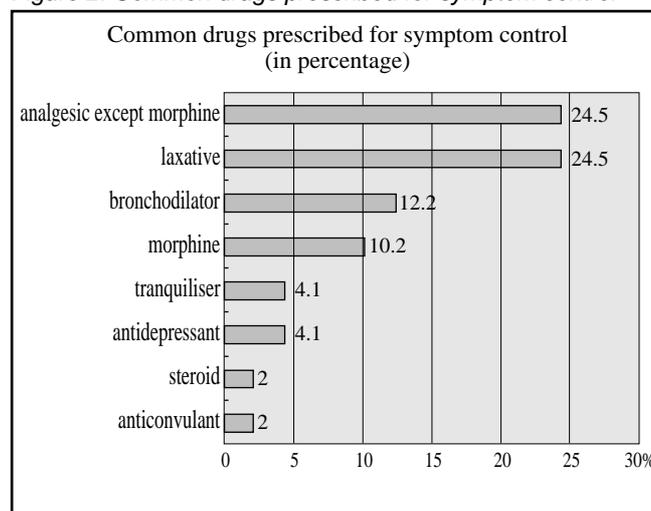


Figure 2. Common drugs prescribed for symptom control



## Discussion

This survey was the first local study to look at the needs of elders with advanced incurable cancer in the setting of aged homes, which has long been a neglected aspect of care amongst elderly health care professionals. Patients with early stage cancers would also have palliative care needs, but they have been omitted from this study.

In our study, the elderly patients with terminal cancer might have been living in aged homes at the time of diagnosis. Alternatively they might just be transferred to aged homes for long-term care if family support at home was not feasible because of the illness. For the latter situation, patients would mostly go to private aged home because of long waiting time at the subvented sector. Leung JYY et al.<sup>9</sup> showed that 5.3% of private aged home residents were suffering from cancer of all sorts. Our study showed that 2.4% of aged home residents (including subvented and private aged homes) were suffering from terminal cancer requiring palliative care. The smaller prevalence in our study could be attributed to larger inclusion criteria of both government-subvented and private aged homes as well as case definition limited to advanced stages of malignancy aiming for symptom control only.

Most aged homes in Hong Kong are privately run<sup>10</sup>. Nursing manpower may not have experience in terminal care<sup>9, 11</sup>. There are a lot of unmet needs of aged homes' residents with advanced cancer. Maccabee J<sup>12</sup> showed that the transfer of a patient to a nursing home might lead to a shortfall in meeting the needs of patients and relatives. Moreover, it is well known that older patients with cancer are often badly managed<sup>13</sup>. Pain is often under-treated in older nursing home patients<sup>14, 15</sup>. Age greater than 70 years has been shown to be a predictor of inadequate pain management for metastatic cancer patients<sup>16</sup>. This was also true in our study. Pain was under-assessed and was under-treated and the adequacy of morphine prescription was doubtful. Although all the elderly cancer residents have been receiving medical care from either specialist out-patient clinics, CGAT or residential general practitioners, almost half (46.9%) were suffering from either physical or psychological symptoms and 14.3% were suffering from both. Less than one-third was known to hospice service of any sort. Ferrell BA<sup>17</sup> suggested that much of what we have learnt over the past years about palliative care of cancer patients could be directly applied to the care of elderly cancer patients in nursing homes. In fact, as can be seen from our study, a significant proportion of elderly

cancer patients in aged homes received inadequate palliative care including pain control, symptom control and psychosocial support. All these can be provided in an aged home setting. Only when they develop acute medical complications, require intensive monitoring, or more sophisticated treatment or when they progress to the terminal phase, should they then be transferred to acute hospital or other settings where appropriate resources are readily available and legal concerns are met.

There has been no doubt that this group of elderly patients with terminal cancer should receive better palliative care service in order to receive optimum symptom control and psycho-socio-spiritual support. Early data from a local pilot project<sup>18</sup> on providing outreach home care support to private nursing homes showed that there was some effect on achieving a longer stay in the community. To date, in Hong Kong, there is no standardized model of liaison between palliative care unit and aged homes. Some hospices (e.g. Bradbury Hospice) have liaison between the hospice nurse specialist and the aged homes so that discharge can be facilitated and continuity of care can be enforced. Some hospices (e.g. Shatin Hospital, United Christian Hospital) work in liaison with the hospital CGAT for cancer patients in subvented and private aged homes so that elderly patients may be followed up at their own aged homes if feasible. Better liaison between different services units (may it be CGAT or Hospices and that depends on ability to develop services in a holistic approach) and aged homes (both subvented and private) may help to ensure provision of satisfactory standards of the care to these patients. Formal linkage between aged homes and appropriate palliative care services would surely benefit elderly cancer patients.

In addition to a new model of service provision and liaison between different specialty teams, much can be done at present within aged homes for frontline physicians to help ameliorate the symptoms and concerns as discovered in this study. Both community geriatricians and general practitioners should be familiar with the basic principles and practice of long term care and palliative care and demonstrate sensitivity to symptom control and psychosocial support in this group of elders. They should also have sound knowledge of the pharmacology of analgesic drug, especially morphine. Besides empathetic communication skills, they also have to recognize that when cure is not possible, active holistic care

of the patients and their quality of life become central to patient management.

The recent development of the palliative care for cancer patients has improved the care of terminal cancer patients. Besides cancer, elderly patients with end-stage diseases other than malignancy may have palliative care needs as well<sup>19-22</sup>. Globally, rates of hospice utilization among dementia patients is low. One major barrier is that dementia patients have highly variable survival times, even in the end-stages of the disease. Hence, guidelines have been developed in the United States to assist physician to identify appropriate dementia candidates for hospice and palliative care<sup>23</sup>. Due to the development of palliative pharmacological treatment as well as the heightened societal awareness of the disease, palliative care for patients with dementia has become an important issue recently. It is very challenging to manage the cognitive, behavioral and nutritional aspects as well as the symptom control of this group of patients. There was report that dementia patients may cease to undergo normal experience of pain!<sup>24</sup>

To improve palliative care service for non-cancer elderly patients in aged homes, alternative approaches have been suggested in western societies<sup>3-5, 25-26</sup>. In Southern Adelaide, Australia, the 'link nurse' programme has been extremely well received. Experienced palliative care nurses provide clinical and educational support for nursing homes and also help each nursing home select a nurse to act as the person who would provide linkage with palliative care service<sup>27</sup>. In fact, the challenge of an aging population regarding the provision of palliative care is increasingly great. Older people with multiple chronic co-morbidities who require palliative care will increasingly need to be supported in aged homes in the community. Whether this group of patients require specialist palliative care or a wider adoption of palliative care approach by physicians or geriatricians will depends on the vision by professional body in respective region. Although there was no consensus about whether a named palliative care physician should provide cover to each home, there was a perceived need to improve palliative care in aged homes<sup>28</sup>, and there was also a strong need for palliative care training and experience for aged homes' residential general practitioner<sup>29</sup>, geriatrician and nursing staff. It has been recommended that specialist palliative care physicians should provide an advisory and educational role to non-hospice physicians to ensure provision of appropriate palliative care to all terminally ill patients, including those suffering

from non-cancer illnesses in aged homes<sup>30</sup>.

There is therefore a growing trend that palliative care will be increasingly practiced in aged home locally. It is important for geriatricians, general practitioners and nursing staff to incorporate good palliative care into their practice for both terminal cancer as well as chronic disabling geriatric diseases. Much research is still needed to determine optimum care strategies and to develop formal linkage between aged home and palliative care service in these institutions in Hong Kong.

## Conclusion

This paper serves to heighten the awareness of this often neglected aspect of care amongst elderly aged home residents. A significant number of elderly advanced incurable cancer patients who lived in aged homes had unmet needs, suffered inadequate control of physical symptoms and had inadequate psychosocial support. Pain was under-treated. Less than one third received care from hospice service. Besides cancer, elderly patients with other end-stage diseases other than malignancy may also have palliative care needs. Therefore, it is important for geriatricians, general practitioners and nursing staff to incorporate good palliative care into their practice. There is also a strong need to develop palliative care service in aged homes locally. Further research is needed to determine optimum care strategies.

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