End-of-life: Insight from administrative data

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Abstract 1

Place of death: Challenges in using administrative data to classify women dying of breast cancer (BC).

The purpose of this study is to develop and test the validity of an algorithm allowing the classification of the decedents as ***were dying of***, ***died of*** and ***died with*** BC, using administrative data, for the study of service delivery to the terminally ill.

Validation was carried out through a chart review of a sample of BC decedents extracted from a tumor registry. The algorithm was then applied to the decedents of a cohort of women with BC. The three groups were compared for their distributions of age and place of death.

The validation showed an excellent crude agreement (0.96). Of the 3334 deaths, 2293 were classified as ***were dying of***, 142 as ***died of***, and 949 as ***died with***. The comparison of age showed that women who ***died with*** were older than women who ***were dying of***. These two groups differed in their distributions of place of death.

Résume 1

Lieu du décès : Les défis rencontrés dans l'utilisation des banques de données administratives pour classifier les femmes *mourantes du* cancer du sein (CS).

L'objectif de cette recherche est de développer et de tester la validité d'un algorithme permettant la classification des décédées comme étant ***mourantes du*** CS, étant ***mortes du*** CS ou étant ***mortes avec*** le CS, en utilisant des banques de données administratives, dans le but d'étudier les services de santés consacrés aux malades terminaux.

La validation a été effectuée en utilisant des dossiers provenant d'un hôpital d'enseignement d'un échantillon de femmes décédées du CS identifiées à partir d'un registre des tumeurs. Après la validation, un group de décédées provenant d'une cohorte déjà existante de femmes diagnostiquées avec le CS, furent classifiées en utilisant l'algorithme. Les trois groupes ont été comparés en ce qui en est de leurs distributions d'âge et de lieu de décès.

La validation a démontré un excellent accord brut (0.96). Des 3334 décès, 2293 ont été classés comme ***mourantes du*** CS, 142 comme ***mortes du*** CS et 949 comme ***mortes avec*** le CS. La comparaison des distributions dâge a montrée que les femmes qui sont ***mortes avec*** le CS étaient plus âgées que celles qui étaient ***mourantes du*** CS. Ces deux groupes avaient des distributions différentes de leur lieu de décès.

Abstract 2.

End-of-life care: Pattern of care received by women dying of breast cancer (BC) in their Last six months of life.

The purpose of this study is to describe the care received by women who ***were dying of*** BC. The population was identified from a cohort of women diagnosed with BC between the years 1992-98, using administrative databases. The last 6 months of life are described using indices of cure/care-oriented models summarized as a care-oriented profile score. A proportional odds ordinal regression model (POORM) was used to test the influence of age on some indices and the profile score.

Some 2293 women were classified as ***were dying of*** BC. The POORM suggests that younger women had a cure-oriented approach (lower odds ratio) consisting of follow-up by specialists at the out-patient clinic, more emergency visits, and frequent re-admissions. Older women were more under the care of general practitioners, had more frequent home visits, and a greater number died at home. However, the overall access to palliative care was limited for all women.

Résume 2

Soins de fin de vie : Les types de soins reçus par les femmes ***mourantes du*** cancer du sein (CS) durant leurs derniers 6 mois de vie.

L'objectif de cette recherche est de décrire les types de soins reçus par les femmes ***mourantes du*** CS. La population a été identifiées à partir d'une cohorte de femmes diagnostiquées du CS durant les années 1992-98, en se servant de banques de données administratives. Les 6 derniers mois de vie sont décrits en utilisant des indices en relation à des models opposant une approche d'abord orientée vers les soins ou d'abord orientée vers la guérison. Une somme résumant le profile du model orienté vers les soins a été crée à partir de ces indices. L'influence de l'âge sur la somme du profile a été testée en utilisant un model régressif ordinal des cotes proportionnelles.

Quelques 2293 femmes étaient ***mourantes du*** CS. Le model régressif ordinal des cotes proportionnelles suggère que les jeunes femmes ont été soignées avec une approche orientée plutôt vers la guérison (un rapport de cotes inférieur) avec suivi par les médecins spécialistes à la clinique externe, des visites a l'urgence et des réadmissions plus fréquentes. Les femmes plus âgées étaient soignées plus souvent par les médecins généralistes, furent visitées plus souvent à la maison, et un plus grand nombre d'entre elles sont décédées à la maison. Cependant, l'accès aux soins palliatifs était limité pour toutes.

PREFACE OF THESIS

Description of Thesis

The structure of the thesis is the manuscript-based thesis, which is supported by the McGill University Faculty of Graduate Studies and Research regulations for the "Guidelines Concerning Thesis Preparation". The format of the manuscript-based thesis requires that the paper should have a cohesive, unitary character and a report of a single program of research.

The thesis contains seven (7) chapters. The first chapter is a short introduction that describes the historico-medico-ethical context justifying this research. The second chapter, general background, contains the literature review and the justification and the rationale for the research questions. The third chapter presents the overall research question for the whole thesis, clarifies specific terminology that will be used in the thesis and outlines the objectives for each of the two subsequent manuscripts. The forth and sixth chapters are the first and second manuscripts written in a format suitable for publication in a scientific journal. The fifth chapter is a small chapter linking the two manuscripts. Each manuscript is written to be an individual document which addresses one or more of the objectives of the research project. There will be necessarily overlap and repetition in the methods of the study. The seventh chapter is a general discussion and conclusion to the research project, summarizing results and discussing implications for further research and health care policies.

Tables and figures with a prefix, which corresponds to the chapters, are included at the end of each chapter. The references are listed at the end of the thesis for all chapters of the thesis. Appendices contain 2 additional graphs.

Authorship

The candidate functioned as principal investigators in all aspect of study design, operationalization of study variables, statistical analysis, interpretation of findings, and writing of the manuscripts. The co-authors of the two manuscripts were member of the Supervisory Committee, except for Dr. Carroll Laurin who was not part of the committee but participated in the first manuscript as the blinded reviewer of the hospital charts for the validation of the algorithm. The candidate would be responsible for the scientific quality of the research, the originality of the ideas, the accuracy of the data and the quality of reporting.

Originality

To the candidate's knowledge, this is the first study with the objective of describing end-of-life care using administrative data. This study contributes to the methodology for the study of end-of-life care and to the knowledge about pattern of care at the end of life.

The first contribution is the methodology to define a population solely composed of terminally ill by introducing the conceptual framework of 'pre-mortality clinical scenarios'. This framework is new as it has never been conceptualized before and as it has never been operationalized for administrative data.

A second contribution concerns the methodology to determine place of death. Most studies on place of death at the population level were unable to define with precision place of death of patients dying outside an institution. By incorporating the physicians billing database to the hospitalization database, it was possible to document place of death even for women dying outside institution, such as small chronic care institutions, hospices, home and even in the emergency room. This is a novel way of ascertaining place of death.

A third contribution is the creation of indices indicative of a care-oriented model at the end of life and of a care-oriented profile score. The profile score allows the evaluation of overall quality of pattern of care at the end of life, while each index points out specific element of the pattern of care that can be individually evaluated and be the object of health care policies.

A forth and last contribution is the knowledge about the pattern of care received by women dying of breast cancer such as distribution of places of death, the specialty of the treating physician, number of home visits, number of admissions, number of emergency room visits, etc. This research also contributes by documenting the influence of age on pattern of care and the emergence of two distinct patterns of care. This research mainly documents the profound lack of end-of-life care resources other than acute care hospital in a period, 1992-1998, before and after the first Senate Committee Report on end-of-life care.

Acknowledgements

This project has been one of my ideas for research in palliative care, dating back when, in 1997, I participated in a research on health services for the terminally ill in Edmonton. This project has become a reality thanks to Dr. Nancy Mayo, my thesis supervisor, who invited me to take advantages of an existing cohort of women with breast cancer. Under her constant and encouraging supervision, I was able to go through the labyrinth of administrative databases and to create meaningful variables for the study of end-of-life care. I recognize in her a talented researcher and teacher who was able to

provide me with guidance and encouragement, and to start to make out of me a more mature researcher.

I would like also to thank the members of the committee, Drs. James Hanley and Neil MacDonald, for their support and suggestions in carrying out this project. Dr. Hanley suggestions regarding creation and analysis of variables were very welcomed. Dr. MacDonald's extensive knowledge in oncology was also most helpful.

I would like to thank also Dr. Carroll Laurin who, graciously, spent hours in reviewing charts for a project about which he was unaware until his work was over. I know he did it out of friendship and this is most appreciated.

This thesis would have not been possible without the constant support of Mrs. Susan Scott who was constantly available to help me find my through S.A.S. programming. I therefore thank her patience and skills she put to help me in this endeavour.

Finally, I thank Dr. Anna Towers, my medical director, for allowing me time free from clinical responsibilities to pursue the completion of my Master Degree during a period when there was a shortage of physician resources.

Chapter 1

Introduction

The practice of medicine at the end of the 19th century was greatly marked by a new approach to diagnosis as exemplified by Osler's intuition to explain the clinical presentation of illnesses with subsequent anatomo-pathologic findings at autopsy. In the 20th century, rapid scientific progress in medicine brought marked improvements to all aspects of care.

The discovery of the microscope revealed the microbes behind certain diseases. The discovery of vaccines and antibiotics soon eradicated the common infectious diseases that previously threatened the life of so many people. Other notable discoveries included the role of insulin in the treatment of diabetic children, the understanding of the role of the ABO groups in blood transfusions for the treatment of the wounded, new anaesthesia techniques allowing more invasive and even safer surgeries suspending impending deaths, effective drugs for the treatment of incurable psychiatric conditions, chemotherapy proven highly effective in childhood lymphomas and leukaemia, dialysis for complete renal failure, and organ transplants when everything has failed.

These and many other advances too numerous to list created in the medical establishment and in the general public a hope to reach immunity from all forms of suffering and death.

In 1971, after man walked on the moon, President Richard Nixon in his State of - the Union Address said: "*I will also ask for an appropriation of an extra $100 million to launch an intensive campaign to find a cure for cancer ... The time has come in America* *when the same kind of concentrated effort that split the atom and took man to the moon should be turned toward conquering this dread disease*" (1). Despite a huge investment of human and financial resources over three decades, the definitive therapeutic approach for most solid malignant tumours still escapes the grasp of scientific medical knowledge. Furthermore, cancer is seen culturally as the most deadly disease even though it comes second after heart disease as cause of death (2).

By the end of the 1970's and the beginning of the 1980's, concerns were raised regarding the care of the dying. The use of aggressive treatments in patients with very limited hope of benefit became the object of intense debate under the rubric of futile treatment (3-8). One of the most challenged procedures has been the use of resuscitation techniques on a dying patient (9). This fierce ethical dispute about "Do-Not-Resuscitate (DNR)" orders resolved itself by taking a common sense view of the adequacy of such orders for patients with a terminal condition (10). However there still are challenges to change clinical practice in this regard (11).

In 1960, Dame Cicely Saunders started to treat dying cancer patients in a different way. Her "person-centred" approach became known as Hospice Care. Her initiative rapidly spread worldwide, especially in English speaking countries, and became known as the Hospice movement. This approach to care centres on the patient as a person and on his/her physical, psychological, financial, social and spiritual needs with the primary goal of improving quality of life rather than prolonging life. This whole-person approach has become the theoretical standard for the care of the terminally ill, but how much this philosophy of care for the terminally ill has penetrated into the medical system still needs to be answered.

Chapter 2

General Background

2.1 Definition of hospice-palliative care

2.1.1 The intuition of Dame Cicely Saunders

As a nurse and as a social worker with terminally ill cancer patients in unrelieved pain, Dame Cicely Saunders had a special encounter. I remember her relating with emotion this turning point in her life in a talk in 1998. She also described it in an article (12): *'I encountered the Polish Jew whose few poignant words proved a powerful catalyst of a new world-wide movement. His statement **"I will be a window in your Home"** gave a challenge to openness of all kinds; **"I want what is in your mind and in your heart"**, set scientific enquiry alongside personal encounter; his very personal journey, into peace, gave the demand for space for freedom of spirit in facing the mystery of death.'* She moved on to study medicine while still volunteering for the care of the terminally ill. Those hours spent alongside the suffering person where she witnessed the benefits of regular dosing of morphine on pain relief, seeded an intuition in her mind that led to the formulation of the concept of 'total pain' that is at the basis of palliative care. She defines total pain as including not only physical symptoms but also mental, social, and spiritual distress (13). This definition has been and still is the driving principle in the provision of palliative care. From her intuition, hospices were opened rapidly and this became the hospice movement, initially in-patient units, but later home-care and day-care programs (14-16).

2.1.2 Terminological clarifications

Before developing the formal definition of hospice-palliative care some indication regarding different terms about hospice care are needed. Hospice refers to the structural organizations, inspired by a specific (hospice) philosophy of care, that provide end-of-life care. A hospice may be a house, building, etc. with all the necessary services where patients come to live 24 hours a day. But it may also refer to other formats such as home care services inspired by the same philosophy. The point in common is that these organisations are self-sustainable. The term hospice care refers to the actual type of care given that should be inspired by hospice philosophy. This type of care can be given anywhere by anybody as long as it corresponds to the type of care that will be provided in a hospice. It is beyond the scope of the present discussion to answer if such a care could be given outside a hospice organisation. Dr. Balfour Mount, when he founded the first 'hospice' in Quebec, created the term palliative care because the term hospice had a negative connotation in the French culture of Quebec. Both terms, hospice-palliative care, are meant to have the same meaning. However, with time both terms diverged so that hospice care is the care provided in hospices and palliative care became to mean the hospice care provided outside a formal hospice organisation, such as in a hospital. With the popularization of the hospice-palliative care, all physicians and nurses were now expected to give a minimal form of hospice-palliative care such as basic pain management, family support, etc., but the care given by specialized teams in palliative care came to be called specialized palliative care.

2.1.3 Reaching a definition f Palliative Care

The World Health Organization (17) Expert committee defined palliative care as the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual distress is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families (17). Therefore, palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death; it offers a support system to help patients live as actively as possible until death; and it offers a support system to help the family cope during the patient's illness and in their own bereavement (17). Clearly, palliative care goes beyond focusing on medical issues. The sole control of pain and other symptoms will fall short of palliative care.

The provision of adequate end-of-life care aims at improving the quality of life of the terminally ill whose life cannot be prolonged significantly. Cohen et al. studied a group of 88 terminally ill cancer patients upon admission to a palliative care unit (18). The subjects answered a questionnaire specifically designed to measure quality of life in people with a life-threatening illness (McGill Quality of Life Questionnaire [MQOL]) within 48 hours of their admission and again 7-8 days later. A significant improvement in quality of life occurred during the week of care in the unit. All dimensions of quality of life, physical, psychological, existential and physical well-being improved significantly. The single item scale (0-10, 0 indicates worse possible and 10, best possible) of the MQOL went from a score of 4.2 ± 2.5 to 6.3 ± 2.3 ($p<0.0001$) (18). This study has the merit of being the first one to document quantitatively improvement in quality of life. Why should palliative care be better than normal care in bringing about an improvement of quality of life?

2.1.4 Present knowledge in end-of-life care

In recent years, the care of the dying has been the object of clinical research. Table 2.1 presents a selection of studies addressing the various aspects of the care of the terminally ill. Pain and symptoms were the first constructs investigated (19-24). All studies agree in describing that patients with advanced cancer and other terminal illnesses as suffering from numerous symptoms such as pain, fatigue, loss of appetite, shortness of breath, anxiety and depression, nausea and vomiting, etc. As an example, more than 80% of the terminally ill cancer patients experience significant pain in their last year of life. These results have been reproduced in many countries (see Table 2.1). Also, the functional status of the terminally ill is starting to be addressed in a more systematic way. Teno et al. (25), in a survey of next of kin of 3,614 decedents, demonstrated that, while patients suffering from diabetes, congestive heart failure, chronic obstructive pulmonary disease and cerebro-vascular disease tended to experience a progressive deterioration of their physical function in a time frame greater than a year, cancer patients experienced a sharp deterioration in their last 6 months of life (see Graph in Appendix I). Kurtz et al. (26) in a prospective cohort of 279 patients found that physical function of cancer patients was associated primarily with the number of symptoms. Furthermore, these investigators found, in the same cohort of patients, that more severe symptoms were associated with worse depression and negative consequences toward quality of life (27). A recent study, already mentioned, demonstrated that palliative care improves quality of life of the terminally ill (18). Grande and his research group (28) have conducted interviews with palliative care patients and family caregivers. Their study clearly suggests that the evaluation of the needs of the patients and the caregivers should be conducted separately as these needs do not necessarily coincide. Transportation, personal care and better communication of information with the health professionals have been identified as areas of unmet need. Lynn et al.(29), in a study of 3357 proxies responding for patients dying of progressive terminal illnesses, demonstrated that family members are distressed by the symptoms experienced by their loved ones at the end of life and they believed that their loved ones preferred comfort-care. Despite the opinions voiced by patients and their families during the time period shortly before death, the study showed that life-sustaining treatments were often administered.

2.1.5 Hospice under scrutiny

One review study, looking at all available studies up to 1988 describing aspects of hospice/palliative care, summarized the difficulties in contrasting hospice and hospital care, and pointed out the lack of sufficient knowledge to arrive at a conclusive judgment about their reciprocal value (30). To the question, "Are hospices different from hospitals?", the author argued that at the beginning of this movement, hospices were different in being better in symptom management, having greater openness about truth telling (talking about death and dying), experiencing a breakdown of barriers of authority, and providing emotional and spiritual support. This difference may have been true in the early time of hospice movement but the gap is closing with improvement in knowledge by physicians about symptom control and a radical change in the culture about truth telling. Hospices that are part of public medical systems are more likely to become more hierarchical and lose the particularity of the 'emotional' care. Despite these difficulties in establishing a clear superiority of hospice care, the different studies confirmed that hospice programs give the personalized care advocated in hospice philosophy.

Another systematic review (31) done a few years after the previously cited review, estimated the effect of specialist palliative care teams on outcomes for cancer patients through a review of 18 studies, including 5 randomized controlled trials. Their conclusions were that conventional care alone is inadequate for patients with advanced cancer and that specialized palliative care teams were superior in many ways. These teams improved satisfaction of the patients and the carers, identified and dealt with patient and family needs, facilitated access to other services, and controlled pain and symptoms better. They could also affect cost by reducing the number of hospital inpatient days and time spent in out-of-home services.

2.2 Demographic issues

It is estimated that, in the next 20 years, the population most likely to require end-of-life care will be persons 65 years of age and older, and this group will increase in size by 69% while the group providing care (persons between 20 and 64 years of age) will increase by only 15% (32). This reason alone justifies a better understanding of the pattern of care at end-of-life, and this becomes even more pressing if the issue of cost of care is raised. The utilization of physician services at the end of life among an elderly population was studied by Latimer (33) using 1992 physician claims data from 3 different health regions (Quebec, British Columbia and the United States Medicare users). This study found that, in the six months before death, the number of evaluations and procedures, was 2-3 times higher than health services billing for a comparable six-month period for elderly survivors. An even sharper increase occurred in the last 30 days of life.

If this pattern continues, then an aging population will put an increasing strain on the financing of the health care system.

2.3 Debates around end-of-life care

The need to improve end-of-life care is not justified on cost issues only; it is also a demand of the public because this is seen as an option to oppose euthanasia. In America, a major research project called "Death in America" was philanthropically funded with the aim of supporting researchers studying how people die in America (34).

In England in 1994, where hospice and palliative care were the most developed, a major political debate on end-of-life care and euthanasia took place. The debate committee of the House of the Lords rejected legalization of euthanasia and reaffirmed the right to adequate care until death (35).

In Canada, a Special Senate Committee was created in 1995 with the responsibility of reviewing the present legal status of euthanasia, physician-assisted suicide and mercy killing as one part and, as the other part, end-of-life care. After hearing many witnesses and reviewing numerous reports from medical and other professional and para-professional associations, and private citizens, their report, entitled *Of life and Death*, made among others, these two recommendations: 1) keep euthanasia and assisted suicide as criminal offences but reduce the penalty associated with them and define in precise terms the concept of 'mercy' that distinguishes these acts from first degree murder; and 2) make palliative care programs a top priority for governments in the restructuring of the health care system (36).

The Netherlands, where euthanasia has been legalized for more than a decade, has come under increasing national and international criticism for both the practice of euthanasia and for the lack of structured palliative care programs. In response to this criticism, on November 28, 2000 the Dutch government mandated 6 academic centres to develop palliative care programs within the subsequent 5 years (37).

This confrontation at the ethical and legal levels between legalization of euthanasia and promotion of good end-of-life care such as palliative care is not just a theoretical debate(38) but has concrete effects at the care level. In countries like Great Britain, Australia and Canada where hospice and palliative care has developed through private funding, governments preferred to support financially this kind of care instead of legalizing euthanasia. In the opinion of Mount (39), and as exemplified by the Netherlands, legalization of euthanasia is likely to delay palliative care service development and could prevent adequate training of physicians in end-of-life care. It still remains to be demonstrated that palliative care and euthanasia can coexist in the same country at the same time. The Netherlands experience will serve as a radical experiment and the decision the government will take after the 5-year trial of academic palliative care will be pivotal. However, in the present situation of increasing demand for care and budget restriction, there is a real risk of lack of financial support for good end-of-life care as euthanasia is less expensive than palliative care. The public may request the liberalization of 'mercy killing' and this may lead physicians to feel that they can make decisions about ending the life of competent terminally ill patients (40). However, there are also voices requesting good end-of-life care as a way to prevent the need for euthanasia (41;42). But what is exactly good end-of-life care? While a theoretical discussion may bring about an ideal model of care, perhaps the best way to answer this question is to look at the existing model of end-of-life care called hospice care.

2.4 Place of death

One feature of good end-of-life is the possibility of remaining at home and dying in relative comfort and dignity. Because of this philosophy, *place of death* has been the most studied aspect of end-of-life care.

2.4.1 Home perceived as a better place to die

It is hypothesized that the proportion of deaths occurring in acute-care institutions shifting to home and palliative care beds indicates better end-of-life care. These studies concentrated mainly on factors associated with home death and referral to hospices or palliative care services (43;44). Home is recognized as a "better" place to die because it corresponds to wishes of the patients, it is perceived as less costly and there is some evidence that specialists attending those patients in acute-care beds lack the training to meet the needs of the dying.

In a prospective cohort study, Townsend et al. showed that 67% of patients dying of cancer, given favourable circumstances, would have preferred to die at home (45). Unfortunately only 27% had this opportunity. Hays et al. found the same wishes in a study performed in a continuing-care, retirement, community in which 62% of patients preferred to die in their residence or nursing facility (46). This wish of dying in a non-medical environment was confirmed by a study of advanced cancer patients in tertiary level, acute-care institutions. As death approached, patients favoured comfort measures over life-extension interventions and wanted to forego resuscitation (20). This change in orientation of care as death approaches has also been documented for patients with congestive heart failure (19) and with chronic obstructive pulmonary disease (47).

The other argument for home as a better place to die is that home may be associated with less aggressive care and subsequently low health care costs. With present-day technology and range of therapeutic options, aggressive care could be offered to a large population of the very ill and the dying. Latimer et al. demonstrated that the cost of care for the last 6 months of life of elderly decedents was greater than a comparative 6-month period for elderly survivors (33). E. J. Emanuel (48) reviewed the different studies on cost saving at end-of-life. He documented cost reductions at the end of life among patients having access to hospices but mainly in the last 30 days. He concluded that, even if the cost reductions were limited, access to proper hospice care should be promoted as it provides a means for patients to exercise their autonomy over end-of-life decisions (48). A population-based study looking at the differences in place of death and hospital utilisation between patients in geriatric long-term care facilities and those living at home, showed that decedents living in geriatric long-term care facilities used less hospital beds, had a lower rate of surgery in their last year of life and were less likely to die in hospital than decedents living at home (49). This and another study (50) showed that the care received by patients depended on where they lived and how the health care system was structured. Therefore, to influence the pattern of care at the end of life, changes in the health care system are needed as single interventions such as advanced directives failed to modify end-of-life care (50).

2.4.2 Studies on place of death

Grande et al. (44) reviewed the literature on place of death up to 1997. Their review is quite complete, covering all articles pertinent to factors associated with death at home among the terminally ill, including cancer patients, and factors associated with referral to home care for cancer patients. The results of their review showed that patients who had informal caregivers (i.e. family members), received home care services, and were young, male and of higher socio-economic status, were more likely to remain home until death. Tzuh Tang et al (43) reviewing the same studies pointed out some revealing nuances. The relationship between socio-economic level and death at home is not linear but rather "V" shaped. The lowest and the highest socio-economic levels are associated with increasing proportion of death at home. Interestingly, the authors pointed out 2 studies that had suggested that the access to hospital resources decreased the number of deaths at home. Higginson and al. demonstrated at the population level that an index of poverty (Underprivileged Area Score) was inversely correlated with death at home for cancer patients (51).

However, Pritchard et al., in 1992 and 1993, studied all Medicare decedents aged 65 years and over within health care regions corresponding to the 5 hospitals participating in the SUPPORT (52). Variation in place of death could not be explained by socio-demographic, clinical characteristics or patient preferences. The major factors were hospital bed availability and use. As the number of hospital beds and their utilisation increased, the proportion of persons dying at home decreased. To a lesser degree, the number and the use of chronic care and hospice beds were associated with a decrease in the proportion of persons dying in acute-care hospital beds. This study strongly suggests that modifications to the health care system, specifically re-allocation of resources to alternative places of death other than hospital beds, must be implemented.

2.4.3 Changing place of death

Studying factors influencing place of death led to the understanding that the strongest factor affecting place of death is the health care system structure and that, within this structure, other factors need to be taken into account mainly to guarantee good care. Can changes be introduced that will lead to a shift in place of death? Indirect evidence suggests that this goal can be reached. Temkin-Greener and Mukamel examined the influence of the Program of All-Inclusive Care (PACE) on place of death (53). They compared the place of death for the enrolees in 12 PACE sites with the place of death for the beneficiaries of Medicare in the host communities. PACE enrolees had twice the probability of dying at home (45%) in comparison to the general population. Participation in the program was associated with a lower proportion of people dying in hospital (21%) than the Medicare beneficiaries (53%). The authors recognized that the two populations were not similar but claimed that the difference in proportion of hospital and home death could not be explained by the disparity in population characteristics. They also evaluated the influence of clinical practice style across PACE sites and found that the practice style explained 26% of the variation in PACE hospital sites. This study, even though not conclusive, supports the possibility of positively influencing place of death.

The weakness of the PACE study is that the quality of care could not be documented. There would be a negative impact on pain and suffering at end-of-life if the number of and the access to acute-care beds was reduced before implementing adequate community services for the terminally ill.

The establishment of a program aiming at shifting the place of death must also be associated with the implementation of optimal standards for end-of-life care. The

Edmonton Regional Palliative Care Program was established in 1995 for the care of cancer patients at end-of-life. This program is comprehensive as it included hospice beds, tertiary level palliative care beds for patients with complex clinical and familio-social problems and consultant teams in palliative care in all major hospitals and in the community. The effect of this comprehensive program was evaluated by following the shift in places of death from 1992 to 1997. In 1992, prior to the introduction of the program, the percentage of people dying in hospital was 86%. In 1997, following the introduction of the program, this percentage had decreased to 49% (54). There was a concomitant increase in home death and hospice death. Changes were also observed in mean length of stay for patients dying in acute care beds. A 70% reduction in the total number of acute-care patient-days attributed to the dying was noticed from 1992 to 1997. This reduction in acute care patient-days was responsible for the overall cost-efficiency of the program (55). Unfortunately the quality of care could not be compared because there were no routine assessments of symptoms, patient and family distress and quality of life performed in the acute care hospitals. The academic excellence of the care providers suggested that patients were receiving better end-of-life care and, with the establishment of the program, more patients could now benefit.

The definitive answer to the effectiveness of an organised palliative care system can only come from well designed randomization trials. To date, few such studies have been performed. Some programs of care were unable to reduce time spent in hospital at the end of life (56-59), while others were successful in reducing the number of in-patient days (60;61). The authors of the latest study suggested that, if time spent at home is to be increased, more resources needed to be allocated for home care, and nursing home beds should be readily available if necessary (56).

2.6 Conclusion

End-of-life care has been and still is attracting the attention of a growing number of researchers. To date, place of death has been the main focus of the investigation. However, there is growing evidence demonstrating the limitation of looking only at the final point (death) in understanding the experience of the dying and the quality of his/her care. The last few months of life could be quite different for two patients dying at home, and not be so different for one patient dying at home and one patient dying in hospital. The existing literature has found great variations in the pattern of care at the end of life defined as days spent at home or in hospital, number of re-admissions, and the continuity of care. Therefore, place of death is only one index for evaluating end-of-life care.

SUPPORT brought a lot of knowledge in end-of-life care but had the disadvantage of being limited to patients treated by tertiary care teaching hospitals. The patterns of care could be quite different across the population. No study has yet tackled these more complex issues.

The care of the dying could be improved upon by the reallocation of financial and human resources. To be able to inform health care reforms, population-based studies on pattern of care are needed. The disease mostly responsible for the death of a patient is a major determinant of pattern of care. The best way to document the illness and follow-up the patient is by a clinical study such as SUPPORT. This type of study is very costly, is difficult (if not impossible) to carry out at the population level, and would require considerable time.

Administrative sources of data are a feasible alternative to clinical studies. Relevant clinical information is included in administrative databases. These databases are usually collected for a whole health care region or specific population (i.e. the elderly). They tend to be reliable enough to be useful for clinical research (62-64). They are readily available at a reasonable price. They could be an excellent source of information for population-based end-of-life studies.

Such studies should go beyond the identification of place of death. They should look at pattern of care. It is only by looking at specific indices of pattern of care that it will be possible to evaluate the magnitude of the influences of palliative care philosophy on the care of the terminally ill. If this philosophy had a positive influence on the organisation of the health care system, the utilisation of the health services, as recorded in administrative databases, by the terminally ill should reflect a more care-oriented model. This study aims at describing the different patterns of care of the terminally ill across a population using administrative data.

Table 1 Clinical studies in End-of-Life Care

CONSTRUCT	SETTING	N	TYPE OF STUDY	DISEASE	STARTING POINT	TIME TO DEATH
Symptoms						
Levenson (19)	5 teaching hospitals	539	prospective cohort	CHF	1st admission during study	6 months
McCarthy (20)	5 teaching hospitals	1,063	prospective cohort	Cancer	1st admission during study	6 months
Ashbury (21)	Community	913	Voluntary survey	Cancer	Within 2 years of treatment	N/A
Rees(22)	PC Units	71	Prospective Cohort	Cancer	5 days before death or discharge	5 days
Addington-Hall (23)	General Hospitals	181	Prospective Cohort	Cancer	At admission	< 1 year
Field (24)	PC Unit	28	Survey	Cancer	One week after Admission	Not specific
Meuser (65)	Pain clinic	593	Prospective cohort	Cancer	Visit to the pain clinic	N/A
Frich (66)	AIDS clinic	95	Prospective cohort	AIDS	Clinic visit	2 years
Sze (67)	PC Unit	218	Prospective cohort	Cancer	At admission	< 3 months
Vainio (68)	PC Units (7)	1840	Survey	Cancer	After diagnosis	< 3 months
Gore(69)	Community	100	Survey	Lung Ca/COPD	Respiratory clinic visit	N/A
Functional Status						
Teno (25)	Family of decedents	3,614	Post-mortem survey	All causes	After death	N/A
Kurtz (26)	Com. Base CC	279	Prospective cohort	Cancer	Around Cancer Treatment	0 to >6 months
Quality of Life						
Cohen (18)	PC Units	194	Prospective cohort	Cancer	At admission	1-32 weeks
Kurtz (27)	Comm. Base CC	150	Prospective cohort	Cancer	Around Cancer Treatment	>6 months
Support needs						
Grande (28)	Community	43 pts 93 Phys.	Interviews Survey	Mostly Cancer	Terminal Phase of Illness	Median 7 months
Davis (70)	Community	56 caregivers	survey	Cancer	After death	N/A

Chapter 3

Objectives and Methodology

3.1 Objectives

The overall aim of this study is to estimate, using administrative data, to what extent the palliative care philosophy has penetrated the care-delivery to a representative group of terminally ill. The specific objectives are: (1) to develop and validate an algorithm to identify the terminally ill (dying of a specific disease) from administrative data; and (2) to estimate the proportion of persons who are dying of breast cancer who experience, in the last 6 months of life, features of care reflecting a palliative care philosophy

3.2 Defining the population

The global aim of studying the pattern of care at the end of life is primordially to identify where and how the structure and financing of the health care system could be altered to improve the care of the terminally ill. According to the SUPPPORT[1] research group, the ideal population to study must meet specific characteristics (71). The people included should have a disease that is common so as to have a significant impact on the health care system: the mortality rate from this disease must be high so as to justify allocation of financial resources for the care patients in their terminal phase; the population should require important decisions to be made during the process of care such that there is a possibility of orienting the patients toward a more care oriented environment; and the disease process should have fairly stable treatment possibilities in

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[1] The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment

the foreseeable future so as not to recommend structures that will be obsolete before they are implemented. Many diseases fulfill these criteria: cancer, end-stage congestive heart failure (CHF), end-stage chronic obstructive pulmonary disease (COPD).

Using clinical data, the SUPPORT group identified that the dying process is highly variable across diseases and across individuals. For example, they found that patients with COPD died within a year after their entry in the study, spent 4 to 6 weeks (15 to 20%) of their last 6 months of life in hospital, experienced moderate to severe dyspnoea and depression, and became increasingly dependent in their activities of daily living (47). However, they found that patients with CHF had a 60% chance of still being alive one year after study entry, spent 2 to 4 weeks in hospital during the last 6 months of life (8 to 18%), experienced severe symptoms only in their last month of life and were relatively independent in activities of daily living up until 3 days before death (19). They also found that not all cancer patients died the same way. Comparing two types of cancers, lung and colon, they were able to demonstrate that persons with lung cancer had a much lower survival probability at one year but that people with colon cancer spent less time in hospital as death approached . However both groups were similar in their physical impairment as both groups experienced a progressive decline in the last 6 months of life culminating with a rapid decline in the last month of life (20). This information suggests that the study of pattern of care for terminally ill needs to focus on specific conditions and that any pattern of care that is estimated on average across many disease populations may not be representative of any one group. This potentially could mislead the clinical community in their conception of program development.

3.3 A population of terminally ill from breast cancer

In view of the current knowledge, we chose breast cancer patients as our population. Breast cancer is the second leading cause of death due to cancer in women (72). There is no cure for breast cancer when it has become disseminated, and physicians are still debating on best end-of-life care for these women. This group of patients fulfill the criteria to be an adequate population for the study of end-of-life care.

We had the opportunity to access a large cohort of women with breast cancer, making the study feasible (63). Obviously, not all women who died in that cohort, died from breast cancer related causes. The group of women dying of breast cancer, terminally ill, needed to be identified. The identification of women dying of breast cancer from among all deaths is the object of the next chapter (4).

3.4 Cure versus care oriented model

The origin of the expression "cure model" is equivocal in the medical literature. This expression was introduced 50 years ago in the context of survival analysis (73-75). This expression was coined to describe subjects that not only survived to a certain point in time but were in fact cured of their illness. This expression was recuperated as a technical term in the last 10 years with the advent of new statistical techniques for survival analysis (76-80).

In the early 1990's, the cure model concept was introduced in the clinical literature in opposition to a prevention model (81). In the cure model, diseases are used as indicators of health status, while the prevention model looks at indicators of wellness, in the presence or not of illnesses. In the nursing literature, the cure model concept started to be opposed to a care model (82). The utilisation of those two terms goes further than in the previous context, as the cure model is associated with physician interventions and roles while the care model is proposed to be the interventions provided by advanced practice nurses (82). A few authors have challenged the adequacy of this point of view (83). While recognizing the greater value of the care model with patients suffering from chronic diseases, defining terms according to type of health care providers may bring tension between different categories of health care professionals. These authors suggest that the cure-care models should be used as two end-points on a continuum of different approaches.

One can see the evolution of the term from a purely statistical concept to a clinico-administrative one. In fact, only in extreme situations do patients need only a cure-oriented model (cardiac arrest) or only a care-oriented model (family support when patient is dying). Between these extremes, patients' needs fluctuate.

We, therefore, define the cure-oriented model as interventions of physicians and nurses offered with the intention of saving life, thereby rejecting death as the natural outcome for a particular patient at a particular point in time. The care-oriented model is defined as medico-nursing interventions aimed at providing comfort and enhancing quality of life; death is seen, in this context, as a foreseeable acceptable outcome. A cure-oriented model is inadequate for the terminally ill (debilitated patient with advanced lung cancer) as much as a care-oriented model is inappropriate for a patient with real potential for cure and a meaningful prolongation of life (leukemia relapse in a child). In fact, as physical function declines sharply in the last 6 months of life and symptoms get worse, clinical practice should reflect a care-oriented model. Indices reflecting this clinical approach will be defined in Chapter (6).

Chapter 4

Article 1

Place of death: Challenges in using administrative data to classify women *dying of* breast cancer.

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Introduction

People of all cultures and all times have attached special meaning to the events of giving birth and of dying. Both events encompass the great mystery of life. In our society, medical research has made possible great advances in the care of the pregnant woman and the newborn baby with the result that, in the developed world, death is a rare event for both in the perinatal period. The same progress has allowed the development of cures for diseases that, not so long ago, lead rapidly to death. Infectious diseases, until the discovery of infectious processes, vaccines and antibiotics, were the most deadly diseases of all times. Now they have been replaced by cancer, end stage cardio-vascular disease, end stage lung disease and Alzheimer's disease, as key contributors to mortality. These diseases have brought new challenges to our society for planning care at the end of life.

In the 1960's, care for the dying was revolutionized by Dame Cecile Saunders (14-16). From her initiative, the hospice movement spread rapidly, first, throughout English speaking countries and then to other countries. Dr. Balfour Mount opened the first hospice in Montreal. Under his initiative the First International Congress on the Care of the Terminally Ill took place in the same city and this congress has been repeated every two years to this day [*14th International Congress on care of the Terminally Ill* will take place in October 2002]. Despite these initiatives, care of the terminally ill remains limited in Canada. In recent years, two Canadian Senate Committees urged for an increase in services and funding for the care of the dying (36;84). Unfortunately, this did not produce appreciable changes in the medical system and no concrete improvement in the care of the dying. Thus, today, the question as to how to organise health services for the terminally ill is still pending.

Thomas J. Smith (85) in his review entitled *Health Service Studies in the Terminally Ill Cancer Patient* concluded that research is very limited and not conclusive. He continues saying "*For some areas of care, such as coordination of care for the dying, the clinical benefit is not clear, but the cost-effectiveness evidence seems compelling enough to provide services*". This study (1998) predated the recent confirmation (2001) that palliative care increases quality of life (18). Also, it is now known that the application of knowledge about pain management results in an 85% success rate in controlling cancer pain (86).

There is little doubt that better coordination of care for the dying is needed. Latimer et al. (33), in a three province study on utilization of physicians' services found that, as death approached, there was an increase in use of health services among decedents relative to use in non-decedents. Of note, in the province of Quebec, in comparison to British Columbia and the United States, there were twice as many procedures carried out at the end of life. Better knowledge of the pattern of care received by the terminally ill is needed for the development of public policies concerning the care of the dying.

Clinical studies are an option to bring light on the care received by the terminally ill. Such studies like SUPPORT[1] found that 79% of the patients who died had a "Do-Not-Resuscitate" (DNR) order written in their chart but half of those orders had been written only in the last 2 days of life (87). SUPPORT also showed that the pattern of care varied across diseases such as chronic obstructive pulmonary disease (47), congestive

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heart failure (19), lung cancer and colon cancer (20). As much as precision and detail are the strengths of these clinical studies, their weakness is selection bias. These studies are performed usually in the best tertiary care hospitals and, therefore, lack generalizability (88). Clinical studies that encompass the whole population would be too costly. In addition, data would need to encompass services offered beyond the walls of the centre and these data are often difficult to systematically obtain. Another option is to make use of the enormous amount of data collected routinely through administrative databases. These databases have already been used for studies focusing on place of death (51;89-92). These databases are available at low cost and allow the study of the whole population. However, these databases do not include sufficient information to affirm directly the cause of death. Researchers are challenged to link these data to vital statistics to obtain, through the death certificate, the cause of death. As death certificates have a high degree of misclassification as to which disease lead to death (93), their use in health services research may introduce error in identifying those in need of end-of-life care. Furthermore, in the study of the terminally ill, the knowledge of cause of death is insufficient to classify them according to the disease responsible for the needed care. The recorded cause of death may not reflect the underlying pathology that was responsible for the care received during the last months of life. Ascertaining of the exact nature of disease causing the terminal state is primordial for the study of pattern of care at the end of life as this pattern varies with different illnesses(19;20;47).

Here, for example, are some possible scenarios of clinical courses of patients dying from cancer. *Scenario 1:* Consider a 60 year old man with disseminated prostate carcinoma with multiple bone and lung metastases. This patient experienced progressive deterioration from full autonomy to complete dependence on his care providers. Death resulted from an expected event associated with a terminal cancer like disseminated intravascular coagulopathy. *Scenario 2*: Consider a 40 year old woman with breast carcinoma after mastectomy and lymph node dissection. The pathology revealed that lymph nodes were positive for the presence of cancerous cell. The treatment involved the use of potent adjuvant chemotherapy that induced severe neutropenia. The patient suffered septic shock and died. *Scenario 3*: Consider an 80-year old man diagnosed with a stage II, non-small cell adenocarcinoma of the lung and treated by radiotherapy alone because the surgery carried unacceptable risks due to general medical condition. He suffered a massive stroke and died few days later in a hospital bed.

These three pre-mortality clinical scenarios represent distinct processes leading to death that are commonly encountered in cancer patients. The experience of the 60-year old man with prostate cancer describes the pre-mortality clinical scenario of a patient who ***was dying of*** cancer. This scenario is characterized by metastatic cancer; progressive deterioration accompanied by increased dependency for personal care, and expected death. The experience of the 40-year old woman with breast cancer represents the pre-mortality clinical scenario of a patient who ***died of*** cancer. This scenario is characterized by a loco-regional disease and unexpected death. This type of patient ***is*** clearly not ***dying of*** cancer. The experience of the 80-year old man with lung cancer describes a third pre-mortality clinical scenario of a patient who ***died with*** cancer. This scenario is characterized by a death caused by a pathology unrelated to the cancer in a patient with loco-regional or disseminated disease. It is thus obvious that those people in need of end-of-life care are those who ***were dying of*** a condition such as cancer. Those persons who

died with cancer but from other disease processes need to be classified according to the specific pre-mortality clinical scenario corresponding to the appropriate medical condition leading to death. Women with breast cancer, who ***died of*** the effects of complications of aggressive therapeutic interventions, should not have died at this stage of their illness. Therefore, they were not in need of palliative care but of acute care. To include them in a study of services on end-of-life care would inflate the proportion of women receiving a cure-oriented model of care.

Using clinical data, it is clear who would fit into these pre-mortality clinical scenarios. But is there a way of ascertaining the pre-mortality clinical scenarios for the population without detailed clinical information? Given the advantage of administrative databases, is it possible to differentiate people who ***were dying of,*** who ***died of*** or who ***died with*** a disease? This question is relevant as the planning of the care of the dying calls for ascertaining not just all people who died but people who need end-of-life care, i.e. those who ***were dying of*** a disease.

The purpose of this study is to validate an algorithm developed to operationalize these three **pre-mortality clinical scenarios** using administrative data. Breast cancer is a good model for developing an algorithm because this cancer is not always fatal and it occurs in women of all ages and in all health states. A secondary objective of this study is to determine the place of death of women dying of breast cancer and to evaluate the influence of the use of this algorithm in modifying the distribution of deaths across place of death.

Method

Description of the base cohort

This study is based on a population of women with breast cancer who were identified using administrative records of physicians' billings, RAMQ[1], and the Quebec hospital discharge database, MedEcho[2], for the years 1992-98. Supplementary data were available for these women for the periods from 1989-91 and 1999. The cohort was created for a study of waiting time for breast cancer surgery in Quebec. The method used to create the waiting-time cohort has been described previously (63). In brief, this cohort included all women of the Province of Quebec who underwent invasive procedures for the diagnosis or treatment of breast cancer with an accompanying diagnostic code indicating breast cancer (International Classification of Diseases, 9th edition (ICD-9) (71) codes 174.0-174.9) on or around the date of the procedure. Owing to this existing data source, we had sufficient material to investigate end-of-life care in a defined population and the necessary coded information to develop an algorithm for ascertaining the pre-mortality clinical scenarios for women with breast cancer who subsequently died.

Identification of deaths

From this cohort, we identified women who died and the date of death. The sources of information used to identify deaths were: hospital discharge status (MedEcho), beneficiary file of the RAMQ, the Quebec Tumour Registry and physician's billing for death certificate (RAMQ). If the only source of information was a record of physician's

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billing for a death certificate, the patient was considered to have died only if no further billings appeared in the RAMQ database.

Description of the Algorithm

Classifying women as loco-regional versus disseminated breast cancer

After identification of deaths, records for women diagnosed concomitantly with other cancer diagnoses were excluded (Figure 4.1, Step 1). The MedEcho database contains for every hospital discharge three fields dedicated to the cancer diagnoses identified during that admission or previously. These fields contain up to 3 topography codes (ICD-9) defining the site of the primary tumor and any metastatic sites. The presence of codes indicating any type of cancer other than breast cancer (ICD-9 codes 140.0-173.9, 175.0-195.9, 200.0-208.9 and 235.0-239.9) in any of the hospitalization records during the years 1989 to1999 lead to the exclusion of these women from the study population. This step was necessary because the topography codes alone could not identify the disseminated cancer responsible for the dying process.

The remaining women were classified either as having loco-regional breast cancer or metastatic breast cancer (Figure 4.1, Step 2). Women were classified as having loco-regional breast cancer if the topography fields included codes for breast cancer with or without lymphatic spread (ICD-9 codes 174.0-174.9 alone or plus 196.0-196.9). Women with breast cancer (ICD-9 codes 174.0-174.9) and codes for metastases (ICD-9 197.0-199.0) are considered to have disseminated disease.

*Classifying women as **were dying of, died of, died with** breast cancer*

Step 3 of Figure 4.1 consisted of classifying women into one of three possible pre-mortality clinical scenarios. Women with disseminated disease who died in hospital and whose hospital discharge record contained a final diagnostic code for a condition encountered in terminal breast cancer patients (Table 4.1) were considered to ***have been dying of*** breast cancer. Table 4.1 includes conditions encountered in end-of-life situations such as septic complications, thrombosis, fractures, gastro-intestinal bleed, delirium and ill-defined medical conditions at the end of life. Diagnoses excluded from this list were related to chronic progressive diseases that by themselves lead to death such as COPD, congestive heart failure, amyotrophic lateral sclerosis, Parkinson's disease, dementia, etc. Women with final diagnoses related to previous pathology are considered to have ***died with*** breast cancer, even though they had a metastatic breast cancer. Cerebro-vascular accidents (CVA) could be related or unrelated to breast cancer. CVA's are rare in women younger than 55 years of age (62) A woman with metastastic cancer, under 55 years of age, with a positive record of a CVA code was classified as ***were dying of*** breast cancer as it is unusual for woman of that age to have a stroke and common for advanced breast cancer women to present coagulopathy. For women older than 55 years of age the CVA was considered the cause of death and the women were classified as to have ***died with*** breast cancer.

Secondly, women with loco-regional breast cancer who died in hospital are considered to have ***died of*** breast cancer if the final diagnosis was breast cancer or a diagnosis compatible with a complication of breast cancer or its treatment (Table 4.2). Table 4.2 differs from Table 4.1 as pneumonia and complications of metastatic disease or terminal stage of the illness are absent in Table 4.2. The removal of pneumonia is based on the presumption that women with limited disease should not die of pneumonia but mainly of sepsis. For all other women with loco-regional disease who died in hospital they were considered to have ***died with*** breast cancer.

Women whose death is not documented in the hospital discharge database and those with metastatic disease were classified as ***were dying of*** breast cancer; women with loco-regional disease were classified as ***died with*** breast cancer.

Validation of the algorithm

The algorithm was validated using the tumour registry of a university affiliated teaching hospital running a multi-disciplinary breast cancer center. The hospital tumour registry contains the same information as the MedEcho file would contain. Using the same years, 1992-98, we extracted records of women, diagnosed with breast cancer, who had died. Again, women with other cancers were excluded from the analysis. The tumour registry contained enough coded information to apply the algorithm described previously. The tumour registry office assures the accuracy of their records by requesting all pathology and cytology reports, surgical protocol, discharge summaries (oncology floor only), radiotherapy treatment reports and hospital death list. The status of patients who remain 'silent' to the system, are traced by sending letters to the treating physician and the patient (or family) for an update on cancer status. One of the authors (BG) carried out the classification of women as ***were dying of***, ***died of*** and ***died with*** breast cancer by applying the algorithm on the tumour registry data. The corresponding hospital charts were retrieved and analyzed by another author (CL) who was unaware of the algorithm and the objectives of this component of the study. His role was to classify, using all clinical information available, these women in the same categories. This author is a trained palliative care physician working in the palliative care service of the same hospital.

Application of the algorithm to the population

After the algorithm was validated, the hospital discharge computerized records of all the deaths occurring in hospital from the base cohort were analyzed using the tested and previously described algorithm. For women who died outside an institution reporting to MedEcho, as mentioned above, the assumption was that, in the presence of metastatic cancer, these women ***were dying of*** breast cancer; in the presence of loco-regional disease, the assumption was that these women ***died with*** breast cancer. Although, for sake of completeness, three groups of women were defined, our study population consisted of only the group of women who ***were dying of*** breast cancer - women in need of palliative care.

Determination of place of death

Figure 4.2 describes the hierarchical steps to assign place of death. For women who died in an institution reporting to MedEcho (these institutions are mainly acute care hospitals), the determination of place of death was done using the institution code. Each institution is coded as being an acute care hospital or chronic care hospital. In most acute care hospitals, some beds are dedicated to chronic care. If a patient dies in one of these beds, the hospital code is of a chronic care institution and not of an acute care hospital. Therefore, women who died in those beds will be considered to have died in chronic care.

The MedEcho database also contains fields for identification of the specialty of the caring services. There is a specific code for palliative care service. Women were considered to have died in palliative care if the palliative care code was mentioned in any service field during the admission leading to death.

For women whose deaths are not reported in MedEcho, the strategy used consisted in dividing women sent to another institution or home according to destination indicated at last discharge before death. The multiple possible codes for destination were collapsed into three categories: chronic care institution, out of province and another acute care institution. Women who were discharged alive from an acute care hospital to chronic care institution or another acute care hospital were considered to have died in the corresponding institution. Women transferred to another province were considered to have a place of death unknown.

Second for the women sent home, we linked the RAMQ database with the MedEcho file and we analyzed the RAMQ file systematically. First, if there were physician billings done from a chronic care institution any times between the last discharge and death, these women were classified as death in chronic care beds. Second, if the last physician billings were done in the emergency room, we kept all billings done in the emergency room for the last 48 hours of woman's life with the exception of the one to fill out a death certificate. To be considered to have died in emergency room, the emergency physician had to have billed for a reanimation or at least two other billings (visits, procedures or acts). One visit was considered insufficient to classify a woman as dying in emergency; in the case of a single billing for a death certificate, the woman was considered to have been dead on arrival to hospital and the death was classified as a home death. Third, if physicians billing were requested from out of province, women were classified as place of death unknown. Fourth, for the remaining group of women, if there were any other physician billings from a physician's private office, from patient's home or from the outpatient clinic, women were classified as home death. Fifth, in the absence of any physicians billing between the last hospital discharge and the death, the women were classified as hospice death. This last classification is justified, first, by the fact that it is very unlikely that women, who were discharged home according to the hospital discharge summary, could remain at home until death without any contact with a physician; and, second, by the fact that there is no specific destination code (MedEcho) for transfers to a stand alone hospice: therefore the code used indicates home as site of destination.

Statistical analysis

The validation of the algorithm using the tumour registry data is described using simple agreement and weighted kappa-coefficient test.

The descriptive analysis first focused on age distribution of the base cohort and, second, compared this distribution with the one reported by vital statistics (72). Then the age distributions of the 3 groups of women corresponding to the 3 pre-mortality clinical scenarios, again with comparison with the distribution reported by vital statistics (72), and their place of death are presented in a descriptive fashion.

Results

Validation of the algorithm using tumor registry data

The tumor registry had records of 84 women who had died between the years 1992-98 and these hospital charts were retrieved. One chart could not be found and 12 women died outside the hospital and were therefore removed from the analysis. Table 4.3 shows the results of the validation in two sections. Section (a) shows that the simple coefficient of agreement is 0.70 and weighted kappa-coefficient is 0.49. The agreement is explained by the high number of women who ***were dying of*** breast cancer (39 according to the tumor registry and 59 according to the chart review). There was also misclassification of the tumor registry: 13 women were classified as ***died of*** and of 6 others as ***died with*** instead of ***were dying of*** as by the chart review. This misclassification was explained by the fact that the tumor registry was not up to date regarding the tumor extension. In 19 women, tumor registry classified these women as having loco-regional disease and the chart review found evidence of disseminated disease. Section (b) presents the new validation after correcting the information in the tumor registry about disease extension. The simple agreement coefficient increased to 0.96 and the weighted kappa-coefficient to 0.87. The discrepancy in classification of the 1 woman classified as ***was dying of*** by tumor registry instead of ***died with*** as by chart review is explained by the physician reviewing the chart considered the death secondary to a surgery unrelated to the cancer while the tumor registry had an ill-defined cause of death. One women was misclassified as ***died of*** by the tumor registry instead of ***died with*** as by chart review; this discrepancy was explained by the fact that the physician reviewing the chart considered the women to have died of an infection unrelated to treatment. The last woman was misclassified as ***died with*** instead of ***was dying of*** because the final diagnosis in the tumor registry was arsenic poisoning while the chart review showed a death secondary to terminal breast cancer.

Description of the base cohort in relation to vital statistics

The initial cohort of breast cancer included 28,100 women. As Figure 4.3 shows, a total of 4,032 women died. For 3,187 women, the death was documented on hospital discharge, for 812 women through the RAMQ beneficiary file, for 32 women by physicians' billing for a death certificate and for one woman through the tumour registry alone. Of this group, 648 women had another type of cancer recorded in the hospital discharge database they were, therefore, excluded.

The age distribution of the remaining 3,384 women is presented in Graph 4.1 along with the age distribution as provided by Canadian vital statistics. As Graph 4.1 shows the greatest proportion of deaths the base cohort was in the age group of 60 years old and older. Deaths among young women seem to be over represented in the base cohort in comparison to vital statistics. But over all, the two distributions, base cohort and vital statistics, could be considered closely similar.

Classification of women of the base cohort in the 3 Pre-Mortality Clinical Scenarios

Of the 3,384 women with breast cancer documented as the sole malignancy, 1,004 women had loco-regional breast cancer and 2,380 women had a disseminated breast cancer (Figure 4.3). Using the algorithm, of the 1,004 women with loco-regional disease, 142 women were classified as ***were died of*** breast cancer and 862 other women as ***died with*** breast cancer. Of the 2,380 women with disseminated disease, 2056 (86.4%) died in an institution. Among this latter group, we classified 88 (4.3%) women as ***died with*** breast cancer. Therefore the end-of-life breast cancer patient group is constituted of 2,292 (2,380-88) women who ***were dying of*** (Figure 4.3).

Graph 4.2 presents the age distribution of death for the pre-mortality clinical scenarios and vital statistics. Women who ***died of*** and ***died with*** were merged as their age distributions were very similar. Through this classification, the age distribution of women who ***were dying of*** breast cancer corresponded more closely to the age distribution of vital statistics. Only the extreme age groups were unbalanced with a slight increase in the proportion for the youngest age group and a decrease in the oldest age group for women who ***were dying of***. Strikingly, the age distribution of women who ***died with*** is shifted to the right.

Place of death

Table 4.4 presents the results of the determination of place of death for the base cohort and for the 3 pre-mortality clinical scenario groups. Overall, only 10.5% of women died at home, 13.4% in palliative care beds, while 65.5% of them in acute-care beds. However, the classification of women by pre-mortality clinical scenario modified these proportions. In comparison to women who ***died with*** breast cancer, the women who ***were dying of*** breast cancer died more rarely at home (6.9%), had more access to a palliative care bed (18.0%), remained in acute-care beds (69.9%) and were almost never transferred to a chronic-care institution (4.1%). As expected, women who ***died with*** breast cancer, therefore from another disease process, were the ones mostly transferred to chronic-care beds (16.7%) in keeping with their older age distribution. Their high rate of home death (20.6%) and higher rate of emergency deaths (7.5%) compared to women who ***were dying of*** (1.3%), suggest more often sudden acute events as causes of death (cardio-vascular disease) for these women. Of note, 12 (8.5%) women who ***died of*** their disease, died in palliative care beds.

Discussion

Validation

The validation of the algorithm after correcting the erroneous information concerning the tumour extension in the tumour registry proved that the algorithm was quite adequate. The maximum estimated error of 4% is not sufficiently large to introduce serious misclassification of women to the appropriate pre-mortality clinical scenarios.

The tumour registry was not up-to-date for the extension of the cancer. This invalidity of the tumour registry was helpful in helping understanding the consequences of this imperfection, if present, in the data of MedEcho. The application of the algorithm on the tumour registry erroneous data, as shown in Table 4.3.a/b, led to an inflated estimate of the number of women classified as ***died of*** (15/71 [21.1%] instead of 2/71 [2.8%]) and as ***died with*** (16/71 [22.5%] instead of 10/71 [14.1%]). In fact, the application of the algorithm to the MedEcho data yielded an estimate of 4.2% for women classified as ***died of*** breast cancer and an estimate of 28% for women as ***died with*** breast cancer. This suggests that MedEcho may also contain errors in the extension of the disease. Supportive of this suspicion is that some of the women, classified as ***died of*** or ***died with,*** died in palliative care beds. Women with loco-regional breast cancer have no reason to be cared for in palliative care beds, except if it is for the palliation of other diseases. (Remember, women with other types of cancer concomitantly have been removed.) It is also rare that patients with non-malignant diseases are cared for in palliative care beds. Most probably, these women who died in palliative care beds but without MedEcho codes indicating metastatic disease, have been misclassified. The magnitude of this misclassification at the population level can be estimated by examining the ratio of acute-care to palliative care deaths in the group ***were dying of***. In Table 4.4, 415 women died in palliative care beds and four (4) times that number died in acute-care beds. Under the assumption that any woman who died in palliative care beds ***was dying of*** breast cancer, the proportional number of misclassified women, in the groups ***died of*** and ***died with***, who died in the acute-care beds would be, according to the 4 to 1 assumption, respectively 48 and 104.

Therefore, for women classified as ***died of*** using the algorithm, we estimate that 60 women (12 in palliative care beds and 48 [4 times 12] in acute-care beds), were misclassified. Similarly, for women classified as ***died with***, we estimate that 130 women (26 in palliative care beds and 104 [4 times 26] in acute-care beds), were misclassified. These estimates suggest a misclassification rate of 5.6% ([60+130]/3384).

These estimates also reduces the size of the group of women classified as ***died of*** to 2.4% (Table 4.4, [142-60]/3384) of the whole cohort. This proportion corresponds to the same proportion found in the tumour registry cohort (Table 4.3b, [2/71]). These same estimates reduces the size of the group of women classified as ***died with*** to 24.2% (Table 4.4, [949-130]/3384) of the whole cohort. This last estimate is higher than the corresponding estimate from the validation process (Table 4.3b, 14.1% [10/71]). The most probable explanation is the absence of women who died outside hospital in the validation cohort. This cohort included only women who died in hospital so as to be able to have the medical chart available for validation purposes. As Table 4.4 shows, a larger proportion of women who ***died with***, in comparison to women who ***were dying of*** breast cancer, died in chronic-care institutions (16.7% versus 4.1%) and at home (20.6% versus

6.9%). Both these higher estimates make clinical sense as it was demonstrated that the group of women who ***died with*** was quite a bit older than women classified as ***were dying of*** breast cancer. Therefore, probably a maximum of 190 women were misclassified out of 3384 women (5.6%). This 5.6% error in classification plus the 4% error from the validation gives and overall approximated error of 9.6% or, said positively, 90.4% of women were accurately classified.

Our validation process did not include women who died outside of an acute care institution. By definition, women with limited breast cancer could not have died of breast cancer at home as we assume that most women in treatment for her cancer will probably reach the hospital before death if a life threatening complication occurs. As stated previously, 2056 (86.4%) women with disseminated disease died in an institution and, of these women, only 88 (4.3%) were classified as ***died with*** breast cancer. If we had access to the final diagnoses for the 334 women who died outside an institution and assuming the same misclassification rate (4.3%), only 12 women would be added to the group of women who ***died with***. This small number will not affect greatly the distribution of place of death and if there was any effect, it would be to reduce the number of non-institutional deaths.

The present algorithm appears therefore to be accurate enough to classify decedents with breast cancer into the appropriate pre-mortality scenarios for the study of end-of-life care. If a higher precision is needed, the place of death could be ascertained, and women, classified as ***died of*** and ***died with***, who died in palliative care, could be reclassified as ***dying of***. However this process leads to a minimal improvement (1.1%).

Women with metastatic cancer, who were dying in acute-care beds, cannot, however, be identified individually, but only their number can be estimated.

Age distributions

The distribution of age at death was affected by applying the algorithm to the base cohort. In comparing Graphs 4.1 and 4.2, women who ***died with*** were older than women who ***were dying of*** breast cancer as strikingly demonstrated by the marked right shift of the age distribution of the former group. By separating these two groups of women, it was possible to demonstrate a better correspondence between the age distribution of women who ***were dying of*** and the age distribution as reported by vital statistics; this is in contrast to the difference in the age distribution for women classified as ***died with*** breast cancer. This finding suggests that it is worthwhile going through this process. Furthermore, for the study of end-of-life care, the mixing of all women who died, having had a diagnosis of breast cancer, would introduce significant errors as 28% (Table 4.4) of women would have died through another disease process, most probably from cardio-vascular diseases, than breast cancer. It is quite probable that these older women would need other health care services than women who ***were dying of*** breast cancer. And reciprocally, women who ***were dying of*** need different health care services that may be proportionally insufficient, especially for specific needs of the younger women because of the falsely lower proportion they would represent in an undistinguished cohort in regard to pre-mortality clinical scenarios.

In fact Graph 4.2 shows that younger women represent a higher percentage and very old women a lower percentage, in the group of women who ***were dying of*** compared to vital statistics. In the original breast cancer cohort, the proportion of older women decreased during the final years of the study for reasons that remained speculative (63). This may explain the lower proportion of oldest women in our group. The higher proportion of younger women could probably be explained by the short period of "follow-up" of the base cohort, only from 1992 to 1999, leading to an overrepresentation of aggressive tumours, those needing less time to cause death. As younger women are known to have a higher proportion of aggressive breast cancer (94;95), they would therefore represent a higher proportion.

Influence on place of death

As Table 4.4 shows, the classification of women into the three pre-mortality clinical scenarios had important influence on the proportion of women who died in each specific place of death. The proportion of women dying at home decreased from an average of 10.5% to 6.9% of women who ***were dying of*** (34% reduction). This means that the majority of women who died at home did not need palliative care services for breast cancer but for other diseases or no such services if they died of a sudden death. It also, more importantly, means that the number of women with terminal breast cancer is much lower than it appears (in fact this is the lowest recorded percentage in the literature, see chapter 5). The application of the algorithm to classify women also had important effect of respective proportions of places of death in regard to acute-care, chronic-care and palliative care beds utilisation. All the shifts in proportion are suggestive of a better identification of women really in need of palliative care services, and of the effect of removing a group of older women not in need of the same type of terminal care.

Conclusions

We have validated an algorithm to classify women as ***were dying of***, ***died of*** or ***died with*** breast cancer using administrative data. The validation process suggested an error of misclassification of 4% and a supplemental error of 5.6% was suspected because of incongruities in place of death when the algorithm had been applied to the base cohort. However, this error size remains small in comparison to the error of 34.2% if the base cohort was taken as such. This algorithm is therefore useful for the study of the terminally ill using administrative data and can be adapted to other cancer types or other disease.

Figure 4.1 Description of the Steps in The Algorithm to classify Women in Three Pre-Mortality Clinical Scenarios

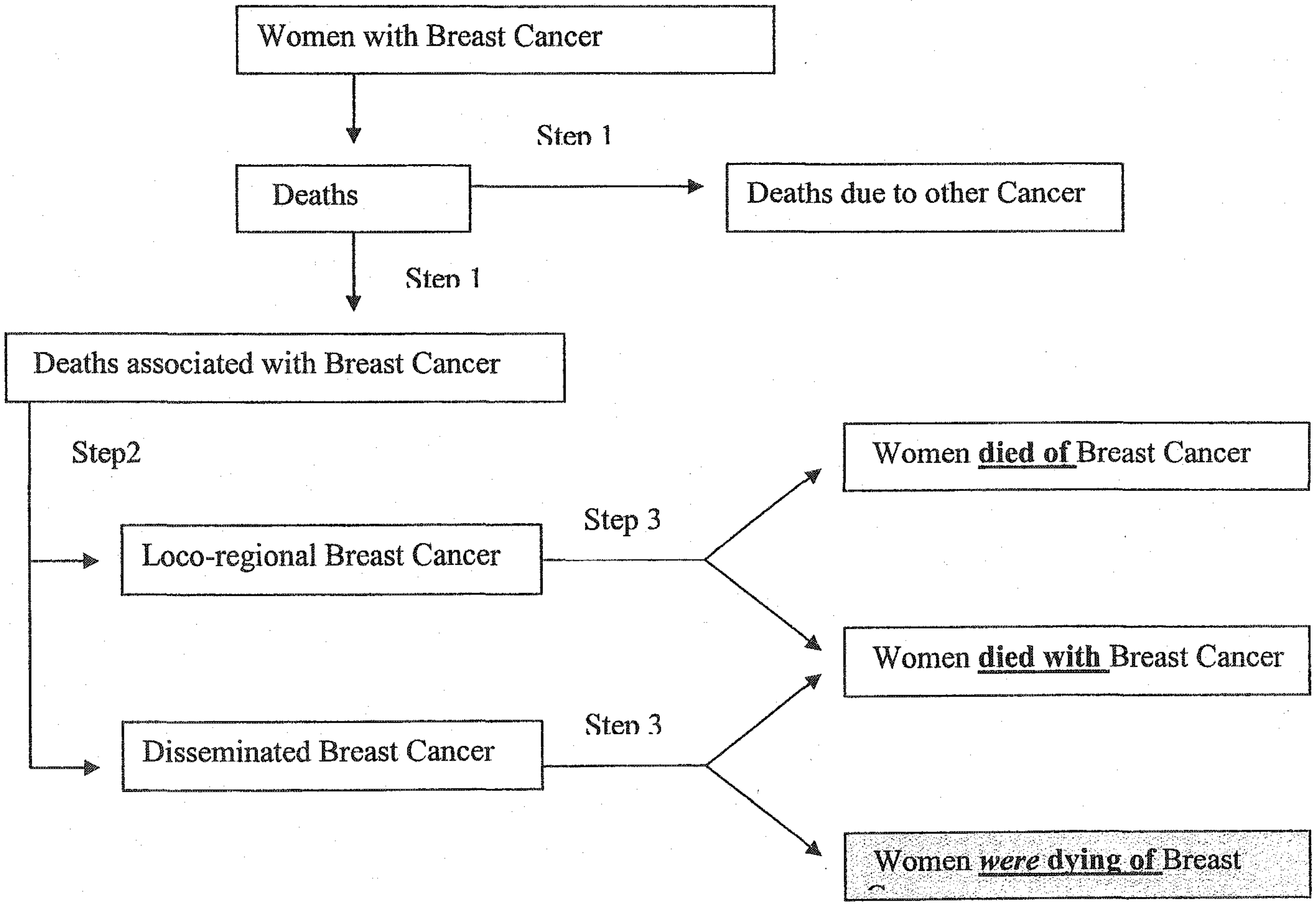

Figure 4.2 Determination of Place of Death

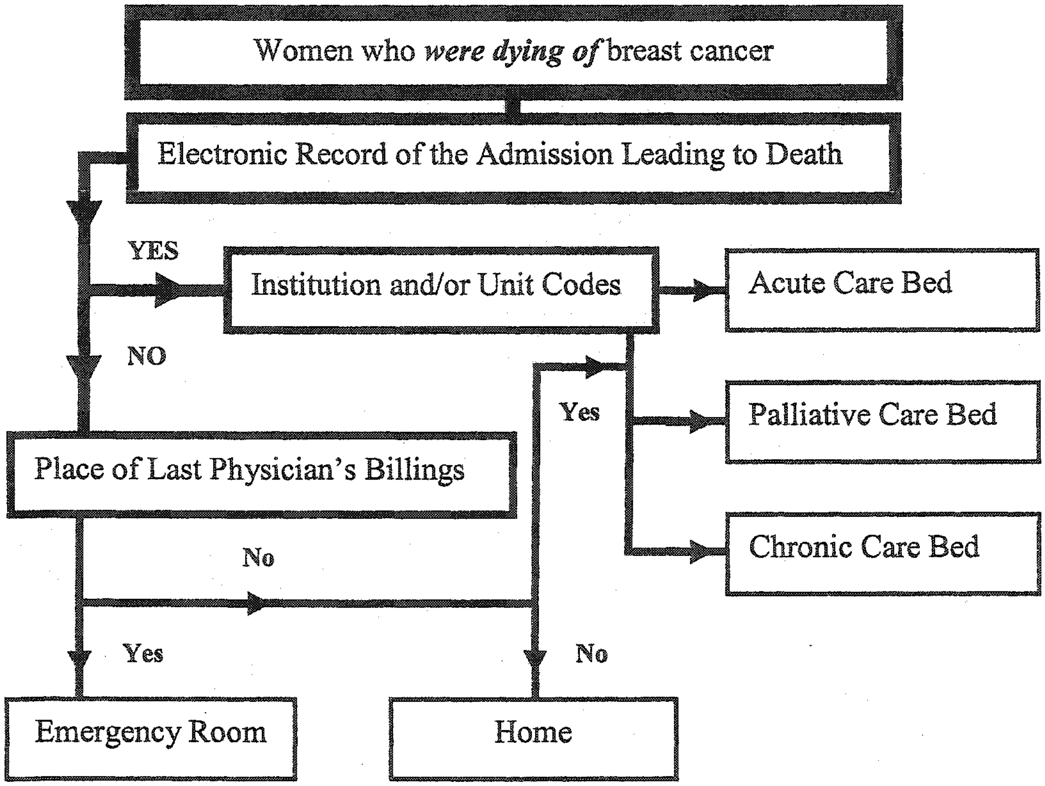

Figure 4.3 Distributions of Women from the Waiting-Time Cohort by Pre-Mortality Clinical Scenarios

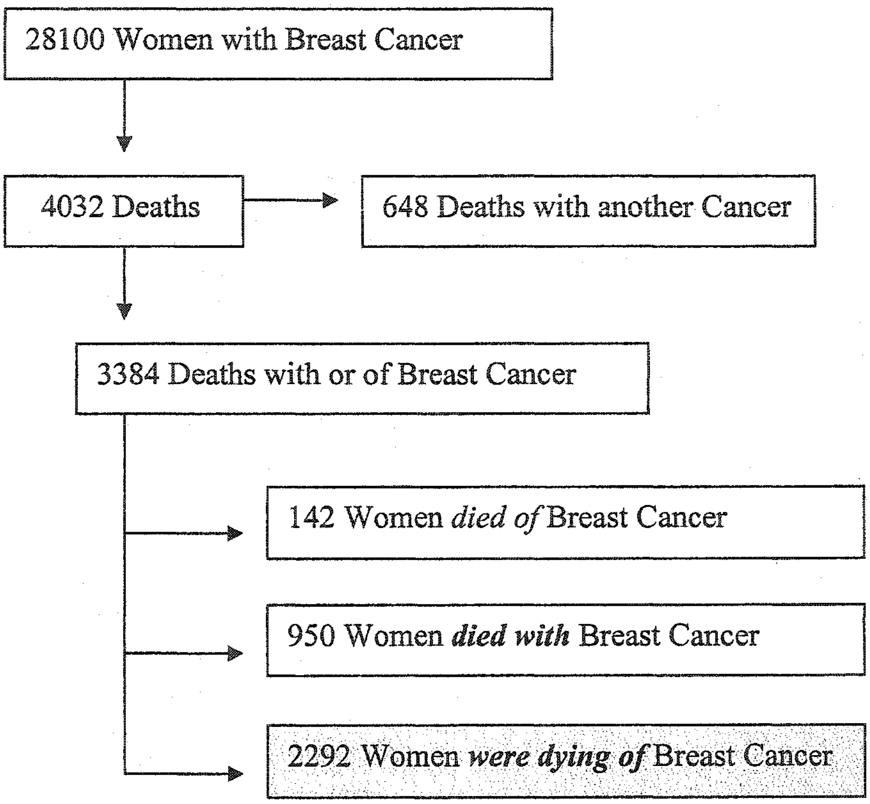

Table 4.1 Diagnostic Coding Used to Classify Women with Metastatic Breast Cancer[1] as ***Dying of***[2]

Final diagnosis included	**ICD-9 Codes**[3]
Any one of the following	
Breast cancer	174.0-174.9, 233.0 611.3, 611.7, V10.3
Metastatic state	197.0-199.9,
Septic complications	
Septicaemia	38.0-38.9
Other bacterial infection	41.0-41.9
Pneumonia	481.0-486.9
Haematological complication	
Anaemia	280.0-280.9
Neutropenia	288.0
Plasma protein disorder	273.1, 273.9
Thrombosis	451.0-453.9
Thrombophlebitis of intracranial venous sinuses	325.0-325.9
Cerebrovascular events (if woman < 55 years old)	431.0-438.9
Electrolytic complications	
Electrolyte disorders	276.0-276.9
Hypercalcemia	275.4
Metastatic complications	
Disease of pericardium	423.0-423.9
Pathological fracture	733.1
Fractures	800.0-829.9
Pleural effusion	511.8, 511.9
Stress induced	
Gastric and duodenal peptic ulcer	531.0-535.9
Gastrointestinal haemorrhage	578.0-578.9
End stage complications	
Non-senile organic brain syndrome	292.0-293.9
Secondary damage to brain	348.1-348.9
Unspecified cardiac arrhythmia	427.9
Unspecified bowel obstruction	560.9
Unspecified renal failure	586.0-586.9
Chronic ulcer of the skin	707.0-707.9
Symptoms	780.0-789.9
Non-specific abnormal findings	790.0-796.9
Ill-defined causes of mortality	799.0-799.9
Specific procedures and aftercare	V50.0-V59.9
Persons in other circumstances	V60.0-V64.9

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[1] Identified using the step 2 of the algorithm (see page 31).

[2] See step 3 of the algorithm in page 31.

[3] ICD-9 codes: International Classification of Diseases, 9th edition (96)

Table 4.2 Diagnostic Coding used to Classify Women with Loco-Regional Breast Cancer[1] as ***Died of***[2]

Final diagnosis included	**ICD-9 Codes**[3]
Any one of the following	
Breast cancer	174.0-174.9, 233.0 611.3, 611.7, V10.3
Lymphatic involvement	196.0-196.9
Septic complications	
Septicaemia	38.0-38.9
Other bacterial infection	41.0-41.9
Haematological complication	
Anaemia	280.0-280.9
Neutropenia	288.0
Plasma protein disorder	273.1, 273.9
Thrombosis	451.0-453.9
Thrombophlebitis of intracranial venous sinuses	325.0-325.9
Cerebrovascular events (if woman < 55 years old)	431.0-438.9
Electrolytic complications	
Electrolyte disorders	276.0-276.9
Hypercalcemia	275.4
Radiation complications	
Radiation pneumonitis	508.0
Fibrosis following radiation	508.1
Stress induced	
Gastric and duodenal peptic ulcer	531.0-535.9
Gastrointestinal haemorrhage	578.0-578.9

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[1] Identified using the step 2 of the algorithm (see page 31).

[2] See step 3 of the algorithm in page 31.

[3] ICD-9 codes: International Classification of Diseases, 9th edition (96)

Table 4.3 Results of the Validation of the Algorithm Using Tumour Registry

a. Before correcting the tumour registry for breast cancer extension

Tumour Registry	Chart Review			
	Dying of	Died of	Died with	All
Dying of	40	0	0	40
Died of	13	1	1	15
Died with	6	0	10	16
All	59	1	11	71

Simple agreement coefficient: 0.70
Weighted kappa coefficient: 0.49

b. After correcting the tumour registry for breast cancer extension*

Tumour Registry	Chart Review			
	Dying of	Died of	Died with	All
Dying of	58	0	1	59
Died of	0	1	1	2
Died with	1	0	9	10
All	59	1	11	71

Simple agreement coefficient: 0.96
Weighted kappa coefficient: 0.87

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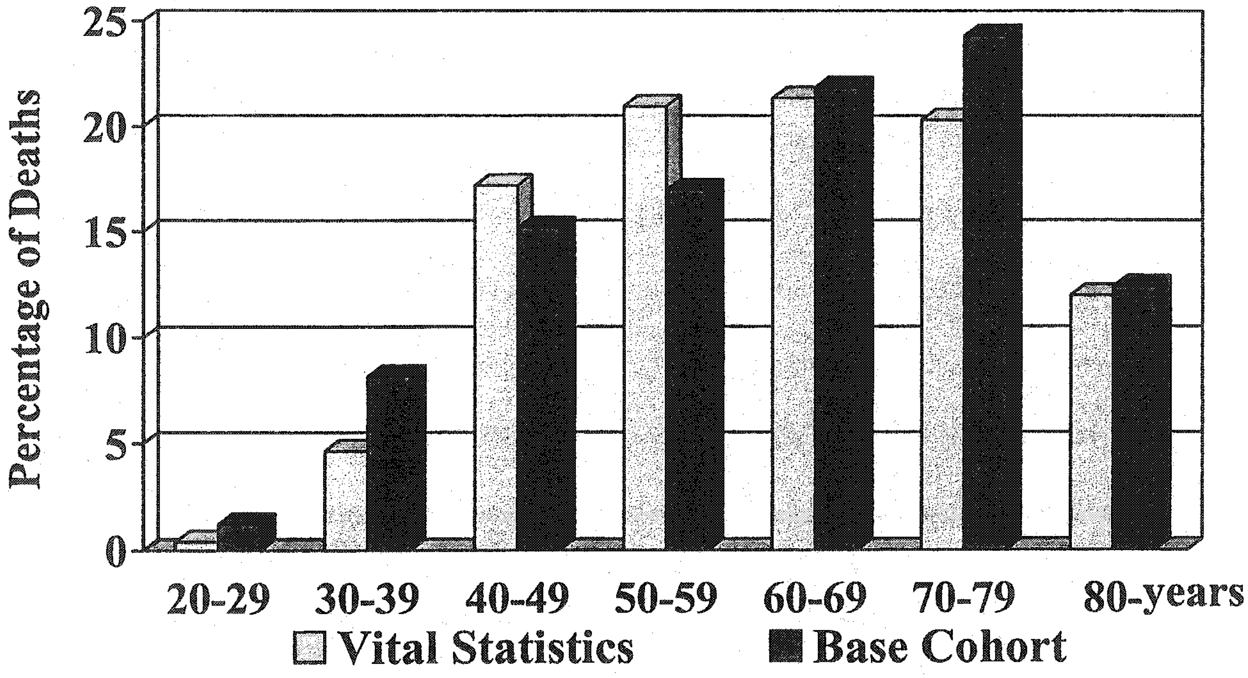
* The tumour registry was not up-to-date for 19 women regarding extent of the disease, all missing the disseminated status of the cancer. By using the stage of the disease from the chart review, 18 (95%) women would have been classified appropriately as shown by table 3b.

Table 4.4 Place of Death According to Pre-Mortality Clinical Scenarios

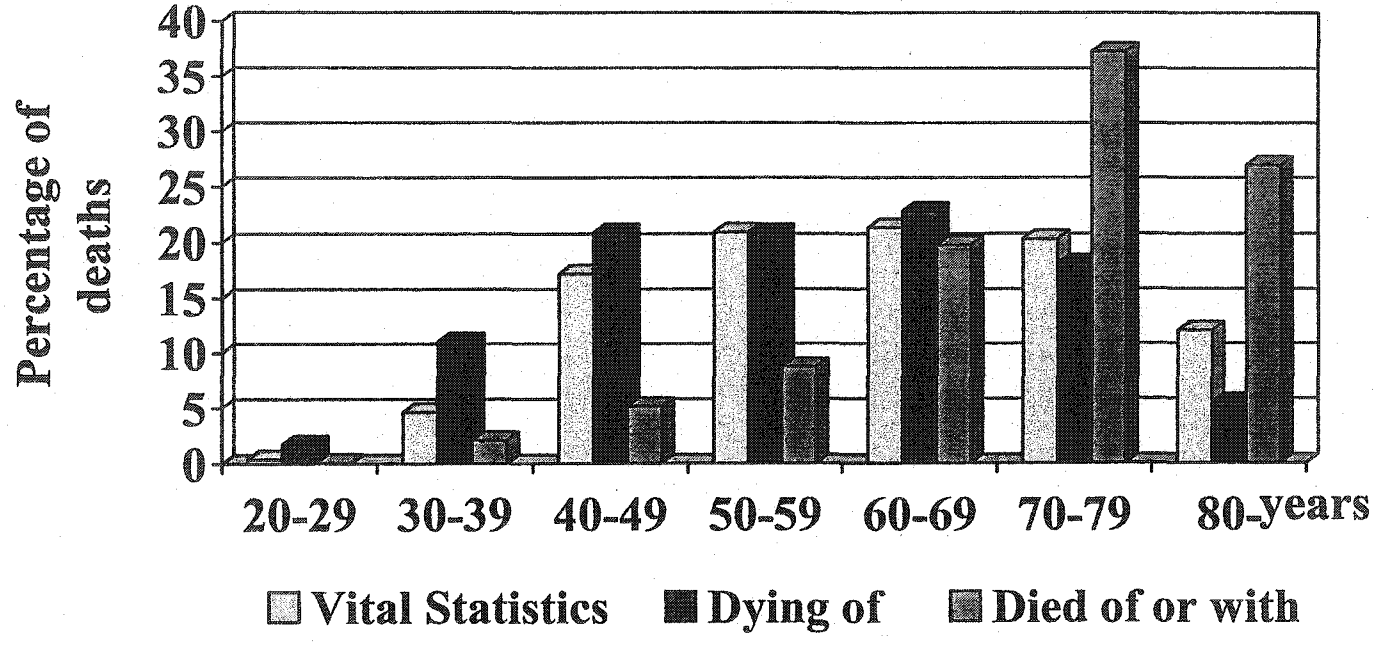
Scenarios	***Dying of***	***Died of***	***Died with***	**All**
Place [number (%)]				
Home	159 (6.9)	0*	195 (20.6)	354 (10.5)
Acute Care Hospital	1595 (69.6)	126 (88.7)	497 (52.4)	2218 (65.5)
Chronic Care Centre	93 (4.1)	4 (2.8)	158 (16.7)	255 (7.5)
Palliative Care Bed	415 (18.0)	12 (8.5)	26 (2.7)	453 (13.4)
Emergency Room	29 (1.3)	0*	71 (7.5)	100 (3.0)
Unknown	2 (0.1)	0*	2 (0.2)	4 (0.1)
Total	2293 (67.8)	142 (4.2)	949 (28.0)	3384 (100.0)

* By definition women who died of breast cancer had to die in an institution

Graph 4.1 Comparing Age Distributions of Breast Cancer Deaths Between Vital Statistics and the Base Cohort



Graph 4.2 Comparing Age Distribution of Deaths Due to Breast Cancer Between Vital Statistics, ***Dying of***, ***Died of*** or ***with***



Chapter 5

Commentaries on place of death

The previous chapter looked at place of death from the angle of the influence of classifying accurately women in to each pre-mortality clinical scenario. However, the distribution of place of death deserves some commentary.

Tang et al. (43) made an extensive review on determinants of place of death for terminal cancer patients. Their review indicated that, on average and in different countries, 18.8% of patients died home; we found a home death rate of only 6.9%, only Japan has reported a rate close to this - 8%. And, indeed, many studies have reported rates above 20%. The low home death rate of the present study, combined with a modest rate of death in palliative care beds, resulted in a hospital death rate at around 70%, placing this study population as one with the highest reported rate for hospital death (43).

What could be some of the reasons for this high rate of hospital death? Factors such as socio-economic level (43;51;97) and family support (43;44;97) have been implicated in explaining variation in the rates of hospital death. System related factors (52;53;97) including clinical policies, such as admission and discharge practices(98), number of beds available, advanced care planning (do-not-resuscitate orders, written wish to be transferred to hospital only if comfort measures failed, etc.), influence the hospital death rate (99). People who have access to home care also are more likely to have a home death (43;89;100;101).

These factors suggest that the evaluation of end-of-life care should go further than an examination of place of death and include other indices defining the type of care received preceding death.

Chapter 6

Article 2

Pattern of Care at the End of Life: What Happens to Women with Breast Cancer

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Introduction

End-of-life care has been the subject of a great deal of debate over the past 50 years. Despite some divergence, a consensus on what constitutes appropriate care is now emerging.

Several landmark policies have had implications for end-of-life care. The use of futile resuscitation procedures was addressed by the development of "Do Not Resuscitate" (DNR) orders and "Advanced Directives" (ADs); these were designed to prevent undue suffering at the end of life and decrease health care costs (102). However, these have not had as great an impact as desired. A major study aiming at increasing the provision of DNR orders through education of physicians and the implementation of other reminders failed to bring about a significant increase in their application (11). Another study unfortunately showed that cost could not be reduced by DNR order and ADs (50). Clearly other avenues are needed to improve end-of-life care.

A strong effort has been made to address the paradigm of futile care such as the use of: i) life-sustaining intervention for patients in vegetative state; ii) resuscitation efforts for the terminally ill; iii) aggressive therapy such as haemodialysis, chemotherapy, or surgery for advanced fatal illnesses without realistic expectation of cure or palliation; iv) less invasive treatments such as antibiotics or intravenous hydration in near-moribund conditions (103). The objective has been and is to educate physicians and the public so as to improve quality of end-of-life care. At this time no published studies have answered the value of this education.

From a different angle, the whole Hospice movement initiated by Dame Cecile Saunders in early 1960 had brought to light the needs of the terminally ill. In response to this awareness, many hospices and palliative care services were opened around the world. The knowledge and the skills concerning the care of the dying have become a field of education and research in its own right. There are now specific textbooks on palliative care: Palliative Care Textbook 9th edition (86), Palliative Care Nursing 1st edition (104) are two examples. Scientific publications are also available such as *Journal of Palliative Care*, *Journal of Pain and Symptom Management*, and *Palliative Medicine*, etc. and conferences devoted to this type of care are an annual event.: the *International Congress on Care of the Terminally Ill* will hold its 14th meeting this year in Montreal. Numerous teaching programs for physicians, nurses, social workers, physiotherapists, and other disciplines have also been opened around the world. This model of care is imposing itself as the optimal approach of care when a person is afflicted with an incurable progressive fatal illness.

After 40 years of progress in the care of the terminally ill, what is the penetration of the philosophy of palliative care into the health care system? Some reports on the value of hospices (30), home care programs (105), specialized palliative care teams in hospitals (31)and regional programs (54) have shown clear benefits to patients and families. Quality of life, the main outcome of the palliative care philosophy, was significantly improved in patients admitted to palliative care units (18).

However, how much has this philosophy of care influenced the care received by ***all*** terminally ill patients? A prospective study using clinical information could answer this question but will be very costly and difficult to carry out at the population level. The utilisation of collected clinical information available in administrative databases (51;89-92) is accessible at a reasonable cost and allows the study of the whole population. As there is no reason that the particular terminal disease process should influence the use of this philosophy, the study of one particular disease could provide some insights applicable to other fatal diseases.

Breast cancer is the second cause of cancer death in women (72). It also affects women of all ages – the young to the very old. (72) When breast cancer has spread beyond lymph nodes, it becomes an irreversible progressive fatal illness. Under a medical approach to care, women, particularly young women, would receive an array of curative treatments and procedures almost up until the end. Older women would likely be treated less aggressively. Hence the medical or curative model would tend to over treat the younger women and to accept more easily the dying process in the older women. Different patterns of care would emerge between women of different age groups.

Under a palliative care philosophy, this age related variation should not exist because the provision of palliative care is based on patient's needs and not on patient's age. Therefore, women dying of breast cancer constitute an ideal group of terminally ill patients to evaluate the influence of palliative care philosophy on the care of the terminally ill as women of all ages are affected by this disease.

The overall aim of this study is to define the magnitude of the influence of the (palliative) care-oriented model on the pattern of care received by women dying of breast cancer in the province of Quebec. The specific objectives are to: (1) define indices a care-oriented approach using the coded information in MedEcho[1] and RAMQ[2] and (2) to estimate the influence of age on the care-oriented profile in the last six months of life.

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The last six months of life has been selected as it is in this period that cancer patients experience their fastest decline in physical function (25).

Method

Population

The population for this study was created from an existing cohort of women with breast cancer who were identified using administrative records of physicians' billing (RAMQ[1]) and the Quebec hospital discharge database (MedEcho[2]) for the years 1992-98. Supplementary data were available for these women for the periods from 1989-91 and 1999. The methodology used to determine this population has been described previously (Chapter 4). In brief, from the cohort created for the study of waiting time for breast cancer surgery in Quebec (63), all women who died were identified. All women who were diagnosed with another cancer (International Classification of Diseases, 9th edition [ICD-9] (96) codes 140.0-173.9, 175.0-195.9, 200.0-208.9 and 235.0-239.9) during any hospitalization were excluded from the study population. For each woman, the extent of the breast cancer (ICD-9 codes 174.0-174.9) was classified as loco-regional (ICD-9 codes 174.0-174.9 alone or plus 196.0-196.9) or metastatic (ICD-9 197.0-199.0) using topography codes of all discharge summaries. The cause of death was identified using the final diagnostic field for the admission leading to death. Using an algorithm defined previously (see Chapter 4), women were classified as ***were dying of***, ***died of*** or ***died with*** breast cancer. The study population for this study consists of all women who had been classified as ***were dying of*** breast cancer.

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[1] Régie de l'Assurance Maladie du Québec

[2] Maintenance et Exploitation des Données pour l'Étude de la Clientèle Hospitalière

Definition of the care and cure oriented models

Place of death

Table 1 describes the indices relevant for the definition of the care-oriented model and the cure-oriented model, the database sources and the data fields used to define each variable. Place of death has been determined previously (Chapter 4) using the MedEcho and RAMQ databases. Patients mainly died in acute care institutions (69.6%) as documented in MedEcho database. Place of death of the other patients was determined using a stepwise approach: a) Medecho database: death in institutions either in chronic care beds or palliative care beds; b) RAMQ database: in chronic care beds (some chronic care institutions do not report to MedEcho database), in hospice (RAMQ silent from last discharge to death suggestive of hospice like institution where physicians are on salary), in emergency rooms and finally, by default, at home.

Characteristics of the hospital admission leading to death

Deaths in acute-care hospitals were further described in term of indices for a care-oriented approach using the characteristics of the admission leading to death (Table 1). Admission was defined as any over-night spent in an acute-care bed. The discharge summary data of the admission (MedEcho) during which the woman died, was analyzed to extract the following information: i) length of stay dichotomized as 7 days or less, or more than 7 days; ii) involvement of a consultant dichotomized as no consultant or at least one consult other than a palliative care specialist; iii) involvement of a palliative care specialist dichotomized as yes or no.

The duration of the hospitalization in days was calculated using only the time during which women were in an acute-care bed meaning that, upon transfer to a palliative care or chronic care bed, the acute admission was considered to have ended. Less than 7 days was chosen as indicative of a care-oriented model because this short of a time period in hospital most likely meant that the majority of the terminal phase was spent at home and hospitalization started because the woman became too ill to be cared for at home and she and/or her family caregivers preferred a transfer to the hospital for the last moments. The medical specialty of each consultant was determined using the specific coded MedEcho fields for consultations. Multiple consultations from different specialists, especially with the absence of a palliative care consultant, most probably indicated that the efforts of medical team were predominantly directed toward finding out the underlying "aetiologies" of the numerous symptoms typically experienced by terminally ill cancer patients (86), instead concentrating on providing comfort care. One consultant, other than palliative care, was sufficient to classify the admission as primarily cure-oriented.

Care in the last 6 months of life

The pattern of institutionalized care received by each woman for the last six months of life was characterized by the number of admissions and the total time spent in acute-care beds (excluding time spent in palliative care or chronic care beds), expressed as the percentage of the 6 month period (182 days). When patients were discharged to chronic care institutions and never re-admitted to acute-care hospitals, they were considered to have died in chronic care. Contiguous admissions were amalgamated and treated as a single admission. The number of admissions for each woman included all admissions but the admission leading to death. The total number of days spent in acute care beds for each woman was calculated by adding the number of days spent in hospital for each admission occurring during the last 6 months of life. For admission that started before the last 6 months period, only the days included in that period were retained. The number of days spent in palliative care beds was calculated for each woman and was excluded from the calculation of percentage of time spent in hospital. A high percentage of time spent in the hospital may suggest failure to redirect the care from a cure-oriented model toward a care-oriented model or it may also reflect the shortage of palliative care beds needed to care for patients unable to stay home.

The number of visits to the emergency room was documented as follows: 1) all care received during consecutive days counted as one visit; 2) an emergency room episode of care resulting in an admission did not constitute a visit. The criteria of "any visit" was chosen as an indicator of cure-oriented because advanced cancer patients with adequate palliative care at home should not need emergency care if an admission is not planned.

The specialties of the physicians assuming care and the place of follow-up are important for the quality of the care. Often hospital-based, specialist, outpatient clinics are far away from home necessitating the dying patient to travel to these locations; often patients have to wait as these clinics are overcrowded due to insufficient number of specialists; the quality of the visits may also be affected by lack of time to address all the concerns of the patients with advanced cancer. Visits to a nearby family physician's office or home visits, apart from being more convenient, are probably more effective in providing symptom control and psychological support.

Therefore, the number of visits to family physicians, medical oncologists, radio-oncologists, medical internists and surgeons, during the periods when the woman was not hospitalized, was used as indicators of the type of care received; these visits were determined using the RAMQ database. One visit was defined as a billing for one visit, in one site, on a particular day and by any physician of a specific specialty. The RAMQ coding system identifies each type of visit and each type of procedure performed by physicians and the place where they were carried out. All visits that occurred in physicians' offices, at home and at CLSC's[1] were classified as community care. The CLSC is classified as an institution but in fact it is located in the community. Visits to the outpatient departments of hospitals were considered hospital-based visits.

We considered that the woman's care was assumed by the family physician if she saw him or her more often than any other specialist or if the proportion of visits to the family physician was at least 20% of all the other specialists together. In case of equal number visits to the family physician and to the specialist, priority was given to the family physician.

Home visits are coded specifically in the RAMQ database. One single visit during the last six months of life was sufficient for this criterion.

Finally, provision of oncology treatment in the last six most should be palliative. There may be some evidence that first line chemotherapy may provide some palliation of the symptoms experienced by women with breast cancer but 2nd line chemotherapy is very doubtful (106). Administrative databases do not record the type of chemotherapy

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[1] Centre Local de Santé Communautaire

administered to patients. There is evidence that patients dying of cancer experience rapid decline in physical function in their last 6 months of life (25). We therefore assumed that chemotherapy given in the last 6 months of life would reflect more a cure-oriented model than a care-oriented model as chemotherapy was probably administered despite physical decline. A physician can bill a special fee using a specific procedure code each time one of his or her patient's receives chemotherapy in a particular day. Therefore, women receiving chemotherapy were easily identified. Only one billing in the RAMQ database for chemotherapy was sufficient for this criterion.

Modeling the influence of age on the care-oriented profile

To test if age had an influence on the access to services suggesting a care-oriented approach, we created an ordinal outcome, called care-oriented profile. The influence of age on this profile and some of its components (number of admissions, number of emergency room visits and number of home visits), was tested using a proportional odds ordinal regression model (107).

The ordinal outcome, the care-oriented profile, was created as an un-weighted sum of the already described indices summarizing aspects of care at the end of life. Place of death was assigned a value according to specific sites: i) home was given a maximum score (5) as it is recognized as, when possible, the best place to receive final care and to die; ii) palliative care units received the second highest score (4); iii) chronic care received a slightly lower score (3); and iv) acute care beds were given a score of 0. However women dying in acute care beds, could receive an additional score (0-3) corresponding to the number of care-oriented indices present during the last admission (see Table 6.1), with a maximum score of 3. To this was added a score for the level of care received during last 6 months of life consisting of 1 point for each of the 7 indices (scores: 0 to 7)(see Table 6.1). The addition of the three scores, place of death, care during the last admission and care during the last 6 months of life, produced a final score (0 to 12) that served to create the ordinal outcome with 13 possible scores for the care-oriented profile.

The care-oriented profile and the above mentioned indices were modeled by age using 5 age groups: 1) less then 40 years old; 2) 40 to 49 years old; 3) 50-59 years old; 4) 60-69 years old, and 5) 70 years of age and older. The age group 50-59 years was used as the reference group.

Statistical analysis

The proportional odds ordinal regression model was used to test the influence of age on the probability of experiencing a care-oriented approach during the last six months of life. Using the 13 possible care-oriented profile scores, an odds ratio for each of the 12 cut-points was calculated and a cumulative proportional odds ratio was calculated for each age group using the 50-59 years old age group as the reference group. For each age group, the consistency of the odds ratios across cut-points was verified by inspection and a test for homogeneity (χ^2) was carried out. The same procedure was used to test the influence of age on the number of admissions (using 5 cut-points), number of emergency room visits (using 4 cut-points) and the number of home visits (using 6 cut-points).

Results

Population

The initial waiting time cohort had 28100 women. From this cohort, 4032 women died of whom 648 suffered from another cancer and were removed from the study population. Of the other 3384 women, 2293 were classified as ***were dying of*** breast cancer. Two of these women were received health care outside of Quebec and were excluded from the final population. The study population, therefore, included 2291 women who ***were dying of*** breast cancer.

Indices of care model

Table 6.2 shows the number and the percentage of women in each age group having each of the indices for a care-oriented approach. The percentage of women with home death over all ages is 6.9%, for women 70 years of age and over the home death rate was 8.3%. The older women died less often in palliative care beds (15.7%), as did the younger women (16.5%). Older women were more likely to die in chronic care beds (10.7%) than younger women (1.7%).

Looking in more detail at the admissions leading to death, 45% of the youngest women had a short final admission compared with 32% of the oldest group of women. Of interest, palliative care consultations were rare in all age groups (9.7%). The pattern of care received by these women in their last 6 months is also presented. More than half of all women had more than one admission but the total time in hospital for 72% of women was less than 20% of the final 6 months of life. As many as 58% of women did not have an emergency room visit (except the ones ending in admissions) but only 16% of women had follow-up through community based physicians, this was even rarer for younger women (8%). There was a tendency, with increasing age, for increasing use of home visits and decreasing use of chemotherapy.

The average number of admissions during the last 6 months of life was 1.8 (SD 1.2), with a median of 2 and a range from 0 to 10. The average number of emergency visits was 0.7 (SD 1.1), with a range from 0 to 11. Figure 6.2 shows the distribution of emergency room visits for the 488 women who had at least one. The average number of home visits was 1.0 (SD 3.3) with a range from 0 to 53; 21.3% of women had at least one home visit and 10 % of women had 3 or more visits.

Factors modifying place of death

Table 6.3 presents the variation in place of death in relation to age of the women and the specialty of the physician caring for them. Table 6.3 shows that general practitioners were the primary physicians in only 22.2% of women (509/2291). Of the women cared for by them, 16.7% died at home while only 4.2% of the women cared for by specialists. However, a smaller proportion of women cared for by generalists died in palliative care beds (13.2%) compared to the women cared for by specialists (19.5%). Table 6.3 also shows that the general practitioners cared for mainly older women (39.3%), while the specialists cared for mainly younger women (36.3%).

Graph6.1 shows the relative percentages of women cared for by general practitioners or by specialists for each place of death. Overall, specialists took care of 77.8% of the women. Similar percentages of women who died in acute-care and chronic-care beds and in the emergency room were cared for by specialists. However, of the women who died home, more than half were under the care of general practitioners

(53.5%). As it can be seen in Table 6.3, as women cared for by general practitioners were proportionally older and those cared for by specialists were younger, relatively older women died at home.

The provision of home support for women dying at home varied depending on the specialty of the physician assuming care at the end of life. Almost all women cared for by a general practitioner had at least one home visit (96.5%), whereas only 18,9% of the women cared primarily by specialists were visited at home. Another important element is also that general practitioners made 96% of the home visits.

The last pattern of interest concerns the distribution of deaths in palliative care beds. The women who died there represented the lowest proportion of women (16.1%) cared for by general practitioners at any place of death.

Modeling of age on care-oriented model and indices

Graph 6.2 gives the number of women for each score of the care-oriented profile. The distribution is quite right-skewed with half of the women with scores of 4 or less and 75% of women with scores 6 or less. This is not surprising in view of low proportion of women having a positive index across all indices (Table 6.2).

Table 6.4 gives the results of the proportional odds ordinal regression model (see appendix II for details). With the age group 50 to 59 years as the reference group, this table shows that women less than 40 years of age (and women between 40 and 49 years) were less likely to experience features of the care-oriented profile (COR: 0.69; 95% CI: 0.54 to 0.90) regardless of the cut-point used to quantify care-oriented end-of-life care. In contrast women 70 years of age and older were more likely to experience a care-oriented approach (COR: 1.85; 95% CI: 1.49 to 2.29). Similarly, younger women were less likely to have home visits but more likely to have a greater number of admissions and a greater number of emergency room visits. For all indices of end-of-life care, the Chi-square tests for the presence of heterogeneity were not significant confirming the homogeneity of odds ratios across all cut-points and age groups. The exception was for the model for number of admissions where the odds of having a greater number of admissions increased at each cut-point for the younger age group.

Discussion

Using administrative data, this study was able to describe for an entire population at the end of life the place of death and the pattern of care as well as the impact of age on end-of-life care.

One striking finding was the very low rate of home deaths. A 6.9% overall home death is the lowest rate documented in the literature and is approached only by a Japanese study with a reported home death rate of 8.2 %.(43). The data offer several explanations for this low rate of home death. The population studied was comprised only of women and one-third of them were younger than 50 years of age. There was also a low involvement of general practitioners in end-of-life care and few home visits. All of these factors have been implicated in the literature as being associated with a lower probability of dying at home (43;51;97;99;100;108). While it was not possible to document other factors such as socio-economic level, presence of family caregivers, or patient's wishes to die at home, a recent study showed that the most important factor contributing to a low rate of home death is the accessibility and utilization of acute care beds - higher accessibility is associated with a lower rate of home death and higher rate of hospital death (52). In our study, 69.6% of women died in acute-care beds.

This study also paints a portrait of Quebec's health care system at the end of life. In particular, there was: i) a low implication of general practitioners in the care of these dying women; ii) a predominance of care by specialists through hospital-based out-patient clinics; iii) a high proportion of women needing to go the emergency room repeatedly to receive care; iv) low access to palliative care beds, specially by general practitioners; v) low access to chronic care beds; and vi) very low proportion of women receiving home visits. All these characteristics are likely to account for the low home death rate and the high hospital death rate encountered in this study.

The second interesting finding is the influence of physician specialty and patient age on the relative proportions of place of death. The general practitioners were more implicated in the care of older women. Women cared for by general practitioners were more likely to die at home and to have a home visit. For example, 95% of women who died at home under the care of a general practitioner had a home visit. However, they were less likely to die in palliative care beds. Younger women were more likely to be followed by specialists and, therefore, they were more likely to die in an acute-care bed, but they had better access to palliative care through these specialists. These two patterns of care, one for youngest and one for the oldest women, were associated with the fact that general practitioners were only marginally involved in the care of the dying women (22.2%), specially the youngest (13.9%). Table 6.2 seems to suggest a dichotomy in the delivery of care with little communication between the specialist and the general practitioner. Also, as the access to palliative care beds was greater for women cared for by specialists, the location of the majority of these beds appears to be in specialized oncology centers not directly accessible to general practitioners. In Quebec there is a lack of community-based palliative care beds accessible to the general practitioners.

Physician knowledge and attitude are fundamental to the type of care received by the dying and therefore the specialty of the treating physician is relevant. For example, the primary challenge in teaching adequate skills needed for the care of the dying has been the proper use of strong analgesics such as morphine. Vainio had nicely shown that the major impediment to the proper use of such drugs in a group of physicians was the lack of knowledge about these drugs. This lack of knowledge was reflected through identification of perceived problems such as lack of efficacy, excessive side effects, and difficulties with follow-up of the patients (109). In a follow-up study, she was able to demonstrate an improvement in physician skills but still 39 % of physicians caring for cancer patients did not acquire the prescription sheets necessary to prescribe opioids to patients living at home(110). Other studies had suggested that oncologists and other specialists very often lack the necessary knowledge and the right attitude to deliver proper end-of-life care (111-114). From another point of view, other studies have suggested that facilities in which the physician's practice could be more influential regarding end-of-life decisions (115;116).

This study is the first one attempting to use administrative data to develop indices, other than place of death, to define a more care-oriented approach in the care of the terminally ill, in our case, with a population of women dying of breast cancer. However most of these indices could be applied with little adjustment to other types of cancer or illnesses.

The indices of the last hospital admission leading to death were created with the objective of distinguishing between terminal admissions, due to insufficient access to palliative care beds, and more cure-oriented medical admissions. The cut point of 7 days was chosen as physicians were likely to recognize the terminal state of the women. With the possibility of imminent death, even if physicians have difficulties in predicting death (117;118), they would be more likely to limit their interventions more towards providing comfort care and family counselling, consulting only the palliative care specialist to assist in symptom control. A shorter length of stay could have been chosen as the definition of terminal admission but, despite the 7-day cut-point, only 38.8% of admissions were classified as terminal. Prolonged terminal admissions with involvement of at least one consultant other than palliative care appeared to be the norm. This is especially true for older women and may reflect that older women failed to cope at home earlier or that discharge to the home was impeded by lack of adequate support in the home for terminal care-giving.

Unfortunately, consultation with specialists in palliative care was especially rare (9.7%). This low rate of palliative care consultation coupled with a comparably low rate of death in a palliative care beds (15.7-16.5%) suggests, probably, not so much a lack of will to refer but rather a scarcity of palliative care specialists working in cancer centers and acute care hospitals. All these findings suggest that, for the period from 1992 to 1999, sufficient resources for end-of-life care were not in place to meet the needs of the women dying of breast cancer.

The indices suggestive of a care-oriented model, during the last 6 months of life, were infrequently present with only a small number of women receiving follow-up by a general practitioner in the community and with home visits. A more cure-oriented model was the norm for this period of time: women were mostly treated by specialists, attended outpatient clinics, and had repeated emergency room attendances, with or without subsequent admissions in acute care beds. This pattern of care was especially the case for the younger women (less than 50 years old) as demonstrated by the results of the ordinal regression models for number of admissions, emergency room visits, and home visits demonstrated. Younger women were also more likely to receive chemotherapy treatments in this time period.

This impression that a care-oriented model was not the norm in the care of younger women was confirmed by the results of the modeling of the care-oriented profile by age. Thus it appears that younger women are less likely to be approached by the treating team with a care-oriented approach whereas older women are more likely to be offered this type of end-of-life care.

It must be remembered that the care-oriented profile is simply a mathematical way of summarizing specific features of care that have been recommended in the literature as being indicative of good end-of-life care. It was constructed for the purposes of facilitating statistical analysis. The validity of this model has not been formally tested. The testing of such of an index is beyond the scope of this paper. However, the hierarchical weighting of the places of death makes clinical sense although the weights are arbitrary.

The indices for the last 6 months of care had either a 0-1 value (follow-up by general practitioner, received chemotherapy, etc.) or a count of the number of admissions, home visits, or emergency room visits. These latter counts were also reduced to any or none thus creating arbitrary cut-point.

The categorization of these indices, although arbitrary, probably made it easier for a death to be credited with a care-oriented approach. Again, the index was used to rank the care received from most suggestive to the least suggestive of the care-oriented approach and the scores were not used to quantify the type of care.

However, by analyzing each of these three indices by the proportional ordinal odds ratio models, it was possible to confirm that the cumulative ordinal odds ratio for each of the three indices (admissions, home visits and emergency room visits) was always in the same direction as the odds ratio for the combined index for the care-oriented profile. This finding suggests that the cut-point used to define "more" for each of the three separate indices did not drive the results for the combined index. With this type of ordinal data, the proportional odds ordinal regression model is an optimal statistical method (107).

The direction of the cumulative odds ratios across age groups suggests that patient-physician relationship regarding treatment decision was influenced by the woman's age in a consistent way. It is impossible to know if this age related disparity in pattern of care was mainly the result of the physician's attitude or patient's request. Surely a mutual influence probably occurred. However, while a more care-oriented approach could be understandable in the care of the very old, the presence of a cure-oriented approach with the younger women cannot be justified by present knowledge regarding breast cancer response to chemotherapy and of the efficacy of other medical interventions for prolonging life. In fact, young women, because of their age and their responsibility to provide care to children, are more likely to experience psychological and existential distress and, therefore, a more care-oriented approach should be offered to them.

It is also worrisome to see that the probability of having multiple admissions, multiple emergency room visits and few, if any, home visits, increased with decreasing age. These younger women dying of breast cancer are probably even more distressed than older women and their pattern of care suggests very frequent visits to the hospital, to be seen by the oncologist and often to receive chemotherapy, to be stabilized by the emergency physicians, or to be hospitalized. They rarely received care by a general practitioner and even more rarely at home.

We recognize the limitations of this study on end-of-life care using administrative data. It is clear that none of the predefined indices guaranty good provision of palliative care. As example a woman could die at home in great distress without proper home care, and another woman could die in an acute surgical unit with good symptom control and great support from the nursing staff. However, we attempted to choose indices which made sense from the present literature. Further work is clearly needed to validate these indices of a care-oriented model and to create others that will capture additional important elements of care such as homecare services, provision of palliative radiotherapy, utilisation of specialized pain control techniques, etc. Nevertheless, we think that our conceptual framework of care-cure oriented model could be useful for further studies of end-of-life care.

Conclusions

The care of the terminally ill is the object of a growing attention. Our study found that, by using administrative data, it was possible to document health services provided, during the last 6 months of life, to a group of women dying of breast cancer. The present study points out that the palliative care philosophy seemed to have had limited influence on the delivery of care to these women as measured by indices compatible with a care-oriented approach at the end of life.

Home is recognized as a desirable place to die but our study found the lowest documented rate in the world (6.9%). Also access to palliative care beds at the end of life remained limited (18.1%). An acute-care bed seemed to be the norm for last place of care (69.6%) and, for the majority of women, the duration of stay spanned many weeks.

For the youngest women, the last 6 months of care is characterized by frequent admissions, follow-up at the hospital by a specialist, frequent visits to outpatient clinics and to the emergency room, and by the use of chemotherapy. Older women were more often followed by general practitioner in the community, died more often at home or in chronic care beds, and rarely received chemotherapy.

The care-oriented approach was not the norm of care at the end of life, especially for younger women. Further studies are needed to confirm these findings with other types of cancer and to clarify the causes of age related differences in the patterns of care.

Table 6.1 Indices of Cure and Care Oriented Models with Corresponding Database Sources and Fields

Indices/Models	**Cure Oriented**	**Care Oriented**	**Database Sources**	**Data Fields**
Place of Death	Acute Care Bed	At Home Palliative/Chronic Care Bed	RAMQ[1] MedEcho[2]	Place of Act Type of Institution
Admission leading to death				
Duration	> 7 Days	≤ 7 Days	MedEcho[2]	Adm./Disc.[3] Dates
Number of consultants	Yes	None	MedEcho[2]	Consultant
Palliative Care consultant	No	Yes	MedEcho[2]	Consultant
Last 6 months of life				
Number of admissions	> 1	1	MedEcho[2]	Discharge
Time spent in hospital	> 20%	≤ 20%	MedEcho[2]	Adm./Disc.[3] Dates
Emergency room visits	>0	0	RAMQ[1]	Place of Act
Home follow-up by	Specialists	Family physicians	RAMQ[1]	Specialty
Place of follow-up	Hospital	Community	RAMQ[1]	Place of Act
Home visits	No	Yes	RAMQ[1]	Specific Act
Chemotherapy	Yes	No	RAMQ[1]	Treatment

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[1] Régie de l'Assurance-maladie du Québec
[2] Maintenance et Exploitation des Données pour l'Etude de la Clientèle Hospitalière
[3] Adm. /Disc. Dates: Admission and Discharge Dates

Table 6.2 Distribution of the Care-Oriented Indices among Women *Were Dying of* Breast Cancer

Indices N (%)		**Age Groups (years)**		
Place of Death	**20-49**	**50-69**	**70 +**	**All**
At Home	50 (6.7%)	64 (6.4%)	45 (8.3%)	159 (6.9%)
Palliative Care Beds	124 (16.5%)	206 (20.6%)	85 (15.7%)	415 (18.1%)
Chronic Care Beds	13 (1.7%)	22 (2.2%)	58 (10.7%)	93 (4.1%)
Acute Care Beds	556 (74.1%)	690 (69.0%)	349 (64.5%)	1595 (69.6%)
Emergency Room	7 (0.9%)	16 (1.6%)	10 (1.8 %)	29 (1.3%)
Admission Leading to Death [1]				
Short Admission (≤ 7 Days)	251 (45.1%)	254 (36.8%)	112 (32.1%)	617 (38.7%)
No Consultant	261 (46.9%)	292 (42.3%)	146 (41.8%)	699 (43.8%)
Palliative Care consultant	57 (10.3%)	67 (9.7%)	31 (8.9%)	155 (9.7%)
Last 6 Months of Life				
Only One Admission[2]	295 (39.3%)	470 (46.9%)	300 (55.5%)	1065 (46.5%)
Time Spent in Hospital (≤ 20%)	543 (72.4%)	727 (72.7%)	383 (70.8%)	1655 (72.2%)
No Emergency Room Visit	402 (53.6%)	586 (58.6%)	345 (63.8%)	1333 (58.2%)
Follow-up by General Practitioner	104 (13.9%)	205 (20.5%)	200 (37.0%)	406 (17.7%)
Follow-up In the Community	63 (8.4%)	150 (20.1%)	162 (29.9%)	375 (16.4%)
At Least One Home Care Visit	103 (13.7%)	201 (20.1%)	184 (34.0%)	488 (21.3%)
Did Not Receive Chemotherapy	360 (48.0%)	596 (59.6%)	475 (87.8%)	1431 (62.5%)
Number of Women	**750 (32.7%)**	**1000 (43.6%)**	**541 (23.6%)**	**2291 (100%)**

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[1] Are included 1595 women who died in acute care beds

[2] The admission leading to death is not included

Table 6.3 Distribution of Places of Death by Physician Specialty and by Women's Age

a. For women cared for by general practitioners

Place of Death	**20-49**[1]	**50-69**[1]	**70 +**[1]	**All**
Acute-Care	67 (64.4)	125 (60.0)	134 (67)	326 (64.0)
Home	21 (20.2)	33 (16.1)	31 (15.5)	85 (16.7)
Palliative Care	13 (12.5)	37 (18.0)	17 (8.5)	67 (13.2)
Chronic Care	1 (1.0)	5 (2.4)	18 (9.0)	24 (4.7)
Emergency Room	2 (1.9)	5 (2.4)	0 (0)	7 (1.4)
Total	**104 (20.4)**[2]	**205 (40.3)**[2]	**200 (39.3)**[2]	**509**[3]

b. For women cared for by specialists

Place of Death	**20-49**[1]	**50-69**[1]	**70 +**[1]	**All**
Acute-Care	489 (75.7)	565 (71.1)	215 (63.0)	1269 (71.2)
Home	29 (4.5)	31 (3.9)	14 (4.1)	74 (4.2)
Palliative Care	111 (17.2)	169 (21.3)	68 (19.9)	348 (19.5)
Chronic Care	12 (1.9)	17 (2.1)	40 (11.7)	69 (3.9)
Emergency Room	5 (0.8)	13 (1.6)	4 (1.2)	23 (1.3)
Total	**646 (36.3)**[2]	**795 (44.6)**[2]	**341 (19.1)**[2]	**1782**[3]

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[1] Number and percentage

[2] Row percentage

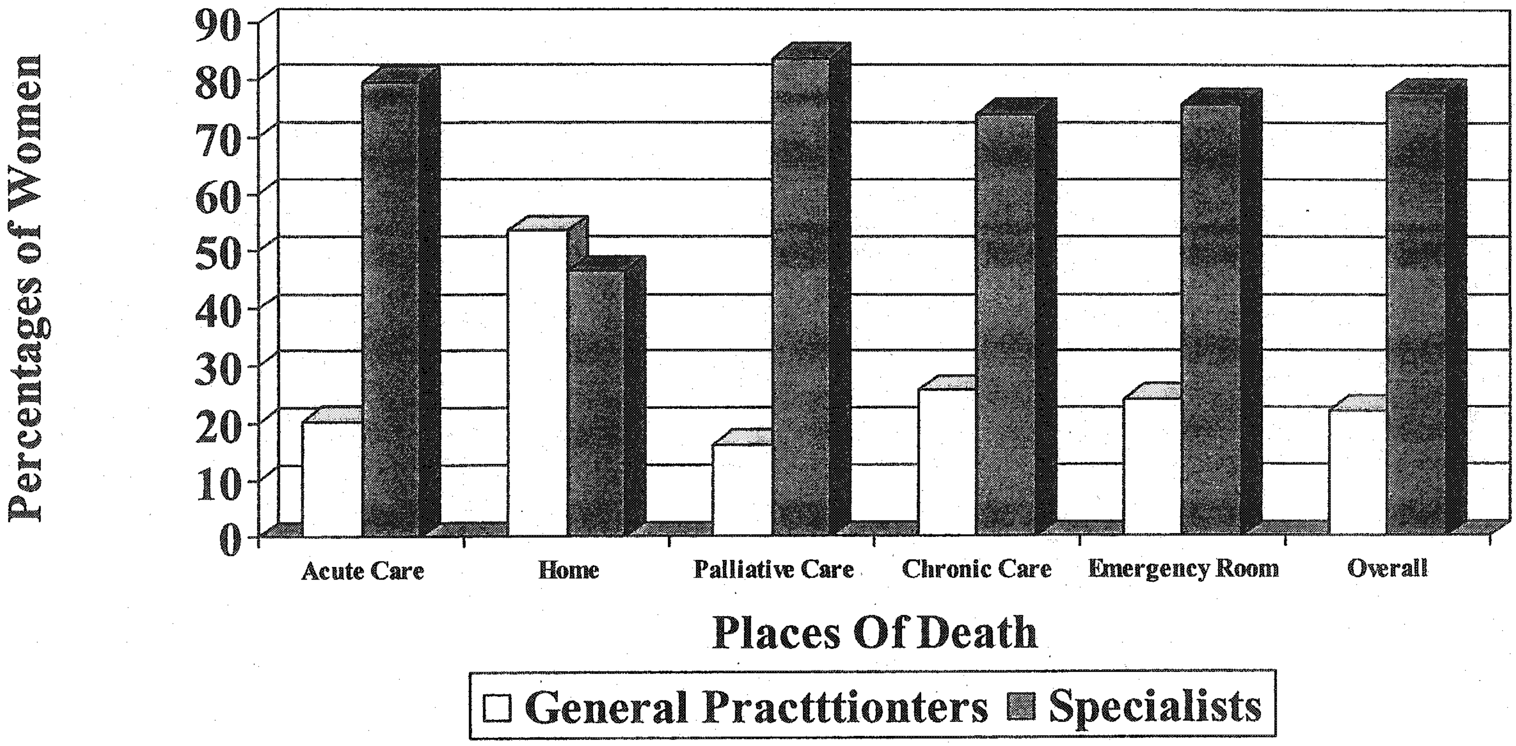
[3] Total of 2291, the 2 women transferred out of province were removed. General practitioners cared for 509 out of 2291 (22.2%)

Table 6.4 Cumulative Proportion Odds Ratio for Having a More Care-Oriented Approach at the End-of-Life

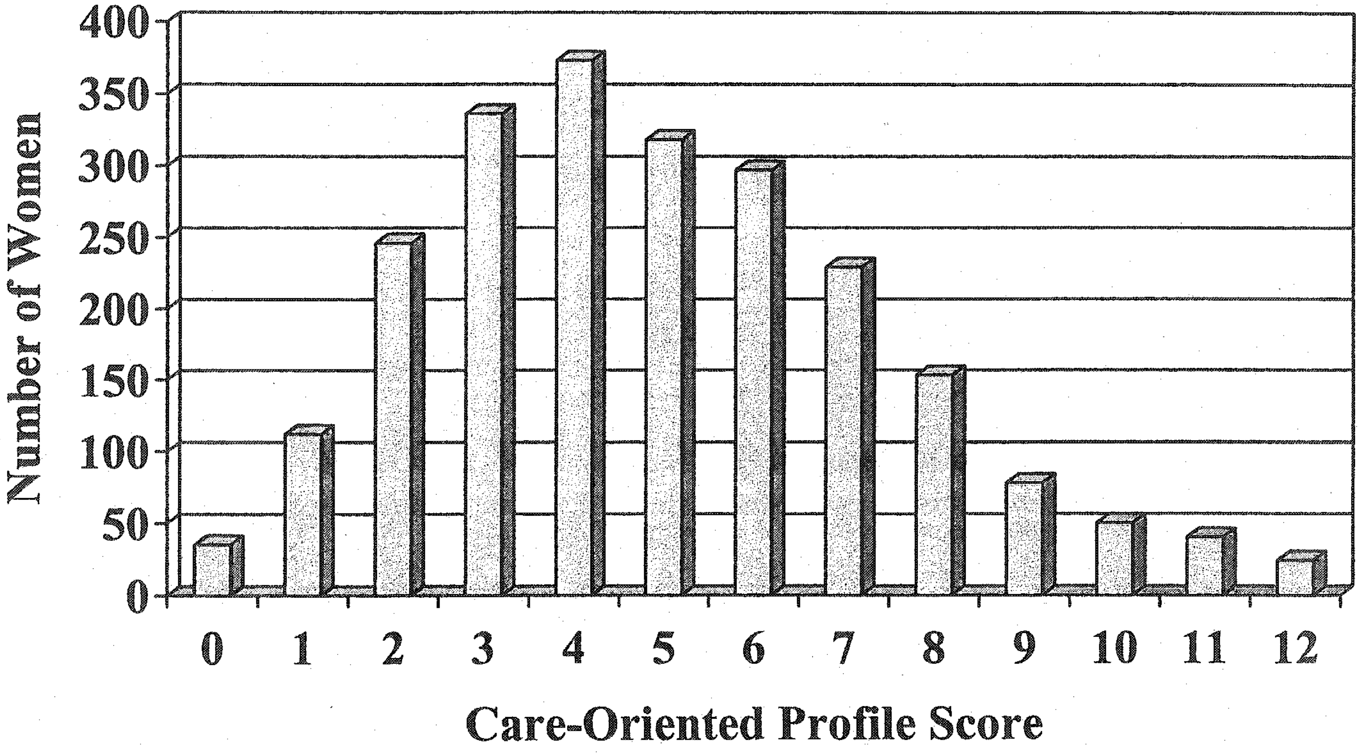
Age group (years)	*Care-Oriented Profile COR*[1]	*Number of Admissions COR*[2]	*Number of Home Visits COR*[3]	*Number of Emergency Visits COR*[4]
	Cut-points: 12	Cut-points: 5	Cut-points: 6	Cut-points: 4
Less than 40	0.69 (0.54, 0.90)	1.57 (1.21, 2.05)	0.55 (0.36, 0.83)	1.21 (0.91, 1.60)
40 to 49	0.70 (0.56, 0.88)	1.67 (0.93, 1.48)	0.69 (0.49, 0.97)	1.35 (1.05, 1.73)
50 to 59[5]	1	1	1	1
60 to 69	1.00 (0.80, 1.24)	0.74 (0.59, 0.93)	1.01 (0.75, 1.38)	1.03 (0.81, 1.32)
70 and older	1.85 (1.49, 2.29)	0.51 (0.40, 0.64)	2.05 (1.54, 2.72)	0.84 (0.66, 1,08)

1. Cumulative proportional odds ratio for having a more care oriented profile, χ^2 test for homogeneity: p=0.68
2. Cumulative proportional odds ratio for having a greater number of admissions, χ^2 test for homogeneity: p<0.0001
3. Cumulative proportional odds ratio for having a greater number of home visits, χ^2 test for homogeneity: p=0.85
4. Cumulative proportional odds ratio for having a greater number of emergency room visits, χ^2 test for homogeneity: p=0.96
5. The age group 50-59 is the reference group

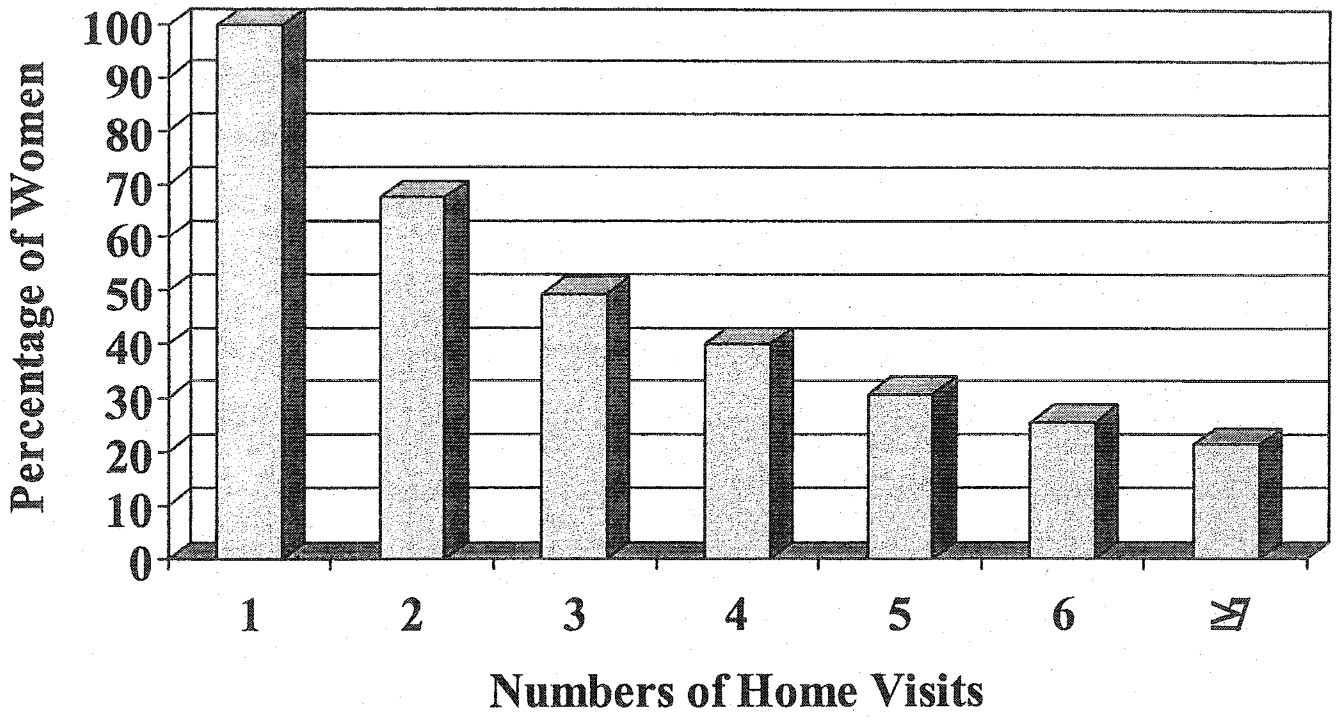
Graph 6.1 Percentages of Women by Physician Specialty for each Place of Death



Graph 6.2 Number of Women for each Score of the Care-Oriented Profile



Graph 6.3 Numbers of Home Visits for 488 Women with at Least One Visit during the Last 6 Months of Life



Chapter 7

Discussion

This health service study of the dying addressed the care of terminally ill women with breast cancer. The main motivation behind this study was the actual and predicted rise in the need for health care resources allocated for the care of the dying. In addition, there have been two requests by a Canadian Senate Committee for the promotion of adequate palliative care for all Canadians and, at the same time, the rejection of euthanasia as an adequate answer to the needs of the terminally ill. There has already been 40 years of experience with hospice and palliative care worldwide but there remains limited knowledge, at a population level, of the actual care received by the dying. The needs of the dying are relatively well known - pain and other symptom control, psychological and spiritual support, and family assistance - and the knowledge and skills to meet these needs are available through trained personnel and are being taught to new generations of health professionals. The knowledge about the existing health care delivery system to the terminally ill is, however, still lacking. This knowledge is needed to evaluate the adequacy of the care provided and to suggest, if needed, necessary improvements. This study aimed to evaluate the penetration of the hospice/palliative care philosophy in the care of the terminally ill by documenting the patterns of care received by women dying of breast cancer.

This study used an existing cohort of women with breast cancer assembled to evaluate waiting time for surgery (63). The information available for this cohort consisted of administrative data from two population level data bases: hospital discharge summaries and physicians billings. This type of information brought specific challenges for the study of the terminally ill. Nowhere in these databases is there a specific coding for the palliative state of the patient or the palliative intent of the intervention. Furthermore, even if the documentation of the women who died was relatively simple, the actual cause of death, and even less the process of death, could not be documented directly. While most studies of the process of death and dying have used death certificates to identify causes of death, this source of information lacks precision and easily leads to misclassification. Therefore, another way to ascertain cause of death using administrative data had to be created in such a way as to be suitable for the study of health services delivery for the terminally ill.

In the study of the terminally ill, ascertaining the cause of death is insufficient because, more than the actual cause of death, it is necessary to ascertain the underlying pathology responsible for the progressive decline in health and physical function. The necessity of establishing the underlying cause of death has been emphasized in this thesis. Each terminal disease such as congestive heart failure, chronic obstructive pulmonary disease, lung cancer, colon cancer, and others, has its specific symptom and complication burden which is responsible for specific needs, and these needs seem to drive the patient interactions with the medical system. As the study population was women with breast cancer, there was an imperative to correctly classify women who were truly dying of their disease apart from women who died from other causes, whether or not they still had evidence of active breast cancer.

This imperative led to the development of the pre-mortality clinical scenarios. This conceptual framework had two advantages. First, it could be described as clinical stories corresponding to actual experiences health professionals encounter in the care of patients who died. A patient who ***died with*** a cancer can easily be characterized by a patient who had been diagnosed with a cancer in the past and is presently in remission but who nevertheless died suddenly of a myocardial infarction. Everybody will agree that the patient did not die of cancer and furthermore did not experience the physical decline that precedes death due to cancer. A patient who ***was dying of*** a cancer is the one experiencing progressive decline in the months preceding death. Even if the final event is pneumonia, this patient ***was dying of*** cancer. And finally, a patient may have died secondary to complications of cancer treatment, for example, from a post-operative haemorrhage. This patient has ***died of*** cancer but was not *dying of* cancer. These three scenarios, clinically important, could also be operationalized by an algorithm applicable to administrative data.

The conceptualisation of the algorithm to classify women as ***was dying of*** a disease is a new step in the study of the terminally ill as it has not been described or used before. Mostly, as we have seen, studies of the dying have been clinical, without any difficulty in ascertaining who is terminally ill. When administrative data have been used, only death certificates were used to ascertain the terminally ill. As mentioned above, one cannot identify persons who are terminally ill through death certificates but only arrive at an approximation. The algorithm, using a combination of all available clinical information about the cancer diagnosis and progression, and the cause of death, was successful in ascertaining the terminally ill. After correcting for the weaknesses of the tumour registry, the validation of the algorithm with tumour registry data and through chart review revealed a concordance of 96% between the two sources of documentation. The algorithm for administrative data is therefore very close to clinical reality. These results are clearly important as the algorithm could easily be modified to fit other cancers or diseases. The availability of this approach will facilitate the study of the terminally ill and health care services at the end of life.

The application of the algorithm to a population of women who died in a context of breast cancer led to a classification of women into the three pre-mortality clinical scenarios. Indirect information of the validity of the algorithm, such as age distribution for each of the three groups, substantiated its clinical strength. While women who ***were dying of*** breast cancer had a similar age distribution as the one reported by vital statistics, women who ***died with*** breast cancer were clearly older suggesting death due to cardio-vascular events? It could be supposed that these women who ***died with*** breast cancer had needs different from the others. It was beyond the scope of this study to go into much detail regarding possible differences in need between these two groups of women; we did look at the effect of misclassification on place of death. The choice of this specific outcome was driven by the large body of studies on place of death. The results of the comparison of place of death were quite striking even if the great majority of women from both groups died in acute care beds. As expected, women who ***were dying of*** breast cancer died more often in palliative care beds than women who ***died with*** cancer. Merging the two groups would result in a misleading low rate of death in palliative care beds, exaggerating the lack of availability of these beds (a lack that nevertheless remains great). The rates are reversed for the chronic care beds and this also makes clinical sense. Finally, home and emergency room death rates were quite a bit higher in the group of women who ***died with***, suggesting acute events more than better care as the cause of the differences. All these differences between the two groups of women strongly suggest that the concept of 'pre-mortality clinical scenarios' and its operationalization for administrative data is valid and relevant for the study of the terminally ill.

Having appropriately classified women dying of breast cancer, it was possible to study the last 6 months of life of these women with the objective of documenting the magnitude of the influence of palliative care philosophy on the delivery of care in a homogenous population of terminally ill. To do so it was necessary to develop proxy indices of "good end-of-life care". The conceptual framework used to do so arose from the concept of a cure-care duality model. The term 'cure model' was introduced 50 years ago as a statistical concept in the survival analysis and was meant to take into account the fact that the patients did not only survive for a certain time but could also be cured of the underlying disease. More recently, it was contrasted with a care model. In this context, the cure model comprised interventions mainly to save life and it is representative of the physician's attitude; the care model reflected a caring attitude toward the patient and it is representative of the nurse role. In our study, the cure-care opposition did not correspond to caregiver roles but to the intention behind the care rendered to the patient. As we have described previously, in the cure model, the caregivers' objectives are about saving the lives at "all costs" with the denial of death as a foreseeable and acceptable event. This attitude is likely to lead to multiple interventions and hospitalizations. Under the care model the primary objective is to provide comfort and maximize autonomy and death is seen as a natural outcome of the patient's medical condition. It is conceivable that the care model should lead to minimal medical interventions, just enough to improve comfort. From this conceptual framework, the indices of a care approach were created.

One of the elements of the care approach was the place of death, which was easily identifiable when the women died in a MedEcho[1] reporting institution. It was more challenging if this was not the case. The linkage of the RAMQ[2] and the MedEcho[1] data allowed the identification of deaths that occurred in chronic care beds, in the emergency room, in hospices and at home. This was an advantage over other studies on place of death. Each place of death was given an ordinal score to be integrated in the care oriented profile score. Place of death was not an outcome by itself, but it is important to note that the results of the present study revealed a remarkably low home death rate and a high acute-care bed death rate. Implications of these findings will be discussed below.

Because so many women died in acute care beds, the last admission leading to death became very important for the analysis of the quality of end-of-life care. Three aspects of this admission were documented: length of stay, palliative care involvement and medical approach through number of consultations to other specialists. It is acceptable to say that a prolonged admission (more than one week), absence of palliative care consultation with the presence of consultations to other

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[1] Maintenance et Exploitation des Données pour l'Étude de la Clientèle Hospitalière
[2] Régie de l'Assurance Maladie du Québec

medical or surgical specialties are suggestive of a cure-oriented approach, while the opposite suggests a care-oriented approach. To die in an acute care bed, when a patient has experienced progressive deterioration and has understood that the illness is incurable remains unacceptable. However, in the absence of a sufficient number of palliative care beds, a short, 'quiet' and terminal admission to an acute care bed could be more tolerable for the patient and the family than an isolated and unsupported death at home. This was the reasoning behind the allocation of some positive value to the last admission for the care-oriented profile score.

The last 6 months of care was described according to the number of admissions, percentage of days spent in hospital during the last 6 months, the number of emergency room visits, specialty of the treating physician, place of follow-up (community versus hospital based), home visits and chemotherapy. The care-oriented approach was defined by no admission except for the one leading to death, less than 20% of days spent in hospital, no emergency room visits, being followed-up by a general practitioner in the community, having received at least one home visit and having not received chemotherapy. Each of these situations was given a score of one toward the care-oriented profile score.

Our results are suggestive of limited access to proper end-of-life care. The distribution of place of death alone, especially the low home death rate, is indicative of a lack of resources for end-of-life care. Our home death rate is the lowest documented in the world literature. As variation in reported rates of home death is attributed to the health care system (number of acute care beds available), our results suggest that, in the breast cancer population, dying women are occupying expensive acute oncology beds probably because of an insufficient number of palliative care beds. Other reasons for the high rate of acute-care bed death emerged from our study. These women were mostly followed up by specialists at the hospital and received aggressive care (chemotherapy) even with quite advanced disease. Specialists do not make home visits, so could not offer medical support at home. It is easily conceivable that admission was the only option when women were no longer able to go to out-patient clinics to receive care. This fact seems to be confirmed by the higher home death rate for women followed up by general practitioners who did home visits. Also, while younger women were most likely to die in hospital, older women tended to have a more prolonged admission before death, suggesting again that specialists had no choice but to admit these women into acute care beds. Our study did not look at other factors such as cultural preferences for place of death (Did this group of women prefer not to die home?), home arrangements (Are the housing of these women appropriate for a dying person?), financial issues, etc.

The care-oriented profile scores which summarized all the indices of type of care were predominately low - but does this really represent 'lower' quality care? To validate the profile would require a prospective study which would have been beyond the scope of this research project but which points to future areas where research would help shed light on end-of-life care.

However, the variability of the profile score with age, which was not likely to be solely a random effect, suggests that the score had some grasp on reality. This age related variability is compatible with the expectation that older women would receive a more care-oriented approach. The majority of women had a score of 5 or less. The low score could be attained by dying at home, in palliative care or chronic care beds but without accruing other positive aspects of the care-oriented profile. Keeping in mind also that most women died in acute care beds, of whom half had a couple of indices for the last admission, and that a high percentage of them had spent less than 20% of days in hospital during their last 6 months, it could be easily imagined that these women had very few indices toward a care-oriented model during the last 6 months.

It is therefore safe to say that the majority of women had a pattern of care consisting of frequent visits to the out-patient clinics and to the emergency room, multiple admissions, prolonged terminal admission without access to palliative care, and ready administration of chemotherapy. It is difficult to conceive that this pattern of care was oriented at providing comfort. This pattern suggests primarily a medical model comparable to all other women not dying of breast cancer. This pattern of care does not leave space for interventions aiming at planning end-of-life care, symptom control, psychological support, etc. as it is not the norm when a physician is treating the cancer of a patient. The contrary can be said of the few who had a care-oriented profile score of at least 9. To reach such a score, the patient had to have died in a more caring milieu (home, palliative care or chronic care beds), to have been followed up by a general practitioner in the community with occasional home visit, and to have no emergency room attendances and not be repeatedly hospitalized. This pattern of care is possible only if the symptoms are under control or are absent (which is unlikely, given our knowledge about the high percentage of cancer patients who experience symptoms at the end of life (86)), if patients psychological and existential needs are relatively well met or inexistent (difficult to conceive of someone dying) and if there was proper care planning to support the family caregivers. Therefore, the care-oriented profile score represents an optimal approach and could be a useful method of monitoring the changes in clinical practice related to the care of the terminally ill or the effect of policy changes with respect to health care services for the dying.

From the results of this study, recommendations can be made to improve the provision of health care services to the terminally ill. First, there needs to be greater access to palliative care beds. Bruera et al. had shown that the care of the terminally ill can be successfully transferred from acute care beds to palliative care beds (54) and this shift in place of death is associated with a cost saving in the acute care institution which largely compensates for the cost of specialized palliative care beds (55).

Beyond the cost issue is evidence that units of care with a specific vocation for symptom control and end-of-life care are a better place to die. The creation of these units would require adequate staffing with health professionals with specific training in palliative care so to prevent these units from becoming a 'dump' for the dying.

Second, the implication of the general practitioner should be valued. This would require better communication and collaboration with the cancer specialists and a transfer of care when cancer patients experience deterioration due to progression of the disease. Of course, if community-based physicians have no access to palliative care beds, the dying will not be better served.

Specific studies also need to be carried out to identify the causes for the very low home death rate, specifically looking at ways to promote home visits and better provision of home care. The creation of positions for palliative care consultants along with a program for specific training in palliative care should be put forward to support the care provided by the general practitioners and the cancer specialists in dealing with situations of great distress and the difficult symptoms experienced by advanced cancer patients.

Despite the inherent limitations of administrative databases for the study of end-of-life care (119), this study was able to provide insights into the pattern of care at the end-of-life. An algorithm for the classification of women in relation to the process leading to death in pre-mortality clinical scenarios was developed and validated successfully. By integrating place of death with other indices of care, a care-oriented profile score corresponding to a cure-care model framework was shown to correspond to clinical reality. Both, the algorithm and the profile score can be used for the study of other cancers or illnesses, or for the monitoring of the effects on pattern of care of the establishment of new health care services for the terminally ill.

Reference List

(1) Nixon RM. State of the Union Address. 22-1-1971.

(2) Statistics Canada. Mortality- summery list of causes, 1997. Shelf tables. Wilkins R, editor. 1999. Ottawa, Canada.

(3) Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: its meaning and ethical implications. Ann Intern Med 1990; 112(12):949-954.

(4) Spielman B. Collective decisions about medical futility. J Law, Med Ethics 1994; 22(2):152-160.

(5) Kapp MB. Futile medical treatment: a review of the ethical arguments and legal holdings. J Gen Intern Med 1994; 9(3):170-177.

(6) Lamb D. Therapy Abatement, Autonomy and Futility: Ethical Decisions at the Edge of Life. Brookfield, Vermont: Avebury, 1995.

(7) Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: response to critiques. Ann Intern Med 1996; 125(8):669-674.

(8) Kopelman LM. Medical futility. In: Chadwick, Ruth, editors. Encyclopedia of Applied Ethics. San Diego, California: Academic Press, 1998: 185-196.

(9) van Delden JJM. Do-not-resuscitate decisions. In: Chadwick, Ruth, editors. Encyclopedia of Applied Ethics. San Diego, California: Academic Press, 1998: 839-847.

(10) Baker R. The Legitimation and regulation of DNR orders. In: Baker R, Strosberg MA, editors. Legislating Medical Ethics: A Study of the New York State Do-Not-Resuscitate Law. Boston, MA: Kluwer Academic, 1995: 33-101.

(11) The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments. JAMA 1995; 274:1591-1598.

(12) Saunders C. The evolution of palliative care. J R Soc Med 2001; 94:430-432.

(13) Saunders C. The symptomatic treatment of incurable malignant disease. Prescribers Journal 1964; 4:68-73.

(14) Taylor H. The Hospice Movement in Britain: Its Role and Its Future. London, England: Centre for Policy on Ageing, 1983.

(15) Lunt B. Terminal cancer care services: recent charges in regional inequalities in Great Britain. Soc Sci Med 1985; 20:753-759.

(16) Ward AWM. Terminal care homes. Hospital Health Service Review 1985; 71:233.

(17) World Health Organization Expert Committee. Cancer pain relief and palliative care. 804. 1990. Geneva, World Health Organization. World Health Organization Techinica Report Series.

(18) Cohen SR, Boston P, Mount BM, Porterfield P. Changes in quality of life following admission to palliative care units. Palliat Med 2001; 15(5):363-371.

(19) Levenson JW, McCarthy EP, Lynn J, Davis RB, Phillips RS. The last six months of life for patients with congestive heart failure. J Am Geriatr Soc 2000; 48(5 Suppl):S101-S109.

(20) McCarthy EP, Phillips RS, Zhong Z, Drews RE, Lynn J. Dying with cancer: patients' function, symptoms, and care preferences as death approaches. J Am Geriatr Soc 2000; 48(5 Suppl):S110-S121.

(21) Ashbury FD, Findlay H, Reynolds B, McKerracher K. A Canadian survey of cancer patients' experiences: are their needs being met? J Pain Symptom Manage 1998; 16(5):298-306.

(22) Rees E, Hardy J, Ling J, Broadley K, A'Hern R. The use of the Edmonton Symptom Assessment Scale (ESAS) within a palliative care unit in the UK. Palliat Med 1998; 12(2):75-82.

(23) Addington-Hall JM, McDonald LD, Anderson HR, Freeling P. Dying from cancer: the views of bereaved family and friends about the experiences of terminally ill patients. Palliat Med1991; 5:207-214.

(24) Field D, Douglas C, Jagger C, Dand P. Terminal illness: views of patients and their lay carers. Palliat Med 1995; 9(1):45-54.

(25) Teno JM, Weitzen S, Fennell ML, Mor V. Dying trajectory in the last year of life: does cancer trajectory fit other diseases? J Palliat Med 2001; 4(4):457-464.

(26) Kurtz ME, Kurtz JC, Given CW, Given B. Loss of physical functioning among patients with cancer: a longitudinal view. Cancer Pract 1993; 1(4):275-281.

(27) Kurtz ME, Kurtz JC, Given CW, Given B. Relationship of caregiver reactions and depression to cancer patients' symptoms, functional states and depression--a longitudinal view. Soc Sci Med 1995; 40(6):837-846.

(28) Grande GE, Todd CJ, Barclay SI. Support needs in the last year of life: patient and carer dilemmas. Palliat Med 1997; 11(3):202-208.

(29) Lynn J, Teno JM, Phillips RS, Wu AW, Desbiens N, Harrold J et al. Perceptions by family members of the dying experience of older and seriously ill patients. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. Ann Intern Med 1997; 126(2):97-106.

(30) Seale CF. What happens in hospices: a review of research evidence. Soc Sci Med 1989; 28(6):551-559.

(31) Hearn J, Higginson IJ. Do specialist palliative care teams improve outcomes for cancer patietns? A systematic literature review. Palliat Med 1998; 12:317-332.

(32) Statistics Canada. Population projections for 2001, 2006, 2011, 2016, 2021 and 2026, July 1. 28-1-2001.

(33) Latimer EA, Verrilli D, Welch WP. Utilization of physician services at the end of life: differences between the United States and Canada. Inquiry 1999; 36(1):90-100.

(34) Kent H. Canadians participate as unique US project puts death under the microscope. Can Med Assoc J 1998; 159(4):395-396.

(35) Kingman S. Lords reject legalisation of euthanasia. BMJ 1994; 308:553-554.

(36) The special senate committee on euthanasia and assited suicide. Of life and death- final report. 1995.

(37) Crul BJ, van Weel C. Providing regular relief; considerations for palliative care in the Netherlands. Ned Tijdsch Geneesk 2001; 145(42):2011-2014.

(38) Miller RJ. Hospice care as an alternative to euthanasia. Law, Medicine and Health Care 1992; 20(1-2):127-132.

(39) Mount BM. End of life care: recent developments in the Netherlands and Canada. Annals of the Royal College of Physicians and Surgeons of Canada 2001; 34:71-76.

(40) Hendin H. Assisted suicide, euthanasia and suicide prevention: the implications of the Dutch experience. Suicide Life Threat Behav 1995; 25(1):193-204.

(41) Sachs.G.A., Abronheim JC, Rhymes JA, Volicer L, Lynn J. Good care of dying patients: the laternative to physician-assisted suicide and euthanasia. J Am Geriatr Soc 1995; 43:553-562.

(42) Matthews H. Better palliative care could cut euthanasia. BMJ 1998; 317(7173):1613.

(43) Tang ST, McCorkle R. Determinants of place of death for termianl cancer patients. Cancer Invest 2001; 19(2):165-180.

(44) Grande GE, Addington-Hall JM, Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? Soc Sci Med 1998; 47(5):565-579.

(45) Townsend J, Frank AO, Fermont D, Dyer S, Karran O, Walgrove A et al. Termial cancer care and patients' preference for place of death: a prospective study. BMJ 1990; 301:415-417.

(46) Hays JC, Galanos AN, Palmer TA, McQuoid DR, Flint EP. Preference for place of death in a continuing care retirement community. The Gerontologist 2001; 41(1):123-128.

(47) Lynn J, Ely EW, Zhong Z, McNiff KL, Dawson NV, Connors A et al. Living and dying with chronic obstructive pulmonary disease. J Am Geriatr Soc 2000; 48(5 Suppl):S91-100.

(48) Emanuel EJ. Cost savings at the end of life: what do the data show? JAMA 1996; 275(24):1907-1914.

(49) Montgomery PR, Kirshen AJ, Roos NP. Long-term care and impending mortality: influence upon place of death and hospital utilization. Gerontologist 1988; 28(3):351-354.

(50) Teno J, Lynn J, Connors A, Wenger N, Phillips RS, Alzola C et al. The illusion of end-of-life resource savings with advance directives. J Am Geriatr Soc 1997; 45(4):513-518.

(51) Higginson IJ, Jarman B, Astin P, Dolan S. Do social factors affect where patients die: an analysis of 10 years of cancer deaths in England. J Public Health Med 1999; 21(1):22-28.

(52) Pritchard RS, Fisher ES, Teno JM, Sharp SM, Reding DJ, Knaus WA et al. Influence pf patient preference and local health system characteristics on the place of death. J Am Geriatr Soc 1998; 46(10):1242-1250.

(53) Temkin-Greener H, Mukamel DB. Predicting place of death in the program of all-inclusive care for the elderly (PACE): participant versus program characteristics. J Am Geriatr Soc 2002; 50:125-135.

(54) Bruera E, Neumann CM, Gagnon B, Brenneis C, Kneisler P, Selmser P et al. Edmonton Regional Paliative Care Program: impact on patterns of terminal care. Can Med Assoc J 1999; 161:290-293.

(55) Bruera E, Neumann CM, Gagnon B, Brenneis C, Quan H, Hanson J. Journal of Palliat Med 2000; 3(2):181-186.

(56) Jordhoy MS, Fayers P, Saltnes T, Ahlner-Elmqvist M, Jannert M, Kaasa S. A pallative-care intervention and death at home: a cluster randomized trial. Lancet 2000; 356:888-893.

(57) Zimmer JG, Groth-Junker A, McCusker J. A randomized controlled study of a home health care team. Am J Public Health 1985; 75:134-141.

(58) McCorkle R, Benoliel JQ, Donaldson G, Georgiadou F, Moinpour C, Goodell B. A randomized clinical trial of home nursing care for lung cancer patients. Cancer 1989; 64:1375-1382.

(59) Kane RL, Wales J, Bernstein L, Leibowitz A, Kaplan S. A randomized controlled trial of hospice care. Lancet 1984; i:890-894.

(60) Raftery JP, Adddington Hall JM, Macdonald LD, et al. A randomized controlled trial of the cost-effectiveness of a district co-ordinating service for terminally ill cancer patients. Palliat Med 1996; 10:151-161.

(61) Hughes SL, Cummings J, Weaver F, Manheim L, Braun B, Conrad K. A randomized trial of the cost effectiveness of VA hospital-based home care for the terminally ill. Health Serv Res 1992; 26:801-817.

(62) Mayo NE. Hospitalization and case-fatality rates for stroke in Canada from 1982 through 1991. The Canadian collaborative study group of stroke hospitalizations. Stroke 1996; 27:1215-1220.

(63) Mayo NE, Scott SC, Shen N, Hanley J, Goldberg MS, MacDonald N. Waiting time for breast cancer surgery in Quebec. Can Med Assoc J 2001; 164(8):1133-1138.

(64) Levy AR, Tamblyn RM, Fitchett D, McLeod PJ, Hanley JA. Coding accuracy of hospital discharge data for elderly survivors of myocardial infarction. Can J Cardiol 1999; 15(11):1277-1282.

(65) Meuser T, Pietruck C, Radbruch L, Stute P, Lehmann KA, Grond S. Symptoms during cancer pain treatment following WHO guidlines: a

longitudinal follow-up study of symptom prevalence, severity and etiology. Pain 2001; 93(3):247-257.

(66) FrichL.M., Borgbjerg FM. Pain and pain treatment in AIDS paitients: a longitudinal study. J Pain Symptom Manage 2000; 19(5):339-347.

(67) Sze FK, Chung TK, Wong E, Lam KK, Woo J. Pain in Chinese cancer patients under palliative care. Palliat Med 1998; 12(4):271-277.

(68) Vainio A, Auvinen A. Prevalence of symptoms among patietns with advanced cancer: an international collaborative study. Symptom Prevalence Group. J Pain Symptom Manage 1996; 12(1):3-10.

(69) Gore JM, Brophy CJ, Greenstone MA. How well do we care for patients with end stage chornic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. Thorax 2002; 55(12):1000-1006.

(70) Davis BD, Cowley SA, Ryland RK. The effects of terminal illness on patients and their carers. J Adv Nurs 1996; 23:512-520.

(71) Murphy DJ, Knaus WA, Lynn J. Study population in SUPPORT: patients (as defined by disease categories and mortality projections), surrogates, and physicians. J Clin Epidemiol 1990; 43 Suppl:11S-28S.

(72) National Cancer Institute of Canada. Canadian Cancer Statistics. 2000. Toronto.

(73) Boag JW. Maximum likelihood estimates of the proportion of patients cured by cancer therapy. Journal of the Royal Statistical Society, Series B 1949; 11:15-44.

(74) Berkson J, Gage RP. Survival surves for cancer patients following treatment. Journal of the American Statistical Association 1952; 47:501-515.

(75) Haybittle JL. The estimation of the proportion of patients cured after treatment for cancer of the breast. Journal of the American Statistical Association 1959; 32:725-733.

(76) Laska EM, Meisner MJ. Nonparametric estimation and testing in a cure model. Biometrics 1992; 48(4):1223-1234.

(77) Goldman AI. The cure model and time confounded risk in the analysis of survival and other timed events. J Clin Epidemiol 1991; 44(12):1327-1340.

(78) Sposto R. Cure model analysis in cancer: an application to data from the Children's Cancer Group. Stat Med 2002; 21(2):293-312.

(79) Price DL, Manatunga AK. Modelling survival data with a cured fraction using frailty models. Stat Med 2001; 29(9-10):1515-1527.

(80) Gamel JW, Weller EA, Wesley MN, Feuer EJ. Parametric cure model of relative and cause-specific survival for gruoped survival times. Computer Methods & Programs in Biomedicine 2000; 61(2):99-110.

(81) Lincoln YS. Fourth generations evaluation, the paradigm revolution and health promotion. Can J Public Health 1992; 83(supplement 1):S6-S10.

(82) Paier GS, Bowdish JR. Primary care fo healthy aging. Advanced Practice Nursing Quaterly 1995; 1(3):65-73.

(83) Baumann AO, Deber RB, Silverman BE, Mallette CM. Who cares? Who cures? The ongoing debate in the provision of health care. J Adv Nurs 1998; 28(5):1040-1045.

(84) Standing Senate Committee on Social Affairs SaT. Quality end-of-life care: The right of every Canandian. 1-27. 2000.

(85) Smith TJ. Health service studies in the terminally ill cancer patient. Cancer Treat Res 1998; 97:81-97.

(86) Oxford Textbook of Palliative Medicine. New York: Oxford University Press, 1993.

(87) Freeborne N, Lynn J, Desbiens NA. Insights about dying from the SUPPORT project. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. J Am Geriatr Soc 2000; 48(5 Suppl):S199-S205.

(88) Layde PM, Broste SK, Desbiens N, Follen M, Lynn J, Reding D et al. Generalizability of clinical studies conducted at tertiary care medical centers: a population-based analysis. J Clin Epidemiol 1996; 49(8):835-841.

(89) Constantini M, Camoirano E, Madeddu L, Bruzzi P, Verganelli E, Henriquet F. Palliative home care and place of death among cancer patients: a population-based study. Palliat Med 1993; 7:323-331.

(90) Sager MA, Easteling DV, Kindig DA, Anderson OW. Changes in the location of death after passage of medicare's prospective payment system. N Eng J Med 1989; 320(7):433-439.

(91) Catalan-Fernandez JG, Pons-Sureda, Recober-Martinez A, Avella-Mestre A, Carbonero-Malberti JM, Benito-Oliver E et al. Dying of cancer: the place of death and family circumstances. Medical Care 1991; 29(9):841-852.

(92) Moinpour CM, Polissar L. Factors affecting place of death of hospice and non-hospice cancer patients. Am J Public Health 1989; 79(11):1549-1551.

(93) Hopkins DD, Grant-Worley JA, Bollinger TL. Survey of cause-of-death query criteria used by state vital statistics programs in the US and the efficacy of the criteria used by the Oregon Vital Statistics Program. Am J Public Health 1989; 79(5):570-574.

(94) Dubsky PC, Gnant MF, Taucher S, Roka S, Kandioler D, Pichler-Gebhard B et al. Young age as an independent adverse prognostic factor in premenopausal patients with breast cancer. Clin Breast Cancer 2002; 3(1):65-72.

(95) Park BW, Kim SI, Kim EK, Yang WI, Lee KS. Impact of patient age on the outcome of primary breast carcinoma. J Surg Oncol 2002; 80(1):12-18.

(96) World Health Organization. International classification of diseases. Geneva: World Health Organization, 1978.

(97) Mor V, Hiris J. Determinants of site of death among hospice cancer patients. J Health Soc Behav 1983; 24(4):375-385.

(98) Wennberg JE, Freeman JL, Shelton RM, Bibolz TA. Hospital use and mortality among medicare beneficiaries in Boston and New Haven. N Eng J Med 1989; 321:1168-1173.

(99) Tolle SW, Rosenfeld AG, Tilden VP, Park Y. Oregon's low in-hospital death rates: what determines where people die and satisfaction with decisions on place of death? Ann Intern Med 1999; 130(8):681-685.

(100) De Conno F, Caraceni A, Groff L, Brunelli C, Donati I, Tamburini M et al. Effect of home care on the place of death of advanced cancer patients. Eur J Cancer 1996; 32A(7):1142-1147.

(101) Grande GE, Todd CJ, Barclay SIG, Farquhar MC. Does hospital at home for palliative care facilitate death at home? Randomised controlled trial. Br Med J 1999; 319:1472-1475.

(102) Singer P. Advance directive fallacies. Health Law Can 1995; 16(1):5-9.

(103) Council on sthical and Judicial affairs AMA. Medical futility in end-of-life care: report of the Council on Ethical and Judical Affairs. JAMA 1999; 281(10):937-941.

(104) Textbook of Palliative Nursing. New York: Oxford University Press, 2001.

(105) Higginson IJ, Finlay I, Goodwin DM, Cook AM, Hood K, Edwards AGK et al. Do hospital-based palliative teams improve care for patients or families at the end of life? J Pain Symptom Manage 2002; 23(2):96-106.

(106) Campora E, Gardin G, Gasco M, Rosso R, Santi L. Metastatic breast cancer patients failing first-line, anthracycline- containing chemotherapy: is further therapy of benefit? Anticancer Res 1999; 19(4C):3429-3432.

(107) Scott SC, Goldberg MS, Mayo NE. Statistical assessment of ordinal outcomes in comparative studies. J Clin Epidemiol 1997; 50(1):45-55.

(108) Thorne CP, Seamark DA, Lawrence C, Gray DJP. The influence of general practitioner community hospitals on the place of death of cancer patients. Palliat Med 1994; 8:122-128.

(109) Vaino A. Practising physicians' experiences of treating patients with cancer pain. Acta Oncologica 1989; 28(2):177-182.

(110) Vainio A. Treatment of terminal cancer pain in Finland: a second look. Acta Anaesthesiol Scand 1992; 36(1):89-95.

(111) Bruera E, MacDonald RN, Macmillan K, Navigante A, Barugel M, Chacon R. Treatment of pain and other symptoms in cancer patients: patterns in a North American and South American hospital. J Pain Symptom Manage 1990; 5(2):78-82.

(112) MacDonald N, Findlay HP, Bruera E, Dudgeon D, Kramer J. A Canadian survey of issues in cancer pain management. J Pain Symptom Manage1997; 14:332-342.

(113) Anonymous. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (support). JAMA 1995; 274:1591-1598.

(114) Seale C, Kelly M. A comparison of hospice and hospital care for people who die: views of the surviving spouse. Palliat Med 1997; 11(2):93-100.

(115) Wachtel TJMV. The use of transfusion in terminal cancer patients. Hospice versus conventional care setting. Transfusion 1985; 25(3):278-279.

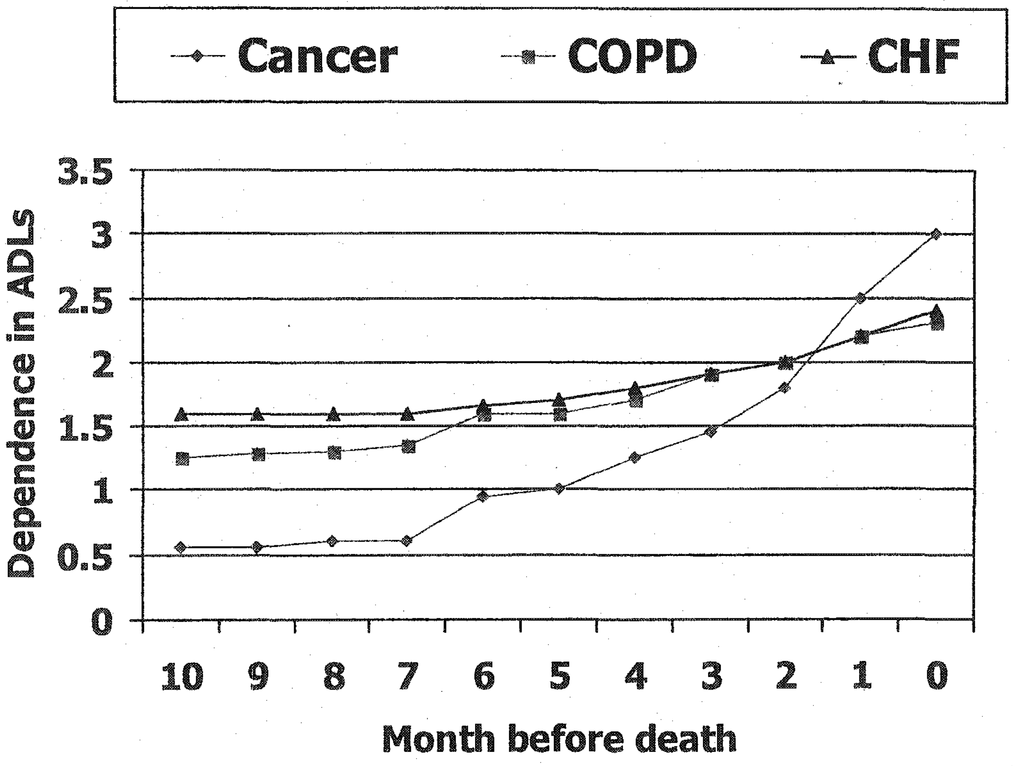
(116) Wachtel TJ, Mor V. Physicians' use of health resources for terminal cancer patients: clinical setting versus physician specialty. South Med J 1987; 80(9):1120-1124.

(117) Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. BMJ 2000; 320(7233):469-472.

(118) Vigano A, Dorgan M, Bruera E, Suarez-Almazor ME. The relative accuracy of the clinical estimation of the duration of life for patients with end of life cancer. Cancer 1999; 86(1):170-176.

(119) Nerenz DR. Capacities and limitations of information systems as data sources on quality of care at the end of life. J Pain Symptom Manage 2001; 22(3):773-783.

Appendice I Sharp Increasing in Functional Dependence toward the End-of-Life in Cancer Patients



Grafh adapted from Teno et al. (25)

Appendix II Graphs representing ordinal odds ratios (estimates only) for each age group