Original Article

Initial Demographic, Symptom, and Medication Profiles in Patients Admitted to Continuing Palliative Care Units

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Abstract
We retrospectively reviewed 110 consecutive admissions to continuing palliative care units, which were designed as part of a regionalized, comprehensive palliative care program in Edmonton, Canada. Ninety-six patient charts met the criteria for evaluation. Demographic characteristics, and, when available, symptom profiles, cognitive status, and risk for a history of substance abuse were described. The medications on admission were tabulated, and in those 93 patients who had consults done by a palliative care consultant, these are compared to recommended medications. This study showed an older cohort of patients (mean ± SD = 75 ± 11 years) than had previously been described in a tertiary unit in the same community. Median length of stay was 21 days (range, 0–200 days). Cognitive impairment was higher than would be anticipated on the basis of age alone, with 32/47 [64% (confidence interval [CI] 55%–81%)] of patients who had had cognitive testing done on the day of consult being found to be cognitively impaired. Symptoms, as measured by the Edmonton Symptom Assessment Scale, were similar to those found for patients admitted to the tertiary palliative care unit. In the 93 patients who had palliative care consults done on admission, there were a total of 179 recommendations for medication or hydration changes. Overall compliance with these recommendations was 84% (CI, 79%–89%). The highest compliance was observed for recommendations to start hydration clysis [27/27, 100% (CI, 100%)], and the lowest rate was observed for altering or decreasing hypnotic medications [11/22, 50% (CI, 29%–71%)]. We conclude that the patients were of higher acuity than anticipated. J Pain Symptom Manage 1998;16:163–170. © U.S. Cancer Pain Relief Committee, 1998.

Key Words
Patient profiles, demographics, symptoms, medication

Introduction
In July 1995, a regional palliative care program was started in Edmonton, Canada, a city of 680,000 with an average of 1300 cancer deaths per year. The purpose of the program was threefold: (1) to provide universally accessible palliative care, (2) to decrease the number of cancer deaths in acute hospitals, and (3) to
provide primary care physicians with the education and support to empower them to provide ongoing care for their palliative care patients.

The program had three main components. First, palliative care consult teams, consisting of nurses and physicians, were available to assist with symptom management of patients at home or in an acute care hospital. Second, a tertiary palliative care unit was available to manage patients who had severe symptom problems and required intensive palliative interventions. Third, three palliative care units within the continuing care hospital system, comprising a total of 56 beds, were established. The intended purpose of these units was to provide a place for patients who either did not wish to or were unable to die at home, but who did not require the intensive services of the tertiary palliative care unit. Although these units were administered separately, all used uniform assessment tools and had similar philosophies of care. Each unit was organized on a multidisciplinary model. Staffing for a sample unit is outlined in Table 1. Patients were assessed by a member of the palliative care consult team prior to transfer to determine their suitability for the units. Patients were followed by a family physician; however, all patients were seen at least once by a palliative care consultant shortly after admission, and whenever a repeat consult was deemed necessary by the family physician.

The primary assumption behind the establishment of these units was that a significant number of palliative cancer patients who did not require intensive symptom management by the tertiary unit would require an alternative to a home death. It was also assumed that palliative care consultants and primary care physicians would be able to work collaboratively so that with the consultant’s training and support, the primary care physicians would be able to manage the majority of the patient care. However, no data were available on either the characteristics of the patient population that would be admitted to these units, or the nature of the consultant/primary physician interaction. This paper describes the demographic and symptom characteristics of patients who were admitted to these units. It also describes the initial management prescribed by the family physician prior to the palliative care consult, the medication recommendations made during the initial consult, and the family physician’s compliance with these recommendations.

**Methods**

We retrospectively reviewed 110 consecutive admissions starting in October, 1995. This date was selected, rather than the program starting date, because uniform charting and a uniform admissions policy was not available until then. The following demographic data were collected: (1) age, (2) gender, (3) primary diagnosis, (4) location prior to diagnosis, (5) length of stay, and (6) discharge location. The CAGE questionnaire, a four-question screening tool for alcohol abuse, was used as a screen for addiction history. Cognition was assessed using the Mini-Mental Status Questionnaire as an initial screening tool. Symptom severity on the consult day was determined using the Edmonton Symptom Assessment Scale, a series of visual analogue scales, rating pain, fatigue, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath. The visual analogue scales were converted to a 0–100 scale, with a higher number indicating greater severity.

<p>| Table 1 |</p>
<table>
<thead>
<tr>
<th>Staffing (for a Unit of 22 Patients)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nursing manager</strong>—1 full-time equivalent (FTE)</td>
</tr>
<tr>
<td><strong>Nurses (per shift)</strong></td>
</tr>
<tr>
<td>1 registered nurse</td>
</tr>
<tr>
<td>1 licensed practical nurse (days, evenings only)</td>
</tr>
<tr>
<td>2.5 nursing assistants (days, evenings), 2 nursing assistants (nights)</td>
</tr>
<tr>
<td><strong>Social work</strong>—0.4 FTE</td>
</tr>
<tr>
<td><strong>Pastoral care</strong>—0.2 FTE</td>
</tr>
<tr>
<td><strong>Physiotherapy</strong>—0.2 FTE</td>
</tr>
<tr>
<td><strong>Occupational therapy</strong>—0.2 FTE</td>
</tr>
<tr>
<td><strong>Recreational therapy</strong>—0.2 FTE</td>
</tr>
<tr>
<td><strong>Pharmacy</strong>—0.3 FTE</td>
</tr>
<tr>
<td><strong>Respiratory therapy</strong>—0.2 FTE</td>
</tr>
</tbody>
</table>
symptom severity. Overall symptom distress was determined using the Symptom Severity Scale, from the averaging of the various subscales. Medications in the following categories—analgesics, both opioids and adjuvants, anti-nauseants, sedatives, anti-psychotics, antibiotics, and calcium-lowering agents—were tabulated as initially prescribed by the treating family physician before the consult, then compared to the consultant’s recommendations. When a medication could be used for several purposes, the medication was categorized under the purpose for which it was prescribed. For example, if a steroid was prescribed for nausea, it would be listed under anti-nauseant, but if it were prescribed for pain, it was listed under adjuvant analgesics. Compliance with the various recommendations was examined.

Descriptive statistics were reported as percentages and 95% confidence intervals (CI) for proportions, and mean ± standard deviation or median (range) for parametric values. Analysis was performed using t test for differences in means and proportions. Analysis was performed using the SAS system (SAS Institute, Cary, NC) for personal computers.

**Results**

Of the 110 consecutive admissions, four charts could not be located and ten patients were excluded because they were transferred from a tertiary palliative care unit where they had been stabilized and had transfer orders written by a palliative care physician. Three of the remaining 96 patients died before an initial consult could be done, and, therefore, only initial demographic and medication information was collected.

Table 2 lists the demographic information for the initial 96 patients. Forty-four patients (46%) were admitted from home, 44 (46%) were admitted from acute hospitals (seven directly from emergency rooms and the rest from inpatient beds), and the remaining eight (8%) were admitted from long-stay hospitals or nursing homes. Eighty-five patients (89%) remained in the continuing palliative care system until their deaths, five (5%) were transferred to a tertiary palliative care center, and two (2%) were transferred to an active treatment hospital. Two patients were transferred to the regular long-term care system, and two patients were still alive at the time of data collection (>200 days).

On the day of the consult, 62 Edmonton Symptom Assessment Scales (ESASs) were completed by either the patient or a surrogate evaluator (either a family member or nurse) and an additional six ESASs were partially completed (73% of all patients who had consults). The average scores of these ESASs and the associated symptom severity scores are shown in Table 3. Of the 69 patients who had a CAGE done as a screen for alcoholism, 12 [17% (CI, 8%–26%)] had a positive CAGE (defined as two or greater positive responses), suggesting that the patient was at high risk for having a history of alcoholism. Of the 47 patients who had Mini-Mental Status questionnaires administered on the consult day, 32 [68% (CI, 55%–81%)] were defined as cognitively impaired (using the cut-off score less than 24/30 or less than 80% correct if only part of the test was completed).
Table 4 lists the initial and recommended analgesic medications and Table 5 lists adjuvant analgesics. Twenty-four patients were on “as needed” opioids on admission. Of these, six were started on fixed-schedule opioids, and the remainder were kept on as needed opioids initially, often for a short period of time while dose requirements were being determined. Two patients who were on regular analgesic doses were switched to as needed, one because of renal failure and the other because the patient was comatose. Opioids were initiated in three patients. Initial average morphine equivalent oral daily dose (MEDD) was 105 ± 92 mg, and the average morphine equivalent daily dose recommended was 88 ± 92 mg (not significant). (Because the number of extra “as needed doses” taken prior to admission could not be determined, only regularly scheduled opioid doses were included in the MEDD, and an MEDD could not be calculated for the patients on “as needed” opioids only). Of the 24 patients for whom a change in MEDD was suggested, an increase was recommended in nine patients and a decrease in 15. Opioids were rotated in 16 patients (17% of the patients who had consults).

Thirty-five patients were on anxiolytics on admission (36%), and 26 (27%) were on benzodiazepines. The main reason for these medications was for the treatment of insomnia. Anxiolytic discontinuation was recommended in 15 patients, and a change in medications (either from a benzodiazepine to zopiclone, which was considered less sedating or to a different benzodiazepine) was recommended in nine patients. No recommendations were made to initiate sedatives.

Initial and recommended anti-nauseants are listed in Table 6. In total, changes were recommended in 26 patients. The most common change was initiating metoclopramide, which was started in 14 patients. Metoclopramide was discontinued in three patients. Dimenhydrinate was discontinued in 12 patients. Dexamethasone was started in two patients and discontinued in two. Only one case of counteractive polypharmacy choice was noted—the simultaneous use of buscopan and metoclopramide.

Seven patients were on neuroleptic medications initially (six on haloperidol and one on thioridazine) for the management of delirium. Initiating haloperidol was recommended in 19 patients, and a switch to haloperidol was recommended for the patient on thioridazine. One other patient was started on haloperidol as an anti-nauseant.

Twenty patients were admitted with subcutaneous clysis for hydration, and clysis was recommended in an additional 27 patients. In no cases was clysis discontinuation recommended.
Table 7

Compliance

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Yes</th>
<th>No</th>
<th>% Compliance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opioids*</td>
<td>35</td>
<td>32</td>
<td>3</td>
</tr>
<tr>
<td>MEDD**</td>
<td>32</td>
<td>30</td>
<td>2</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>8</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Adjuvants</td>
<td>9</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Antinauseants</td>
<td>26</td>
<td>22</td>
<td>4</td>
</tr>
<tr>
<td>Neuroleptics</td>
<td>20</td>
<td>17</td>
<td>3</td>
</tr>
<tr>
<td>Sedatives</td>
<td>22</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Hydration</td>
<td>27</td>
<td>27</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>179</td>
<td>151</td>
<td>28</td>
</tr>
</tbody>
</table>

* Includes opioid rotation (16), initiation of opioids (3) and change in formulation (5) or route (12). Multiple changes in one patient were counted as one recommendation.

** Includes changing from prn to regular or from regular to prn as well as change in morphine equivalent daily dose (MEDD) of regular dosing.

Eighteen patients were on antibiotics on admission, and the initiation of antibiotics was recommended in an additional eight patients. No patients required calcium-lowering treatment on admission.

Compliance rates for the various types of recommendations are listed in Table 7. Compliance was highest for initiating hydration [27/27, 100% (CI, 100%)] and lowest for alteration of sedatives [11/22, 50% (CI, 29%–71%)]. Compliance for altering sedatives was 6/15 (40%) when it was recommended that sedatives be discontinued and 5/7 (71%) when a change of sedatives was recommended.

**Discussion**

Compared to a previous study of characteristics of patients admitted to a tertiary palliative care unit, the patients were significantly older [75 ± 11 years, compared to 65 ± 12 years (P < 0.001)]. This may reflect the higher likelihood that the elderly will either not have spouses as their primary caregivers, or the spouses may be in frail health and unable to provide care. Because persons dying young are expected to have a higher degree of psychosocial stress, younger patients may have been admitted with higher frequency to the tertiary palliative care unit, contributing to the age difference. An older cohort of patients would statistically be expected to have a higher incidence of comorbid illness. Information on co-morbid illness, support systems, and the reason for admission was not systematically collected on this cohort, but these factors are currently being studied on a prospective basis. When the continuing care system was being developed, anticipated length of stay was 2 months. The short median length of stay—21 days—suggests that patients were able to stay in the community for the greater part of their illness process, and needed institutional care only for the final stages of their illness. The inability of any of the patients to return to the community, suggests that the decision to institutionalize was secondary to longstanding care needs and not to transient exacerbations of symptoms.

The assessment of the degree of cognitive impairment, alcohol abuse, and symptom acuity is limited by the lack of complete data collection using the CAGE, Mini-Mental Status examination, and the Edmonton Symptom Assessment Scale. The reasons for the lack of completion of the assessment tools could not be determined from the charts. It is likely that the main reason for the lack of data is that staff were trying to care for patients with limited resources and were in the early stages of learning the value of systematized assessments. Nevertheless, certain trends are evident from the data.

Cognitive impairment was much higher than would be anticipated based on age alone. Of the patients tested, 64% (CI, 55%–81%) were found to be cognitively impaired, compared to an expected rate of cognitive impairment for this age group of approximately 15% and a rate of 44% in patients admitted to the tertiary palliative care unit. Because of the large number of untested patients on the day of consult, this result may be falsely elevated, particularly if patients who showed evidence of cognitive impairment were preferentially tested. However, because we use the MMSQ as a screening
test, our policy is to test all patients regardless of whether there is clinical evidence of cognitive impairment and it is possible that patients with an obvious clinical diagnosis of delirium were not tested as the screening value of the test would disappear. Even if all the untested patients were normal, at least 33% were cognitively impaired. Alternately, cognitive impairment may have been the reason for the institutionalization, making this group skewed compared to the total cancer death population. In the geriatric population, cognitive impairment has been found to be a significant predictor of institutionalization in the elderly. Rockwood et al.8 found an unadjusted odds ratio of 58.16 for institutionalization in the cognitively impaired elderly compared to the cognitively intact. Examination of the underlying reasons for the cognitive impairment and its clinical course was beyond the scope of this study, but previous studies on cognitive impairment in palliative cancer patients has shown that the majority of patients with cognitive impairment have a component of delirium,7,9 and that, in one-third of cases, the cognitive impairment is reversible.7

The percentage of positive CAGEs, which has an 81% sensitivity and an 89% specificity for alcohol abuse,10 was at 17% lower than the 27% that has previously been described in patients who were admitted to the tertiary palliative care unit (although this difference was not statistically significant)11 and was within the range of the 12%–20% that has been described for the general hospitalized population.12 Because a history of alcoholism has been found to be an adverse prognostic factor for achieving good pain control,13 and these patients require intensive counselling to help them deal with their tendency to cope chemically, patients with positive CAGEs may have been triaged to the tertiary unit more frequently accounting for their lower prevalence in the continuing care units. The high prevalence of both cognitive impairment and a history of substance abuse underscores the need to teach the health-care providers for these patients to assess for these conditions and modify treatment accordingly.

Symptom distress was also higher than anticipated. Fainsinger et al.14 in describing the symptom profiles of patients admitted to a tertiary palliative care unit reported average admission scores of 35 ± 25 for pain, 23 ± 23 for nausea and 43 ± 12 for drowsiness and an overall symptom distress score of 47 ± 29. In that study, it was suggested that these scores were most likely materially higher than would be expected for the general population, reflecting the more acute population that was admitted to the tertiary unit. In this cohort of patients admitted to continuing care, scores for these same symptoms were almost identical: 38 ± 28 for pain, 28 ± 29 for nausea, and 48 ± 32 for drowsiness, and an overall symptom distress score of 46 ± 32. This suggests that the number of patients with severe symptom distress in the general population is higher than previously anticipated. The highest symptom scores were for fatigue (62 ± 30), appetite (61 ± 32), drowsiness (48 ± 32), and well-being (47 ± 29). Fatigue and drowsiness would be expected to be correlated with decreased activities of daily living (ADL), which may have led to the need for institutionalization. Symptom scores for pain, nausea, and dyspnea, for which effective treatments are available, were lower. This may reflect either the triaging of patients with these symptoms to the tertiary palliative care unit, or that these symptoms were being effectively managed in the community prior to admission. As with the comparative ESAS data from the study of the tertiary palliative care unit,14 ESAS information from surrogates and patients was pooled, and it was not possible to determine from the data when the ESAS had been completed by the patient or a surrogate.

Initial medications showed fewer inappropriate medications than expected. No patients were admitted on meperidine or pentazocine, which are usually contraindicated for cancer pain.15,16 This compares favorably with the pattern found among cancer specialists in this same community in 1987, at which time 7% of patients were prescribed either meperidine or pentazocine.17 Metoclopramide, which is the preferred antiemetic for cancer-associated nausea,18 was prescribed for 70% of the patients using antiemetics. This compares favorably with the 49% use which was found among cancer specialists in 1987.17 Compared to a study of cancer patients admitted to a tertiary palliative care unit in the same community in 1990–1991,19 in which 92/120 patients (77%) were receiving hypnotics for insomnia, sedative use was lower at 36% (P < 0.001). (Although insomnia is frequently encountered in palliative patients, pharmacological management with sedatives is often avoided because of the devel-
development of tolerance to nighttime sedation, resulting in rebound insomnia if the medication is stopped, and the risks of causing cognitive impairment or excessive somnolence.\textsuperscript{20,21}

The reasons for a decreased use of hypnotics are not fully understood. It may be that physicians were responding to the needs of a cognitively frail cohort of patients and avoiding medications which they would prescribe to a more robust population. Or medications may have already been altered by the palliative care consultant or nurse prior to admission. Alternatively, it may indicate better awareness of palliative care knowledge on the part of primary care physicians. Whatever the reason for the improvement in prescribing patterns, it suggests that primary care physicians have adopted some palliative care principles into their practice.

The number of changes recommended is suggestive of the acuity of these patients and the perceived need to alter treatment to try to affect symptom outcome. In total, 152 medication recommendations were made and 27 recommendations were made regarding hydration, for a total of 179 recommendations on the medical aspects of treatment only. The pattern of changes, in particular for opioids, suggests a change in treatment patterns by family physicians. Previously, it has been assumed that the major error in opioid administration was under-prescribing opioids.\textsuperscript{22} In this cohort of patients, the recommendations were to decrease the morphine equivalent daily dose more frequently than to increase it (15 versus 9) and the overall initial versus recommended MEDD was not significantly different. Opioid rotation was suggested a total of 16 times. This finding suggests that much of the need for physician education has shifted from increasing the physicians willingness to prescribe opioids to focusing on appropriate use of opioids. In particular, our group has found a tendency to mis-diagnose psychosocial stress and delirium as nociception, and to treat with escalating doses of opioids, leading to increased problems with opioid neurotoxic side effects such as delirium and excessive sedation.\textsuperscript{23} This highlights the need for vigilance in assessing for delirium and non-nociceptive sources of suffering, so that appropriate treatments of these problems can be started.

Compliance with recommendations was generally high, with 84% [C.I. 79–89%] of the recommendations being accepted. The culture on the units, where the multidisciplinary team was supportive of the consult teams, and their approach to patient management, may have contributed to the high level of compliance. Compliance was highest for recommendations concerning hydration, starting antibiotics, and altering the opioid type and dose. The high acceptance of recommendations for starting hydration and antibiotics suggests a willingness to accept a more active pattern of palliative care practice than has usually been associated with the hospice model. Because of evidence suggesting that maintaining renal function in patients on opioids reduces the incidence of agitation delirium,\textsuperscript{6} treating dehydration was routinely recommended. Similarly, because antibiotics can in some cases reduce cancer pain\textsuperscript{24} and treat delirium,\textsuperscript{7} antibiotics were recommended in selected patients. Although some of these recommendations could be considered controversial,\textsuperscript{25} we did not find this impacted on compliance. Compliance was lowest for stopping sedative medications at 50% (CI, 29%–71%) compliance. Because fewer patients were on these medications than expected, it may be that those physicians who were prescribing sedatives had a higher commitment to continuing the medication. The benefits of stopping sedatives are delayed, and the initial response will be rebound insomnia and increased anxiety. It may take more education for physicians to support a measure which may result in a transient increase in symptoms, even if the long term effects, in improving cognition and alertness, are beneficial. Giving physicians the option to prescribe a less potent sedative, rather than trying to have the sedative discontinued entirely, was an effective way of increasing compliance.

In summary, three major findings were made in this cohort of patients. First, patient acuity was high, as manifested by symptom assessment scores equivalent to those found on the tertiary unit, and the number of medical interventions recommended. This suggests the need for a strong medical and nursing component on these units to manage the physical aspects of these patients’ care. The high rate of compliance with hydration and antibiotic suggestions suggests that there is support among the attending family physicians and patients for a medical model of care. Second, there was a trend for the consultants to recommend the reduction or change of medications with central...
neurological effects, including opioid medications, rather than increasing the dose. This suggests that there has been shift away from the problem of undermedicating pain and symptom distress, and there is now more of a issue of inappropriate or excessive medication use, particularly when the medications have the potential to worsen cognitive function. Finally, the pattern of initial management by family physicians suggests that some palliative care practices have been successfully incorporated into family physicians’ practice and, as manifested by the high compliance rates, that they are willing to further adapt their patterns of practice as required. This suggests that family physicians and palliative care consultants can work collaboratively, thus allowing a relatively small number of palliative care consultants to oversee care of a large number of patients.

References