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Chart Review of Current End-of-Life Care Needs and Care Practices in Acute Care Hospitals:

Final Report of an Investigation

by

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Abstract

A total of 1,018 charts of people who died from August 1, 2008 through July 31, 2009 were reviewed to describe and examine current end-of-life care needs and care practices provided in two acute care hospitals. The mean age of those who died was 72.5, the majority of decedents were elderly (73.8%), a slight majority were male (53.0%), a slight majority were not married (53.0%), and most were urbanites (79.5%). The most common primary diagnosis was cancer (36.2%). More than half of deaths were expected (54.6%). Only 40.3% of those who had an expected death had a palliative care referral. Of all decedents, 13.8% had CPR performed, and a total of 13.9% of people died without having a DNR order. A written will was provided in 30.8% of cases. Most had technologies in use at the time of death (97.3%). Of those who died with pain, most received analgesia (98.6%).

Key Words: Chart Review, End-of-life, Palliative, Care Needs, Care Practices, Hospital, Research

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List of Symbols, Nomenclature, or Abbreviations

-Activities of Daily Living (ADL)

-Cardio-Pulmonary Resuscitation (CPR)

-Chi Square ($\chi 2$)

-Critical Care Unit (CCU)

-Do Not Resuscitate (DNR)

-End-of-life (EOL)

-Intravenous (IV)

-Intensive Care Unit (ICU)

-Palliative Care Unit (PCU)

Chart Review of Current End-of-Life Care Needs and Care Practices in Acute Care Hospitals: Final Report of an Investigation

Chapter 1. Introduction and Significance

The care of dying hospitalized patients poses many challenges. One of the most important of these challenges is ensuring appropriate end-of-life (EOL) care. As there is no clearly accepted understanding of what constitutes appropriate EOL care, a descriptive study was undertaken to examine current EOL care needs and the EOL care provided in two modern western Canadian acute care hospitals. All charts for patients who died from August 1, 2008 to July 31, 2009 at two hospitals were examined through a standardized (post-death) review process. These hospitals provide a full range of acute care services, including emergency room, intensive care, and palliative care services. Although the findings of this study cannot be generalized to all hospitals, this study of two mid-sized full-service hospitals revealed current EOL hospital care practices and patient care needs, and identified consistencies and variations from a previous study of EOL care and EOL patient care needs (Wilson, 1997).

Significance

Around 60% of all deaths each year in Canada take place in hospitals now (Wilson et al., 2009). It is therefore imperative that the care needs of dying hospitalized patients be identified, in order to make appropriate policy and practice changes if needed. This requirement is emphasized by the findings of a study that found dying patients in hospital had higher rates of unmet needs than those who died at home (Morrison, Siu, Leipzig, Cassel, & Meier, 2000). The descriptive chart review study that will be described in this report should help to identify what the care needs are of people at the EOL and what is being done for them in hospital. This study should help to discover gaps in care and identify where future research needs to be conducted.

The timing of this study is opportune, as many changes have taken place in health care over the past decade. Issues with healthcare financing and cost have been significant for some time now in decision making about EOL care (Wilson, 1997). In Canada, hospital downsizing was common in the 1990s (Greenglass & Burke, 2003; Wilson, 1997). With downsizing, the number of admissions to hospital has decreased, outpatient/day surgery care has increased, and dying people being cared for more often or longer at home (Wilson et al., 2009). This trend was not confined to Canada. Worldwide, inpatient hospital care has been reduced since at least 2003 (Tang et al., 2009). Hospitalized patients are consequently at a much higher care acuity than prior to hospital downsizing. Lengths of stay in hospitals are also decreasing; with this occurring now not only because of the downsizing of hospitals but also with technological advances that permit shorter stays (Wilson et al., 2009). With all of these changes happening in such a short period of time, and with terminally ill and dying persons among the most vulnerable of all people, it is imperative that the needs and care of hospitalized dying patients today are examined.

The recently completed study described here is similar to a previous Canadian study involving 1992 data, entitled: *A report of an investigation of end-of-life care practices in health care facilities and the influences on those practices* (Wilson, 1997). That study involved chart reviews completed at one large and two small acute care facilities, as well as one continuing care facility. Another difference was that the charts reviewed in Wilson’s study were of people 18 years of age or older. Wilson’s study was helpful for determining what types of EOL care were being employed at that time, with the main findings summarized as a “prevalence of technologically assisted, institutionalized death and (having) an infrequency of [cardio-pulmonary resuscitation] (CPR) at the EOL” (Wilson, 1997, p. 37). Wilson (1997) identified a need for further research to be undertaken to substantiate whether the reliance on EOL technologies was common, and to determine whether they are an appropriate response to dying peoples' needs.

Some recent healthcare changes have included an increase in community-based EOL care (Wilson et al., 2009) and greater support overall for palliative care (Murray & Kok, 2008). "Palliative care improves the quality of life of patients and their families facing life-threatening illness by providing pain relief and management of other distressing and debilitating symptoms" (World Health Organization [WHO], 2007, p. 1). Palliative care is both a philosophy of care and a structured system for delivering appropriate EOL care (National Consensus Project for Quality Palliative Care [NCPQPC], 2009). WHO identifies palliative care services as being "appropriate from the time of diagnosis of a life-threatening illness and throughout the course of the illness" (p. 1). Palliative care extends the traditional medical disease-model treatments to comprise the goals of improving quality of life for patient and family, optimizing the person's function, and assisting with decision-making (NCPQPC). The NCPQPC indicated palliative care can be delivered either together with life-prolonging care or as the key focus of treatment. Considerable concern exists regarding life-prolonging treatments being carried out in hospitals, treatments that could possibly be futile interventions (Teno et al., 2004). It is imperative that EOL care be as humane as possible, as life-extending care can be in opposition to the care needs and preferences of patients near the EOL (Teno et al).

As indicated above, this retrospective hospital chart review was undertaken to reveal current EOL hospital care practices and patient care needs, and allow for the identification of similarities to a previous study of EOL hospital care and patient care needs (Wilson, 1997). In addition, it was in part conducted to identify if the healthcare team is recognizing EOL care needs and what EOL care is being provided. This study was also designed to describe who is currently dying in hospital; including age, sex, diagnoses, and if advance directives or living wills are present and utilized. Since Wilson’s (1997) study, advance directives legislation was passed in Alberta (Canadian Legal Information Institute, 2010). It is important that the care needs of hospital patients near the EOL are recognized and met.

Chapter 2. Literature Review

Literature Search

A literature search involving four key library databases (Medline, CINAHL, Embase, and HealthSTAR) was conducted to assess the published research on hospital deaths. The keywords used were: End of life or palliative, chart review, care trends, and hospital. A total of 107 articles were identified, with 12 found relevant to this research study. Most of the rejected 95 studies were concerned with a specific population, such as those who died of sudden cardiac causes. The studies that were chart reviews concerning EOL care for cancer patients were retained for review as cancer deaths are common. Rejected also were the studies that only pertained to one factor at the EOL (e.g. hydration) or only focused on the cost analysis of hospital use at the EOL. Of the 12, 10 were retrospective chart reviews.

This literature review revealed significant gaps in research, many common concerns, and considerable differences in EOL care in hospitals across developed countries. No studies appear to have replicated or substantiated the results found in Wilson’s (1997) chart review study of EOL care practices and their influences. One related study was on location of death trends in Canada; however, this study found a major shift of death and dying out of hospital since 1994 (Wilson et al, 2009). Canada could be experiencing a paradigm shift in EOL care, and given the significance of EOL care, factors relating to care trends and care practices need to be known (Wilson et al., 2009). The literature summary below is divided into two sections: (a) the care provided to dying people in hospital, and (b) the needs of dying people in hospital, as the thesis study described here sought information on those two general areas.

The Care of Dying People in Hospital

The following outlines findings from the 12 studies on the care of dying patients in hospital. Some of these studies also contained findings on the needs of dying people in hospital. The 12 studies outlined here provide similar, and at times conflicting, information about the care provided to dying hospital patients. The 12 studies are described in chronological order to show a possible progression in EOL care provision.

The earliest study was by Paice, Muir, and Shott (2004); they completed a retrospective chart review study involving 195 patients who died over a six month period at a Midwestern U.S. tertiary care medical centre. Only adult (i.e. age 18 and over) patients who died on a medical, oncology, or palliative care unit (PCU) were included in this study. Similar to Wilson's (1997) study, they examined: (a) patient demographics, (b) diagnosis, (c) management of symptoms, (d) diagnostic procedures and treatments, (e) advance directives, and (f) resuscitation orders. Contrary to many of the other studies identified in this review, 91% of patients who died had do-not-resuscitate (DNR) orders, with 75% of these orders having been written within one day of admission. This late but still common order may have been due to expected deaths. Patients who had pre-existing DNR orders before coming into hospital for the final time tended to be younger than those who did not have a DNR order. Diagnostic and therapeutic procedures were common in the final two days of life; however, including intravenous (IV) fluids and medications, urinary catheters, blood draws, antibiotics, and ventilators. Another concern was that just over 20% of people did not receive opioids during their last 24 hours of life, which raises the concern that a considerable proportion of persons could have died in pain.

A chart review was also conducted in New Hampshire, U.S., although it involved 782 deaths in hospitals, nursing homes, and hospice care to provide "a benchmark for different care systems to identify areas for improvements in EOL care" (Solloway, LaFrance, Bakitas, & Gerken, 2005, p. 789). Among those who died in hospital, 4% were in hospital palliative care beds, 56% were situated in acute care beds, and 30% were being cared for in intensive care beds. In the 48 hours preceding death, 19% received cure-oriented interventions such as surgery and/or intubation, and then being placed on a ventilator.

Similarly, Seah, Low, and Chan's (2005) chart review study acknowledged that death and dying in Singapore often occurs in hospital. A one-year retrospective chart review at one hospital was completed on all deaths that took place on geriatric units, and for those patients aged 75 and over on other units. A total of 189 charts were reviewed. Among other findings, men were usually younger at the time of death. Dependency in activities of daily living tended to increase with age for both sexes. Although 88% of these deaths were expected, 25% of these patients still had CPR initiated at the point of collapse. However, 31% of those who died also had input from palliative care experts. Those who had palliative specialist input prior to death were said to be better managed for common symptoms experienced by the elderly at the EOL, as compared to those who did not have palliative care input. Common symptoms included: Fever, pain, difficulty breathing, and respiratory secretions. All patients who had pain and palliative input were treated for pain. Many patients were found to have easily manageable symptoms, but most did not have any treatment used to correct them. The number of co-morbid conditions ranged from 0 to 8, with 82% of the patients having 1 to 4 chronic diseases.

The fourth retrospective chart review was done by Cardenas-Turanzas, Grimes, Bruera, Quill, and Tortolero-Luna (2006) for 866 people, aged 18 and over, who were treated at a cancer centre in Texas. Of these, 58.2% died in hospital. This study examined factors associated with hospital deaths, including: socio-demographic, clinical, and local healthcare system factors. The most important factor was that people living in lower income brackets were more likely to die in hospital as compared to those in higher income brackets. Also, those living in rural areas were more likely to die in hospital as compared with their urban counterparts (66% and 57% respectively). Another interesting finding was that people with hematological cancers were more likely to die in hospital, as compared with people with other types of cancer.

Another American retrospective chart review by Kelley, Gold, Roach, and Fins (2006) was undertaken to reveal differences between EOL care decisions on medical and surgical units. Their chart review was done to compare care differences attributed to medical staff in the two care settings. Medical unit doctors conducted and documented more than half of all EOL conversations with patients; whereas surgical unit doctors rarely documented EOL discussions. This difference was said to be due to the varying relationships between these types of doctors and their patients, such as ongoing care versus short-term surgical intervention only. The surgeon's sense of obligation to treat and heal was thought to potentially impede the transition to palliative care. Kelley et al. also found patients who had withdrawal of treatment tended to be older and had much longer lengths of stay prior to their treatments being withdrawn.

The sixth retrospective chart review study was completed in Belgum by Van den Block et al. (2007) who described hospital use during the last three months of life. It also identified associated disease and healthcare factors affecting these dying patients. This study found hospitalizations increased exponentially in the last weeks before death, with 72% of patients who died in hospital hospitalized at least once in the three months prior to death. They indicated that this high rate of hospitalization showed an "institutionalized nature of dying" in Belgium (Van den Block et al., p. 1).

The seventh retrospective chart review was completed in Germany by Becker et al. (2007), who assessed the charts of all 226 patients who died in a large teaching hospital during a three month period in 2004. Fifty percent of people who die in Germany do so in hospital. Furthermore, the palliative care movement is relatively new in Germany and used infrequently (Becker et al.), unlike in Canada where the palliative care movement is well established (Murray & Kok, 2008). A noticeable trend identified in Becker et al.'s study was that patients who had a written advance directive were more likely to have a DNR order. This study found 65% of patients had DNR orders written on their charts an average of six days prior to death. Thirty-eight percent of charts indicated that hospital staff had been aware of their impending deaths. However, comfort care plans were rarely completed on the charts, with only 14% of all charts having them fully completed, and 59% of charts having no evidence of comfort care planning. Becker et al. emphasized that cancer patients had significantly more comfort care plans completed than those dying of cardiovascular disease. Moreover, the majority of patients who had comfort care plans also had life-sustaining treatments continued until death. Another interesting fact was that almost 1/3 of all patients who died were receiving life-sustaining treatment at the time of death. Becker et al.'s findings suggested to them that the transition from acute cure to palliative care is difficult in hospitals, as healthcare professionals working in hospitals tend to provide active treatment throughout or until the very end of a dying process.

Sato et al. (2007) conducted a retrospective chart review in a hospital in Japan, and focused on the quality of EOL treatment for cancer patients in general wards versus a PCU used by cancer patients. The study found most patients had DNR orders (usually consented to by the family), and that significantly more patients on general wards received futile life-sustaining treatment (including resuscitation, over hydration, mechanical ventilation, and intubation) and less palliative care medications as compared to those on PCUs.

A study (that was not a chart review) by Miyashita, Nakamura, Morita, and Bito (2008) was done to identify quality indicators for EOL cancer care in Japan. Seventeen medical experts were asked to rate quality EOL indicators using a modified Delphi method. The resulting quality indicators were “within four domains: (a) symptom control, (b) decision-making and preference of care, (c) family care, and (d) psychosocial and spiritual concerns” (Miyashita et al., p. 34). This study highlighted the importance of ordering treatment in anticipation of symptoms to prevent suffering. The researchers emphasized patient preferences and having advance directives. They also identified the need to sustain family involvement in all care decisions.

The ninth retrospective chart review was conducted by Tang et al. (2009) in Taiwan to examine trends in quality EOL care among cancer patients who died between 2000 and 2006. This study raised concerns about the suitability of increasingly aggressive care in the final month of life. Based on evidence of futile life-sustaining treatments, identified indicators for poor quality EOL care in the last month of life were: (a) the use of CPR, (b) intubation, (c) ventilator use, (d) admission to the intensive care unit (ICU), and (e) chemotherapy. The use of aggressive chemotherapy during the last month of life increased over the years. Over time, cancer patients in Taiwan also became significantly more likely to die in an acute care hospital, even though the use of hospice services also increased. A total of 65.4% of patients reviewed in this study died in hospital, despite the significance placed on dying at home by the Taiwanese people. However, the use of CPR, intubation, and mechanical ventilation use in the last month of life decreased on the years studied. This decrease in futile life-prolonging modalities coincides with the *Palliative Care Act* passed in 2000 by the Taiwanese government, an Act that allows advanced care directives.

Lin, Farrell, Lave, Angus, and Barnato (2009) published a cross-sectional mixed-method survey which examined hospital-level variation in EOL treatment intensity from June, 2001 to March, 2005. This study was done by surveying Chief Nursing Officers at 124 Pennsylvania hospitals to examine overall hospital and/or ICU programs and policies. Six standardized ratios were used including: ICU admission rate, ICU length of stay, intubation and mechanical ventilation rate, hemodialysis rate, tracheostomy rate, and gastrostomy rate. A significant positive relationship between larger hospitals and EOL treatment intensity was found. However, the information gained offered little additional explanatory power in understanding hospital differences in EOL treatment intensity.

Of all 10 retrospective chart reviews, only one was Canadian, a recent review by Napolskikh et al. (2009). Their study focused on one PCU, so it did not include all deaths that occurred elsewhere within the hospital. More specifically, this study (done for quality assessment purposes) explored length of stay, wait times, and patient demographics in the one Canadian PCU (Napolskikh et al.). This study found referrals to PCUs occurred too late in many cases, with this said to be possibly due to inadequate awareness of palliative care services. This study raised attention to the claim that palliative care that allows adequate time to address holistic needs of the patient is a necessity in the provision of quality EOL care.

In summary, these 12 studies provide an array of information on the care provided in hospital to dying patients. Clearly, EOL care practices differ from one hospital to another, with many concerns similar to those raised in Wilson’s (1997) study.

The Needs of Dying People in Hospital

Ten of the 12 reviewed studies outlined care needs of dying hospital patients. All of these 10 studies were described in the previous section for how they relate to the care provided in hospital to dying persons. Instead of a separate outline of each study again, as presented previously, the findings from the 10 studies are grouped as many similar findings were evident across these 10 studies.

Three of the ten studies pointed out that providing appropriate EOL care for dying patients is very important (Miyashita et al., 2008; Sato et al., 2007; Van den Block et al., 2007). A fourth study, by Solloway et al. (2005), recommended that healthcare providers work to strengthen methods of determining appropriate approaches for EOL care. A fifth study pointed out that the palliative approach to care may have a significant role to play in symptom management for the terminally ill, especially in hospitals where the emphasis is naturally on prolonging life (Seah et al., 2005). Two additional studies revealed decisions about admissions to hospital in the final days before death should be more carefully considered, as many people indicated a preference to die at home (Cardenas-Turanzas et al., 2006; Van den Block et al., 2007). Finally, Cardenas-Turanzas et al.'s (2006) study indicated that "most cancer patients tend to die in short-stay hospitals and hospices, which makes characterization of the dying, as well as recognition of the determinants of in-hospital death important tools in planning and implementing quality end-of-life services" (p. 72).

Two studies focused on the "good death." Paice et al. (2004) and Seah et al. (2005) both showed that important components of the "good death" are attention to the psychosocial and spiritual needs of the patient and their family. Furthermore, it is essential that, no matter the location where EOL care is given, these needs should be met. Paice et al. also reported that interdisciplinary teamwork was necessary in order to meet patient care needs.

Three studies focused on palliative care in hospital. Becker et al. (2007) revealed differences in the quality of EOL care that were based on the location of death. Patients in a PCU were much more likely to have all of their needs met, and they also had no futile life-sustaining treatment (Becker et al.). Becker et al. advised that medical staff be educated about palliative care to allow patients to die in comfort and with dignity within hospitals. The use of a comfort care plan was also highly recommended (Becker et al.). Becker et al.'s study additionally revealed that medical interventions aimed at life-sustaining treatment in Germany continued even when death was imminent. Their study suggested that routine medical interventions can be traumatic for seriously-ill people, and should be replaced with comforting actions as death nears (Becker et al.). According to Tang et al. (2009), comfort care was mostly preferred by terminally-ill cancer patients in Taiwan, although healthcare professionals are reluctant to discuss a transition from cure-oriented care to palliative care. Tang et al. recommended exploring knowledge specific to patient EOL care preferences will help healthcare professionals meet the actual care needs of the patient, and not simply assume a curative approach. Sato et al. (2007) also recommended that EOL (cancer) care should be less aggressive, and physicians should be further educated on the use of palliative care drugs.

Three of the studies reported on futile care. Kelley et al. (2006) suggested that surgeons keep a log of their EOL discussions with patients, and evaluate the educational impact of programs designed to foster competence and comfort in EOL discussions to avoid futile treatment. Paice et al. (2004) advised that all unnecessary fluids should be minimized as death approaches, in order to avoid pulmonary congestion and the discomfort it causes. Seah et al. (2005) similarly indicated that treatment that is aimed at prolonging life in the face of futility raises patient and family hope unnecessarily. Seah et al. also indicated that futile care is sometimes given despite the cost to a patient's comfort level.

Two studies focused on EOL decision making. Becker et al. (2007) found 65% of patients had decision-making capacity on admission to hospital, but 58% of these lost this capability during their hospital stay. Also, almost 80% of all people who died lost consciousness within 48 hours prior to death. The large number of patients who lose decision-making capacity as death approaches is a major indicator that EOL discussions need to occur well before signs of death appear; perhaps indicating that EOL discussions should be a part of routine admission (Becker et al.). Paice et al. (2004) similarly identified that 54% of patients who had indicated they did not want CPR did not have a DNR note on their chart. This finding establishes the need to determine patients' wishes before they lose decision-making capacity.

In summary, the findings in the 10 studies in other developed countries have some similarities to Wilson's (1997) study. The way dying patients are treated at different hospitals and the amount of futile care they receive appears to differ globally. A study on the care needs and care provided to dying hospital patients in Canada should help ensure care is humane.

Conclusion

This literature review of 12 relevant studies was divided into two sections: (a) the care of dying people in hospital, and (b) the needs of dying people in hospital. As shown, few studies have been done and of the 12, 10 were retrospective chart reviews. Studies on EOL care in hospital can provide important information to improve the planning and the implementation of plans for hospitalized dying patients (Van den Block et al., 2007). Of the 12 studies, many illustrated (as did Wilson's [1997] study), that aggressive treatment-oriented care is still a common type of hospital care, which suggests EOL care needs may not be adequately met.

Chapter 3. Method

For many years chart reviews have been a common method of acquiring information that is useful for healthcare policy and practice changes (Gilbert, Lowenstein, Koziol-McLain, Barta, & Steiner, 1996). A chart review allows for many data variables to be studied. Chart reviews are also done because concurrent studies may burden dying persons and their caregivers.

In this study, a chart review in two mid-sized full service urban acute care western Canadian hospitals for deaths occurring over 12 months was undertaken to determine the needs of patients at the EOL and current EOL hospital care practices. This chart review also identified characteristics of these persons. The following section describes the purpose of the study, the methods that were used to gather and analyze data, and concludes with common issues associated with chart reviews.

Purpose of Study

As indicated, a retrospective chart review was completed to determine current EOL care needs and EOL care provided in two acute care hospitals. More specifically, this study described socio-demographic information, EOL care, and EOL care needs as identified in the charts of persons who died in two full-service western Canadian hospitals from August 1, 2008 through July 31, 2009. Data were sought to answer the following five questions:

1. What are the ages, gender, marital status, and rural, suburban, or urban place of residence of persons who died in hospital?

2. What are the diagnoses of persons who died in hospital?

3. What hospital care was provided near the EOL; and did this care differ by diagnosis, age, gender, marital status, and rural or urban place of residence?

4. What hospital care was needed at the EOL; and did these cares vary by diagnosis, age,

gender, marital status, or rural/ urban place of residence?

5. What proportion of these deaths were expected, and was care appropriate to expected versus unexpected deaths?

Data Collection and Analysis Methods

Ethics approval was received from the University of Alberta Health Research Ethics Board on May 21, 2009, and renewed on April 20, 2010. Caritas Covenant Health administrative approval for the study was obtained on June 16, 2009. These two permissions allowed the collection of individual-anonymous data for persons who were hospitalized and died over the one year period (see Appendix A for the research ethics approval form). A developed data collection tool was prepared and utilized (see Appendix B for the chart review data collected and data coding), to collect data as follows:

1. Demographics:
    (a) residence (i.e. urban, suburban, or rural),

(For the purpose of classifying decedents based on where they had lived, urban was defined as the person having lived within the city of Edmonton. Suburban was defined as the person having lived outside of the Edmonton city boundaries, but in metro areas surrounding Edmonton. Rural was defined as the person having lived outside of metro Edmonton and also outside the suburban areas of Edmonton.)

    (b) age,
    (c) gender,
    (d) marital status,
    (e) diagnosis,
    (f) length of stay prior to death,

(g) the month of death,

(h) time of day of death,

(i) if they had an advance directive (i.e. living will) or not,

(j) if they had a DNR order on their chart and if so how many days in advance of death this order was written,

(k) if it was an unexpected death or expected death, and

(l) their level of consciousness near or at the time of death,

2. Care Needs:
    (a) symptoms when dying,
    (b) if they were walking on the day of death or in the days prior, or bedridden,
    (c) ability to complete activities of daily living and/or instrumental activities of daily living, and
    (d) if they had pain in the last 1-3 days of life.
3. EOL care provided in hospital:
    (a) if the patient had surgery or not,
    (b) if the patient was admitted to the ICU or not,
    (c) the general type of care provided (palliative or acute cure-oriented),
    (d) technologies used or technologies in place at the time of death,
    (e) if CPR was in use at time of death, used prior to the dying process, or used at any time during the hospital stay (up to and including time of death), and
    (f) if analgesia was utilized on the day of death or three days prior to death.

Data. The data were collected from the charts between July and December of 2009, and checked for data gaps or issues and then analyzed to answer the research questions. Of all data, no data were collected on names or addresses of any individuals. A non-traceable, unique identification number was assigned to each patient and their chart to ensure that data were not collected on the same patient twice. This number was not the patient's Alberta Health Care number. Data were stored (and analyzed) on a password protected computer system in a secure (locked) office. Only the thesis supervisor (Dr. Donna Wilson), the researcher, and two designated research assistants who assisted with data collection had any access to the data. The original media (paper or electronic record of data collected) was secured in a locked cabinet within the supervisor's office, and accessible only to the researcher and supervisor. No presentation, report, or publication of this study now or in the future will contain any information that identifies any individual. The presentation of findings will involve age groups and other aggregates. Future reports will not name the hospitals where the chart reviews were completed.

Statistical tests. The data obtained were analyzed using the statistical software package of SPSS (version 18). Statistical testing primarily involved bivariate tests, as comparisons were made (i.e. chi-square [$\chi 2$] and t-tests as appropriate for the level of the variables) as well as basic descriptive statistics.

The bivariate tests undertaken were Pearson correlations, $\chi 2$ tests, and t-tests. Pearson correlation tests are used to explore the strength of the relationship between two continuous variables (Pallant, 2007). This correlation gives an indication of both the direction (positive or negative) and the strength of the relationship. A positive correlation indicates that as the value of one variable increases, so does the value of the other. A negative correlation indicates that as one variable's value increases, the other decreases. When using only categorical variables, chi square tests can be used to explore their relationship. The chi square test for independence compares the expected and observed values of two categorical variables. This test compares the frequency of cases found in the different categories of one variable across another variable's various categories (Pallant). T-tests are used to compare the mean scores of two groups or two sets of data (Pallant). Independent samples t-tests are used to compare the mean scores of two different groups of people or two different conditions. Paired samples t-tests are used to compare the mean scores of the same group of people on two different occasions, or compare the means of matched pairs.

Common Issues with Chart Reviews

There are several issues pertaining to chart reviews that are relevant to identify and consider. First, chart reviews are retrospective, in that they collect past or historical information; but chart reviews are valuable when they provide a way to acquire a large amount of data, such as on the care and care needs of patients who recently died. As the care of dying people is important, prospective studies are inappropriate when they burden the patient and/or family and other caregivers. Chart review studies can also be limited as they may investigate EOL care trends through only collecting data on specific diagnoses and age groups; and many also only focus on specific determinants of hospital use (Van den Block et al., 2007).

Another issue with chart reviews is that the written information may deviate from the actual care; furthermore, some events may be missed completely (Becker et al., 2007; Paice et al., 2004; Sato et al, 2007; Solloway et al., 2005; Tang et al., 2009; Van den Block et al., 2007). Much of the psychosocial context that is fundamental to EOL care may also be missed in chart reviews (Kelley et al., 2006). Important clinical information may not be recorded (Tang et al.). Tang et al. said much depends on the prudency and charting competency of those entering the information into charts. Another important issue is that the detailed reasons for treatments (i.e. blood tests, transfusions, hydration therapy, or other procedures) cannot be clearly differentiated in chart reviews (Becker et al.). It is difficult then to know if this care was a curative attempt, or oriented to comfort care (Becker et al.).

Clearly, the only data normally available in charts is that which is entered by healthcare providers. With a potential underestimation (or lack of attention) to symptoms associated with EOL, or a possible lack of documentation, chart reviews are limited to the available information (Seah et al., 2005). This potential barrier of missing data can be addressed in part by having a large number of charts reviewed and by an acknowledgment of missing data. Chart reviews need to be held to high methodological standards, or the conclusions of these studies are less valid or reliable (Gilbert et al., 1996).

Another relevant issue with chart reviews is that one hospital’s findings may not be generalizable or transferrable to another hospital; or generalizable to another region of country or from one country to another country. Hospital-based care may also differ from the care provided in nursing homes or homes. Regardless of these drawbacks, a chart review study was devised and conducted because retrospective chart reviews continue to be a highly useful research method. As there are approximately 125,000 acute care hospital beds in Canada and more than 230,000 people die each year now in Canada, with around 60% of these deaths in hospital, it is important to have up-to-date Canadian studies on the EOL care needs and care practices for dying hospitalized patients (Canadian Cancer Society, 2010; Transgenerational Design Matters, 2011; Wilson et al., 2009).

Chapter 4. Findings

As indicated previously, the charts of all patients who died August 1, 2008 through July 31, 2009 in the two hospitals were reviewed. A total of 1,018 persons died in the emergency departments or inpatient units of these two hospitals, and all 1,018 charts were reviewed. Almost all charts yielded data on all variables, with only a few charts missing data for 2 or 3 variables. The majority of these decedents (69.8%) were admitted to hospital via the emergency room (ER) and 92 of the 1,018 persons (9.0%) died in the ER. Of all patients, 899 (88.5%) did not have any surgery done. In around two out of every three cases (68.5%), a family member was present at the time of death.

The month with the highest proportion of deaths was March with 10.8% (n=110) of the total, the next highest share of deaths occurred in January with 9.5% (n=97) of deaths. The month with the lowest proportion of deaths was August with 6.4% (n=65) of deaths. The day with the highest share of deaths was Friday with 16.6% (n=169), and the day with the lowest proportion of deaths was Sunday with 12.6% (n=128). A large number of people died between 0300 and 0359, accounting for 28.0% (n=283) of deaths, while the next most frequent times of death were between 1700-1759, 1900-1959, and 2100-2159 with 3.9% (n=39) each. The following outlines the findings for questions 1 through 5.

Findings for Question 1

Question: What are the ages, gender, marital status, and rural or urban place of residence of persons who died in hospital?

Findings for question 1 are contained in Table 1. As illustrated, the mean age was 72.5, the majority of decedents were elderly (73.8%), a slight majority were male (53.0%), a slight majority were not married (53.0%), and most were urbanites (79.5%).

Table 1. Socio-demographic Findings

Decedents		N=1,018 (100%)
Gender	Female	486 (47.0%)
	Male	532 (53.0%)
Age	Mean (median) years	72.5 (77.0)
	Mode (range) years (SD)	83 (0-101) (16.42)
	Over 64 years of age	751 (73.8%)
	Under 65 years of age	267 (26.2%)
Region	Urban	809 (79.5%)
	Suburban	128 (12.6%)
	Rural	81 (8.0%)
Marital Status	Not married	540 (53.0%)
	Married	478 (47.0%)
Primary Diagnosis (Main cause of death)	Cardiovascular	234 (23.0%)
	Cancer	369 (36.2%)
	Respiratory	191 (18.8%)
	Other	224 (22.0%)

Findings for Question 2

Question. What are the diagnoses of persons who died in hospital?

Findings for question 2 are also contained in Table 1, with key findings highlighted below. The most common main or primary diagnosis among all those who died was cancer (36.2%), with just over 1/3 deaths due to some type of malignancy. Two other diagnoses were also common, cardiovascular-related deaths (23.0%) and respiratory-related deaths (18.8%). All other diagnoses combined accounted for 22.0% of deaths. Multi-diagnoses were common; however, the total number of diagnoses for all those who died ranged from 1-25, with a mean of 5.85, median of 5, and mode of 4 (SD = 3.64).

Findings for Question 3

Question. What hospital care was provided near the EOL, and did this care differ by diagnosis, age, gender, marital status, and rural, suburban, or urban place of residence?

For question 3, the following care was determined to have been a care option that was provided to some, if not most, patients prior to death: CPR at the very EOL (8.8% of all patients had CPR started and then stopped to have death pronounced), CPR performed prior to the EOL but not at the EOL (10.1%), CPR at some point during the entire hospital stay (13.8%), oxygen in use at the EOL (89.0%), IV in use at the EOL (89.0%), ICU/critical care unit (CCU) care (16.5%), died on a PCU (21.7%), had a palliative care referral (25.7%), and/or had a withdrawal of technology near the EOL (7.0%).

EOL care provided. The findings for question 3 are outlined in Table 2, with key findings below. Table 2 contains descriptive and chi square test findings. Among all of the chi square tests performed, many showed significant differences.

Table 2. EOL Care Provided

	Diagnosis: Ca Cv Resp Other	Age: Younger Older	Gender: Male Female	Marital Status: Married Not married	Residence: Urban Suburban Rural
(Unsuccessful) CPR at End of Life	Ca – 1.1% Cv – 31.2% Resp – 2.1% Other – 3.6% _*χ2 =192.84, df=3, p=.000_	Younger –11.7% Older – 7.7% _χ2 = 3.80, df=1, p = .051_	Male- 11.9% Female- 5.3% _*χ2=13.49, df=1, p= .000_	Married- 9. 8% Not married- 7.8% _χ2=1.32, df=1, p=.250_	Urban- 7.8% Suburban-7.8% Rural- 19.8% _*χ2=13.34, df=2, p=.001_
(Successful) CPR Before Death	Ca- 0.5% Cv- 34.6% Resp- 3.1% Other- 6.7% _*χ2=202.73, df=3, p=.000_	Younger- 15.0% Older- 8.5% _*χ2=9.08, df=1, p=.003_	Male- 12.4% Female- 7.8% _*χ2=5.88, df=1, p=.015_	Married- 9.3% Not married- 11.3% _χ2=1.13, df=1, p=.288_	Urban- 9.0% Suburban- 7.0% Rural- 27.2% _*χ2=27.98, df=2, p=.000_
CPR at Any Time of Hospital Stay	Ca- 1.6% Cv- 44.0% Resp- 4.7% Other- 9.9% _*χ2=242.25, df=3, p=.000_	Younger- 18.4% Older- 12.1% _*χ2=6.58, df=1, p=.010_	Male- 17.5% Female- 9.7% _*χ2=13.15, df=1, p=.000_	Married- 14.6% Not married- 13.0% _χ2=0.59, df=1, p=.444_	Urban- 12.4% Suburban- 10.2% Rural- 33.3% _*χ2=28.85, df=2, p=.000_
Oxygen in use at Time of	Ca- 89.2% Cv- 91.0% Resp- 95.8% Other- 80.8%	Younger- 87.0% Older- 89.7%	Male- 89.8% Female- 88.1%	Married- 90.0% Not married- 88.1%	Urban-88.5% Suburban- 90.6% Rural- 91.4%

Death	*χ2=25.41, df=3, p=.000	χ2=1.64, df=1, p=.200	χ2=0.83, df=1, p=.364	χ2=0.85, df=1, p=.357	χ2=1.01, df=2, p=.604
Intravenous Infusing at Time of Death	Ca- 86.7% Cv- 93.2% Resp- 91.1% Other- 86.6% *χ2=8.22, df=3, p=.042	Younger- 90.6% Older- 88.4% χ2=1.01, df=1, p=.316	Male- 90.2% Female- 87.6% χ2=1.75, df=1, p=.186	Married-89.7% Not married- 88.3% χ2=0.50, df=1, p=.478	Urban- 88.3% Suburban- 90.6% Rural- 93.8% χ2=2.64, df=2, p=.267
Unassisted Walking on Day of Death	Ca- 1.6% Cv- 23.1% Resp- 2.5% Other- 1.8% *χ2=141.73, df=6, p=.000	Younger- 9.0% Older- 5.9% χ2=3.12, df=2, p=.210	Male-9.2% Female- 3.9% *χ2=12.26, df=2, p=.002	Married- 7.7% Not married- 5.7% χ2=1.75, df=2, p=.418	Urban- 6.8% Suburban- 4.7% Rural- 8.6% χ2=3.10, df=4, p=.541
Needed Assistance Walking on Day of Death	Ca- 10.8% Cv- 16.7% Resp- 15.2% Other- 12.5% *χ2=141.73, df=6, p=.000	Younger- 12.7% Older- 13.6% χ2=3.12, df=2, p=.210	Male- 13.9% Female- 12.8% *χ2=12.26, df=2, p=.002	Married- 13.6% Not married- 13.1% χ2=1.75, df=2, p=.418	Urban- 13.0% Suburban- 17.2% Rural- 11.1% χ2=3.10, df=4, p=.541
Needed Bedrest Care	Ca- 87.5% Cv- 60.3% Resp- 82.7% Other- 85.7% *χ2=141.73, df=6, p=.000	Younger- 78.3% Older- 80.6% χ2=3.12, df=2, p=.210	Male- 76.9% Female- 83.3% *χ2=12.26, df=2, p=.002	Married- 78.7% Not married- 81.1% χ2=1.75, df=2, p=.418	Urban- 80.2% Suburban- 78.1% Rural- 80.2% χ2=3.10, df=4, p=.541
Able to Perform Self Care on Day of Death	Ca- 0.8% Cv- 18.4% Resp- 1.0% Other- 0.4% *χ2=151.34, df=6, p=.000	Younger- 8.2% Older- 3.6% *χ2=10.56, df=2, p=.005	Male- 7.2% Female- 2.3% *χ2=13.38, df=2, p=.001	Married- 5.5% Not married- 4.3% χ2=.79, df=2, p=.675	Urban- 4.8% Suburban- 3.1% Rural- 7.4% χ2=2.18, df=4, p=.703
Needed Assisted ADL Care on Day of Death	Ca- 13.0% Cv- 23.9% Resp- 12.0% Other- 11.7% *χ2=151.34, df=6, p=.000	Younger- 12.4% Older- 16.0% *χ2=10.56, df=2, p=.005	Male- 15.1% Female- 15.0% *χ2=13.38, df=2, p=.001	Married- 14.9% Not married- 15.2% χ2=.79, df=2, p=.675	Urban- 15.0% Suburban- 16.4% Rural- 13.6% χ2=2.18, df=4, p=.703
Needed Total ADL Care on Day of Death	Ca- 86.2% Cv- 57.7% Resp- 86.9% Other- 87.9% *χ2=151.34, df=6, p=.000	Younger- 79.4% Older- 80.4% *χ2=10.56, df=2, p=.005	Male- 77.8% Female- 82.7% *χ2=13.38, df=2, p=.001	Married- 79.7% Not married- 80.6% χ2=.79, df=2, p=.675	Urban- 80.2% Suburban- 80.5% Rural- 79.0% χ2=2.18, df=4, p=.703
Received ICU/CCU Care	Ca- 3.0% Cv- 29.2% Resp- 21.5%	Younger- 20.7% Older- 15.0%	Male- 19.2% Female- 13.6%	Married- 15.9% Not married- 17.0%	Urban- 13.2% Suburban- 20.3%

	Other- 21.4% *χ2=83.45, df=3, p=.000	*χ2=4.52, df=1, p=.034	*χ2=5.83, df=1, p=.016	χ2=0.22, df=1, p=.636	Rural- 43.2% *χ2=49.47, df=2, p=.000
Received Unit-Based Palliative Care	Ca- 53.9% Cv- 2.6% Resp- 2.6% Other- 4.5% *χ2=356.13, df=3, p=.000	Younger- 39.0% Older- 15.5% *χ2=63.88, df=1, p=.000	Male- 20.5% Female- 22.9% χ2=.832, df=1, p=.362	Married- 27.2% Not married- 16.7% *χ2=16.35, df=1, p=.000	Urban- 21.1% Suburban- 29.7% Rural- 14.8% *χ2=7.27, df=2, p=.026
Had a Palliative Care Referral	Ca- 55.8% Cv- 6.0% Resp- 10.6% Other- 9.4% *χ2=276.49, df=3, p=.000	Younger- 35.2% Older- 22.3% *χ2=17.09, df=1, p=.000	Male- 25.3% Female- 26.2% χ2=0.11, df=1, p=.742	Married- 30.4% Not married- 21.6% *χ2=10.34, df=1, p=.001	Urban- 23.9% Suburban- 39.1% Rural- 22.2% *χ2=13.78, df=2, p=.001
Had Withdrawal of Technology (1 or more)	Ca- 1.4% Cv- 11.5% Resp- 10.0% Other- 9.0% *χ2=29.37, df=3, p=.000	Younger- 10.2% Older- 5.9% *χ2=5.52, df=1, p=.019	Male- 7.5% Female- 6.4% χ2=0.52, df=1, p=.471	Married- 6.3% Not married- 7.6% χ2=.72, df=1, p=.397	Urban- 5.5% Suburban- 7.8% Rural- 20.9% *χ2=27.43, df=2, p=.000

(* Significant findings)

Findings from Table 2.

CPR. As shown in Table 2, three of the five χ2 tests were significant when the care-unsuccessful CPR at the EOL immediately prior to death- was compared by diagnosis, age, gender, marital status, and residence (rural, suburban, or urban). Among these findings, it is notable that people dying of cardiovascular causes were 10 times more likely to have had CPR performed immediately before death was pronounced than people who died of other causes, males were almost twice as likely to have CPR performed, and rural people were more than twice as likely to have CPR (unsuccessfully) performed immediately prior to death.

As indicated in Table 2, four of the five χ2 tests were significant when the care-successful CPR before death- were compared by diagnosis, age, gender, marital status, and residence. Among these findings, it is notable that people who died of cardiovascular causes were over 5 times more likely than people with any other diagnoses to have had CPR performed in the hospital prior to death, younger persons were almost twice as likely to have received successful CPR prior to death as compared to older persons, males were also almost twice as likely to have received CPR before death occurred, and persons from rural areas were over three times as likely to have received successful CPR in the hospital before death.

As also shown in Table 2, four of the five $\chi 2$ tests were significant when the care- CPR (either successful or unsuccessful) at any time of hospital stay- were compared by diagnosis, age, gender, marital status, and residence. Of these findings, it is relevant to note that people dying of cardiovascular causes were over four times more likely to have had CPR performed (as compared to those who died of other causes), those who were younger were also more likely to have had CPR performed, males remained almost twice as likely to have had CPR performed, and rural people were nearly three times as likely to have had CPR performed at any time during hospital stay.

Technologies. As indicated in Table 2, only one of the five $\chi 2$ tests were significant when the care- oxygen in use at the time of death- was compared by diagnosis, age, gender, marital status, and residence. The one significant finding demonstrates that decedents who had a respiratory diagnosis were significantly more likely than any other diagnosis to have oxygen in use at the EOL.

As also indicated in Table 2, only one of the five $\chi 2$ tests were significant when the care- IV infusing at the time of death- was compared by diagnosis, age, gender, marital status, and residence. This notable finding showed that those who died of cardiovascular related causes were significantly more likely to have an IV in place at the EOL as compared to any other diagnosis.

Mobility. As identified in Table 2, two of the five $\chi 2$ tests were significant for unassisted walking on the day of death, assisted walking on the day of death, and needing bedrest-related care, when compared by diagnosis, age, gender, marital status, and residence. Of these findings, it is notable that decedents with a cardiovascular diagnosis were over 10 times more likely to be able to walk unassisted at the EOL, and were also more likely to be able to walk with assistance at the EOL (as compared to any other diagnosis). Decedents who had a main diagnosis of cancer were the most likely to need bedrest-related care; whereas decedents who had a main diagnosis of cardiovascular disease were the least likely to need bedrest-related care. Also of significance, males were more often able to walk (unassisted or assisted) up until the EOL; whereas females were more likely to require bedrest-related care.

Activities of daily living (ADL). As shown in Table 2, three of the five $\chi 2$ tests were significant for the decedent's ability to perform self care on the day of death, needing assistance with ADL care on the day of death, and needing total ADL care on the day of death, when compared with diagnosis, age, gender, marital status, and residence. Among these findings, it is notable that those who died with a primary diagnosis of cardiovascular disease were about 20 times more likely to be able to perform self care on the day of death, and about twice as likely to only need assistance with ADLs on the day of death (as compared to any other diagnosis). Decedents with a main diagnosis of cardiovascular disease were also the least likely (of any other diagnosis) to require total ADL care. Another significant finding was that younger persons were over twice as likely to be able to perform self care on the day of death (as compared to older persons); whereas older persons were more likely to require assistance with ADLs at the EOL. Also of significance, males were over three times more likely to be able to perform self care on the day of death; whereas females more often required total ADL care.

ICU/CCU care. As illustrated in Table 2, four of the five χ2 tests were significant for the care- admitted to the ICU or CCU- when compared by diagnosis, age, gender, marital status, and residence. Among these findings, it is notable that those who died with a primary diagnosis of cardiovascular disease were significantly more likely to have received ICU or CCU care; whereas those who had a primary diagnosis of cancer were almost 10 times less likely to have received ICU or CCU care. Decedents who were younger (as compared to those who were older) were also more likely to receive ICU or CCU care. Also, males (as compared to females) were significantly more likely to receive ICU or CCU care while in hospital. Decedents who were from rural areas were also two to three times more likely to receive ICU or CCU care (as compared to those from urban or suburban areas).

Palliative care. As indicated in Table 2, four of the five χ2 tests were significant for receiving PCU care when compared by diagnosis, age, gender, marital status, and residence. Among the findings, it is notable that of those who died in a PCU, a slight majority had a primary diagnosis of cancer. Those who died in the PCU were also more than twice as likely to be younger and more likely to be married. Decedents from rural areas were the least likely to die in a PCU, whereas those from suburban areas were the most likely to die in a PCU.

As also indicated in Table 2, the findings above are similar to those for having a palliative care referral on the chart, with four of the five χ2 tests being significant when compared by diagnosis, age, gender, marital status, and residence. Among these findings, it was significant that the majority had a primary diagnosis of cancer; they were more likely younger, more likely married, and more likely to be from a suburban area.

Withdrawal of technology. As indicated in Table 2, three of the five χ2 tests were significant for having one or more technologies withdrawn when compared by diagnosis, age, gender, marital status, and residence. Among the findings, it is notable that those who died of cardiovascular-related causes were the most likely to have a withdrawal of one or more technologies; whereas those who had a primary diagnosis of cancer were significantly less likely to have any withdrawal of technology. Those who had a withdrawal of technology were almost twice as likely to be younger (as compared to those who were older), and about three times more likely to have resided in a rural area (as compared to urban or suburban areas).

Findings for Question 4

Question. What hospital care was needed at the EOL; and do these care needs vary by diagnosis, age, gender, marital status, or rural, suburban, or urban place of residence?

One of the most important care needs at the EOL is adequate pain control, with question 4 thus focused on pain and analgesia. Analgesia use was only recorded when potent analgesics, such as opioids were given. Acetaminophen and acetylsalicylic acid were excluded as both are over the counter mild pain relievers.

Of all 1,018 patients, 77.1% had pain recorded on the day of death and 62.3% had pain recorded three days prior to death. Of those who indicated or showed signs that they were having pain three days prior to death, 98.7% received analgesia. Similarly, for persons who indicated that they had pain on the day of death, 98.6% received analgesia. In addition, 4.7% of the people who did not indicate that they were having pain on the day of death received analgesia and 1.0% of those who did not have pain three days prior to death also received analgesia on that day.

Pain and analgesia- additional findings. People with cancer were significantly (p=.000) more often in pain on the day of death (94.6%, n=349), as compared to people with cardiovascular-related deaths (59.7%, n=139), respiratory-related deaths (71.7%, n=137) and all other diagnoses deaths (70.5%, n=158). Diagnoses were also a significant factor for pain three days before death among subjects (p=.000); with 88.0% (n=322) of those with cancer, 36.9% (n=86) of those with a cardiovascular diagnosis, 51.3% (n=98) of those with a respiratory diagnosis, and 56.1% (n=125) of all other diagnoses indicating that they had pain three days prior to death.

A significant difference between younger and older persons was found in relation to pain on the day of death by age (p=.01); 82.7% of those who were younger indicated they had pain, while 75.0% of those who were older indicated they had pain. There was also a significant difference for those who were younger and those who were older for having had pain three days prior to death (p=.000); with 75.9% of younger persons and 57.4% of older persons indicating that they had pain.

Analgesia use for decedents who had pain. The findings for question 4 are outlined in Table 3, with key findings outlined below. Table 3 contains descriptive and chi square test findings to identify whether or not the decedents who had pain (either on the day or death or three days prior to death) received analgesics when compared by main diagnosis, age, gender, marital status, and residence.

Table 3 key findings. As shown in Table 3, among the 10 χ2 tests performed, only one showed a significant difference when compared by diagnosis, age, gender, marital status, and residence. Of those who died from cardiovascular-related causes, 4.7% did not receive analgesia three days prior to death (when they were having pain), as compared to 0.3% to 2.0% for the people who died of the other outlined causes. Persons dying of cardiovascular diseases thus were over twice as likely to have uncontrolled pain three days prior to death. Although this was a significant difference, the small n and relatively small difference (from 0.3 or 2.0% to 4.7%) suggests minimal clinical significance.

Table 3. Analgesia Use for Those with Pain on the Day of Death and Three Days Prior to Death

	Had Pain on Day of Death		Had Pain 3 Days Prior to Death	
	Analgesic on Day of Death		Analgesic 3 days Prior to Death	
	No	Yes	No	Yes
Main Diagnosis: CV	2.9% (n=4)	97.1% (n=135)	4.7% (n=4)	95.3% (n=82)
CA	0.3% (n=1)	99.7% (n=348)	0.3% (n=1)	99.7% (n=321)
RESP	2.2% (n=3)	97.8% (n=134)	2.0% (n=2)	98.0% (n=96)
OTHER	1.9% (n=3)	98.1% (n=155)	0.8% (n=1)	99.2% (n=124)
	χ2=6.216, df=3, p=.102		**χ2=10.908, df=3, p=.012*	
Age: Younger	0.9% (n=2)	99.1% (n=218)	0.5% (n=1)	99.5% (n=201)
Older	1.6% (n=9)	98.4% (n=554)	1.6% (n=7)	98.4% (n=422)
	χ2=.543, df=1, p=.461		*χ2=1.417, df=1, p=.234*	
Gender: Male	1.8% (n=7)	98.2% (n=392)	1.6% (n=5)	98.4% (n=313)
Female	1.0% (n=4)	99.0% (n=380)	1.0% (n=3)	99.0% (n=310)
	χ2=.781, df=1, p=.397		*χ2=.475, df=1, p=.491*	
Marital Status: Married	1.6% (n=5)	98.4% (n=369)	1.5% (n=5)	98.5% (n=324)
Not Married	1.2% (n=6)	98.8% (n=403)	1.0% (n=3)	99.0% (n=299)
	χ2=.198, df=1, p=.656		*χ2=.349, df=1, p=.555*	
Place of Res: Urban	1.6% (n=10)	98.4% (n=602)	1.6% (n=8)	98.4% (n=488)
Suburban	1.0% (n=1)	99.0% (n=104)	0.0% (n=0)	100% (n=90)
Rural	0.0% (n=0)	100% (n=66)	0.0% (n=0)	100% (n=45)
	χ2=1.328, df=2, p=.515		*χ2=2.205, df=2, p=.332*	

(* Significant findings)

Findings for Question 5

Question. What proportion of these hospital deaths were expected, and was care appropriate to expected versus unexpected deaths?

Of the 1,016 charts that identified if a death was expected or not, 54.6% of deaths were identified as expected (n=555) and 45.4% were not identified as such (n=461). People who had an expected death typically had a DNR order (96.4%); much more so than for people who did not have an expected death (77.0%). A total of 13.9% of people died without having a DNR order. The following further explores the care of persons who had expected versus unexpected deaths.

Care for expected versus unexpected deaths.

Living wills. Of those who had expected deaths, 33.0% had a living will; whereas of those who had unexpected deaths 31.3% had a living will (a non-significant difference). Also, of all persons who died, 311 (30.8%) had written living wills, another 7 persons verbalized their wishes (0.7%), and for another 7 patients, family wishes for no-CPR orders were documented (0.7%).

Analgesic use. It was a significant finding that for those whose deaths were expected, 88.5% received analgesic on the day of death; whereas 63% of those whose deaths were not expected received analgesic on the day of their death ($\chi 2= 91.25$, df= 1, p = .000). Of those whose deaths were expected, 78.5% received analgesia three days prior to death; whereas 41.9% of all people having unexpected deaths received analgesia three days prior to death. Having pain and receiving analgesia were thus significantly more likely when death was known to be expected and imminent.

Family present. It was a significant finding that of those who died expected deaths, 72.0% died with family members present; whereas of those who died unexpected deaths, 64.0% had family members present ($\chi 2=6.86$, df= 1, p = .009).

Admission information. Of all decedents, 69.8% were admitted through the emergency department. Of the patients who died expected deaths, 68.0% were admitted through the emergency department, 12.8% were transferred in from another hospital, 16.4% were planned direct inpatient admissions, and 2.7% died in an emergency department. For those who died unexpected deaths, 71.8% were originally admitted via the emergency room, 7.4% were transferred from another hospital, 4.1% were planned inpatient admissions, and 16.7% died in an emergency department ($\chi 2= 97.2$, df= 3, p = .000).

Independent samples t-tests.

Technologies in use and age. An independent samples t-test was conducted to compare whether having technologies in use or not having technologies in use differed by age. A significant difference was not found (p = .66) for having technologies in use (M = 72.56, SD = 16.19) and not having technologies in use ([M = 70.48, SD = 23.72]; t = .452).

Age and expected vs. unexpected deaths. Another independent samples t-test was conducted to compare whether deaths were expected or unexpected based on age. Age had a significant effect (p=.000) on whether a death was expected (M = 70.59, SD = 15.3) or unexpected ([M = 74.86, SD = 17.4]; t = 4.16), indicating that people with expected deaths were significantly younger on average. The magnitude difference in the means was significant at 4.27 (CI: 2.25 to 6.28). This suggests it is harder to discern when to expect death when the person is older. There was a negative correlation between age and expected death, Pearson correlation (-.129), a test which was significant at the .000 (two-tailed) level. This finding also reveals that the younger the person who died, the easier it was to tell if the death was expected.

Technologies in use and expected vs. unexpected deaths. An independent samples t-test was also conducted to compare whether expected versus unexpected deaths had an effect on the number of technologies in use at the time of death. Technologies in use did differ significantly (p = .001) on the basis of whether a death was expected (M = 1.78, SD = .485) or unexpected ([M = 1.89, SD = .494]; t = 3.36); although the magnitude difference in the means was very small at 0.103 (CI: .043 to .164).

Expected versus unexpected deaths. Further findings related to question 5 are contained in Table 4, with significant findings outlined below. As illustrated in Table 4, 14 of the 17 $\chi 2$ tests were significant.

Table 4. Expected Versus Unexpected Deaths

		Death Was Expected	
		No	Yes
Main Diagnosis:	CV	74.8% (n=175)	25.2% (n=59)
	CA	12.2% (n=45)	87.8% (n=324)
	RESP	56.1% (n=106)	43.9% (n=83)
	OTHER	60.3% (n=135)	39.7% (n=89)
		*χ2=285.623, df=3, p=.000	
Age:	Younger	35.1% (n=93)	64.9% (n=172)
	Older	49.0% (n=368)	51.0% (n=383)
		*χ2=15.285, df=1, p=.000	
Gender:	Male	45.8% (n=243)	54.2% (n=288)
	Female	44.9% (n=218)	55.1% (n=267)
		χ2=,068, df=1, p=.795	
Marital Status:	Married	41.0% (n=196)	59.0% (n=282)
	Not Married	49.3% (n=265)	50.7% (n=273)
		*χ2=6.954, df=1, p=.008	
Place of Residence:	Urban	43.8% (n=354)	56.2% (n=454)
	Suburban	42.2% (n=54)	47.8% (n=74)
	Rural	66.3% (n=53)	33.7% (n=27)
		*χ2=15.386, df=2, p=.000	
Had Sudden Death:	Yes	79.2% (n=229)	20.8% (n=60)
	No	31.9% (n=232)	68.1% (n=495)
		*χ2=186.873, df=1, p=.000	
CPR at EOL:	Yes	91.0% (n=81)	9.0% (n=8)
	No	40.9% (n=379)	59.1% (n=547)
		*χ2=82.184, df=1, p=.000	
CPR Prior to the EOL:	Yes	86.4% (n=89)	13.6% (n=14)
	No	40.7% (n=371)	59.3% (n=541)
		*χ2=78.093, df=1, p=.000	
CPR During the Entire Hospital Stay:	Yes	85.6% (n=119)	14.4% (n=20)
	No	38.9% (n=341)	61.1% (n=535)
		*χ2=105.507, df=1, p=.000	
IV Therapy in Use at Death:	Yes	47.0% (n=424)	53.0% (n=479)
	No	32.1% (n=36)	67.9% (n=76)
		*χ2=8.821, df=1, p=.003	
Oxygen in Use at Death:	Yes	45.4% (n=410)	54.6% (n=494)
	No	45.5% (n=51)	54.5% (n=61)
		χ2=.001, df=1, p=.971	
Had Withdrawal of Technology: (One or More)	Yes	59.2% (n=42)	40.8% (n=29)
	No	44.3% (n=417)	55.7% (n=525)
		*χ2=5.905, df=1, p=.015	
Died on a Palliative Care Unit:	Yes	6.8% (n=15)	93.2% (n=205)
	No	55.9% (n=444)	44.1% (n=350)

	*_χ2=167.633, df=1, p=.000_	
Had a Palliative Care Referral: Yes	14.6% (n=38)	85.4% (n=223)
No	56.0% (n=421)	44.0% (n=331)
	*_χ2=134.172, df=1, p=.000_	
Had a Living Will: Written Will	43.8% (n=137)	56.2% (n=176)
Verbal Will	42.9% (n=3)	57.1% (n=4)
No Living Will	45.9% (n=316)	54.1% (n=372)
Family Wish No Resuscitation	57.1% (n=4)	42.9% (n=3)
	_χ2=.819, df=3, p=.845_	
Had a DNR Order: Yes	39.9% (n=355)	60.1% (n=535)
No	84.1% (n=106)	15.9% (n=20)
	*_χ2=87.152, df=1, p=.000_	
Had ICU or CCU Care: Yes	65.1% (n=108)	34.9% (n=58)
No	41.5% (n=352)	58.5% (n=497)
	*χ2=31.206, df=1, p=.000	

(* Significant findings)

Diagnosis, age and marital status. Patients with a primary diagnosis of cancer were discovered to be two to three times more likely to have an expected death (as compared to any other diagnosis). Cardiovascular-related deaths were found to be the least likely to be expected. Younger persons were identified as dying an expected death more often than older persons. Married persons are also more likely to die an expected death, as compared to those who were not married.

Residence. Place of residence also had a significant effect on whether a death was expected or unexpected. Those who resided in a rural area were notably more likely to have had an unexpected death; whereas decedents who resided in an urban area were more likely to have had an expected death.

Sudden deaths. Persons who died expected deaths were significantly more likely to have a non-sudden death. Approximately 1/5 of decedents who had a sudden death also had an expected death (where death is expected, but not as quickly as it occurred).

CPR. CPR implementation was shown to be significant for unexpected versus expected deaths at the EOL, prior to the EOL, as well as at anytime of the hospital stay. CPR at the EOL is

10 times more common when death was unexpected; as well as much more common prior to the EOL, and at anytime during the hospital stay when death was unexpected (as compared to expected deaths). Another significant finding was that of those who had expected deaths, 1.4% received CPR at the EOL; whereas of those who had unexpected deaths, 17.6% received CPR at the EOL. It was also a significant finding that 2.6% of those who had expected deaths received CPR (in which they were resuscitated); whereas 24% of those who had unexpected deaths received CPR prior to the EOL. It was again a significant finding that of those who died expected deaths, 3.7% still received CPR at the time of death, as compared to 25.9% of those who died unexpected deaths.

IV therapy. It was a significant finding that a slight majority of those with IVs in place as compared to those without IVs died expected deaths, as 86.3% of those who had expected deaths had an IV in use (at the time of death), and 92.2% of those who had unexpected deaths had an IV in use. However, this difference (5.9%) is relatively small clinically.

Oxygen therapy. For those whose deaths were expected, 89.0% had oxygen in use at the time of death. Even for those whose deaths were unexpected, 88.9% had oxygen in use at the time of death. As such, there was no difference in oxygen use over time, and across expected and unexpected deaths.

Withdrawal of technology. Leading up to death, only 7.0% of patients had any withdrawal of technology. It was significant that of those who died expected deaths, only 5.2% had a withdrawal of technology; whereas of those who died unexpected deaths, 9.2% had a withdrawal of technology.

Palliative care. It was a significant finding that 40.3% of those who had an expected death had a palliative care referral; whereas 8.3% of those who did not have an expected death had a palliative care referral. Another significant finding was that 36.9% of those who had expected deaths died in a PCU, whereas 3.3% of those who did not have expected deaths died in a PCU.

DNR order. It was a significant finding that of those who died an expected death, most had a DNR order (96.4%), as compared to those who had an unexpected death, where just over ¾ had a DNR order (77.0%).

ICU/CCU care. The final significant finding was in relation to the test that found the majority of those who had ICC/CCU care died unexpected deaths; as compared to approximately 1/3 who had expected deaths.

Conclusion

This chapter summarized the people who have recently died in two western-Canadian hospitals. These findings outlined the decedents' primary diagnoses, EOL care provided (i.e. CPR use, technology use, patient's ADL needs, and palliative care), EOL care needed (i.e. pain and analgesic use), and information concerning expected and unexpected deaths. These findings will be further discussed with regards to Wilson's (1997) study and other published literature in the ensuing chapter.

Chapter 5. Discussion

In this retrospective descriptive chart review of all decedents at two mid-sized urban hospitals in Western Canada, data were collected and analyzed to identify the current EOL care needs and EOL care provided to dying patients. A secondary aim was to identify variations and consistencies of the current findings from those of the Wilson (1997) study. The following discussion is grouped into four sections: (a) a summary of key current findings, (b) Wilson's (1997) findings, (c) other reviewed studies, and (d) a conclusion focused on the current findings.

Summary of Key Current Findings

The decedents were as expected- most were older (73.8%) and most were urbanites (79.5%) as people who lived in the study city understandably died in one of their city's hospitals. Similarly, as expected, the most common main diagnosis among all those who died was cancer (36.2%), with over 1/3 deaths due to some type of malignancy. Two other diagnoses were also common and expected- cardiovascular-related deaths (23.0%) and respiratory-related deaths (18.8%). Multi-diagnoses were also common, as expected, given the age of the decedents and the commonality of multiple chronic illnesses now.

Of all the decedents, 8.8% had CPR performed at the very EOL, and 13.8% had CPR performed at some point during their hospital stay. Younger persons were over 1/3 more likely to have had CPR immediately prior to death. People who died of cardiovascular-related causes were 10 times more likely to have had CPR performed at the EOL. As such, CPR was not a common event overall, but relatively much more common for persons who had cardiovascular health problems.

Those who died in the PCU were more than twice as likely to be younger, more likely to be married, and much more often urbanites. Also, those who had a cancer diagnosis were over 10 times more likely to die in the PCU than people with other diagnoses. These findings were also similar for persons who had a palliative care referral on their chart, with the majority of these persons having a primary diagnosis of cancer, more likely to be a younger age, more likely to be married, and more likely to be from a suburban area. A total of 21.7% of all the decedents died in a PCU and a total of 25.7% of all decedents had a palliative care referral. Of those patients who died an expected death (54.6% of the total), 40.3% (of these expected-death decedents) had a palliative care referral. Of all patients who died, 30.8% had provided a written living will, 0.7% verbalized their wishes for EOL care, and for another 0.7% of patients had family wishes for no-CPR or DNR documented. Most decedents had an IV infusing at the EOL (89.0%) and also oxygen in use (89.0%). A total of 97.3% of all decedents had one or more technologies in use at the time of death. Only 7.0% had a withdrawal of one or more technologies near the EOL.

People who had expected deaths almost always had a DNR order on their chart (96.4%); although 77.0% of people who did not have an expected death also had a DNR order. Only 13.9% of people died without having a DNR order on their chart.

Of all patients, 77.1% had pain recorded on the last day and 62.3% had pain recorded three days prior to death. People with cancer were more often in pain on the day of death (94.6%), as compared to people with any other diagnosis. For persons who indicated that they had pain on the day of death, 98.6% of these received analgesia. Having pain and receiving analgesia are significantly more likely when death is known to be imminent.

In summary, these findings confirm what many previous studies and reports have pointed out. Namely, that EOL care is technologically-based (Wilson, 1997), the most common cause of death is cancer (Canadian Cancer Society, 2010; Statistics Canada, 2010), and most palliative care beds are utilized primarily for persons dying from cancer (Bookbinder & McHugh, 2010).

Current Findings and Previous Published Literature

The following is comprised first of an outline of variations and consistencies from the current findings to Wilson’s (1997) study findings, and then to the findings of studies previously outlined in the literature review.

Wilson’s previous EOL study. Wilson’s (1997) study identified that the average age at the time of death was 70.9 years, and with a difference in the mean ages of women (76.1) and men (65.4). The current study indicated instead the mean age of women as 73.2 and the mean age of men as 71.9, suggesting that the gap that used to exist between men’s and women’s lifespan is closing. The average age of those who are currently dying was 72.5. Another possible reason for the variance in age from the previous study to now, is that Wilson’s (1997) study included only those who were aged 18 and over, while this current study included all deaths (with the exclusion of stillborn births), regardless of age.

Wilson’s previous study (1997) indicated that no-CPR decisions tended to be made when it appeared evident that patients were in their final days or hours before death. In the current study, 13.9% of people died without a DNR order, and of the 86.1% who had a DNR order, 11.9% were written on the day of death, with almost 1/3 of the DNR decisions being made within three days prior to death (32.0%). The use of CPR thus appears to have increased in practice since 1997, from 2.9% to 8.8% at the time of death, and with a current total of 13.8% receiving CPR at some point during the hospital stay (either prior to death or at death). Clearly, however, DNR orders are still being written (for the most part) when it is obvious that death will occur in the near future. Also, in the current study, although 125 patients did not have DNR orders at the EOL, 43 of these did not receive CPR at the EOL. As well, of the 891 people who did have a DNR order on their chart, 7 received CPR. Of all those who died without a DNR order, 34.4% of these did not receive CPR at the EOL; although this should have happened according to hospital policy. In addition, 0.8% of people who asked for no-CPR still received CPR. These practices should be reviewed by the managers and staff of the two hospitals. In Wilson’s (1997) study, no patients provided a living will, and only 13.1% of patients verbalized their preferences about CPR. In the current study, 30.8% of patients provided written living wills, another 7 persons verbalized their EOL wishes, and for another 7 patients, family wishes of no-CPR or DNR orders were documented. These findings show a major shift in patient and perhaps family preparation for the EOL, one illustrating an increased acceptance of death.

Wilson’s (1997) previous study also identified which technologies were in place at the time of death and leading up to the time of death. In keeping with Wilson's study, gender did not correlate with technologies in use. Wilson’s study showed 72.3% of people who died had oxygen in place and 67.9% had an IV in use at death. In the current study, most patients had an IV infusing (89.0%) and also oxygen in use (89.0%) at the time of death. The withdrawal of any technology was minimal, both for patients in the current study and those in Wilson’s previous chart review. As such, an increased use of technologies is indicated, but this difference may be due to sampling issues.

The current study found 16.5% of people died in the ICU/CCU, whereas previously 27.0% of people died in the ICU/CCU (Wilson, 1997). This difference suggests a decrease in ICU/CCU deaths, such that it is possible that healthcare professionals are better able to recognize those who are dying and thus have time to move them out of ICU/CCUs prior to death. In addition, this recognition could help to prevent ICU/CCU admission. Care on units that are not ICU/CCU in type means the family has more freedom for visitation and invasive monitoring and treatment procedures are avoided.

Another positive finding is that almost all persons with pain received analgesia. More specifically, of all those who indicated that they were having pain on the day of death (77.1%), 98.6% received analgesia. Similarly, among those who had pain recorded three days prior to death (62.3%), 98.7% received analgesia. These findings are in contrast to Wilson's (1997) previous study which indicated analgesia was given infrequently during the last one to three days of life- although this was possibly due to the vast majority being unresponsive (i.e. comatose) leading up to death.

As such, the findings of the current study suggest some improvements in EOL care over that of 14 years ago. Although technologies still appear to be a normal practice, and CPR is increasing in use, there are several indications that EOL care in hospitals is improving.

Other reviewed studies. The following discussion is divided into two sections: (a) EOL care provided, and (b) EOL care needs. For these two sections, the findings of the current study will be discussed with regards to findings from other studies, in order to clarify findings, issues, and developments.

EOL care provided.

Technologies. The current study found only 7.0% of patients had one or more technologies withdrawn as death approached. Technologies included tube feeds, IV, oxygen, mechanical ventilation, and/or foley catheters. In the younger population, 10.1% had technologies withdrawn, while 5.9% of older persons did, a finding which is in contradiction to a study by Kelley et al. (2006) who found that those who had technologies withdrawn tended to be older. However, the current study showed age did have a significant effect on whether a death was expected or not, indicating that people with expected deaths were significantly younger on average, a finding which could explain why there were more technologies withdrawn on average in the younger patients. There was virtually no difference in the numbers of technologies in place at the EOL between the older population and the younger population. With only 7.0% withheld, and most people dying with an IV and oxygen, this again demonstrates a heavy reliance on technologies to ease the dying process.

However, Paice et al. (2004) ascertained that fluids should be minimized as death approaches in order to avoid pulmonary congestion and the discomfort it causes. Seah et al. (2005) also indicated the problem that treatment aimed at prolonging life in the face of futility raises patient and family hope unnecessarily, and furthermore these treatments are sometimes given despite the cost to a patient's comfort level. Historically, artificial ways to deliver nutrition and hydration were developed to offer temporary support for acutely-ill patients (American Academy of Hospice and Palliative Medicine [AAHPM], 2006). Whether a treatment is justified today depends on the evaluation of its efficacy or the benefits attainable for each patient, as well as consideration for the potential burdens that the care option may impose (Hospice and Palliative Nurse Association [HPNA], 2008). According to the AAHPM, when artificial nutrition or hydration is used on persons nearing the EOL, these practices are often not beneficial as a means of preventing suffering. As death approaches, concerns such as alleviating thirst can be achieved through less invasive measures such as ice chips and excellent mouth care.

The information about decisions on technology use was limited in the patient charts, but the findings showed that the use of technologies was almost as high for those who received palliative care as those who did not. As was previously mentioned in the findings, there was a significant difference between expected and unexpected deaths in terms of technologies in use at the EOL, but with this finding not clinically significant. Based on these findings alone, it is impossible to say whether the EOL care was appropriate, however it appears as though technologies should decrease further as death is approaching and this decrease does not appear to be occurring.

Palliative care use. Becker et al.’s (2007) study in Germany suggested that the transition from acute cure to palliative care is difficult in hospitals, as healthcare professionals tend to provide active treatment throughout or until the very end of a dying process (a finding that was similar to the high use of technologies in the current study). The current study showed cancer patients were the highest users of palliative care services; as they were over 10 times more likely to die in the PCU than people with other diagnoses. Inequalities by age were also identified, as younger persons were much more likely to receive these services, and over twice as likely to die in the PCU. These findings are in keeping with other studies (Ahmed et al., 2004; Burt & Raine, 2006), which could suggest that older people die less painful or symptomatic deaths. This finding could also illustrate ageism in palliative care.

The issue then appears to be on how to improve access to palliative care services to non-cancer and older populations (Bookbinder & McHugh, 2010). In the current study, a total of 25.7% of people who died had a palliative care referral on their chart and only 21.7% died in a PCU. Seah, Low and Chan’s (2005) study found that 31% of all patients who died had input from palliative care experts, a finding that indicates appropriate EOL care may not yet be given to all dying patients. This is a concern, as those older persons who had palliative input prior to death were better managed for common EOL symptoms as compared to those who did not (Seah, Low, & Chan). Napolskikh et al.'s (2009) Canadian study found an inadequate awareness of palliative care services, with referrals occurring too late in many cases. Palliative care that allows adequate time to address all EOL needs of the patient is necessary to the provision of quality EOL care. The main consensus of Sato et al.'s (2007) team was that EOL care could be improved on general wards in Japan, with this consensus appropriate for all countries. There is an urgent need to improve basic palliative care assessment and treatment skills among clinicians caring for critically-ill patients, with a goal of reserving specialty-level palliative care services (consults and PCU admissions) for problems beyond their proficiency (Weissman & Meier, 2011).

EOL care needs.

*Treating EOL pain***.** The adequate treatment of pain is a primary concern in EOL care (Setoguchi et al., 2008). Previous studies have suggested that 25% to 70% of people suffer significant pain at the EOL (Setoguchi et al.; Carr et al., 2002). Although the level of pain was not discerned in the current study, it did identify that 77.1% of people had it recorded that they were having pain on the day of death, and 62.3% of people had it recorded that they were having pain three days prior to death. Paice et al. (2004) found that 20% of people did not receive opioid analgesics during their last 24 hours of life. The current study found 23.0% of all decedents did not receive analgesics during the last 24 hours of life. However, this study also revealed that only 1.4% of those who had pain identified on the day of death did not receive opioid analgesic. Although the findings should show that 100% of those who were having pain received analgesic, these results are positive as the vast majority received analgesic. The results were similar for those showing signs of pain three days prior to death, with only 1.3% not receiving analgesic. It should be emphasized that for the most part, those who died in hospital with pain either on the day of death or three days prior to death received analgesia, although it could not be determined if the required analgesics were effective for pain management. Further studies of pain and pain management are needed to determine the efficacy of analgesic practice.

Patient's EOL wishes and decision-making capacity. In the current study, on the day of death, only 22.2% of people were alert and able to communicate their needs effectively. This finding shows that people's wishes surrounding EOL care should be addressed upon admission, when most people are still able to communicate their wants and needs (Becker et al., 2007). In the current study, almost 1/3 of DNR orders were made within three days prior to death; clearly indicating that many times DNR orders are being written when it becomes obvious that death will occur. However, it was encouraging that the current study found many people had a living will available on their chart, indicating that people are more aware of their options at the EOL.

Conclusion

This chapter discussed the findings of the current study, and first discussed them with regards to Wilson's (1997) prior similar study and then to other relevant studies reviewed in Chapter 2. Clearly, many similarities in care needs and care provision between the current study and other previous studies were evident. Some progress however, in keeping with palliative care principles is evident, as more patients had living wills and approximately half had expected deaths. Although twice as many people received CPR in the current study as compared to Wilson's study, this change could reflect the shift of death and dying to the home, as people who know they are dying may be increasingly avoiding hospitals at the EOL. It is possible that people who are currently dying in hospital are more hopeful of (and thus appropriate for) cure-oriented care. If this is the case, then it follows that hospitals may have an even more difficult and rapid transition from curative to palliative care, as compared to 1997. It is also possible that a lack of family to provide home-based EOL care or family caregiver burnout also contributed to these deaths in hospital. More research needs to be undertaken in the near future on EOL practices and care needs for those who are dying in the home, nursing home, and hospital; as the number of deaths in Canada are expected to double in the next 30 years over the more than 230,000 per year now (Canadian Cancer Society, 2010; Transgenerational Design Matters, 2011).

Chapter 6. Conclusions and Implications of Findings

This study described EOL care needs and EOL care provision as identified in the charts of persons who died in two urban western-Canadian hospitals from August 1, 2008 through July 31, 2009. Data were obtained using a developed data collection tool. The data were then analyzed using the statistical software package of SPSS (version 18). Statistical testing primarily involved bivariate tests, as comparisons were made (i.e. $\chi 2$ and t-tests as appropriate for the level of the variables) as well as descriptive statistics.

This chart review identified a few areas for attention or improvement in EOL care. Although people are living longer, with more diagnoses on average; there is little evidence that EOL care is progressing sufficiently when it comes to deciphering appropriate technology use and ensuring advanced and appropriate EOL decision making. Considerable concern exists regarding life-prolonging (futile) treatments being carried out in hospitals (Becker et al., 2007; Teno et al., 2004). With the advancement of technology, has come longer life (Eues, 2007); however, some of these advancements might also create unrealistic expectations resulting in medical interventions being continued past the point of being beneficial; a continuance which may no longer promote quality of life at the EOL (Nelson, 2006).

A few key considerations from this study are the need to encourage all patients to have an advance directive, one that will assist in the decisions and the coordination of care that is appropriate with each patient’s culture, family structure, religion, and financial condition. These advance directives should provide support to the patient and significant others, and with other ways to monitor the effectiveness of pain management and other EOL symptom management treatments or care efforts (Eues, 2007).

Closing Implications

The following section outlines: (a) the importance of identifying goals of care, (b) futile or over-treatment issues in hospitals, (c) the primary and secondary criteria that healthcare professionals should consider when assessing palliative care needs of in-hospital patients, and (d) conclude with final remarks.

Identifying goals of care. Goals of care have been identified as a way of advancing the quality of communication among patients, patient's families, and clinicians in an attempt to make EOL decision-making a goal-oriented process (Kaldjian, Curtis, Shinkunas, & Cannon, 2009). Goals of care are identified as physical, spiritual, social, or other patient-focused goals that develop after an in-depth discussion about the current state of the disease, prognosis, or treatment options, and are recommended to be part of the discussion about EOL care (Kaldjian et al.; Weissman & Meier, 2011).

It is crucial to identify goals of care both with the patient and with all members of the healthcare team (Mahon, 2010). The most noteworthy hindrance in organizing and providing EOL care is inadequate communication (Eues, 2007). Making good decisions regarding EOL care includes “knowing how and when to provide and when to discontinue certain therapies to achieve the goals of care” (Mahon, 2010, para. 73). The lengthening of life by life-supporting technologies is of particular concern if the dying process is uncomfortable (Wilson, 1997). According to Mahon (2009), some of the principles of withdrawing or withholding life-extending therapies include: Identifying the goals of care, never starting a therapy that you would not consider removing at some point, and patient care should always be uninterrupted- meaning that no matter which therapies are started or stopped, the management of patient symptoms should be at the forefront of care.

Futile interventions. The following elaborates on identifying futile treatments with regard to legal and ethical standards. In keeping with the *Joint Statement on Resuscitative Interventions,* policymakers need to determine what futile treatments are and apply these considerations to the use of CPR, with ongoing consideration of legal and ethical advancements (Catholic Health Alliance of Canada [CHAC], 1995). According to the CHAC, excellent healthcare requires open communication, as well as consideration for cultural variation among patients, caregivers, and family members. For the majority of the patients in this study, it was difficult to identify from the charts alone what kind of communication regarding EOL discussions doctors were having with their patients. Patients and their significant others need to be given substantial information regarding the risks and benefits, as well as likely outcomes (if known), of all treatment options. This information will enable the patient and their family members to make informed decisions regarding care. Perhaps a future study could identify the types of EOL discussions occurring between doctors, patients, and family members; a study that would enable the identification of futile versus appropriate care. A close examination of holistic care, encompassing mental, physical and spiritual comfort, is also needed to ensure that each patient receives appropriate EOL care; as a decision to not receive CPR should not impede on other care options.

According to Mills, Davies, and Macrae (1994), EOL care in hospitals is often concentrated on disease processes and attempted recovery. When it has been identified that death is expected, palliative treatment should take the place of curative attempts. Comfort care is not always at the forefront of hospital care; however, dying patients are an everyday occurrence in hospitals. Cardenas-Turanzas et al.’s (2006) study recommended that the “recognition of the determinants of in-hospital death (are) important tools in planning and implementing quality end-of-life services” (p. 72). Action needs to be taken in order to recognize the symptoms of dying earlier in the process. Research remains inconclusive as to whether hydration, oxygenation, and other technologies help or hinder a good death (HPNA, 2008; Mahon, 2010). As was previously stated by Wilson (1997), “it is possible that end-of-life technologies are used by dutiful caregivers in an effort to be actively and visibly doing something” (p. 39). Quality of life during dying is not only about extending life but about how the process of dying proceeds.

As identified in this study, palliative care may be too often underused. There are prevalent differences in the quality of EOL care provided based on location of death within hospitals (Becker et al., 2007). Patients who die in a PCU are much more likely to have their holistic needs met and to avoid futile treatment (Becker et al.). According to Tang et al. (2009), healthcare professionals are reluctant to discuss a transition to palliative care from a curative approach, although comfort care is often preferred by dying individuals. Each surgeon’s sense of obligation to treat and heal was thought by Kelley et al. (2006), to potentially impede the transition to palliative care. Palliative care services should be brought to the forefront as the gold-standard in EOL care.

Bergum (1999) explained that technological overtreatment at the EOL would be something few clinicians would choose for themselves. There are comforting ways in which to care for patients at the EOL without technological overtreatment. Open communication between healthcare professionals and the patient is vital to improving the quality of dying (MacLeod, 2007). Exploring knowledge specific to patient's EOL care preferences will help healthcare professionals meet the actual care needs of the patient, and not automatically take on a curative approach.

More in-depth research is required to assess the use of technology at the EOL. Studies that reveal specific outcomes for the technologies in use need to be completed which focus on comfort care at the EOL, and whether the technologies in use are providing comfort or are simply easier for those providing healthcare to give than not give. This consideration may limit the use of futile aggressive treatment at the EOL.

Assessing the patient's need for palliative care. The following section outlines suggestions from Weissman and Meier (2011) regarding palliative care assessment. They identify primary and secondary criteria for healthcare professionals to consider when deciding on a course of action for particular patients. These criteria are currently not being used in the hospitals where the current study was conducted. With acute care professionals often acting as the gatekeepers to palliative care services (McGrath & Henderson, 2008), the following criteria on when to refer someone to palliative care is an important consideration for healthcare professionals to make. Weissman and Meier offered standards for healthcare professionals to follow regarding palliative care assessment components; including the criteria to follow at the time of the patient's admission and the minimum decisive factors that hospital staff should examine during each subsequent day of the patient's hospital stay. These principles are specialized indicators that can show additional unmet palliative care needs (Weissman & Meier). Weissman and Meier's identified criteria for assessing a patient on a daily basis while in the hospital is cited as follows:

> A potentially life-limiting or life-threatening condition and . . .
>
> Primary Criteria:
>
> -You would not be surprised if the patient died within 12 months or did not live to adulthood

> -Difficult-to-control physical or psychological symptoms
>
> -ICU length of stay greater than or equal to 7 days
>
> -Lack of Goals of Care clarity and documentation
>
> -Disagreements or uncertainty among the patient, staff, and/or family concerning major medical treatment decisions, resuscitation preferences, use of non-oral feeding or hydration
>
> Secondary Criteria
>
> -Awaiting, or deemed ineligible for, solid-organ transplantation
>
> -Patient/family/surrogate emotional, spiritual, or relational distress
>
> -Patient/family/surrogate request for palliative care/hospice services
>
> -Patient is considered a potential candidate, or medical team is considering seeking consultation, for: feeding tube placement, tracheostomy, initiation of renal replacement therapy, ethics concerns, left ventricular assist device or automated implantable cardioverter-defibrillator placement, long term acute care hospital or medical foster home disposition, and (high risk) bone marrow transplantation (p. 19).

It is important for clinicians to remember that palliative care referrals for service are not just for those who are actively dying. These services are important to utilize for those who are having inadequate pain and symptom management, and are not only for those who have cancer.

With only approximately ¼ of decedents who were reviewed for this study having had a palliative care referral, there is much room for improvement. The greater issue is identifying when people will likely die in the near future- but because this cannot be foretold accurately, it is crucial that the most appropriate care be given to each patient at the time, with care needs perhaps varying day by day or hour by hour. Weissman and Meier’s (2011) table to identify at-risk patients in the hospital is an excellent idea, an idea which could be adapted within any hospital to assist in identifying patients at risk of having unmet palliative care needs.

Final remarks. Many possibilities were offered to assist in planning and moving EOL health care in hospital beyond cure-oriented care. A palliative needs assessment tool was outlined which could assist healthcare professionals to decide on an appropriate course of action for a particular patient. Nevertheless, Becker et al. (2007) aptly stated: “It is easier to criticize a treatment retrospectively than to reach a decision while currently caring for a patient” (p. 716). Although many times it is appropriate to aggressively treat a patient near the EOL, this chart review served to highlight potential areas for improvement in quality EOL care.

The withdrawal or withholding of life-sustaining care is a complex situation requiring deep consideration of the patients’ wishes and medical information (Kelley et al., 2006). The current literature has suggested the need for careful evaluation of all aspects of EOL care (Napolskikh et al., 2009), as there may be a lack of accountability for providing excellent EOL care (Paice et al, 2004). Analyses of the nature of hospital use by patients who are dying can provide important information on the planning for, and implementation of, best-practice hospital care for dying patients (Van den Block et al., 2007). The ultimate goal at the EOL should be to promote a comfortable death, with the least amount of suffering, by offering care that meets all of the needs of the patient and their family (Engleberg, 2006; Eues, 2007). This goal is an accomplishable one; by maintaining open communication, reducing futile life-prolonging treatments, and offering sensible options concerning EOL care (Engleberg; Eues). EOL care can be comforting, and “letting die” is not giving up on the patient, but giving them the dignity to die peacefully (Becker et al).

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Appendix A

RESEARCH ETHICS APPROVAL FORM

Date: May 22, 2009

Principal Investigator:	Donna Wilson
Study ID:	Pro00005828
Study Title:	Chart Review of Current End-of-Life Care Needs and Care Practices in Acute Care Hospitals

Expiration Date: May 21, 2010

Thank you for submitting the above study to the Health Research Ethics Board (Health Panel). Your application, along with revisions submitted May 20, 2009, has been reviewed and approved on behalf of the committee.

The Research Ethics Board assessed all matters required by section 50(1)(a) of the Health Information Act and determined that this project is a retrospective chart review for which subject consent would not be reasonable, feasible or practical to obtain. Subject consent for access to identifiable health information is therefore not required for the research described in the ethics application.

The ethics approval is valid until May 21, 2010. A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Capital Health or other local health care institutions for the purposes of the research. Enquiries regarding Capital Health administrative approval, and operational approval for areas impacted by the research, should be directed to the Capital Health Regional Research Administration office, #1800 College Plaza, phone (780) 407-1372.

Sincerely,

Glenn Griener, Ph.D.
Chair, Health Research Ethics Board (Health Panel)

Sincerely,

Glenn Griener,
Associate Chair, Health Research Ethics Board - Panel B

Note: This correspondence includes an electronic signature (validation and approval via an online system).

Appendix B

Chart Review Data Collected and Data Coding

1. Hospital:
   1= Misericordia
   2= Grey Nuns Hospital

2. Personal identifier

3. Day of week of death:
   1= Monday
   2=Tuesday
   3=Wednesday
   4=Thursday
   5=Friday
   6=Saturday
   7=Sunday

4. Month of death:
   1=January
   2=February
   3=March
   4=April
   5=May
   6=June
   7=July
   8=August
   9=September
   10=October
   11=November
   12=December

5. Year of death:
   2008
   2009

6. Time of death:
   Coded on the 24 hour clock

7. Residence:
   1=Urban
   2=Suburban
   3=Rural

8. Age:
   Coded by age in years

9. Sex:
   1=Male
   2=Female

10. Marital status:
    0=No
    1=Yes

11. Main diagnosis:
    1=Cardiovascular
    2=Cancer
    3=Respiratory
    4=Other

12. Admit type
    1=Died in ER
    2=Admitted via ER
    3=Planned inpatient Admission
    4=Transferred from another Hospital

13. Number of diagnoses:
    Coded by the actual number

14. Length of stay:
    Coded by number of days: 0-24 hours= 1 day

15. Living will:
    0=No living will
    1=Written will
    2=Verbal will
    3=Family wish no resuscitation

16. DNR order:
    0=No
    1=Yes

17. Number of days between DNR order and death:
    Coded by number of days

18. Withdrawal of technology:
    0=No
    1=Yes

19. Sudden death:
    0=No
    1=Yes

20. Level of consciousness:
    1=Conscious, Alert
    2=Semi-conscious, Confused
    3=Unconscious, Comatose

21. Expected death:
    0=No
    1=Yes

22. Mobility:
    1=Unassisted walking
    2=Assisted walking
    3=Bedridden

23. ADL requirement:
    1=Self care
    2=assisted with ADL
    3=Total assistance with ADL

24. Pain 3 days prior to death:
    0=No
    1=Yes

25. Pain on day of death:
    0=No
    1=Yes

26. Surgery:
    0=No
    1=Yes

27. ICU/CCU care:
    0=No
    1=Yes

28. Palliative care (unit):
    0=No
    1=Yes

29. Palliative care referral:
    0=No

1=Yes

30. Technologies in use (at death):
    Coded by the number of technologies in use at EOL

31. CPR at end-of-life:
    0=No
    1=Yes

32. CPR prior to end-of-life:
    0=No
    1=Yes

33. CPR during entire stay:
    0=No
    1=Yes

34. Analgesic on day of death:
    0=No
    1=Yes

35. Analgesic 3 days prior to death:
    0=No
    1=Yes

36. Oxygen at death:
    0=No
    1=Yes

37. IV at death:
    0=No
    1=Yes

38. Family present at death:
    0=No
    1=Yes