

A Clinical Audit of Palliative Care Needs and Services Provided to Dying Patients in Institutional and Community Settings in Capital Health

Final Report

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Highlights

- ▶ Each year approximately 6,000 people die in the Capital Health Region. This study describes and evaluates the care provided to a representative sample of 175 patients.
- ▶ Statistical analysis is used to assign patients to groups with similar profiles of resource utilization and need. A scoring algorithm helps to identify appropriate settings of care and potential mismatched needs and resources at end-of-life.
- ▶ Of patients admitted to a facility, 52.8% were directly admitted from the home while a third are admitted from hospital.
- ▶ Acute care patients also spent a significant time in emergency averaging 26.3 hours with a maximum of 104.3 hours.
- ▶ Average documentation rates for 25 core variables varied from 66.8% in palliative care settings to 43.0% in non-palliative care settings.
- ▶ Physician order changes varied from 0.52 per visit in palliative home care to 9.99 per day in acute care. Physicians see patients once every two days or visits across all settings (0.4 per day in palliative home care to 2.1 times per day in acute care). Respiratory, physical and occupational therapists see patients about every ten days.
- ▶ Nursing care interventions (defined by a list of 13 procedures requiring intensive nursing resources) vary from 0.2 procedures during a palliative consult, to 0.9 procedures in long term care facilities to 3.8 in acute care.
- ▶ Chart review is a viable means to address quality of care provided to dying patients but is limited by the degree of documentation. It is therefore recommended that efforts to improve assessment, documentation and data capture be encouraged.
- ▶ The findings of this study confirm that the location of care provided to patients in Capital Health is for the most part, appropriate.
- ▶ Dying patients in acute care settings receive high levels of care. However, transfer to alternative settings may not be appropriate or economical without further study.
- ▶ Providing adequate support to address anxiety and other psychosocial symptoms at end of life is clinically important and should be documented.
- ▶ The fact that some patients seen in hospices resemble those of tertiary care and the fact that patients dying in long-term care facilities resemble those in hospice suggest that additional resources may be warranted in these settings.

Executive Summary

Background: Palliative care is a relatively new discipline and is rapidly evolving. As a result, the objectives, limits and nature of palliative care are neither clearly defined nor unequivocally agreed upon. Nonetheless, guidelines and best practices need to be continually developed, even if the research evidence to guide clinical practice is limited. Clinical audit is one approach to quality assurance and has been defined as “the systematic critical analysis of the quality of health care”. Lack of time, expertise and validated tools have been identified as the most frequent barriers to conducting audit. In a desire to identify and implement opportunities for improvement, ALPACA (Alternate Level of Palliative and End of Life Care Audit Instrument) was developed to assess appropriateness of resource use and effectiveness of organizational structures. The purpose of this study therefore is to continue to develop and refine a clinical audit tool to evaluate appropriateness of care provided to patients at end of life, across both institutional and community settings.

Objectives: 1. To evaluate chart review as a method to describe the health care needs and resource use by palliative and end-of-life patients in the Capital Health Region. 2. To refine and validate ALPACA as an audit tool for the evaluation of appropriate resource utilization by palliative and end-of-life patients. 3. To describe the potential population for palliative care services:

Approach: We abstracted data from the first three consecutive days (visits in community settings) to describe patient acuity and procedures for a single point in time and to improve the likelihood of observing a full assessment and clinical plan. The items abstracted by the ALPACA tool include: age, gender, culture/ethnicity, language, education, income, diagnosis, advance directives, interdisciplinary care, morphine equivalent daily dose (MEDD), physician order changes, symptoms assessment, social work / psychological assessment, interdisciplinary progress notes, pressure ulcer risk assessment and nursing care. A total of 175 medical charts were selected from sites selected randomly from the patient population that has died between January 1 and

December 31, 2005 across six sites in Capital Health. Inclusion criteria consisted of: lengths of stay/care exceeding 3 days (or visits) in length, episode of care coded as medical (surgery, obstetrics and psychiatry are therefore excluded). All causes of death were considered. Data was abstracted using ALPACA and periodically reviewed by the investigators. ALPACA v2.3 is the product of this process and included three revisions. ALPACA v2.3 was converted to TELEFORM™ v9.0 format, which allows automated conversion of data entered with pen and paper to electronic format. The research nurses used pen and paper to enter the data into the forms. A research assistant entered this data into TELEFORM™ v9.0 format and converted the resulting database into SPSS™ v14.0 format for analysis. ALPACA results in the collection of 254 observations (variables) for each patient and three consecutive days (visits) of care. Data reduction (aggregation and averaging) was applied to convert this dataset to approximately 100 variables. A two-step cluster analysis was then used to assign patients to groups with similar profiles of resource utilization and need. A scoring algorithm then provides insight into the optimal number of clusters, cluster frequencies and descriptive statistics. Cluster frequencies and variable importance charts help to describe determinants of appropriateness and identify potential mismatched needs and care settings for patients at end-of-life. Although these are determined statistically, review of descriptive data and the use of subjective criteria by clinicians and program administrators help to establish the validity of the results. Ability to assess appropriateness however is limited to information recorded on charts. Standards differ across sites and for levels of appropriate care. Ethics and administrative approvals were granted for this study.

Findings: A total of 175 patient charts were abstracted and represent six care settings and seven institutions or programs yielding a total of 501 days of observation. Of patients admitted to a facility, 52.8% were directly admitted from the home while a third were admitted from hospital. Median length of stay varied from 15.5 days for patients in acute settings to 430 days for patients in long term care facilities. Acute care patients also spent a significant time in emergency averaging 26.3 hours with a maximum of 104.3 hours. Average documentation rates for 25 core variables varied from 66.8% in palliative care settings to 43.0% in non-palliative care settings. Approximately two-thirds of

patient charts contained a DNR order, varying from 48% in long term care settings to 96% in tertiary care and hospices. Physician order changes varied from 0.52 per visit in palliative home care to 9.99 per day in acute settings. Opioid pain medications are most prevalent in tertiary care and lowest for patients in long-term care facilities. Physicians see patients about once every two days or visits across all settings (0.4 per day in palliative home care to 2.1 times per day in acute care). Respiratory, physical and occupational therapists see patients on average every ten days. Nursing care interventions (defined by a list of 13 procedures requiring intensive nursing resources) vary from 0.2 procedures during a palliative consult, to 0.9 procedures in long term care facilities to 3.8 in acute care. Long term care facility population describes an older female population while the tertiary care unit looks after a younger population with an average age of 64.9 years. The age of acute care patients average 77.5 years which is lower than the 84.6 years of long term care but much higher than tertiary care. Personal directives can be found in 8% of palliative consult records and 68% in long term care facility records. A total of 65.1 patients are being cared for on account of cancer. Palliative home care patients are characterized with higher functional status while patients in acute and hospice settings averaged lower scores. On average, patients in tertiary palliative care unit are more symptomatic while patients in long-term care facilities are less symptomatic. Two-step cluster analysis identified three cohorts: Group 1 or “Acute EOL” is homogenous and is comprised solely of acute care patients. Group 2 or the “chronic palliative care” group is comprised of all the long term care, most hospice patients plus some acute and tertiary care patients. Finally, group 3 or “Acute palliative care” group is comprised mainly of the tertiary unit and a handful of hospice patients.

Limitation: Chart review is limited primarily by the reliance on documentation. Documentation rates may be understated in that some institutions and units include the use of temporary means of recording information and therefore not available to the abstractor at the time of review.

Implications for Decision Making:

Is chart review a viable means to address quality of care provided to dying patients? The answer is yes as the audit generated a considerable insight into the care of dying patients across multiple care settings. The chart review results in considerably more information than is available in electronically available datasets and less costly than surveillance using prospective observational tools. However the findings in this study are conditioned on the level of documentation. It is therefore recommended that efforts to improve assessment, documentation and data capture be encouraged.

Did ALPACA identify the optimal location of care provided to dying patients? This tool performed very well with relatively few variables requiring additional research and revision. The two-stage clustering procedure was fairly robust and underlying statistical assumptions were considered in detail. The findings confirm that the location of care provided to patients in Capital Health are for the most part, appropriate.

Is the palliative care program sufficiently resourced to address all end of life care needs in the region? In other words, does ALAPCA allow us to identify: (1) diagnoses that are more likely to benefit from palliative consultation, (2) cancer patients more likely to benefit from earlier referral and (3) patients that would benefit from more intense palliative services at their current location as opposed to transferring to another location? This is an important question to answer. On the one hand, there is some solace in the fact that the majority of patients dying in acute care are different from those seen in the palliative program. They are receiving high levels of care which suggest that transfer to alternative settings may not be appropriate or economical.

Unexpected Findings and Recommendations:

1. These findings are primarily limited to the physical care of the patient as charts inadequately describe the psychosocial needs and care plans. It is well known that patients and their families experience anxiety during care and bereavement across all care

settings. Providing adequate support to address anxiety and other psychosocial symptoms at end of life is clinically important and should be documented. Through the accreditation process, the palliative care program should set a standard for appropriate documentation for psychosocial support in end of life care.

2. The fact that some patients seen in hospices are resemble those of tertiary care and the fact that patients dying in long-term care facilities resemble those in hospice suggest that additional resources may be warranted in these settings.

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1. Background

Palliative care is a relatively new discipline/specialty and is rapidly evolving to include non-cancer diseases and services such as bereavement (Charlton et al 2002). As a result, the objectives, limits and nature of palliative care are neither clearly defined nor unequivocally agreed upon (James and Macleod 1993). Nonetheless, guidelines and best practices need to be continually developed, even if the research evidence to guide clinical practice is limited (Higginson et al 1999). Although most agree with the World Health Organization (2002) definition of palliative care:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

A rapidly changing environment is challenging for healthcare professionals. Some have argued that palliative care has not evolved sufficiently for a mature evaluation of quality (Charlton et al 2002). According to Scholfeld et al (1990) evaluation of quality in health care is concerned with ensuring that people work together and use available resources to provide the best possible care for patients. Audit is a specific approach to quality assurance and has been defined as “the systematic critical analysis of the quality of health care. Its purpose is to identify and implement opportunities for improvement (Charlton et al 2002). Audit is multipurpose however in that it aims to improve the care of individual patients, provide high quality training of individuals in the field and to

ensure the effective use of resources (Shaw et al 1993). Although research is absent from this list, it should be included in this definition.

Lack of time, expertise and validated tools are the most frequent barriers to conducting audit (Charlton et al 2002). As a result, we conducted a thorough review of the literature and identified a number of potential clinical audit tools used in community and specialized palliative care settings (Rogers et al 1998, Coll et al 2002, Dendaas et al 2001, Duggelby and Alden 1998, Fowell et al 2002, Higginson et al 1996, Holden 1996, Paice et al 2004, Radbruch et al 2002, Sulmasy et al 1996 and Charlton et al 2002). Varying objectives and domains of these audits reveal a plethora of approaches and instruments. For example, Higginson's Palliative Outcome Scale (POS) has been used to prospectively measure outcomes for patients with advanced cancer and their families in various specialist and non-specialist palliative care settings throughout the UK. Acceptable validity and reliability of the POS has been demonstrated (Hearn and Higginson 1999). As with other instruments however, the POS does not provide sufficient insight into assessment of appropriate resource use and effectiveness of organizational structures.

In 2005, the Ontario Ministry of Health and Long Term Care (MOHLTC) and the Sisters of Charity Ottawa Health Service (SCOHS) contracted Konrad Fassbender and Sarah Downey to perform an operational review and clinical audit. The absence of instruments to assess appropriate resource use and effectiveness of organizational structures resulted in the convening of an expert committee to address the need for an appropriate clinical audit tool. As a result, ALPACA (Alternate Level of Palliative and End of Life Care Audit Instrument) was constructed and applied. The results of the audit resulted in the identification of significant recommendations to SCOHS (Fassbender and Downey 2006). In particular, the review enabled the MOHLTC to understand the needs of palliative patients in the Ottawa Region and averted the elimination of 12 palliative beds.

ALPACA is comprehensive and there is some evidence of face validity. ALPACA was however developed and applied to a single setting and is therefore not validated for use in a coordinated and integrated setting. Since resource use and

effectiveness of organizational structures vary by site, further refinement, application and evaluation of ALPACA is warranted for both institutional and community settings.

In 2005, the Capital Health Region granted the authors funding to evaluate the use of ALPACA across both institutional and community settings. The purpose of this study therefore is to continue to develop and refine a clinical audit tool to evaluate appropriateness of care provided to patients at end of life.

2. Objectives

- 2.1 To evaluate chart review as a method to describe the health care needs and resource use by palliative and end-of-life patients in the Capital Health Region.
- 2.2 To refine and validate ALPACA as an audit tool for the evaluation of appropriate resource utilization by palliative and end-of-life patients.
 - 2.2.1 To refine the data elements comprising ALPACA
 - 2.2.2 To refine the scoring algorithm
 - 2.2.3 To address methodological considerations
- 2.3 To describe the potential population for palliative care services:
 - 2.3.1 To identify whether more patients would benefit from referral to the palliative care program, especially non-cancer populations;
 - 2.3.2 To determine whether the timing of referral to the palliative care program is appropriate, especially cancer patients; and
 - 2.3.3 To determine whether the number and length of referrals to the palliative care program is appropriate.

3. Approach

We continue to refine an instrument to describe a summary measure of whether appropriate palliative care is provided to dying patients. Appropriateness is an indicator of the right care provided to the right patients at the right time and in the right place. Fundamental to the approach is an assumption that the right care is provided to the right patients. In other words, we assume that the care provided matches that deemed necessary by assessment of need. Furthermore, we are assessing care at a single point in time. As a result this tool does not make an attempt to assess whether care is provided at the right time. ALPACA therefore is limited to assessing whether the care is provided in the right place. In particular, the instrument is designed to identify alternate levels of care by assessing patient acuity and resource utilization. Alternate level of care includes all non-acute care, including home, residential hospice and long term care settings.

Audit is a resource intensive process. Although it may be desirable to evaluate all care-days for a given patient and all patients within a given time period, resource constraints of this type of review require a compromise. We propose a tradeoff whereby only the first three days are evaluated in order to increase the number of patient charts evaluated. While this allows for evaluation of appropriateness at the time of admission, it should be noted that length of stay (LOS) and time from admission to death differs by setting of care.

Due to the inherent clinical variability of this population, a minimum of three consecutive days are required to describe patient acuity and procedures for a single point in time. Three consecutive days also allows for the recording of events taking place during weekdays and thereby minimizes bias associated with sampling on weekends. Days 1, 2 and 3 (where day 0 is the day of admission) are considered. During this period of time a full assessment and clinical plan should be observed. This method captures clinical data recorded during a calendar day and avoids the need to evaluate partial days. Note that this approach does not evaluate cases where $LOS < 4$.

Audit of community settings include palliative home care and community consult services. Services are not always provided on consecutive days. As a result, consecutive visits are proposed. Community consults may not always involve more than one or two visits and therefore fewer than three visits were included for these settings.

The items identified in ALPACA were developed by an iterative process of literature synthesis and review by the investigators. Feasibility and face validity are established through consultation between the investigators, abstractors, medical record personnel and administrators at the various institutions. The items include: age, gender, culture/ethnicity, language, education, income, diagnosis, advance directives, interdisciplinary care, morphine equivalent daily dose (MEDD), physician order changes, symptoms assessment, social work / psychological assessment, interdisciplinary progress notes, pressure ulcer risk assessment and nursing care.

Two domains (MEDD and pressure ulcer risk assessment) incorporate validated scales. The MEDD was developed by clinicians at the Capital Health Palliative Care Program in Edmonton. The MEDD is expressed in mg equivalent dose of oral morphine. Pressure ulcer risk assessment is measured with the Braden Scale, created by Barbara Braden and Nancy Bergstrom in 1987. As the Braden Scale scores become lower, predicted risk becomes higher, where scores are interpreted as follows: 15 to 18, at risk; 13 to 14, moderate risk 10 to 12, high risk; and 9 or below, very high risk. In an acute setting, these levels of risk should correspond to the level of nursing effort and technology required to prevent pressure ulcers.

3.1 Medical Chart Selection Criteria

A total of 175 medical charts were selected from the following (mutually exclusive) sites selected randomly from the patient population that has died between January 1 and December 31, 2005. Inclusion criteria consisted of: lengths of stay/care exceeding 3 days (or visits) in length, episode of care coded as medical (surgery, obstetrics and psychiatry are therefore excluded). All causes of death were considered.

- Tertiary Palliative Care Unit at the Grey Nuns (n=25)

- Acute Care (n=50)
 - Grey Nuns Community Hospital (n=25)

- Misericordia Community Hospital (n=25)

- Continuing Care Facilities (n=25)
 - St Joseph's Auxiliary Hospital (n=8)
 - Norwood Extended Care Centre (n=8)
 - Edmonton General Hospital (n=9)

- Hospices (n=25)
 - St. Joseph's Hospice at St Joseph's Auxiliary Hospital (n=8)
 - Norwood Hospice at Norwood Extended Care Centre (n=8)
 - Mel Miller Hospice at the Edmonton General Hospital (n=9)

- Palliative Home Care (n=25)

- Capital Health Regional Palliative Care Program (Community Consults, n=25)

3.2 Data Abstraction

Data was abstracted from the first three full days (or visits) in patient's final episode of care as identified in charts by nurses with research training. Data was abstracted using ALPACA and periodically reviewed by the investigators. ALPACA v2.3 is the product of this process and included three revisions. A subset of charts were re-abstracted to collect new data elements when deemed necessary by subsequent revisions.

3.3 Data Management

ALPACA v2.3 was converted to TELEFORM™ v9.0 format, which allows automated conversion of data entered with pen and paper to electronic format. The

research nurses used pen and paper to enter the data into the forms. A research assistant entered this data into TELEFORM™ v9.0 format and converted the resulting database into SPSS™ v14.0 format for analysis.

3.4 Scoring Algorithm and Methodological Considerations

ALPACA results in the collection of 254 observations (variables) for each patient and three consecutive days (visits) of care. Data reduction (aggregation and averaging) was applied to convert this dataset to that of around 100 variables. Exclusion of variables with insufficient observations or variation was also used when appropriate.

Cluster analysis is a statistical procedure to assign group membership to individuals or items with an array of characteristics. Although used extensively in marketing, it was used in this project to assign patients to groups with similar profiles of resource utilization and need. The two-step cluster analysis procedure from SPSS was used in this project.

Codification of ALPACA results in a database containing 250 variables describing patient acuity and treatments. A scoring algorithm (that is reductive in nature) will result in a single indicator which rates the appropriateness of each episode of care. Our objective then is to identify whether patients, at a single point in time, are receiving appropriate clinical care i.e. in settings such as tertiary, acute, long term care, residential hospice or palliative home care.

In general, there are three approaches to scoring. The first is to rely on parameter estimates from the literature which summarize the relationships between subsets of variables. Mature medical disciplines are characterized by the presence of clinical practice guidelines which specify treatments and consensus as to appropriate outcomes. Palliative care medicine however is not mature and a paucity of practice guidelines precludes this approach.

The second approach is to rely on expert opinion. To illustrate consider the mean equivalent daily dose of morphine equivalent medication. Which level and variability (over three days) describes appropriate care can not be determined without taking into

consideration many other factors. Although ALPACA is comprehensive, it could be argued that a person-centered approach requires more information than is collected by the instrument. Differences in standards of practice arising from palliative medicine as a relatively new discipline further serve to prejudice an expert committee from making a decision. In other words, an expert committee will find it difficult to render a decision on appropriateness.

A third approach is to employ a form of classification analysis. Two-step cluster analysis was used as an exploratory tool designed to reveal natural groupings (or clusters) within a dataset that would otherwise not be apparent. This technique is routinely employed to develop marketing and product development strategies by examining retail and consumer behavior which describes customers' buying habits, gender, age and income level. In the present context, cluster analysis is able to determine natural clustering of patient treatments and characteristics given the large amount of available information.

Two-step cluster analysis provides insight into the optimal number of clusters, cluster frequencies and descriptive statistics. Pie charts of cluster frequencies and variable importance charts help to describe determinants of appropriateness. Cluster analysis requires consideration of the following methodological decisions and parameters.

Distance Measure. Different measures (log-likelihood and Euclidean) can be employed to determine the differences between clusters. Inclusion of categorical variables limits the choice to log-likelihood.

Number of Clusters. More than three clusters are difficult to interpret and were not considered in this study.

Case Order. Two-step cluster final solutions may depend on the order of cases. The file was sorted by a selection of final variables and re-run.

Independence and Distributional Assumptions. The likelihood distance measure assumes that variables in the cluster model are independent and that each continuous variable is

assumed to have a normal (Gaussian) distribution. Although empirical evidence indicates that the procedure is fairly robust to these violations, bivariate correlations (Pearson's correlation coefficient and p-values) were used to exclude certain variables.

3.5 Analysis and Interpretation

Descriptive analysis of patients in all care settings will provide insight into the care provided to and the needs of patients at end of life.

Cross-tabulation of individuals by group membership and care setting identifies potential mismatched needs and care settings for patients at end-of-life. Although these are determined by a statistical procedure, review of descriptive data and the use of subjective criteria by clinicians and program administrators help to establish the validity of the results.

3.6 Limitations

Ability to assess appropriateness is limited to information recorded on charts. Standards differ across sites and for levels of appropriate care. Furthermore, two-step cluster analysis requires assumptions which will be discussed more fully below.

3.7 Ethics and Admin Approvals

Ethics and administrative approvals were granted for this study.

4. Findings

4.1 Descriptive Analysis

Study Population

A total of 175 patient charts were abstracted and represent six care settings and seven institutions or programs (Table 1). This sample yielded a total of 501 days of

observation (Table 2). An average of two visits per community consult were observed (52 days for 25 patients). Of patients admitted to a facility, 52.8% were directly admitted from the home while a third were admitted from hospital (Table 3). Table 4 provides statistics for length of stay by setting. Median time varied from 15.5 days for patients in acute settings to 430 days for patients in long term care facilities. Mean times vary significantly due to inclusion of outliers in all these populations. Acute patients also spent a significant time in emergency averaging 26.3 hours with a maximum of 104.3 hours.

Documentation

Out of 100 summary variables, 25 were used to assess the rate of documentation. The other 75 variables are considered fully documented. Completeness of these 25 variables by setting of care is given in Table 5. For example, culture/ethnicity is not documented at all in the palliative home care program but documented in about half of cases in long term care. The last column provides summary documentation rates by variable (arithmetic average of all institutions) varying from 9.1% for income to 100% for age and gender. The last row provides summary measures of documentation (arithmetic averages across these 25 variables) by setting of care. These summary measures are grouped according to palliative and non-palliative settings of care in Figure 1 where we observe average documentation rates of 66.8% and 43.0%, respectively.

End of Life Care: Supply Variables

Approximately two-thirds of the patient population contains a DNR order (Figure 2). This varies from 48% in long term care settings to 96% in tertiary care and hospices.

Physician order changes were classified as medications, diagnostic, interdisciplinary, discharge planning and consults and tabulated for each patient-day (or patient-visit in palliative home care and consult services). They vary from 0.52 in palliative home care to 9.99 in acute settings (Figure 3). Medication and diagnostic orders are the most frequent at 1.99 and 1.67 per day, respectively.

MEDD is a summary measure of opioid pain medication. MEDD scores are greatest for tertiary care and lowest for long-term care facilities (Figure 4). Delta MEDD is defined as the percentage variation $((\text{Max}-\text{Min})/\text{Mean})$, a measure of instability which is observed as highest in the acute care setting.

Interdisciplinary care is measured by the presence of progress notes by non-nursing professional staff. Figures 5 and 6 illustrate the presence of progress notes by setting of care and discipline. Physicians average 54.8% across all settings (about once every two days or visits). By setting, these vary from 0.4 progress notes per day in palliative home care to 2.1 progress notes per day in acute care charts. Figures 7-10 provide the percentage breakdown by institutional setting. In all settings, there is evidence of varied care with physicians accounting for the majority of non-nursing encounters in each setting.

Interdisciplinary care issues were tabulated. Count data are presented in Table 6 which demonstrates an average of 7.9 “issues” per patient with little variation across sites of care.

Nursing care provided to each patient is described by a vector of 13 procedures requiring intensive nursing resources. These vary from 0% for TPN to 46.9% for having blood drawn CL (Figure 11). These also vary from 0.2 procedures during a palliative consult, to 0.9 procedures in long term care facilities to 3.8 in acute care (Figure 12). Figures 13-16 illustrate the complexity of nursing care interventions across all institutional settings.

End of Life Care: Demand Variables

The Anderson framework for health care utilization is used to group these variables into predisposing, enabling and need characteristics.

Age and gender are the predisposing measures that we included (Figures 17 and 18). Notable is that the long term care facility population describes an older female population while the tertiary care unit looks after a younger population with an average age of 64.9 years. The age of acute care patients average 77.5 years which is lower than

the 84.6 years of long term care but much higher than tertiary care. Religion, language and ethnicity are not reported due to low documentation rates.

Tables 7-11 provide descriptive statistics for enabling characteristics. These include marital status, residence type, living arrangements, size of family and size of household. Income was not included due to low documentation rates.

Need for end of life care is captured by personal directives, diagnosis and various clinical assessments. Personal directives can be found in 8% of palliative consult records and 68% in long term care facility records (Figure 19). Table 12 lists the primary diagnosis by setting of care and ICD10 chapter heading. A total of 65.1 patients are being cared for on account of cancer. Patients in all settings were at some risk for pressure ulcers (Figure 20). Only acute care and community palliative consult patients averaged moderate risk. Although not reported many individual patients are at high risk or very high risk in tertiary care, acute care and hospices.

The palliative performance score (PPS) was used to assess functional status and is illustrated in Figure 21. Palliative home care patients were most functional (mean PPS=55.3) while acute and hospice settings averaged lower (mean PPS =33.0). Finally, Figure 22 provides a picture of symptom burden according to the ESAS (Edmonton Symptom Assessment Score) categories. A higher score indicates increasing symptom burden. Average tertiary palliative care unit scores are highest (most symptomatic) while long-term care facilities look after patients with the lesser symptoms.

4.2 Classification Analysis

Two-step cluster analysis was limited to the care provided in facilities (Tertiary palliative care unit, acute care, hospice and long term care). Figure 23 provides a summary illustration of the final groupings. Three groups are identified and have been labelled “Acute EOL”, “Chronic Palliative” and “Acute Palliative” care. Each group is cross tabulated by setting of care. Group 1 is homogenous and is comprised solely of acute care patients. Group 2 or the “chronic palliative care” group is comprised of all the long term care, most hospice patients plus some acute and tertiary care patients. Finally,

group 3 or “Acute palliative care” group is comprised mainly of the tertiary unit and a handful of hospice patients.

Tables 13 and 14 provide summary statistics for continuous and categorical variables used in the final classification analysis model. For example, the average length of stay for the three groups is 19, 471 and 23 days respectively.

4.3 Limitations

The primary limitation to this analysis is the fact that we are relying on chart review. In other words, if it isn’t written down, then we assume that care was not provided or symptoms were not present. This is problematic in that assembly of charts for storage does not include all documentation. Many institutions and units use temporary means of recording information that is not available to the abstractor at the time of review.

Inclusion of variables in the final analysis are also dependent on documentation rates. In particular, many predisposing and all enabling variables were insufficiently documented for inclusion in the classification model. It is not known if this would have altered the outcomes of the study.

Finally, we make the assumption that appropriate care is provided to appropriate patients. In other words, we assume that patients are receiving all the care that is demanded (or needed). This is an attractive assumption in that it presumes clinicians are equally trained and resourced at all sites. On the other hand, there is literature to suggest that this may not be the case.

ALPACA is comprehensive and there is some evidence of face validity. Our analysis reveals a description of patient acuity and care that is in agreement with clinical and administrative perception. To our knowledge however, exploratory statistical analysis is rare and two-step cluster analysis has not been applied to palliative care data in any setting. As such, methodological limitations to this approach and the steps taken to address these limitations need to be described. Our efforts to address these potential limitations are as follows:

Sample Size. The sample of 175 patient charts and 501 days was insufficiently powered to determine significance for all variables. Although the direction and magnitude of individual statistics conform to expectations a formal calculation is warranted.

Choice of Variables. Several principles were employed to reduce the 100 variables to the final list of 28. Firstly, statistics coded by day were aggregated across the three days. In some cases an average was applied (medications), in other cases a maximum was applied (symptoms) and finally totals were provided for services. Secondly, limitations in data quality precluded use of certain variables. Thirdly, insufficient variation precluded the use of other variables. For example, the use of TPN was excluded as it was not observed in this dataset. Finally, the principle of parameter stability is employed. That is to say as variables were serially considered, those having no effect on the end result were excluded.

Distance Measure. Different measures (log-likelihood and Euclidean) can be employed to determine the differences between clusters. Inclusion of categorical variables limits the choice to log-likelihood. Our conclusion was not influenced by the choice of measure.

Number of Clusters. Three clusters were identified by SPSS. A greater number of clusters could have been specified but would have been more difficult to interpret.

Case Order. Two-step cluster final solutions may depend on the order of cases. The file was sorted by each of the thirteen variables and re-run. In each case, the assignment of group membership did not vary.

Independence and Distributional Assumptions. The likelihood distance measure assumes that variables in the cluster model are independent and that each continuous variable is assumed to have a normal (Gaussian) distribution. Although empirical evidence indicates that the procedure is fairly robust to these violations, bivariate correlations (Pearson's correlation coefficient and p-values) were used to verify that this was not a concern for the final model.

5. Discussion

Study Population

Each year approximately 6,000 people die in the Capital Health Region. This study describes and evaluates the care provided to 175 patients over the first three days in their last episode of care. We evaluated the care provided in a wide variety of care settings and institutions.

Both palliative home care and the community consults presented problems for this review. Firstly, care is not necessarily provided on consecutive days. As a result, we used consecutive visits. Secondly, community consults averaged two per person. As it was not possible to observe three visits, we dropped the requirement of three visits from the chart selection criteria. Finally, it was hard to identify care. For example, MEDD could not be calculated as medications were not sufficiently charted by home care staff or consultants. We therefore excluded community patients from the two-stage classification procedure. Descriptive results are however included and are helpful in assessing aspects of patients' care and need at end of life.

Best efforts were made to reduce selection bias so that population inferences could be made. This study represents 175 days and a total of 501 days of observation. In most cases, the first three days of an episode were sampled. Of patients receiving care in facilities, about one-half were directly admitted from the home. In these cases an episode of care is better defined than in the one-third cases that were admitted from hospital. Another issue relates to the length of stay. In the case of long-term care facilities, a median LOS of 430 days means that care was assessed at quite some time prior to death.

Comparability could have been improved had we measured care at a consistent time point relative to the date of death, say one week prior to death. On the other hand, our study design assumes that the probability of assessment and documentation are better at the time of admission to an institution as compared with other days during an episode of care.

Documentation

Quality of documentation is typically assessed by measuring completeness and accuracy for a given set of variables. Accuracy, is comprised of accuracy of charting plus accuracy associated with abstracting. Accuracy is then assessed by comparison with independently collected data. As such we limited assessing the quality of documentation to completeness and deemed assessment of accuracy a separate study. Quality of documentation was defined in this study as the arithmetic average of completeness for 25 variables. Note that an arithmetic average gives equal weighting to all variables.

The choice of 25 variables was based on two factors. Firstly, these are variables have been shown in the literature to be important indicators of use and outcomes associated with care at end of life. Secondly, we excluded variables whose documentations rates cannot be assessed under the assumption “if it isn’t written down, then it wasn’t done”. In other words, we assumed that documentation of end of life care is 100%.

A major limitation to the assumption of 100% documentation rates for end of life care is that the archived medical record may not contain everything that was written down during care. In particular, exclusions include notations in pencil that may be erased and forms which are not included by medical records staff during the archiving process. This may be particularly true of the tertiary palliative care unit and the documentation of care plans.

Documentation rates varied from 39.9% in long term care facilities to 69.4% in the tertiary care unit. Settings of care vary significantly in terms of resources available for management of medical records. For example, the need for accurate medical records and reporting is high in acute care facilities. While it may have been expected that documentation rates would have been low in community settings, this was not observed. Documentation rates for hospice and palliative home care were 66.1% and 62.7% respectively.

Grouping the settings of care by association with the regional palliative care program did provide strong evidence of an association with documentation rates. Non-palliative care documentation rates averaged 43.0% whereas they averaged 66.8% for palliative care settings. These results are largely attributable to standardized clinical

assessment tools allowing for communication and comparability of information (in particular driven by compilation of a data-intensive annual report).

The Capital Health Palliative Care Program balance scorecard benchmarks for documentation of functional status and symptoms (a subset of the 25 core variables) are 100% yet the average is 70.0% for settings providing palliative care services. Although this statistic is much higher than the 14.0% for non-palliative settings, there is room for improvement. A review of the literature did not reveal documentation rates in any other setting. It is important to point out that these statistics include not only the use of standardized assessments but also documentation of symptoms using non-standardized assessment tools. For example, 'appetite' was documented 81.3% of the time using ESAS and an additional 5.4% of time elsewhere in the chart for a total of 86.7%.

End of Life Care: Supply Variables

It is assumed that DNR orders limit the amount of costly care provided at end of life. While this is true of technologies aiming to extend life, this may or may not be true of technologies aiming to improve the quality of life. The observed rate of 96% in the tertiary palliative care unit and hospice is due to the fact that a DNR is a prerequisite for admission. A 48% DNR rate in long term care facilities is an acknowledgement of the advanced state of disease in this patient population, even at the median 430 days prior to death. Whether these rates are appropriate requires further dialogue and study.

Physician order changes were reclassified to include discharge planning and consult in addition to medications, diagnostic and interdisciplinary care. The variation is very large and partially reflects the role of physicians in daily care of patients in these various settings. An observation of 0.52 orders per visit for patients in palliative home care setting is not surprising given that this population is relatively more stable and that care is predominantly organized and delivered by nurses. An observation of 9.99 orders per day for patients seen in acute care settings is not surprising given that these patients are seen a median of 15.5 days prior to death. A total of 3.77 orders per day in the tertiary palliative care unit can be explained by the fact that these patients received

palliative care prior to admission. On the other hand, it may reflect the fact that physicians are sharing the orders with other disciplines. Palliative consults result in 5.93 orders per visit which, in theory, are additive to orders they are receiving at their respective settings of care. It is important also to remember that these orders are recommended and may not be followed. A high number of orders either reflects instability and acuity of patients or a 'correction' addressing cumulative deficiencies in care received at their respective settings.

The majority of physician orders are medication and diagnostic orders which illustrates the importance of managing medications at end of life. Diagnostic orders in the acute care setting are observed at 3.48 orders per day and, as expected, 0.72 orders per day in tertiary palliative care.

Of the medications, opioids are perhaps most closely associated with end of life care. The MEDD is a summary measure of opioid use in units of morphine equivalents per day. We measure the average MEDD over the three day time period in addition to the variation over the three days. Although the drugs are often charted by the palliative consult team and by palliative home care, the dose is not. Even if the dose were to be recorded, the MEDD is a measure of actual use and includes what is known as breakthrough doses, or medication taken as needed. The results clearly demonstrate that the patient population in acute care settings differs from hospice and tertiary care with mean MEDD scores of 13.1, 68.5 and 119.2, respectively. A score of 1.9 for long term care reflects the early stage of disease progression in the patient's trajectory of care.

We assess interdisciplinary care through the use of progress notes by non-nursing professional staff. It is difficult from progress notes however to determine if care was delivered personally or through case review (ie not requiring face-to-face contact with the patient). As well, there are no reliable measures of intensity of case. As a result, we can only provide an index whereby each discipline is scored as 0 or 1 for each patient-day. The interpretation of the resulting index is one of intensity (percent of days) and mix (number) of disciplines. This index excludes nursing as it is assumed that nurses see all patients at least once a day (or visit) in all settings. With the exception of most physicians, the addition of FTE and bed data by discipline can be used to express these numbers in terms of hours per patient-day.

Physicians average 54.8 across all settings which means that they see patients on average about once every two days or visits. At 98.0% for acute care, physicians see patients every day. Respiratory, physical and occupational therapists see patients on average every ten days. In total 2.1 progress notes are observed for acute care charts as compared to 1.5 for tertiary care. Palliative consult is 0.1 which means that charting is done primarily by nurses. In all other settings, physician care is the most evident, and significant for community settings such as hospice, palliative home care and long term care settings.

Interdisciplinary care issues is a nebulous concept. For this report, we rely on the presence of progress notes by discipline, assessment of symptoms and documentation of diagnosis. Issues however refer to a conglomerate of symptoms, diagnoses and other items which influence quality of life (eg financial). They also include process of care such as desired location of care. Some issues require a major amount of care while others involve little resources. At best, this concept should capture documentation of a care plan. For example, we may capture that a social worker assesses anxiety on behalf of the patient and family. Or that a dietician observes weight loss as a concern. Was a plan documented? Did the plan conform to guidelines? Was patient progress charted against the resulting goals of care? These questions suggest that much work is needed to adequately assess quality of care while capturing the notation of “issues” in medical charts.

Nursing care interventions explains the majority of resources provided to patients in all care settings. Nursing care is recorded through extensive charting and by nursing workload measurement systems. For the purposes of this study we identified a vector of 13 procedures requiring intensive nursing resources that are characteristic of end of life care. These should easily differentiate settings which provide intensive nursing resources from those that do not. Draw blood CL, SubQ, oxygen, intravenous hydration and medication are the most frequent nursing interventions. Acute care settings average 3.8 interventions per day while tertiary palliative care and hospice care average 2.3 and 2.1 procedures respectively. The reasons for this discrepancy may be explained by the goals of care at the time of admission: to improve survival or to improve quality of life. In this way, the measure is accurate but only tells us that more physical care is being done in

acute care settings – not necessarily that more end of life care is being provided as we are unable to capture psychosocial care. ALAPCA attempted to capture notations and phrases which are correlated with significant emotional care. Providing adequate support to address anxiety and other psychosocial symptoms at end of life is clinically important and should be documented. Further refinement to ALAPCA is therefore warranted. In the meantime, comparison of these measures with information collected by nursing workload measurement may shed some insight into this question.

End of Life Care: Demand Variables

The Anderson framework is used in this study to explain health care utilization as a function of predisposing, enabling and need characteristics.

Age and gender are the predisposing measures that we included. Not surprisingly, long term care facilities serve an elderly female population. The tertiary palliative care unit looks after a predominantly younger population by about 20 years. We know that age is highly correlated with disease burden and these populations therefore describe greatly differing needs. The use of care at end of life has been documented to vary by religion, language and ethnicity. The low documentation rates preclude an analysis of these factors.

Enabling characteristics refer to the patients' private use of resources. These are particularly important in explaining the use of long term, hospice and palliative home care. In these settings marital status, residence type, living arrangements, size of family and size of household may serve to influence the use of health care resources and associated outcomes. These variables are also highly correlated with age. Nonetheless, long-term care patients are more likely to be unmarried, live alone and have small families. Conversely, you need to live in a home to receive palliative home care.

Personal directives, diagnosis and clinical assessments are used to measure the need for end of life care. The fact that personal directives are most prevalent in long term care facility records reflect the admission process for long-term care settings.

Cancer explains roughly two-thirds of our patient population which is not surprising given that we excluded surgical, obstetric and psychiatric patients from

institutional care settings. Again, age may explain the fact that acute care patients are more likely to be at risk for pressure ulcers and are less functional. A confounder is the rather low rate of assessment of functional status on the tertiary palliative care unit.

Documentation of symptoms leads to the identification of three different populations. Clearly, the tertiary palliative care unit is providing care to patients with identified symptomology. The consult, hospice and palliative home care programs describe a slightly less symptomatic population. Finally, acute and long term care settings describe patients with rather low symptom burden, aside from some anxiety and appetite problems. Again, the long term care results are explained by the rather long time period prior to death. It is difficult to know to what extent this finding may be driven by poor documentation and under-use of standardized assessment instruments.

Classification Analysis

The limitations of ALPACA with regard to auditing end of life care provided in palliative home care and palliative consult settings, means that the classification analysis is limited to institutional settings. Taking into account all variables at the same time, three groups of individuals are identified and have been labelled “Acute EOL”, “Chronic Palliative” and “Acute Palliative” care. These terms best describe the constellation of care and needs of the patients.

Group 1 is homogenous and is comprised solely of acute care patients. They describe a population with a mean age of 77.5 years that receives intensive care but is low in symptoms. Intensive care includes 4.18 medication order changes per day, 87.2% IV hydration per day and 4.83 litres of oxygen per day. Assessment of pain averages 16.2/100 and is indicative of low symptoms.

Group 2 or the “chronic palliative care” group is comprised of all the long term care, most hospice patients plus some acute and tertiary care patients. These findings are significant in that patients in long-term care facilities are equivalent to patients dying in hospices. It should also be noted that the sub-population of acute and tertiary care patients with sufficiently long-stays, lower care and needs may already be identified as “alternative level of care” (ie waitlisted for long term care placement).

Finally, group 3 or “acute palliative care” group is comprised mainly of the tertiary unit and a handful of hospice patients. These patients are younger and have significantly higher symptom burden. Care levels are intermediate. This group is significant because it indicates that a portion of patients currently served in hospices are equivalent to tertiary care.

It is tempting to conclude that a subset of patients in acute, hospice and tertiary units could be relocated to more appropriate locations. The limitations in the analysis, especially the low documentation rates, suggest caution in this recommendation. An important finding is that the small percentage of patients in acute care imply that the majority of care is being provided in an appropriate setting. A subgroup of interest is the long-term care cohort and the recognition that they are comparable in acuity to hospice patients at more than one-year prior to death. This finding is not surprising when considering that organ-failure and frailty patients are associated with higher costs as early as two years prior to death.

The small numbers in Group 2 are perhaps comprised of patients already designated ALC or alternative level of care and awaiting long term care facility placement. The small but equal proportion of patients cross-placed in hospice and tertiary units reflect the extreme difficulty the palliative care program has in determining the optimal admission times and transfers. In particular, this assessment is retrospective while real-life clinical decisions are prospective and require better prognostication.

6. Implications for Decision Making

We began by asking whether chart review is a viable means to address quality of care provided to dying patients? This audit has provided generated an insight into the care of dying patients across multiple care settings. The acknowledged limitation is the requirement to base findings on the level of documentation. Addressing this limitation would require data capture that is even more costly than chart review. The expense of data capture is relevant for performance measurement in that the utility of an approach is also limited by the frequency of measurement. The chart review is a compromise

between assessment of quality of care using electronically available data and surveilling care using prospective observational tools.

Is ALPACA a viable means to address the location of care provided to dying patients? This tool performed very well with relatively few variables requiring additional research and revision. It confirms that the location of patients in the Capital Health Region are for the most part, appropriate. The two-stage clustering procedure is fairly robust and underlying assumptions have been considered in some detail.

Is the palliative care program sufficiently resourced to address all end of life care needs in the region? In other words, does ALAPCA allow us to identify: (1) diagnoses that are more likely to benefit from palliative consultation, (2) cancer patients more likely to benefit from earlier referral and (3) patients that would benefit from more intense palliative services at their current location as opposed to transferring to another location? This is an important question to answer. On the one hand, there is some solace in the fact that the majority of patients dying in acute care are different from those seen in the palliative program. They also are receiving high levels of care which suggest that transfer to home may not be appropriate or economical. These findings cannot be generalized to surgical, obstetric or psychiatric patients.

As well, these findings are limited to the physical care of the patient. They do not include the role of psychosocial care. Both patients in acute settings and their families experience anxiety during care and bereavement. Should the communication and counselling required be addressed by the palliative program? This is the subject of another study.

The fact that some patients seen in hospices are resemble those of tertiary care and the fact that patients dying in long-term care facilities resemble those in hospice suggest that additional resources may be warranted. A more directed study is warranted to address this last question.

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8. Tables and Figures

Appendix 1: Team Biographies

Dennie Hycha, RN, BScN, MN, CHPCN. Acting Program Director for Capital Health's Regional Palliative Care Program. Dennie has developed and implemented a framework for a rural regional palliative care program that includes consultation at the primary and secondary levels and integrated program development. Dennie completed the Canadian Healthcare Association certificate course in quality improvement, working as a quality improvement coordinator which included development and implementation of a regional quality framework. Dennie has been actively involved in accreditation processes as a team leader for the hospice palliative accreditation team, a regional coordinator, and at the national level as an advisor in the development of the hospice palliative care accreditation standards. She is involved in provincial and national policy development and leadership, and in palliative care nursing leadership and education.

Nicole Bonville, RPN, RN, BScN. Manager of South Edmonton Palliative Home Care. Extensive experience in a variety of acute and community palliative nursing settings.

Karen Macmillan, RN, BScN, CHPCN. Karen Macmillan graduated from the Royal Alexandra Hospital School of Nursing in 1984. In 1986, she graduated from the University of Alberta with a Bachelors of Science in Nursing. Karen has completed a Certificate in Adult and Continuing Education and has the Canadian Nurses Association Certification in Hospice Palliative Care Nursing. Karen is the program manager for the Tertiary Palliative Care Unit and Ambulatory Services at the Grey Nuns Community Hospital in Edmonton, Alberta Canada. Karen is active in education and research and has over 60 abstract, article and book chapter publications in palliative care. Karen sits as a member of the Health Ethics Research Board of the University of Alberta and is currently enrolled in a Masters of Nursing program.

Carleen Brenneis, RN, MHSA. Adjunct Assistant Professor, Faculty of Nursing, University of Alberta and Program Director for Capital Health's Regional Palliative Care Program, Edmonton, active on national and provincial working committees in surveillance, community development and quality assurance from a population health perspective. Published in the area of model development for hospice palliative care.

Robin Fainsinger, MD, CCFP. Dr. Fainsinger graduated from the University of Cape Town in South Africa in 1981. In 1991, he completed the first fellowship in palliative medicine at the University of Alberta in Edmonton, Canada. He continues to reside in Edmonton where he has been Director of the Palliative Care Program at the Royal Alexandra Hospital since October 1994. He is Director of the Division of Palliative Care Medicine in the Dept of Oncology, and Clinical Director for the Capital Health Regional Palliative Care Program. He is an Associate Professor (promoted to Professor effective July 1, 2006) in the Division of Palliative Care Medicine, Department of Oncology at the University of Alberta. He is active in education and research, and has published articles on a number of palliative care topics, with an interest in dehydration, delirium, sedation at the end of life, and a classification system for cancer pain. He has over 120 publications in journals and book chapters.

Appendix 2: ALPACA Instrument

Table 1: Study Population by Institution and Setting of Care (patients)

	Tertiary Care	Acute Care	Palliative Consult	Hospice	Palliative Home Care	Long Term Care	Total
Edmonton General Hospital				9		9	18
Grey Nuns Community Hospital	25	25					50
Misericordia		25					25
Norwood				8		8	16
Palliative Home Care					25		25
Regional Palliative Care Program			25				25
St. Joseph's				8		8	16
Total	25	50	25	25	25	25	175

Table 2: Study Population by Institution and Setting of Care (days)

	Tertiary Care	Acute Care	Palliative Consult	Hospice	Palliative Home Care	Long Term Care	Total
Edmonton General Hospital				27		27	54
Grey Nuns Community Hospital	75	75					150
Misericordia		75					75
Norwood				24		24	48
Palliative Home Care					74		74
Regional Palliative Care Program			52				52
St. Joseph's				24		24	48
Total	75	150	52	75	74	75	501

Table 3: Patient Referral by Setting of Care (percent)

	Tertiary Care	Acute Care	Hospice	Long Term Care	Total
Home	36	86	44	12	52.8
Hospital	56	2	56	56	34.4
Long Term Care Facility		2		16	4.0
Other	8	8		16	8.0
Unknown		2			0.8
Total	100	100	100	100	100.0

Table 4: Length of Stay by Setting of Care (days)

	Tertiary Care	Acute Care	Hospice	Palliative Home Care	Long Term Care	Total
Minimum	5	4	4	4	13	4
Maximum	71	60	756	502	3,284	3,284
Mean	24.6	19.6	57.6	78.0	935.0	189.1
Median	19.0	15.5	21.0	60.0	430.0	24.0

Table 5: Documentation by Setting of Care (percent)

	Tertiary Care	Acute Care	Palliative Consult	Hospice	Palliative Home Care	Long Term Care	Total
Age	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Gender	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Postal Code	100.0	100.0	100.0	100.0	100.0	88.0	98.3
Religion	88.0	84.0	8.0	56.0	16.0	68.0	57.7
Language	24.0	22.0	24.0	12.0	48.0	44.0	28.0
Culture or Ethnicity	8.0	10.0	8.0	24.0	0.0	52.0	16.0
Education	76.0	4.0	68.0	72.0	76.0	40.0	48.6
Income	0.0	4.0	0.0	0.0	28.0	28.0	9.1
Marital Status	88.0	64.0	100.0	100.0	96.0	100.0	87.0
Residence Type	64.0	68.0	68.0	100.0	96.0	84.0	78.0
Living Arrangements	88.0	94.0	88.0	92.0	100.0	76.0	90.0
Family Size	40.0	2.0	56.0	32.0	68.0	36.0	34.0
Household Size	72.0	76.0	84.0	72.0	76.0	64.0	74.0
Braden Score	48.0	46.0	6.7	5.3	5.3	6.7	23.4
Palliative Performance Scale	32.0	10.0	80.0	40.0	76.0	0.0	35.0
Symptom: Pain	81.3	60.0	78.7	89.3	68.7	8.0	63.7
Symptom: Tiredness	81.3	4.7	73.3	80.0	55.3	1.3	43.0
Symptom: Nausea	81.3	9.3	73.3	82.7	68.0	1.3	46.5
Symptom: Depression	81.3	2.0	69.3	52.0	51.3	0.0	36.9
Symptom: Anxiety	81.3	15.3	72.0	54.7	51.3	8.0	42.6
Symptom: Drowsiness	82.7	4.7	73.3	89.3	51.3	0.0	43.7
Symptom: Appetite	86.7	62.0	73.3	92.0	61.3	50.7	69.7
Symptom: Well Being	81.3	5.3	41.3	54.7	50.0	0.0	34.0
Symptom: Dyspnea	81.3	34.7	77.3	85.3	63.3	2.7	54.2
Table Average	69.4	40.9	63.4	66.1	62.7	39.9	54.7

Table 6: Interdisciplinary Care Issues by Setting of Care (number)

	Tertiary Care	Acute Care	Palliative Consult	Hospice	Palliative Home Care	Long Term Care	Average
Minimum	2	2	2	2	2	3	2
Maximum	13	16	16	15	17	19	19
Mean	6.1	7.6	6.8	9.0	8.1	10.4	7.9
Median	5	8	6	9	8	10	8

Table 7: Marital Status by Setting of Care (percent)

	Tertiary Care	Acute Care	Palliative Consult	Hospice	Palliative Home Care	Long Term Care	Total
Married	59.1	59.4	52.0	52.0	50.0	28.0	50.3
Common Law	4.5	0.0	4.0	0.0	4.2	0.0	2.0
Single	22.7	3.1	20.0	4.0	16.7	8.0	11.8
Divorced	9.1	0.0	8.0	16.0	8.3	4.0	7.2
Widow	4.5	37.5	16.0	28.0	20.8	60.0	28.8
Col %	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Table 8: Residence Type by Setting of Care (percent)

	Tertiary Care	Acute Care	Palliative Consult	Hospice	Palliative Home Care	Long Term Care	Total
Home	60.0	46.0	56.0	80.0	88.0	64.0	62.9
Assisted Living	4.0	14.0	8.0	4.0	8.0	16.0	9.7
Nursing Home		4.0	4.0	16.0		4.0	4.6
Other		4.0					1.1
Unknown	36.0	32.0	32.0		4.0	16.0	21.7

Table 9: Living Arrangements by Setting of Care (percent)

	Tertiary Care	Acute Care	Palliative Consult	Hospice	Palliative Home Care	Long Term Care	Total
Alone	12.0	44.0	16.0	36.0	20.0	40.0	30.3
Spouse Only	56.0	32.0	40.0	36.0	40.0	12.0	35.4
Spouse and Others	4.0	4.0	4.0		8.0	4.0	4.0
Others Only	16.0	14.0	28.0	20.0	32.0	20.0	20.6
Unknown	12.0	6.0	12.0	8.0		24.0	9.7

Table 10: Size of Family by Setting of Care (percent)

	Tertiary Care	Acute Care	Palliative Consult	Hospice	Palliative Home Care	Long Term Care	Total
1		100.0			5.9	44.4	10.2
2				50.0	17.6	11.1	13.6
3	30.0		28.6		47.1	33.3	30.5
4	20.0		14.3	37.5	11.8		15.3
5	30.0		28.6		5.9	11.1	15.3
6	10.0		21.4		11.8		10.2
7	10.0						1.7
8			7.1				1.7
9				12.5			1.7

Table 11: Size of Household by Setting of Care (percent)

	Tertiary Care	Acute Care	Palliative Consult	Hospice	Palliative Home Care	Long Term Care	Total
1	16.7	52.6	14.3	27.8	21.1	50.0	33.1
2	77.8	44.7	66.7	61.1	52.6	18.8	53.1
3	5.6	2.6	14.3	5.6	15.8	6.3	7.7
4			4.8	5.6	5.3	6.3	3.1
5						18.8	2.3
6					5.3		0.8

Table 12: Diagnosis by ICD10 Chapter and Setting of Care (percent)

	Tertiary Care	Acute Care	Palliative Consult	Hospice	Palliative Home Care	Long Term Care	Total
1: Certain infectious and parasitic diseases		2.0			4.0		1.1
2: Neoplasms	100.0	34.0	96.0	88.0	96.0	8.0	65.1
3: Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism		2.0					0.6
4: Endocrine, nutritional and metabolic diseases		4.0					1.1
5: Mental and behavioural disorders		4.0				20.0	4.0
6: Diseases of the nervous system		4.0					1.1
8: Diseases of the ear and mastoid process		2.0					0.6
9: Diseases of the circulatory system		22.0				36.0	11.4
10: Diseases of the respiratory system		16.0		12.0		24.0	9.7
11: Diseases of the digestive system		8.0	4.0			4.0	3.4
14: Diseases of the genitourinary system						8.0	1.1
19: Injury, poisoning and certain other consequences of external causes		2.0					0.6

Table 13: Cluster Profiles for Continuous Variables (natural units, proportions and standard deviations)

	1: Acute EOL Care	2: Chronic Palliative Care	3: Acute Palliative Care	Combined
Length of Stay	19.11 (12.97)	470.51 (806.30)	22.88 (18.52)	211.29 (568.00)
Age	77.50 (11.27)	77.89 (12.59)	66.15 (13.65)	75.30 (13.12)
Average Pain	16.20 (30.74)	17.36 (27.26)	65.00 (24.21)	26.84 (34.03)
Average Tiredness	0.00 (0.00)	17.36 (28.77)	66.92 (19.14)	21.28 (32.13)
Average Nausea	1.52 (7.88)	3.21 (8.50)	32.31 (30.63)	8.64 (19.77)
Average Depression	0.43 (2.95)	5.47 (11.86)	48.85 (31.54)	12.64 (24.79)
Average Anxiety	6.63 (22.19)	8.40 (18.96)	61.92 (29.26)	18.88 (31.51)
Average Drowsiness	0.00 (0.00)	20.57 (31.77)	69.23 (19.98)	23.12 (33.92)
Average Appetite	34.78 (45.04)	30.57 (38.40)	71.15 (26.88)	40.56 (41.85)
Average Well Being	0.00 (0.00)	8.87 (21.90)	65.00 (22.85)	17.28 (30.41)
Average Dyspnea	2.83 (13.77)	7.17 (17.03)	53.08 (35.41)	15.12 (28.78)
Physician Order Changes: Medications	4.18 (3.59)	0.94 (1.53)	2.06 (1.63)	2.37 (2.88)
Physician Order Changes: Diagnostic	3.67 (4.28)	0.79 (1.47)	0.81 (0.91)	1.86 (3.11)
Physician Order Changes: Interdisciplinary	2.09 (2.16)	0.33 (0.67)	0.49 (0.45)	1.01 (1.62)
Physician Order Changes: Discharge Planning	0.41 (0.64)	0.08 (0.16)	0.17 (0.24)	0.22 (0.44)
Average MEDD	13.16 (49.68)	17.88 (40.51)	147.79 (186.28)	43.17 (107.16)
Progress Notes: Physician	0.98 (0.11)	0.47 (0.37)	0.79 (0.28)	0.72 (0.36)
Progress Notes: Chaplain	0.02 (0.08)	0.03 (0.09)	0.13 (0.19)	0.05 (0.12)
Progress Notes: Dietitian	0.07 (0.13)	0.01 (0.05)	0.01 (0.07)	0.03 (0.09)
Progress Notes: Pharmacist	0.09 (0.18)	0.02 (0.08)	0.01 (0.07)	0.05 (0.13)
Progress Notes: Respiratory Therapist	0.47 (0.42)	0.00 (0.00)	0.06 (0.21)	0.19 (0.35)
Oxygen (litres)	4.83 (6.65)	0.74 (1.47)	3.71 (3.76)	2.86 (4.83)

Table 14: Cluster Profiles for Categorical Variables (percent)

	1: Acute EOL Care	2: Chronic Palliative Care	3: Acute Palliative Care	Combined
Do Not Resuscitate Status: No	51.4	48.6	0.0	100.0
Do Not Resuscitate Status: Yes	31.1	40.0	28.9	100.0
ICD10 1: Certain infectious and parasitic diseases	100.0	0.0	0.0	100.0
ICD10 2: Neoplasms	21.2	39.4	39.4	100.0
ICD10 3: Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	100.0	0.0	0.0	100.0
ICD10 4: Endocrine, nutritional and metabolic diseases	100.0	0.0	0.0	100.0
ICD10 5: Mental and behavioural disorders	28.6	71.4	0.0	100.0
ICD10 6: Diseases of the nervous system	100.0	0.0	0.0	100.0
ICD10 8: Diseases of the ear and mastoid process	100.0	0.0	0.0	100.0
ICD10 9: Diseases of the circulatory system	55.0	45.0	0.0	100.0
ICD10 10: Diseases of the respiratory system	47.1	52.9	0.0	100.0
ICD10 11: Diseases of the digestive system	60.0	40.0	0.0	100.0
ICD10 14: Diseases of the genitourinary system	0.0	100.0	0.0	100.0
ICD10 19: Injury, poisoning and certain other consequences of external causes	100.0	0.0	0.0	100.0
IV Hydration: No	6.4	67.9	25.6	100.0
IV Hydration: Yes	87.2	0.0	12.8	100.0
IV Medication: No	21.3	54.3	24.5	100.0
IV Medication: Yes	83.9	6.5	9.7	100.0
SubQ: No	40.7	53.7	5.6	100.0
SubQ: Yes	33.8	33.8	32.4	100.0
Draw Blood CL: No	6.0	68.0	26.0	100.0
Draw Blood CL: Yes	57.3	25.3	17.3	100.0

Figure 1: Documentation Rate by Setting of Care

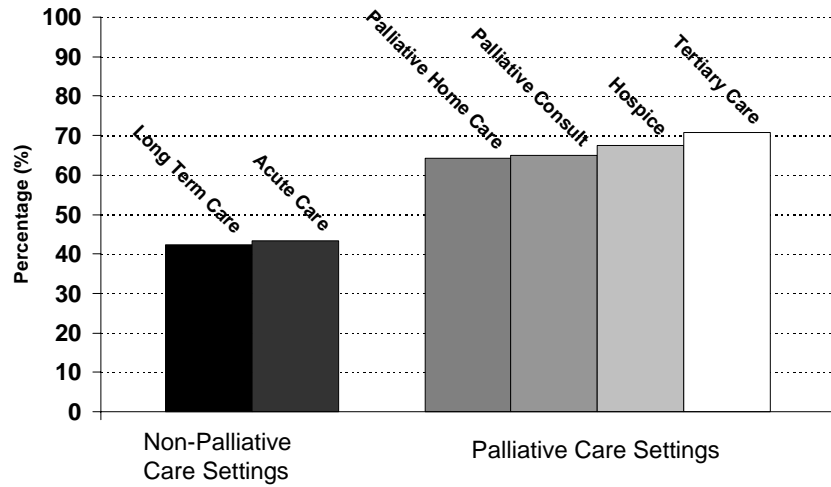


Figure 2: DNR Status by Setting of Care

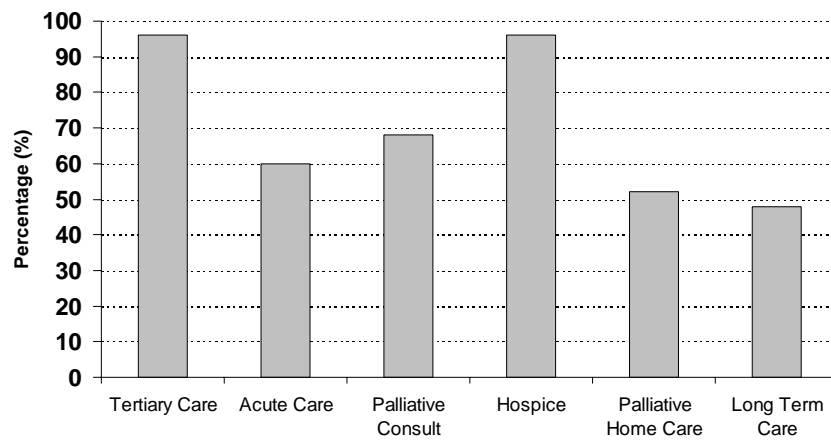


Figure 3: Physician Order Changes by Setting of Care

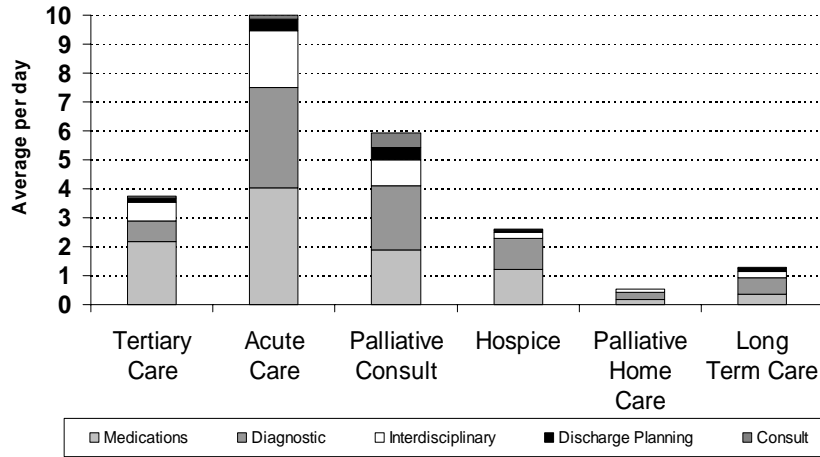


Figure 4: Morphine Equivalent Daily Dose (MEDDD) by Setting of Care

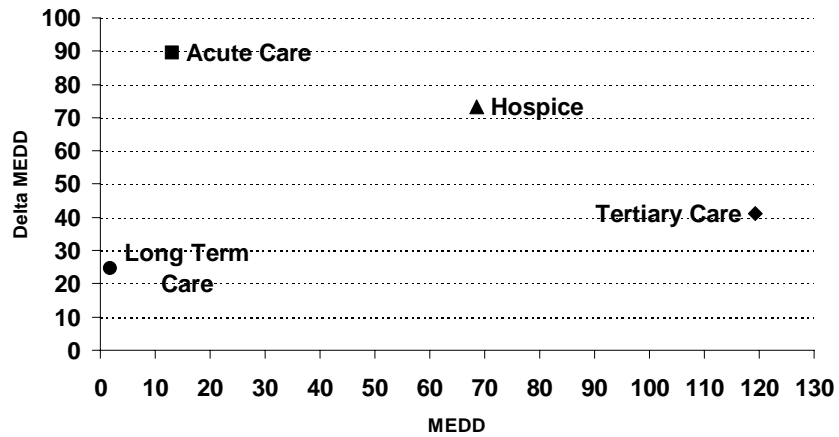


Figure 5: Interdisciplinary Progress Notes by Discipline (% average)

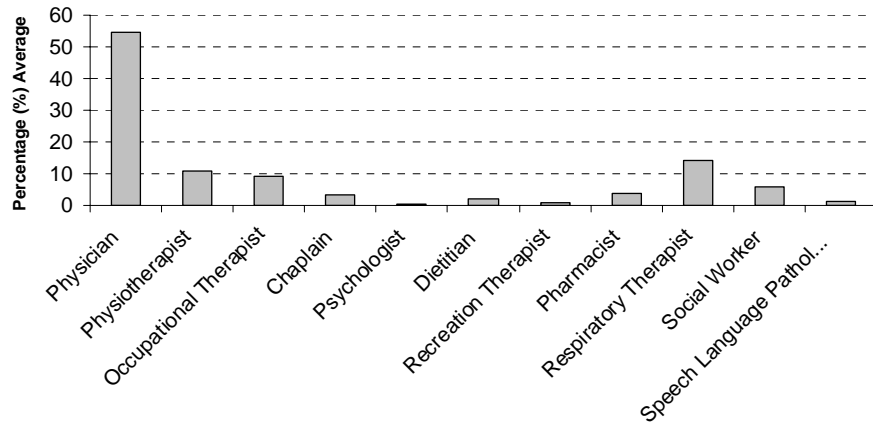


Figure 6: Interdisciplinary Progress Notes by Discipline and Setting of Care

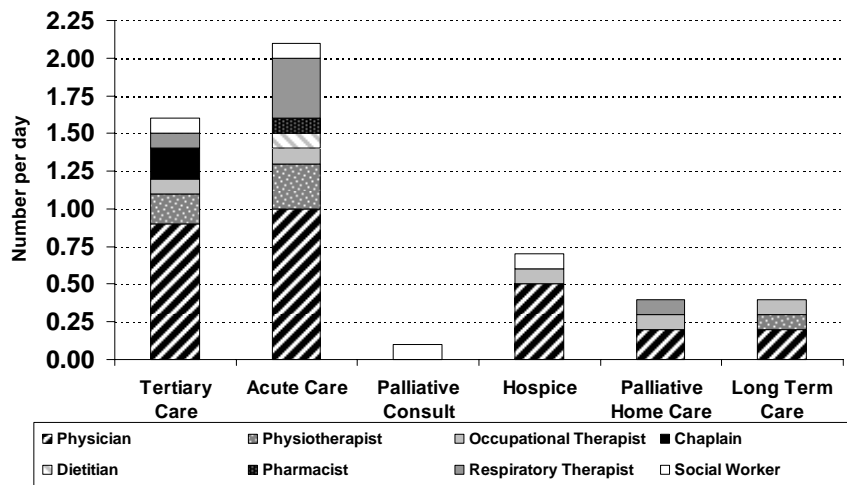


Figure 7: Interdisciplinary Progress Notes by Discipline in Tertiary Care Unit

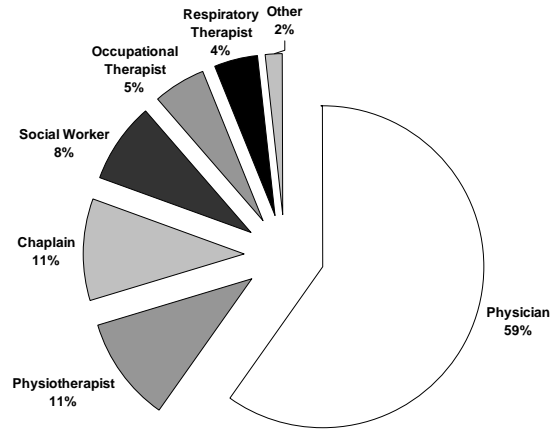


Figure 8: Interdisciplinary Progress Notes by Discipline in Acute Care

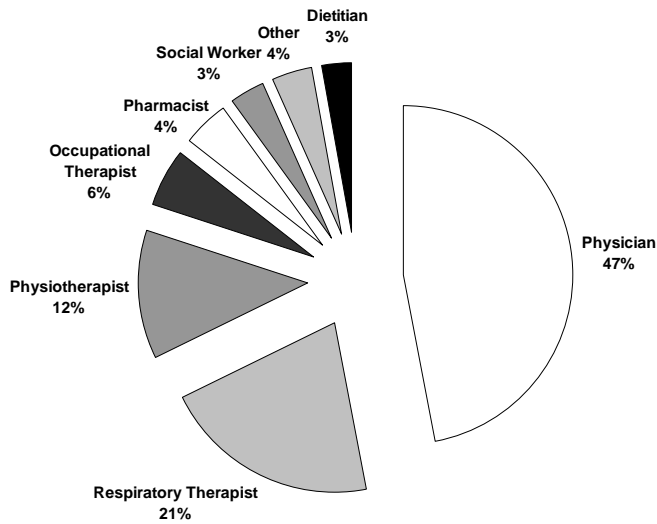


Figure 9: Interdisciplinary Progress Notes by Discipline in Hospices

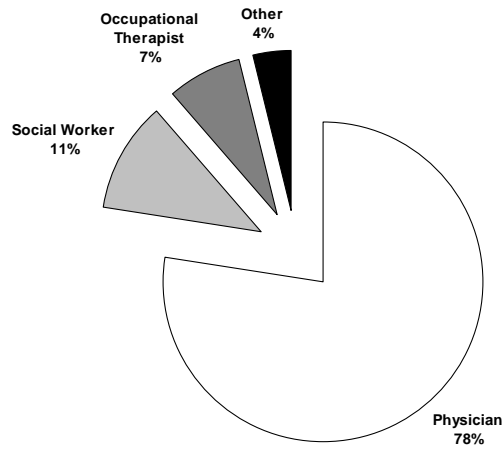


Figure 10: Interdisciplinary Progress Notes by Discipline in Long Term Care Facilities

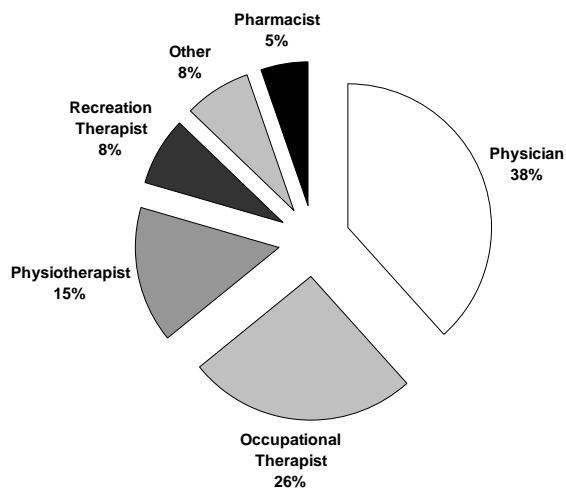


Figure 12: Nursing Care by Setting of Care

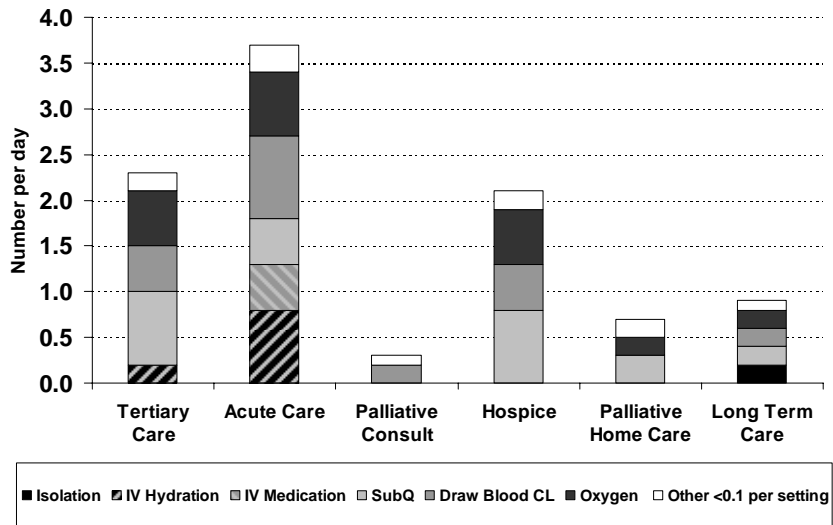


Figure 13: Nursing Care Interventions in the Tertiary Care Unit

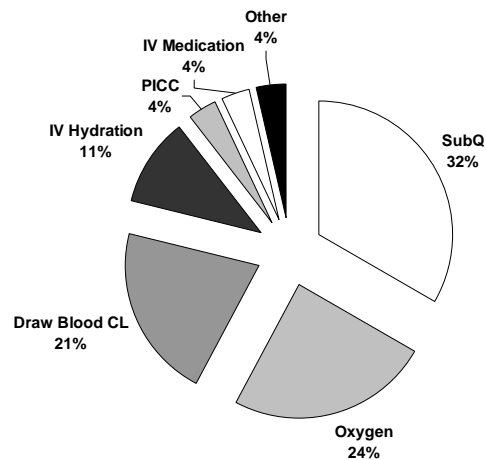


Figure 14: Nursing Care in Acute Care

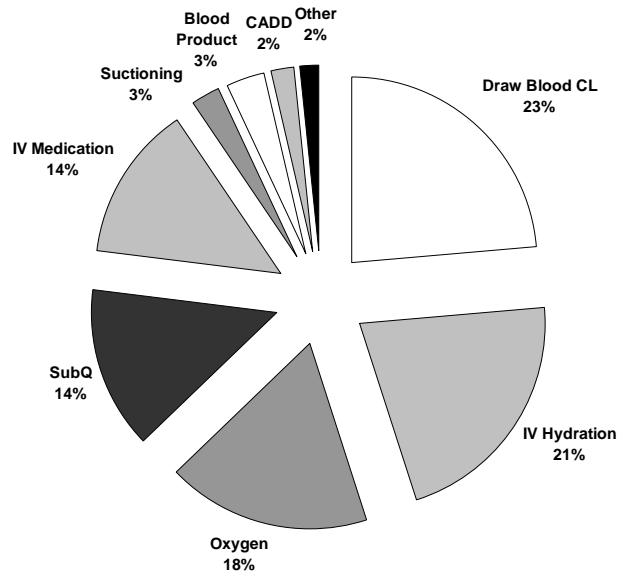


Figure 15: Nursing Care in Hospices

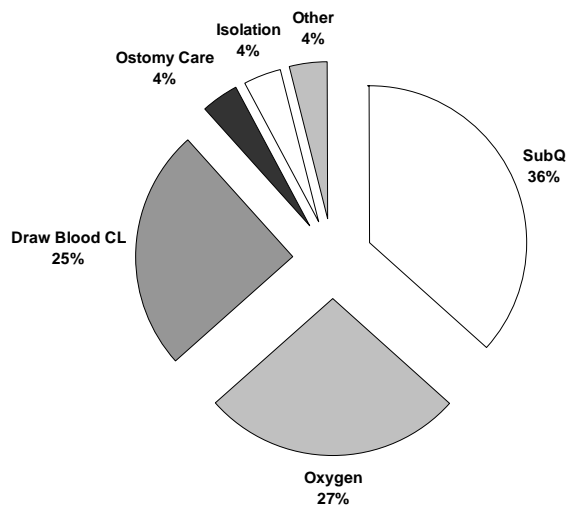


Figure 16: Nursing Care in Long Term Care Facilities

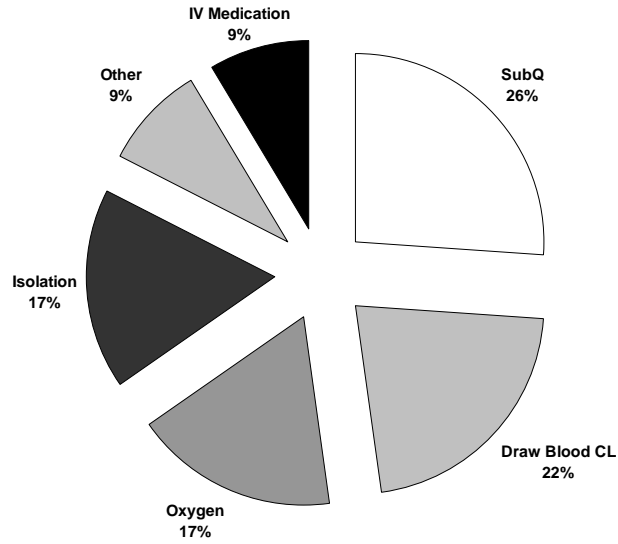


Figure 17: Age by Setting of Care

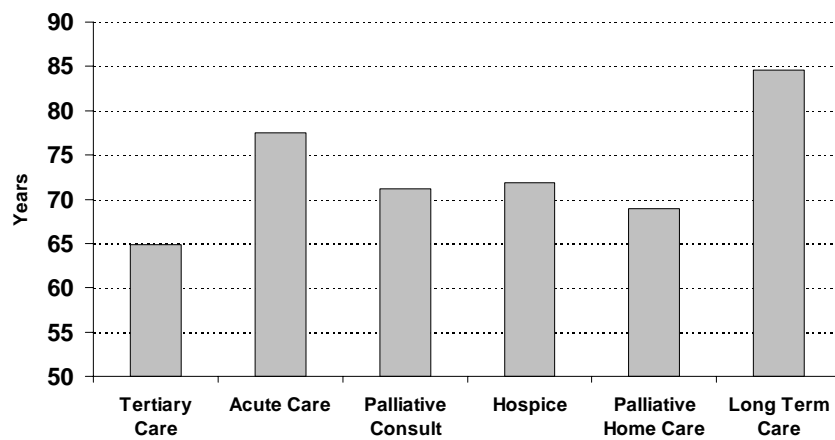


Figure 18: Gender by Setting of Care

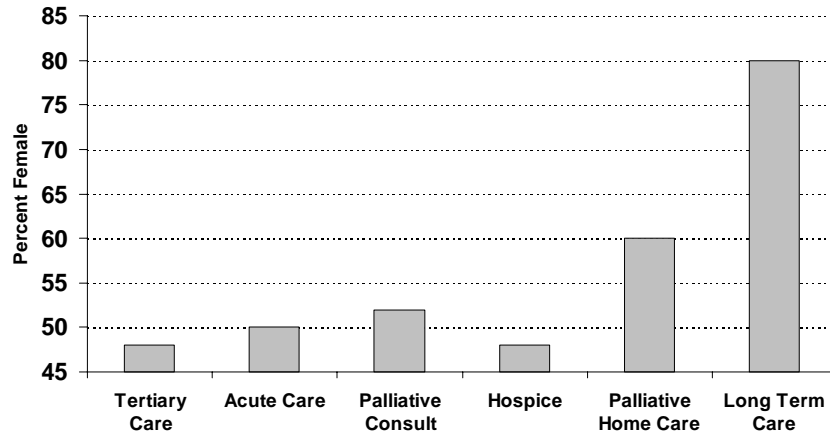


Figure 19: Personal Directives on Health File by Setting of Care (percent)

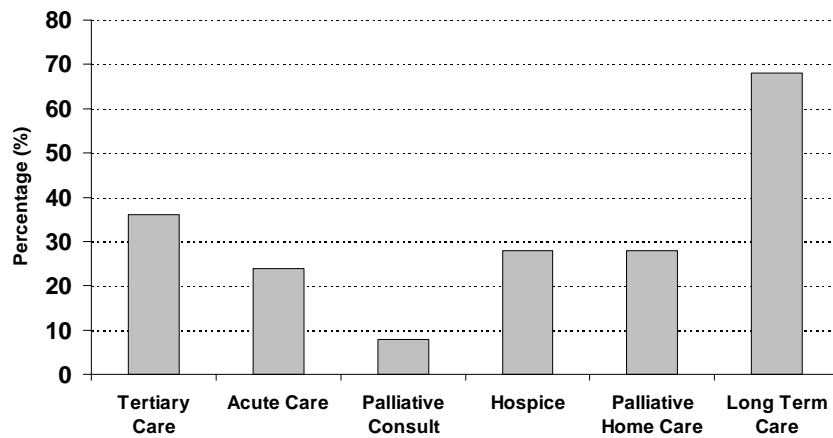


Figure 20: Pressure Ulcer Risk by Setting of Care

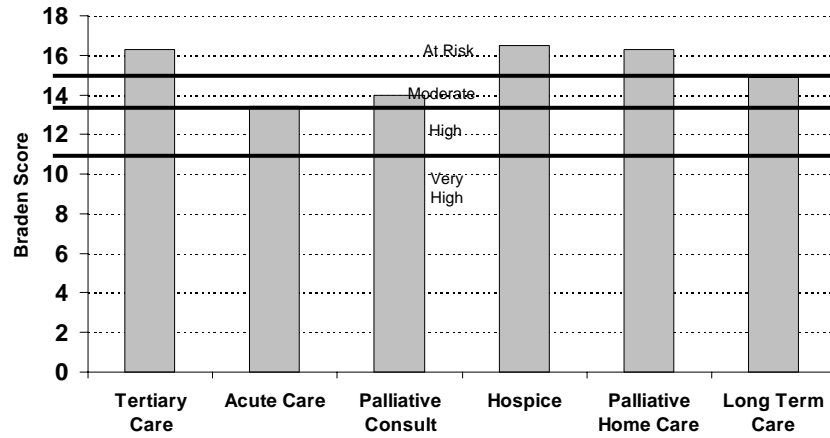


Figure 21: Functional Status by Setting of Care (PPS Score)

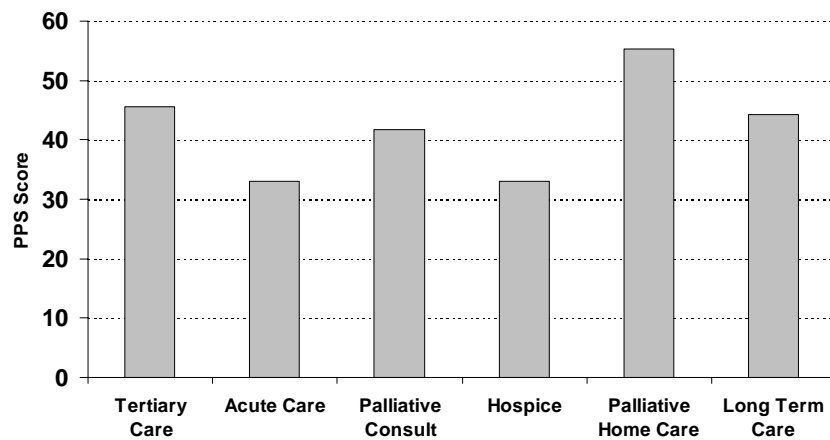


Figure 22: Symptoms by Setting of Care

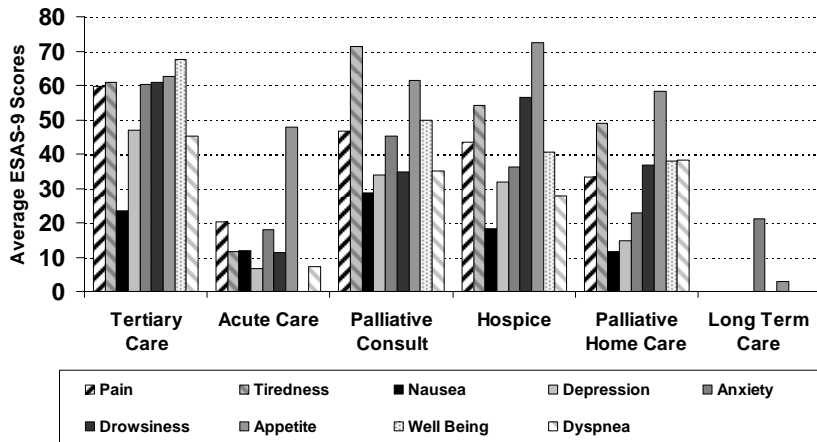
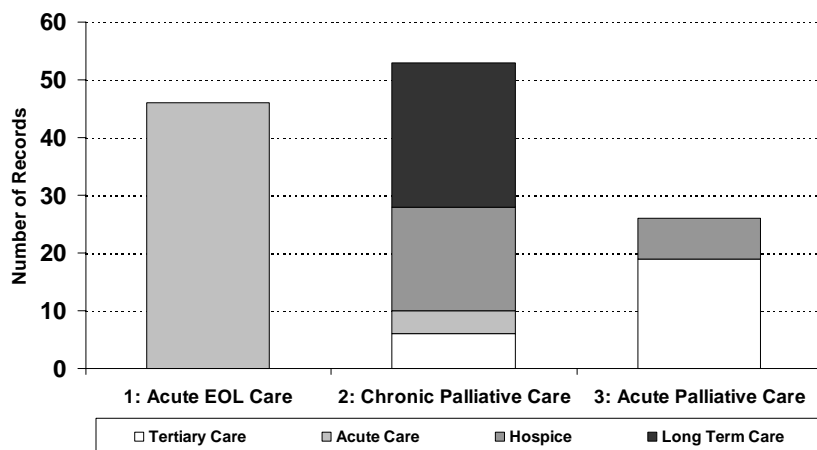


Figure 23: Group Membership by Setting of Care



ALPACA (Alternative Level of Palliative and End-of-life Care Audit Instrument)
Version 2.3 December 15, 2006 © 2006

1. **ID (001, 002, ..., 250)**

REGISTRATION RECORD ONLY

2. **Time Index**

	Day 1	Day 2	Day 3
Dates	<input style="width: 60px; height: 20px; border: 1px solid black;" type="text"/>	<input style="width: 60px; height: 20px; border: 1px solid black;" type="text"/>	<input style="width: 60px; height: 20px; border: 1px solid black;" type="text"/>
	Date	Time	LOS
Admission to hospital	<input style="width: 60px; height: 20px; border: 1px solid black;" type="text"/>	<input style="width: 60px; height: 20px; border: 1px solid black;" type="text"/>	<input style="width: 60px; height: 20px; border: 1px solid black;" type="text"/>
Discharge from hospital			<input style="width: 60px; height: 20px; background-color: #cccccc; border: 1px solid black;" type="text"/>
Admitted through Emergency? Circle one	Yes	No	

NB. Day 1 is first calendar day following admission to the institution/program.

3. **Postal Code (Primary Residence)** _____

4. **Date of birth**

5. **Gender (M/F)**

6. **Marital Status** _____

7. **Advance / Personal Directives**

NB: Personal Directives are not always known at the time of admission and may not be reflected on registration record but may be included elsewhere.

Enter Y/N/U **Reg. Record** Enter Y/N **PD on Chart.** If Y, Date (on PD)

8. **Health Insurance Plans**

Provincial Plan (Circle one) Yes No

From what other sources do the patient, family and caregivers expect reimbursement of health related expenses? Provide the name(s) of the insurer(s), the names of the plan(s) (if known), and premiums.

9. What is this patient's religion?

For example, Roman Catholic, Ukrainian Catholic, United Church, Anglican, Lutheran, Baptist, Greek Orthodox, Jewish, Islam, Buddhist, Hindu, Sikh, etc. Specify the primary denomination or religion if more than one are provided.

10. Languages. What language(s), other than English can the patient speak well enough to conduct a conversation?

NB Although religion and language can be found on DATABASE 1/2 (self report) or other assessments, please limit searching to registration record.

DISCHARGE SUMMARY

11. Most Responsible Diagnosis (List all if more than one)

12. Family Support Network

Note: If not in the Discharge Summary, check for Social Work, OT/PT assessments, Geriatric or Regional Palliative Assessments

Residence Type _____

Living Arrangements _____

Family Size _____

Household _____

EMERGENCY RECORD

13. Admission to Emergency Date Time

HEALTH HISTORY (please note other locations of data)

14. Transferred From	Yes	No	N/A
f. Transferred from HOME	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Transferred from HOSPITAL	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Transferred from LTC	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Transferred from OTHER	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. **Interdisciplinary Care Issues**

Note: If not in Health History, check for Social Work, OT/PT assessments, Geriatric or Regional Palliative Assessments

Days 1-3

Issue 1 _____
Issue 2 _____
Issue 3 _____
Issue 4 _____
Issue 5 _____
Issue 6 _____
Issue 7 _____
Issue 8 _____
Issue 9 _____
Issue 10 _____
Issue 1 _____
Issue 2 _____
Issue 3 _____
Issue 4 _____
Issue 5 _____
Issue 6 _____
Issue 7 _____
Issue 8 _____
Issue 9 _____
Issue 10 _____
Issue 1 _____
Issue 2 _____
Issue 3 _____
Issue 4 _____
Issue 5 _____
Issue 6 _____
Issue 7 _____
Issue 8 _____
Issue 9 _____
Issue 10 _____

DOCTOR'S ORDERS

16. Number of Physician Order Changes

Note: Total the number of physician order changes for three consecutive days by the following types of orders. Use physician's orders, Standing Order Sheet (Medical Directives) and Diet Orders.

	Day 1	Day 2	Day 3
a. Medications	<input type="text"/>	<input type="text"/>	<input type="text"/>
b. Diagnostic (Lab, x-rays, etc)	<input type="text"/>	<input type="text"/>	<input type="text"/>
c. Nursing (eg observation requests)	<input type="text"/>	<input type="text"/>	<input type="text"/>
d. Interdisciplinary (other staff)	<input type="text"/>	<input type="text"/>	<input type="text"/>
e. Other _____	<input type="text"/>	<input type="text"/>	<input type="text"/>
f. Other _____	<input type="text"/>	<input type="text"/>	<input type="text"/>
g. Other _____	<input type="text"/>	<input type="text"/>	<input type="text"/>

17. Do Not Resuscitate (DNR) Status

Y/N	Day 1	Day 2	Day 3
	<input type="text"/>	<input type="text"/>	<input type="text"/>

PROGRESS NOTES

18. Interdisciplinary Progress Notes (in hospital progress notes are for doctors and all disciplines except nursing)

Were progress notes made by the following disciplines? (Note that progress notes do not mean face-to-face contact was made). NB Psychiatrists are MDs and recorded under Physician. No distinction made between attending and consulting physicians.

	Day 1	Day 2	Day 3
Physician	<input type="text"/>	<input type="text"/>	<input type="text"/>
Physiotherapy	<input type="text"/>	<input type="text"/>	<input type="text"/>
Occ. Therapy	<input type="text"/>	<input type="text"/>	<input type="text"/>
Chaplain	<input type="text"/>	<input type="text"/>	<input type="text"/>
Psychology	<input type="text"/>	<input type="text"/>	<input type="text"/>
Dietetics	<input type="text"/>	<input type="text"/>	<input type="text"/>
Recreation	<input type="text"/>	<input type="text"/>	<input type="text"/>
Pharmacy	<input type="text"/>	<input type="text"/>	<input type="text"/>
Respiratory	<input type="text"/>	<input type="text"/>	<input type="text"/>
Social Worker	<input type="text"/>	<input type="text"/>	<input type="text"/>
SLP	<input type="text"/>	<input type="text"/>	<input type="text"/>

Was a discipline specific assessment form(s) completed?

	Day 1	Day 2	Day 3
Physician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occ. Therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chaplain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dietetics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recreation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pharmacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respiratory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social Worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
SLP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

NURSING ASSESSMENT RECORD

NB. Only complete if admitted to unit from emergency. Otherwise, date and time of admission to hospital recorded earlier.

19. Admission to unit Date Time Hrs in Emerg

20. Nursing Assessment

Note: Use Pressure Ulcer Risk Assessment Score (Braden Scale).

Total Score Day 1 Day 2 Day 3

21. Palliative Performance Scale (PPS): _____

22. Functional Status (other, specify eg ECOG) _____

23. **Nursing Care**

Note: Check for Basic Care Flowsheet items, litres for O2 flow rate and comment regarding emotional support.

This info found on Medication Records, Lab Reports, Purple Blood Sheets?

	Day 1	Day 2	Day 3
Isolation			
IV Hydration			
IV Meds			
Blood Prod			
SubQ			
Ostomy Care			
TPN			
Suctioning			
PICC			
Draw Blood CL			
CADD			
Chest Tube			
O2 Y/N			
If Y O2 Flow			

Emotional Support (by nursing): _____

24. Mean Equivalent Daily Dose Opioids (MAR, ER/ICU?)

Instructions: Enter route and 24-hour dose for all opioids. NB MEDD is a calculated field and need not be entered at the time of chart abstraction.

ROUTE: EP, IM, IT, IV, PO, R, SC, SL, TD

	Day 1	Day 2	Day 3
CODEINE			
DIAMORPHINE			
DIAMORPHONE			
FENTANYL			
HYDROCODONE			
HYDROMORPHONE			
LEVO-DROMORAN			
MEPERIDINE			
METHADONE			
MORPHINE			
OXYCODONE			
PROPOXYPHENE			
SUFENTANIL			
TRAMADOL			
Oth: _____			

DOSE

	Day 1	Day 2	Day 3
CODEINE			
DIAMORPHINE			
DIAMORPHONE			
FENTANYL			
HYDROCODONE			
HYDROMORPHONE			
LEVO-DROMORAN			
MEPERIDINE			
METHADONE			
MORPHINE			
OXYCODONE			
PROPOXYPHENE			
SUFENTANIL			
TRAMADOL			
Oth: _____			
 MEDD			

25. **Palliative Symptom Assessment**

NB: Enter # (eg 0-10 or 0-100) if ESAS, ☑, M-Mild, O-Moderate, S-Severe, etc)

	Day 1	Day 2	Day 3	
Pain	<input type="text"/>	<input type="text"/>	<input type="text"/>	_____
Tiredness	<input type="text"/>	<input type="text"/>	<input type="text"/>	_____
Nausea	<input type="text"/>	<input type="text"/>	<input type="text"/>	_____
Depression	<input type="text"/>	<input type="text"/>	<input type="text"/>	_____
Anxiety	<input type="text"/>	<input type="text"/>	<input type="text"/>	_____
Drowsiness	<input type="text"/>	<input type="text"/>	<input type="text"/>	_____
Appetite	<input type="text"/>	<input type="text"/>	<input type="text"/>	_____
Wellbeing	<input type="text"/>	<input type="text"/>	<input type="text"/>	_____
Dyspnea	<input type="text"/>	<input type="text"/>	<input type="text"/>	_____

OTHER

26. Ethnicity/Cultural: To which ethnic or cultural group(s) did this patient's ancestors belong?

For example, Canadian, French, English, Chinese, Italian, German, Scottish, Irish, Cree, Micmac, Métis, Inuit (Eskimo), East Indian, Ukrainian, Dutch, Polish, Portuguese, Filipino, Jewish, Greek, Jamaican, Vietnamese, Lebanese, Chilean, Somali, aboriginal, First Nations, Métis, North American Indian, Inuit or Eskimo etc. Specify as many groups as applicable

27. Education

What is the highest grade of secondary (high school) or elementary school **attended** by the patient (completed or not)?

How many years of education has the patient **completed** at university?

How many years of schooling has this person ever **completed** at an institution other than a university, a secondary (high) school or an elementary school?

28. Family Income

Family income refers to the total income earned by all persons who live in the same dwelling (address) and are related to each other by blood, marriage, common-law or adoption.

Total from all sources AND individuals: _____