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University of Alberta

Health Care Restructuring and Consumer Preferences For End-of-Life Health Care in Alberta in the 1990s

by

Delaine Denise Jodoin

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment
of the requirements for the degree of **Master of Arts**

Department of Sociology

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ABSTRACT

Beginning in 1993, the Alberta government began balancing the provincial budget through reducing expenditures in health care, education, and other government funded services. More specifically, from 1993 to 1997, the provincial health system has undergone restructuring based on themes of reallocation, de-institutionalization, and end-of-life health care preferences including 'the high cost of dying'. By using a secondary analysis of 1990 All Alberta Survey data, this study provides an evaluation of end-of-life health care preferences for Albertans prior to the onset of the Alberta government's deficit elimination strategy. Furthermore, this study examines whether end-of-life health care preferences are influenced by socio-demographic factors such as age, marital status, gender, household income, education, region, religiosity, current health status, number of members in household, and subjective feelings of depression. Using crosstabulations, the data suggest that age, sex, and education were related to end-of-life health care preferences of Albertans in 1990. In addition, the comparative/evaluative examination of the data analysis against Alberta Health's Annual Reports from 1989-90 to 1997-98 reveals that with regards to home care and personal directives, health care restructuring in Alberta has been consistent with public opinion.

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HEALTH CARE RESTRUCTURING AND CONSUMER PREFERENCES FOR END-OF-LIFE HEALTH CARE IN ALBERTA IN THE 1990S

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CHAPTER ONE

INTRODUCTION

Considerable debate exists on whether most industrialized nations, especially in Western Europe and North America, are in crisis over health care costs (Chappell, 1993; McDaniel, 1997). Questioning the affordability of the universal Canadian health care system seems to bring about national and provincial deliberations, and periodic changes in health care policy. In addition, at times, restructuring and reforming the health system become strategies undertaken by provinces in order to reduce health care expenditures. More specifically, the province of Alberta executed changes in health care to eliminate a fiscal deficit beginning in 1993. Prior to and during funding cutbacks, the provincial government stated that they would listen to the concerns and views of Albertans as they conducted their deficit elimination strategy:

> And this government's fourth commitment is to listen to the people it is privileged to serve; to consult with them; and to be as open, compassionate and fair as possible in reflecting their wishes, their hopes and their dreams. *Speech from the Throne,* Alberta Hansard, August 31, 1993: 3.
>
> My government understands the principle that the customers, the people of Alberta, are always right. In pursuing its mandate for change, the government will continue to assess, reassess, and adjust the route it is taking to reach its destination mindful of the effects of change on the people it serves. *Speech from the Throne*, Alberta Hansard, February 13, 1995: 2.

Beginning their deficit elimination strategy in Alberta in 1993, the Klein government began balancing the provincial budget through reducing expenditures. By aiming to cut spending by 20% between 1992-3 and 1996-7, the Alberta government implemented a reduction in the costs of education, health care, and other public services (Hughes, Lowe, & McKinnon, 1996). Since most Albertans utilize education and health care services, restructuring affected each Albertan. While there has been some investigation over the economics of the plan and its impact on the popularity of the Klein Progressive Conservative government, little research exists on the relationship of cuts to the preferences for health care that Albertans had prior to the government cutbacks.

During these years of government funding reductions, increasing attention has occurred in the field of end-of-life care (Emanuel & Emanuel, 1994; Scitovsky, 1994). Generally, end-of-life discourse is filled with moral discussions of ensuring patients with high quality care during end-of-life situations (Emanuel & Emanuel, 1994). Hence, discussions of and research on hospice and palliative care has become more common. In addition, the reality of an aging population has also brought about concern over end-of-life issues (McWinney, Bass, & Orr, 1995). Moreover, the topic of cost saving in end-of-life care has been discussed (Emanuel & Emanuel, 1994; Scitovsky, 1994). Consequently, when examining health care restructuring in Alberta, it is important to focus on end-of-life preferences for care.

An analysis of public opinion regarding end-of-life preferences prior to government cutbacks permits a discussion of the socio-demographic variables associated with public attitudes on end-of-life care, as well as a comparison of the Alberta government's health system reform with public opinion. In addition, since most existing literature on end-of-life focuses on the elderly or terminally ill, examining end-of-life health care preferences for the general public extends existing literature beyond individuals who are terminally ill or aged. Consequently, this thesis provides an evaluation of public opinion regarding preferences for end-of-life health care prior to the onset of the Alberta government's deficit elimination strategy. Moreover, this thesis comments on whether the basic direction of the Alberta government's health care restructuring has been consistent with public opinion.

Fiscal pressures and challenges in the 1990s led to a focus on Canadian governmental debts and deficits. Beginning in May 1993, the Alberta government began an approach to reduce its provincial deficit. In addition to a plan to cut government spending by 20%, the Klein government's proposed fiscal plan aimed to eliminate the deficit by privatizing government services, imposing user fees, and maintaining current levels of taxation (McMillan & Warrack, 1995). Their tactics included "stringent cost-cutting by restructuring health care provision and, to a lesser extent, development of 'community care' as a substitute for institutional care" (McDaniel, 1997: 214). Hence, with health care restructuring an important component of the Klein government's deficit elimination strategy and the provincial government's claim to 'put the customer first', health care preferences of Albertans prior to restructuring are significant. This thesis examines, in general, whether government policies reflect public opinion and whether the deficit elimination strategy imposed by the Alberta government was consistent with pre-existing public opinion in relation to end-of-life care.

The intent of this research project is to examine end-of-life health care preferences of Albertans prior to 1993-1998 government cutbacks and restructuring. By using a comprehensive analysis of demographic factors and questions aimed at identifying end-of-life care preferences of Albertans, the thesis attempts to show which factors contribute to preferences for health care alternatives, such as home versus hospital care or familial versus formal caregivers.

Although some research has provided information on public attitudes or concerns after budget cuts (Hughes et al., 1996; Wilson & Kerr, 1998), little research exists on whether changes in health care policies were consistent with public opinion. Hence, an understanding of whether public opinion influences policy decisions is far from complete. This research project attempts to make up for these deficiencies by questioning whether socio-demographic factors, such as age, gender, and religiosity, influence end-of-life health care preferences and whether the basic direction of health care restructuring in Alberta has been consistent with public opinion. Results of the analysis will facilitate the examination of potential reasons in regard to whether the Alberta government's restructuring strategy may or may not have been successful. In addition, this analysis demonstrates whether the Alberta government's tactics based on themes of reallocation, de-institutionalization, and possibly end-of-life health care preferences, including the 'high cost of dying', may be a model for other provincial and national governments.

The thesis begins by discussing health care restructuring and end-of-life discourse in Chapter Two, "Literature Review". This chapter begins with a detailed discussion of the provincial/federal health care relationship in Canada and health care funding issues of the Alberta government. In addition, a brief review of three restructuring themes: resource allocation, de-institutionalization, and possibly end-of-life health care decisions, including the 'high cost of dying', illustrates the crux of Alberta's deficit elimination strategy. Also, the chapter examines existing literature about public influence on government policy and public participation in government policy and ends with a statement on comparing health care policy themes against public opinion data.

Chapter Three, “Research Questions and Methodology” details the specific research questions being addressed and describes the research design used in this study. The chapter proceeds with a description of the 1990 All Alberta Survey and the logic behind the questions that were selected for secondary data analysis. The chapter concludes with an outline of the methods of analysis.

Chapter Four, “Research Findings”, presents a quantitative analysis using relevant statistical procedures such as crosstabulations, chi-square tests, and frequency distributions. The chapter begins with a summary of the characteristics of the Alberta and Edmonton samples, and is accompanied by statistical analysis consisting of univariate and bivariate techniques. The chapter proceeds with an comparative/evaluative analysis whereby public opinion data is compared against government policy changes that occurred from 1993-1998.

Chapter Five, “Discussion”, summarizes the results in the previous chapter in relation to the research questions presented in Chapter Three. This chapter also discusses possible reasons why health care restructuring in Alberta endures public scrutiny and concludes with an analysis of the societal implications of the Alberta deficit elimination strategy on a more general level both provincially and nationally. This chapter also discusses limitations and recommendations by identifying methodological weaknesses of the study and concludes with recommendations for future research including the importance of future researchers to replicate asking end-of-life health care preferences on surveys conducted after health care restructuring has taken place.

CHAPTER TWO

LITERATURE REVIEW

INTRODUCTION

Exploring the relationships of end-of-life health care preferences amidst Alberta's deficit elimination process begins with an explanation of the Canadian health care system. Furthermore, the provincial/federal relationship of health care is explored; followed by a discussion of health care restructuring in Alberta, including resource allocation, de-institutionalization, and the "high cost of dying". End-of-life discourse is presented and this chapter concludes with a discussion of public opinion and public participation. Outlining these bodies of literature creates the foundation for the subsequent analysis on the relationship between socio-demographic variables and end-of-life health care preferences and the comparative/evaluative inquiry of health care restructuring and planning with public opinion.

CANADIAN HEALTH CARE

In order to illustrate health care restructuring in Alberta, a description of the Canadian health care system is necessary. Di Marco and Storch (1995) detailed the beginnings of the Canadian system of universal publicly funded health or Medicare. Observing three eras, pre-Confederation, post-Confederation, and post-World War II, the authors explain 'how and why' the Canadian health care system evolved. During the pre-Confederation era, public health care was minimal with the majority of social problems being resolved by families, churches and community organizations (Guest, 1985). Health care services were both a federal and provincial responsibility whereby the federal government was assigned marine hospitals and other health responsibilities and provincial governments were responsible for "the establishment and management of hospitals" (Di Marco & Storch, 1995: 6). In addition, the signing of the *British North America Act* in 1867 reinforced a dual partnership in health care (Di Marco & Storch, 1995).

During the second era, between Confederation and the end of World War II, health issues focused on infectious diseases and untreatable injuries (Di Marco & Storch, 1995). It was widely recognized that churches, families, and communities could not adequately support all needy people. Consequently, numerous health insurance plans developed. Unfortunately, only the wealthy could truly afford these. Charitable organizations still catered to the poor, and the majority of working and middle class individuals were left without consistent health care coverage. Hence, a universal health care insurance program appealed to many Canadians.

In the post-World War II era, Medicare or Canadian health insurance emerged (Di Marco & Storch, 1995). During this period, "increased diagnostic and therapeutic capabilities in health care assisted ... in creating a perceived need for a more organized, and humane, approach to health care provision" (Di Marco & Storch, 1995: 9). Medical and scientific developments enhanced the shifting of health care from the "home and community to the hospital" (Di Marco & Storch, 1995: 9). In Saskatchewan, in 1947, the provincial government created the "first universal (insurance) program in North America providing hospital care to all residents of the province regardless of means" (Baumgart, 1992: 29). Saskatchewan was followed by British Columbia, Alberta, and Newfoundland. The passage of the *Hospital Insurance and Diagnostic Services Act* in 1957 established the provisions for the federal government to give grants to provinces for hospital services. Immediately, British Columbia, Alberta, Saskatchewan, Manitoba, and Newfoundland joined, and by 1961 all the provinces had joined.

Additional legislation led to more changes in how Canadian health care was funded and thus provided. For example, the *Medical Care Act* of 1966 implemented a 50/50 federal-provincial cost sharing of medical costs on the condition that provincial plans provided comprehensive, portable, universal, and publicly administered health care coverage to Canadian residents. Furthermore, the passage of the *Federal Provincial Fiscal Arrangements and Established Programs Act* in 1977 "replaced federal cost sharing with block transfers and grant payments to provinces" (Di Marco & Storch, 1995: 10). Eventually, the perceived erosion of the Medicare system accompanied by political, economic, and public pressures encouraged the 1984 passage of the *Canada Health Act* (Di Marco & Storch, 1995).

The *Canada Health Act* indicated that the role of Canadian health policy is to "protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers" (Taylor, 1986: 33). By promoting the five principles of accessibility, comprehensiveness, portability, universality, and public administration, the Act assured all Canadians of comprehensive, publicly funded health care administered on a non-profit basis. Although the federal government strengthened the "strong social value of equality" (Di Marco & Storch, 1995: 11) and contributed to a "more equitable distribution of service availability across the population" (Evans, 1983: 4), Canada did not have a single national health care system, but rather twelve provincial and territorial health care systems.

Within the guidelines of the *Canada Health Act*, territories and provinces were able to define what health services were funded. Consequently, this variability in interpreting the guidelines of the Act results in some differences in provincial and territorial health care plans across Canada (Chappell, 1993; Di Marco & Storch, 1995). Nevertheless, financial penalties were imposed on provinces and territories that neglected to follow the five principles. Hence, across Canada, the federal government could withhold funding from provinces and territories to enforce the Act, and resulting variable provincial and territorial health care plans existed.

The health care financial relationship between provincial and federal governments has changed over the years since the onset of Medicare (Di Marco & Storch, 1995; McDaniel, 1997; Northcott, 1995). Prior to 1957, health care was based on a collection of taxes or premiums or through private health plans. The passage of the *Hospital Insurance and Diagnostic Services Act* (1957) by the Canadian federal government indicated that federal grants would be given to provinces following specific conditions (Roy, Williams, & Dickens, 1994). By agreeing to provide comprehensive, universal, non-profit, portable health care coverage, provinces were entitled to federal grants. Hence, health care was 'cost-shared' by provincial and federal governments.

The *Federal Provincial Fiscal Arrangement and Established Programs Act* was passed in 1977 by the federal government in response to fiscal constraints and increasing health care expenditures (Roy et al., 1994). This Act "replaced cost sharing with block transfers and grant payments to provinces, thus leading the way for decreased federal payments" (Di Marco & Storch, 1995: 10). Costs then passed on to consumers through hospital user fees and extra-billing by physicians were later outlawed in 1984 by the addition of the accessibility principle in the *Canada Health Act.* After 1984, fiscal restraints continued to result in the federal government cutting back transfer payments to provinces and territories. These cutbacks culminated in the *Canada Health and Social Transfer Act* of 1995 whereby separate transfers for health and other social services were combined into one single transfer - block funding (Di Marco & Storch, 1995).

From 1985 to 1991, Canada experienced periods of changing economic climate (Eyles, Birch, and Newbold, 1995). Fiscal crises during the late 1980s and early to mid 1990s forced governments to create policies which focused on cost containment. As part of a broader federal deficit reduction plan, funding to provinces was gradually reduced (Eyles et al., 1995). By 1994, federal transfer funds to the provinces were reduced to approximately one-half of what they were in 1990 (McDaniel, 1997). Hence, federal economic changes could have resulted in subsequent changes at the provincial level.

Due to ongoing limitations in federal transfers, provincial governments increasingly had to find a way to afford their own provincial health care plans, either that or contain costs. Since charging user fees violate the *Canada Health Act*, provinces must develop alternative policies to contain spending, yet maintain current standards of health care. Consequently, at the provincial level, health care policy has typically focused on controlling and reducing costs (Eyles et al., 1995). More specifically, beginning in 1993, the Alberta provincial government implemented health care policies which emphasized downsizing, cutbacks, and health system reform as part of their deficit reduction plan.

HEALTH CARE RESTRUCTURING

To reduce health care costs, governments must acknowledge where health care dollars are spent. Some of the most expensive health components include hospital care, physician fee for service payments, and prescription drugs, medicines and health aids (Northcott, 1995). Consequently, to reduce health care costs, strategies may embody restructuring in each of these areas. For example, hospital costs may be decreased by 'downsizing' the number of hospital beds and hospital staff, and thus rationing health care. In addition, expenses due to prescription drugs and health aids, such as eye glasses and hearing aids, may be reduced by having the consumer pay directly for these items (Northcott, 1995). Currently, many health related items are already paid for by individuals, and if reductions in hospital stays continue, health care clients are carrying more of the financial burden of their care, since only medications and supplies taken directly in hospitals is covered. Often when individuals are discharged from the hospital, the expense of prescriptions and other supplies becomes their responsibility or their employers. Beginning in 1993 in Alberta, the Klein government implemented some of these strategies such as reducing hospital stays and decreasing the number of hospital beds. Consequently, some financial costs of health care were shifted from hospitals to individuals and their families.

Leading up to the June 1993 election, Ralph Klein's Conservatives used the Alberta Treasury's *Budget '93* as the basis for their campaign. Focusing on cutbacks, privatization and promoting the *Deficit Elimination Act* of May 1993, the Klein government was elected later in 1993 and once in office moved quickly continuing to produce plans and budgets that would reduce provincial deficits within the next three years (Hughes et al., 1996). After being elected in 1993, the Klein government's main objective was to eliminate the deficit in three years by reducing government spending (Hughes, Lowe, & McKinnon, 1995; Wilson & Kerr, 1998). More specifically, reducing the cost of health care was one method used to decrease budgetary deficits (Northcott, 1995). By promoting the vision of "Healthy Albertans in a Healthy Alberta", the three-year business plan for Alberta Health proclaims to "reorganizing the health system to emphasize wellness-based approaches while sustaining essential treatment services under a value-for-money orientation to the health system" (Alberta Health, 1995a: 3).

The three-year business plan was based on four goals: "1) maintain a continuum of affordable, accessible and appropriate high-quality health services in appropriate settings and locales that ensure a client-oriented focus, 2) increase the ability of Albertans to lead healthy and independent lives, 3) increase financial contributions by Albertans based on ability to pay for health programs where premiums or other charges are currently levied, and 4) increase the ability of partners in the health system to demonstrate accountability for the use of health resources and the outcomes levied" (Alberta Health, 1995a: 9). Furthermore, net spending for health care was to be reduced by $844.8 million over four years (from $3,567.5 million in 1993-94 to $2,722.7 in 1997-98) and health care premiums would rise from 11% to 20% of health care expenditures (Alberta Health, 1995a). Overall, in order to implement these four goals and reduce health care expenditures, the Alberta health system would undergo restructuring.

During 1993-96, massive health care restructuring took place. Seventeen new Regional Health Authorities were created, agreements with the Alberta Medical Association to "reduce expenditures on physician services, restructure laboratory services, restrict billing numbers for new physicians, de-insure medically unnecessary items, and establish clinical practice while potentially reducing costs" (Alberta Health, 1995a: 3) were arranged, and public sector wage rollbacks of approximately $150 million dollars occurred. In addition, hospital services in Calgary and Edmonton were reduced, approximately $70 million from the acute care sector was reallocated to community-based services (e.g. home care), and health care insurance premiums increased (Alberta Health, 1995a). Furthermore, seniors' benefits through Extended Health Benefits program were reduced, and legislation passed delegating that all but low income seniors would pay Alberta Health Care Insurance Plan premiums. Consequently, due to these health care revisions, seniors were one group of individuals affected dramatically by health care and other cutbacks (Wilson & Kerr, 1998).

A large portion of the individuals affected by the 'Klein Revolution' were public sector employees (Hughes et al., 1996; Maurier, 1996). Budgetary constraints directed an overall reduction of 25 percent in public sector employment from 1992-93 to 1997-98 whereby the majority of this target would be achieved "primarily through a hiring freeze, attrition, and a severance program" (Alberta Treasury, 1995: 35-56). In addition, the government acknowledged that layoffs in health care and other sections would occur (Alberta Treasury, 1995). Consequently, the health workforce became smaller. Furthermore some individuals, such as hospital nurses and therapists, were laid off and then applied for work in the community (Alberta Health, 1995a).

In summary, Alberta's new restructured health care system is organized on a regional basis which aims to make service delivery more integrated (Alberta Health, 1995a). Community care services, such as home care and rehabilitation have been expanded, and homes have become the site of more acute, palliative and long-term care. Hospitals have fewer inpatient beds and more day-surgery, whereas laboratories produce economies of scale. Higher health care premiums have been implemented, new health care cards issued, and individuals can now indicate their wishes regarding future health care through advance directives. Consequently, many health system modifications have occurred, with decisions being influenced primarily by the theme of how to allocate health care services and resources more cost effectively.

Resource Allocation

Debate over Canada's health system is often a political controversy "among provincial governments, special interest groups and the public" (Rosenberg & James, 1994). These groups often deliberate about trying to maintain the principles of the health care system while attempting to control costs. When deciding how to cutback and restructure health care, policy analysts often use cost-effectiveness/cost benefit analyses to allocate health resources (Phillips & Holtgrave, 1997). Current literature shows that some examples of issues discussed in cost-benefit analyses are bed closures in hospitals, reduction in the number of items covered by health care plans, and prevention of health care problems (Marriott, 1994-95; Rosenberg & James, 1994; Phillips & Holtgrave, 1997).

Bed closures in hospitals challenge the principle of accessibility (Rosenberg & James, 1994). This strategy of cost reduction has been observed in provinces such as Alberta, Manitoba and Ontario (Alberta Health, 1995a; Rosenberg & James, 1994; Vingilis & Burkell, 1996). By conducting a thorough analysis of Ontario's closure of hospital beds in response to funding challenges, Rosenberg and James (1994) detail how "spatial inequality is increasing" simultaneously as health care costs are attempted to be controlled. Emphasizing methods of rationalization, spatial relocation, and centralization/decentralization, the authors show that restructuring increased overall inequality. They conclude "overall inequality has increased in the spatial distribution of hospital beds relative to the spatial distribution of the population" (Rosenberg & James, 1994: 978). Hence, this suggests a violation of the accessibility principle whereby all individuals should have reasonable access to all medically necessary services. In addition, researchers studying bed closures in Winnipeg, Manitoba indicated that downsizing, with respect to the number of hospital beds, resulted in a reduction in hospital care access (Vingilis & Burkell, 1996). Nevertheless, regional health authorities in Alberta stated that due to "changing health practices, new technologies, and medical advances ... the need for acute care inpatient hospital beds is declining" (Capital Health Authority, 1994: 10).

Questioning which services to cover under health care insurance plans could also challenge the principle of comprehensiveness. Comprehensiveness means that "all medically required services provided by hospitals, medical practitioners, and dentists have to be covered by the health care insurance plan of a province" (Angus, Auer, Cloutier, & Albert, 1995:13). Currently, there exists considerable debate about which services are 'medically necessary' (Charles, Lomas, Giacomini, Bhatia, & Vincent, 1997; Marriott, 1994-95).

On December 1, 1994, the Klein government de-listed three services. Wart removal, routine eye examinations, and general anaesthetic for dental surgeries were no longer covered by the Alberta health care insurance plan (Crockatt & Pedersen, 1994). Consequently, the costs of such procedures were shifted from the government to individual Albertans. Furthermore, the issue that "provinces have not defined 'medically required services' or the criteria on which they are established, but have simply listed them in regulations which may be changed through administrative procedures" leaves ample room for more items to be de-listed in the future (Marriott, 1994-95: 41).

Resource allocation debates also center on preventive versus curative health care (Phillips & Holtgrave, 1997). To save health care costs and improve health status, prevention is promoted and implemented by health care administrators (Phillips & Holtgrave, 1997). For example, Alberta's three-year business plan encourages health promotion and disease prevention (Alberta Health, 1995a). By providing tools, training, knowledge and skill development in health promotion, the government planned to expand public education with regards to health promotion and injury prevention (Alberta Health, 1995a). When stating that one of the four goals is to "increase the ability of Albertans to lead healthy and independent lives", the Alberta government felt that healthy behaviors should increase while unhealthy behaviors should decrease. For instance, Alberta Health implemented a health promotion project aimed at young parents, funded approximately $1.5 million on a variety of strategies including advertising, interactive displays and community events, and provided ongoing support to the Alberta Heritage Foundation for Medical Research and the Cancer Board to promote health promotion research (Alberta Health, 1997). Thus, resources, both financial and workforce related, were allocated to some new programs and initiatives focusing on health promotion and prevention.

Throughout the Alberta government's deficit elimination strategy, resource allocation frequently coincided with funding changes in programs. That is, government programs centering on health promotion and home care often become important areas for future funding. Furthermore, prior to provincial cutbacks to health care, it is uncertain which end-of-life health services (regarding home-based or hospital-based), Alberta consumers preferred or needed. Hence, by examining public opinion regarding end-of-life preferences, this thesis will indicate which areas of health care (home care versus hospital care and hospice care versus life prolongation) Albertans felt were important in 1990.

De-institutionalization

Another theme existing throughout health care restructuring in Alberta is de-institutionalization (Alberta Health, 1995a). The creation of the seventeen Regional Health Authorities was to help make the health system more streamlined. In addition, approximately $110 million dollars divided into three years ending in 1997, was "distributed to community health/home care agencies" (Wilson & Kerr, 1998: 203). Hence, health care restructuring was to facilitate a transition from hospital-based to home-based care (Alberta Health, 1994a). This shift accompanied bed closures, a reduction in hospital stays, and increases in outpatient surgery. When health care is pushed out of hospitals and into homes, there is a financial and emotional shift from formal health care providers to individuals and families. For example, existing research shows how shifting nursing care, health care supplies and medications onto individuals and families impacts seniors profoundly (Wilson & Kerr, 1998).

In addition, when the Alberta government began questioning the affordability of its health care system, de-institutionalization became a possible resolution:

> Across Canada, in every province and territory, and around the world, questions are being raised about health ... how can we maintain quality services, accessible to all people, but at a cost we can afford? (Alberta Health, 1997a: 1).

In response to the above quote, the government of Alberta indicates how their system changed and now focuses on people (Alberta Health, 1997a). For example, the provincial government implemented a new population-based formula to calculate funding to each of the seventeen Health Authorities (Alberta Health, 1997a). In turn, some

Regional Health Authorities established community health networks within their jurisdictions (Capital Health Authority, 1994). These community health networks may connect with community health centres which once again promote individuals to meet health care needs within their own homes and communities. In addition, some Regional Authorities assist individuals by providing more long-term care in non-hospital settings. Aided by home support, alternative residence arrangements, and special programs, long term care of Albertans has indeed shifted to care within communities and homes (Capital Health Authority, 1994).

Moving services out of hospitals and into homes advocates care for individuals in their own surroundings (Capital Health Authority, 1994). The Capital Health Authority, the board for Edmonton and immediate surrounding areas, issued a clear mission to "work in partnership with the community to create and maintain an integrated, accessible and affordable health system with quality client service as the focus" (Capital Health Authority, 1994: 2). In response to community public hearings, meetings and submissions, administrators in this Authority revealed key messages given to them from the community. One message was to shift the focus of care to home and community care. Since this report, as well as many others, was issued by a government agency, there is a lack in academic literature on public opinion prior to health care cutbacks. Consequently, this thesis will fill that gap by addressing questions regarding end-of-life health care preferences of Albertans prior to the onset of the Klein government's deficit elimination strategy.

End-of-Life Care Preferences and The High Cost of Dying

Recently, as fiscal restraints affect health care institutions, the topic of cost saving in end-of-life care has been discussed (Emanuel & Emanuel, 1994; Scitovsky, 1994). Moreover, reducing cost expenditure in end-of-life situations may be indirectly imposed as a restructuring strategy by the Alberta government. In addition, advance directives and hospice care have been developed to "ensure patients' autonomy and to provide high-quality care at the end-of-life" (Emanuel & Emanuel, 1994: 540). However, these tactics used to improve 'quality of life' rather than 'quantity of life' have also been proposed as methods of reducing medical costs at the end-of-life. Consequently, reducing costs at the end-of-life has been an area of controversial debate (Kelner, 1995).

Since expenditures at the end-of-life seem disproportionately large, this realm can become a prime target for financial cutbacks (Emanuel & Emanuel, 1994). For example, in the United States, researchers report that payments for dying patients increase exponentially as death approaches, and the last month of life constitutes approximately 40 percent of payments during the last year of life (Lubitz & Riley, 1993). In addition, costs for patients who died are 6.9 times higher than for all other Medicare patients indicating that end-of-life costs are relatively high (Lubitz & Riley, 1993). Hence, health professionals, politicians, and financial advisors may have hidden agendas when they promote advance directives and hospice care.

Throughout society there has been a growing concern about the "quality of life throughout the life cycle" (Alberta Health, 1995a: 4). Moreover, issues of dying a 'good' death, euthanasia, and assisted suicide have become contentious topics in the public and medical community. Numerous studies have been focused on public opinion and public preferences regarding end-of-life decisions (Allen-Burge & Haley, 1997; Kelner, 1995; Perry, Nicholas, Molzahn, & Dossetor, 1995; Reilly, Halm, Phillips, Hofman, & Wenger, 1998; Singer, Choudhry, Armstrong, Meslin, & Lowy, 1995; Storch & Dossetor, 1994b; Wilson, 1998). Researchers indicate that, often, end-of-life decisions are affected by prognosis or circumstance of patient, personal experiences, and availability of support (Genuis, Genuis, & Chang, 1994; Singer et al., 1994; Wilson, 1998). Currently, data exists on whether individuals approve of euthanasia and assisted suicide, but little data exists on which socio-demographic variables influence end-of-life decisions. Consequently, investigation of which groups of individuals prefer to be cared for and die at home, be cared for in a hospital, refuse pain medication, or end their own lives is required.

Legislation passed in December 1997 exposed health care professionals in Alberta to the use of advance directives in hospitals. Advance directives are documents whereby "individuals will be able to indicate their wishes regarding future health care in advance of becoming incapacitated and to appoint an agent to make health care decisions on their behalf" (Alberta Health, 1995a: 17). Consequently, individuals decide whether they would like to order a 'DNR' - 'Do Not Resuscitate', would like hospice care whereby no extraordinary measures are taken to save their life, or would like all available medical means used to preserve their life. In addition, more discussions about end-of-life preferences and more advanced planning for end-of-life care could be facilitated by living wills (Storch & Dossetor, 1994; Perry et al., 1995; Walker et al., 1995; Wilson, 1998).

Hence, health care has shifted from medical professionals making decisions to giving individuals and their families more autonomy for making end-of-life decisions.

End-of-life care preferences also combine discussions of the high cost of dying, de-institutionalization, and localization of death. At the beginning of this century, most individuals died in their homes, but by the 1970s, approximately 70% of deaths in Canada occurred in institutions (Mount & Ajemian, 1980). Furthermore, 73% of all deaths in Canada in 1996 occurred in acute care hospitals, 3% occurred in long-term facilities, 5% were unrecorded, and 20% of deaths occurred in all other places combined (Wilson et al., 1998). Although death occurs predominately in hospitals, most people now appear to prefer to die at home (Dudgeon & Kristjanson, 1995; McWinney, Bass, & Orr, 1995; Wilson, 1998). Consequently, preference for localization of death differs from actuality.

Possible linkages as to why more individuals die in hospitals, as compared to homes, are found when examining financial aspects of home care. In particular, although the reduction in hospital beds promotes an attempt to lower the demand for institutional care and increases pressure for patients to be cared for in the home, resources for home care and support services have not been forthcoming (Dudgeon & Kristjanson, 1995). Often, the prevalence of hospital deaths can be explained by examining publicly-funded hospital care and availability of beds (Wilson et al., 1998), and furthermore, low income is linked to increased rates of hospitalization (Wilkins & Park, 1997). In addition, costs of medications when staying home and the prohibitive cost of private home care can deter individuals from dying at home even though they would prefer to. Therefore, since health care restructuring in Alberta involves de-institutionalization and cost-containment, examining public preferences for end-of-life care prior to funding cutbacks will reveal whether Albertans preferred home or institutional care at the end of life, and consequently will allow a comparison to the government's allocation of funding towards institutions and home care.

Prior to the imposition of the Klein government's deficit elimination strategy, it is unclear as to what health care preferences Albertans had with regards to end-of-life care. Therefore, this analysis will examine and comment on which socio-demographic factors influence health care preferences when individuals are presented with hypothetical situations where they have recently been diagnosed with cancer, become old and frail, developed a serious illness or have become old with a serious illness.

INFLUENCE OF PUBLIC OPINION AND PUBLIC PARTICIPATION

Public opinion polls are taken periodically throughout the years on subjects such as abortion, euthanasia, and government approval ratings (For examples see Angus Reid, 1994-97; Gallup, 1991-95; Genuis, Genuis, & Chang, 1994; Wetstein & Albritton, 1995). Various research exists on whether public opinion influences health care policy and whether health care policy influences public opinion (Hadorn, 1991; O'Neill, 1992; Wetstein & Albritton, 1995). Within Alberta, public opinion polls have been undertaken by both Angus Reid and Gallup, but little academic literature exists as to whether these public opinions have any impact on government action.

Within Canada, a few researchers have examined consumer control and community participation, especially in Quebec's health care system (Godbout, 1981;

O'Neill, 1992). More recently, researchers have started to discuss the emergence of public participation as a theme in Canadian health reform (MacKean & Thurston, 1996; Yeo, 1996). By grounding the theory of public participation in autonomy, Yeo (1996) examines how the public, first as tax payers and secondly as users of the system, can incorporate their opinions in the process of deciding health care issues. He concludes by indicating that increased public participation "should be an integral part of any comprehensive health reform strategy" (Yeo, 1996: 51). In addition, MacKean and Thurston (1996) developed a conceptual model of public participation in health care combining S.R. Arnstein's 'ladder of citizen participation' with influencing factors. Overall, given current fiscal imperatives, public participation and public opinion issues become pertinent in discussions of health care reform. Since Alberta's approach to deficit reduction raises important public policy issues regarding the impact of public opinion on government decisions and the impact of government decisions on public opinion, comparing health care policy themes against public opinion data permits the discussion of possible reasons why the Alberta government's restructuring strategy may or may not be successful.

CHAPTER SUMMARY

In this chapter, the purpose of the study was defined within the context of existing health care restructuring and end-of-life discourse. Since existing literature contains very little on detailing which variables influence end-of-life health care preferences, this area needs to be explored. Moreover, current literature lacks discussion on what end-of-life health care preferences existed prior to cutbacks, and hence, one cannot examine whether Alberta's health care restructuring, due to its deficit elimination strategy, has been consistent with public opinion. Consequently, this study, through its analysis of socio-demographic variables and end-of-life preferences, and its comparative/evaluative examination of whether health care restructuring and public opinion are consistent, will fill these gaps.

CHAPTER THREE

RESEARCH QUESTIONS AND METHODOLOGY

RESEARCH QUESTIONS

Given the concerns detailed in Chapter Two, a comprehensive analysis of the 1990 All Alberta Survey data will allow the two main research questions in this thesis to be answered:

1. What are the public's end-of-life health care preferences and are these preferences influenced by socio-demographic factors such as age, marital status, gender, household income, education, region (Edmonton, Calgary, or other Alberta and rural versus urban), religiosity, current health status, number of members in household and subjective feelings of depression? That is, which socio-demographic factors affect how individuals see themselves at the end-of-life? How do these factors affect their end-of-life health care preferences?

2. Has the basic direction of health care restructuring in Alberta been consistent with public opinion regarding end-of-life health care issues?

RESEARCH DESIGN

This descriptive/applied study employs a secondary data analysis using a cross-sectional quantitative survey research design. The data source chosen was the 1990 All Alberta Survey which included end-of-life health care preference questions. The following sections detail the chosen data source, the dependent and independent variables, and the statistical techniques which are used to answer the two research questions.

DATA SOURCE: 1990 ALL ALBERTA SURVEY

A secondary data analysis using 1990 All Alberta Survey data is used in this thesis. A detailed account of this survey is explained further in the subsequent section.

1990 All Alberta Survey

Data from this survey were obtained using a random sample survey of households in the province of Alberta (Kinzel & Odynak, 1990). A total of 1245 respondents were interviewed in three separate samples representing Edmonton, Calgary, and the remainder of the province. The Edmonton sample of households was selected randomly from the computerized list of addresses compiled in the 1989 city enumeration. Interviewing was done face-to-face and interviewers were instructed to select on adult (18+ years of age) respondent from each household and to obtain an equal number of male and female respondents. The response rate for the Edmonton sample was 75%.

The Calgary and other Alberta samples were chosen by selecting, with replacement, simple random samples of working five-digit telephone banks covering Calgary and the remainder of Alberta. A random number between 00 and 99 was appended to each bank selected and duplicate numbers discarded. Interviewing was done by telephone and interviewers were instructed to select on adult respondent (18+ years of age) from each eligible household contacted (numbers not in service and non-residential contacts were excluded) and to obtain an equal number of male and female respondents. The response rate for the Calgary sample was 75% and for the other Alberta sample was 80%.

The Edmonton, Calgary, and other Alberta samples were combined using appropriate weights so as to make the combined sample proportional to the Alberta population. The combined sample, when compared with the Alberta population, was shown to have similar age and marital status distributions (index of dissimilarity 6.2 and 3.6 respectively; Kinzel & Odynak, 1990).

Respondents were asked about their health care preferences given four different scenarios: terminal cancer, frail old age, serious illness, and elderly with a serious illness. More specifically, respondents were asked the following:

1. Suppose you have just found out that you have cancer and you have been told you have less than a year to live. How much would you agree or disagree with the following statements? (1=strongly disagree; 7=strongly agree).

    a) I would accept whatever medical treatment is suggested by my doctor.
    b) I would refuse all treatment except pain medication.
    c) I would seriously consider ending my own life.
    d) I would prefer to be cared for in a hospital.
    e) I would prefer to be cared for in my own home.
    f) I would prefer to die at home.

2. Now suppose you have become old and frail. You live alone and can no longer care for yourself. Still using the 7 point scale, please tell me how much you agree or disagree with the following alternatives for your care (1=strongly disagree; 7=strongly agree).

    a) My family would care for me.
    b) Professional care givers would come to my home.
    c) I would move into a long-term facility (e.g. nursing home).
    d) I would prefer to die rather than become dependent on others.

3. If you were to develop a serious illness please tell me how much you would agree or disagree with the following statements (1=strongly disagree; 7=strongly agree):

    a) I would rather leave the major decisions to my doctor.
    b) I would be in favor of donating my organs after death for transplanting to others.

c) It is important to leave written instructions ("*living will*") in the event I am no longer able to make important decisions.

4. For the next three statements, imagine you are elderly with a serious illness. How much would you agree or disagree with the following? (1=strongly disagree; 7=strongly agree).

    a) I would want to have my life prolonged regardless of its quality.
    b) Even if my mind had failed permanently, I would want my life prolonged indefinitely.
    c) I would want to know about all the possible outcomes from my illness so I could provide treatment directives for doctors and others.

These questions and the cross-sectional survey methodology have certain limitations. Initially, the questions were designed to distinguish between the perceived availability of a given care option, the perceived likelihood of utilizing that option, and the perceived desirability of that option. Because of space limitations on the survey, these distinctions were lost. A second limitation concerns the inability of a cross-sectional design to separate age and cohort effects (the period effect is constant in a cross-sectional study).

In addition, the first two scenarios were asked of all respondents in Alberta whereas the last two questions were only asked of respondents in the Edmonton region. Consequently, most of the analysis will feature discussions on the cancer and frail old age scenarios since Alberta's health care restructuring is province-wide. The serious illness and elderly with a serious illness scenarios will be used to supplement the analysis when necessary. Nevertheless, these data are sufficient to indicate whether socio-demographic factors influence health care preferences.

MEASUREMENT: DEPENDENT VARIABLES

Each of the questions asked in the previous sections will represent the dependent variables. Since a seven point likert scale is used, some analyses will retain the seven point scale and other summaries will use collapsed categories in order to describe whether respondents agree, disagree, or are neutral (categories 1-3 will represent disagree, 4 = neutral, and 5-7 = agree).

MEASUREMENT: INDEPENDENT VARIABLES

Socio-demographic factors such as respondent's age, marital status, gender, household income, education, region (Edmonton, Calgary, or other Alberta and rural versus urban), religiosity, current health status, number of members in household and subjective feelings regarding depression are all used as independent variables. A depression scale was created using eight questions (feeling no interest, blue, lonely, hopeless, sad or depressed, worthlessness, having thoughts of death and dying or ending your life). For details on the exact wording of each of the eight questions and on scaling see Appendix A.

STATISTICAL TECHNIQUE

The 1990 All Alberta Survey sample is examined first using descriptive statistics. Frequency tables indicate frequencies of each of the variables: age, marital status, gender, household income, education, region (Edmonton, Calgary, or other Alberta and rural versus urban), religiosity, current health status, and number of members in household for each sample. Crosstabulations are then used to describe relationships between each of the independent variables and each of the dependent variables.

In order to address the research questions, certain statistical techniques will be applied. For the first research question regarding end-of-life health care preferences, cell frequencies (and percentages) will be presented to illustrate general findings. In addition, crosstabulations and chi-square tests are used to demonstrate the relationship between each of the questions asked in the four different scenarios (representing the dependent variables) and proposed socio-demographic factors. Figures and tables are also used to supplement the analysis. This examination indicates which socio-demographics, in general, influence end-of-life health care preferences and what public opinion regarding end-of-life treatment decisions existed prior to government health care restructuring.

Analysis of the second research question, regarding whether the basic direction of health care restructuring in Alberta has been consistent with public opinion of end-of-life health care preferences, is performed by executing a type of summative evaluation (Herman, Morris, & Fitz-Gibbon, 1987). The summative evaluation's goal is to "collect and ... present information needed for summary statements and judgments about the program and its value" (Herman, Morris, & Fitz-Gibbon, 1987: 16). In this study, a portion of the government's deficit elimination strategy regarding home care and personal directives, which is presented in Alberta Health's Annuals Reports, will be summarized and described. In addition, these reforms of health care restructuring will then be compared against public preferences. Throughout this study, this method will be referred to as a comparative/evaluative examination.

More specifically, health care restructuring themes deduced from Alberta Health's Annual Reports from 1989-90 to 1997-98 will be presented along with frequencies of Albertans that agreed and disagreed with end-of-life alternatives prior to the provincial cutbacks. For example, annual reports indicate that health care resources and funding were reallocated to home care. The responses to questions asked on the 1990 All Alberta Survey would determine what types of health care preferences, including home care, Albertans had prior to health care restructuring. In conclusion, comparing these frequencies with health care policy would indicate whether the basic direction of health care restructuring in Alberta was consistent (or not) with public opinion.

CHAPTER SUMMARY

In this chapter, the research questions to be answered within this descriptive/applied study have been put forth. In addition, a detailed description of the data source, survey questions, dependent variables, independent variables, and statistical techniques have been outlined. Hence, the methodology of the study has been indicated. In the following chapter, univariate and bivariate findings of the study are reported.

CHAPTER FOUR

RESEARCH FINDINGS

INTRODUCTION

This chapter begins with a brief examination of some of the characteristics of the 1990 All Alberta sample of respondents and the Edmonton-only sample. The statistical analysis of the first research question follows and is divided into ten sections based on the dependent variables from the cancer and frail old age scenarios. A descriptive and bivariate analysis is reported for each of the dependent variables. In the following section, the serious illness and elderly with a serious illness scenarios for the Edmonton sample are presented using a univariate analysis. These findings are succeeded by the comparative/evaluative analysis for the second research question, and the chapter ends with a brief chapter summary.

CHARACTERISTICS OF THE 1990 ALL ALBERTA SAMPLE AND THE EDMONTON-ONLY SAMPLE

This chapter begins with a description of the Albertans and Edmontonians who participated in the 1990 All Alberta Survey. A total of 1245 respondents were interviewed for this survey. This section presents some of the characteristics of the 628 (50.5%) male and 617 (49.5%) female Albertan respondents (see Table 4.1). In addition, characteristics of the 157 (49.6%) male and 160 (50.4%) female Edmonton-only sample are presented (see Table 4.2).

Age

The age range for the All Alberta sample was from 18 to 90 years of age, with a mean age of 41.1 years. More specifically, 25% (309) were 18 to 29 years of age, 49% (604) were 30 to 49 years of age, 16% (197) were between the ages of 50 and 64, and 11% (130) were 65 years and older.

For the Edmonton-only sample, the age ranged from 19 to 89 years, with a mean age of 39.5 years. More specifically, 30% (94) were 18 to 29 years of age, 48% (152) were 30 to 49 years of age, 13% (41) were between the ages of 50 and 64, and 10% (31) were 65 years or older. Overall, the two populations were quite similar in age range and mean age. The Edmonton sample did contain 5% more respondents in the youngest age category, but otherwise the population age composition was similar.

Marital Status

The majority of the respondents in the survey were married or living common law (67% for the All Alberta sample and 55% for the Edmonton only sample). Never married respondents followed next in frequency (18% for the All Alberta sample and 25% for the Edmonton only sample), and the remaining (16% for the All Alberta sample and 20% for the Edmonton only sample) were separated, divorced or widowed.

Number of Members in Household

For the Alberta sample, the average number of household members was 2.9. More specifically, 18% (226) of respondents lived alone, 31% (382) lived in two-member households, 17% (215) of respondents lived in three-member households, 20% (253) of respondents lived in four-member households, and 14% (169) of respondents lived in households with five or more members.

For the Edmonton sample, the average number of household members was 2.7. More specifically, 23% (74) of respondents lived alone, 28% (90) lived in two-member households, 19% (62) of respondents lived in three-member households, 19% (60) of respondents lived in four-member households, and 10% (32) of respondents lived in households with five or more members. Overall, the majority of respondents lived in two-member households for both Alberta and Edmonton samples.

Health Status Compared to Others Their Age

The majority of respondents, 51% (635) in Alberta and 49% (157) in Edmonton felt that their health was better or much better than other individuals the same age. In addition, 44% (548) of Albertans and 43% (135) of Edmontonians felt that their health was about the same as other individuals the same age. A small proportion of respondents, 5% (59) in Alberta and 8% (25) in Edmonton, felt that their health was worse or much worse than other individuals the same age.

Education

From the Alberta sample, the average education level was high school completion, with some courses completed at non-University institutions. Just over 23% (293) of the respondents had not completed high school. In addition, 23% (283) graduated from high school, 27% (340) had completed some courses and/or graduated from non-University programs, and 10% (124) of respondents had some University education. Also, approximately 16% (202) of Albertan respondents had graduated from University (Bachelors, Masters and Doctorate included).

From the Edmonton sample, the average education level was completion of non-University. Overall, 20% (64) of the respondents had not completed high school. In addition, 20% (64) graduated high school, 28% (89) had completed some or graduated from non-University programs, and 12% (38) of respondents had some University education. Also, approximately 20% (62) of Albertan respondents had graduated from University (Bachelors, Masters and Doctorate included). Overall, the two samples were quite similar, despite the Edmonton sample having a higher proportion of University graduates.

Income

The average household income was approximately $37,000 for all Albertans surveyed and $33,000 for Edmontonians. Overall, 16% (161) of respondents in Alberta had a household income under $20,000 whereas from the Edmonton sample 24% (70) had a household income under $20,000. For both samples, the majority of respondents had a household income between $20,000 and $59,999 (54% (544) for the Alberta sample and 61% (181) for the Edmonton sample). For Alberta respondents, 30% (296) had a household income more than $60,000, but only 15% (45) of Edmontonians fell into this category. Hence, the distributions varied quite a bit between the Alberta and Edmonton-only samples.

Religiosity

Religiosity was coded in terms of strong, somewhat strong, and not very strong. The majority of respondents felt their religiosity was strong (49% for Alberta and 53% for Edmonton). This category was followed by 35% of Albertans and 38% of Edmontonians falling in the not very strong category. Only 16% of Albertans and 9% of Edmontonians felt their religiosity was somewhat strong.

Region

Region will only be discussed for the Alberta sample. The majority of respondents were from Calgary (28%), followed by Edmonton (26%), and then town or village (18%). The remaining respondents lived in other cities (15%) and rural communities (14%). Consequently, the majority of respondents were from urban areas.

Table 4.1 Characteristics of Respondents in the Study (All Alberta)

Characteristics	Percent	N
Total	100.0	1245
Sex		
Male	50.5	628
Female	49.5	617
Age		
18-29	24.9	309
30-49	48.7	604
50-64	15.9	197
65+	10.5	130
Marital Status		
Married/Common Law	66.6	829
Never Married	17.6	219
Other (Separated, Divorced or Widowed)	15.8	197
Number of Members in Household		
1	18.1	226
2	30.7	382
3	17.3	215
4	20.4	253
5+	13.6	169
Health Status Compared to Others		
Much Better/Better	51.1	635
The Same	44.1	548
Worse/Much Worse	4.8	59

Table 4.1 (Continued)

Characteristics	Percent	N
Education		
Less than High School	23.6	293
High School Graduate	22.8	283
Some & Graduate Non-University	27.3	340
Some University	10.0	124
University Graduate	16.3	202
Income		
Less than $6,000	1.8	18
6,000-11,999	5.6	56
12,000-19,999	8.7	87
20,000-31,999	19.6	196
32,000-44,999	18.1	181
45,000-59,999	16.7	167
60,000+	29.6	296
Religiosity		
Strong	49.4	614
Not Very Strong	34.7	431
Somewhat Strong	15.9	198
Region		
City	14.5	180
Town/Village	18.2	226
Rural	13.7	171
Calgary	28.1	349
Edmonton	25.5	317

Table 4.2 Characteristics of Respondents in the Study (Edmonton-Only)

Characteristics	Percent	N
Total	100.0	317
Sex		
Male	49.6	157
Female	50.4	160
Age		
18-29	29.5	94
30-49	47.8	152
50-64	12.9	41
65+	9.8	31
Marital Status		
Married/Common Law	54.7	174
Never Married	25.2	80
Other (Separated, Divorced or Widowed)	20.1	64
Number of Members in Household		
1	23.4	74
2	28.3	90
3	19.4	62
4	18.8	60
5+	10.0	32
Health Status Compared to Others		
Much Better/Better	49.4	157
The Same	42.7	135
Worse/Much Worse	7.8	25

Table 4.2 (Continued)

Characteristics	Percent	N
Education		
Less than High School	20.1	64
High School Graduate	20.4	64
Some & Graduate Non-University	28.2	89
Some University	11.9	38
University Graduate	19.5	62
Income		
Less than $6,000	2.1	6
6,000-11,999	11.0	33
12,000-19,999	10.5	31
20,000-31,999	20.3	60
32,000-44,999	22.7	67
45,000-59,999	18.1	54
60,000+	15.3	45
Religiosity		
Strong	52.5	166
Not Very Strong	38.4	122
Somewhat Strong	9.2	29

STATISTICAL ANALYSIS

RESEARCH QUESTION #1: What are the public's end-of-life health care preferences and are these preferences influenced by socio-demographic factors such as age, marital status, gender, household income, education, region (Edmonton, Calgary or other Alberta and rural versus urban), religiosity, current health status, number of members in household, and subjective feelings of depression?

STATISTICAL ANALYSIS: Cancer and Frail Old Age Scenarios for Albertans

This section is divided into ten parts representing each of the ten dependent variables from the cancer and frail old age scenarios for the Alberta sample. For each dependent variable, a univariate analysis including frequencies, percentages and means is presented. The univariate analysis is followed by a bivariate analysis using crosstabulations and chi-square tests. Hence, a brief description of each dependent variable contains mean response level (1 = strongly disagree and 7 = strongly agree), frequency distributions, and a bivariate analysis using crosstabulations. Although the crosstabulations were conducted using the seven point likert scale for each of the ten dependent variables, in order to describe general findings of agreement and disagreement from the crosstabulations, some categories were collapsed. That is, categories 1-3 are combined to represent disagree, 4 will represent neutral, and 5-7 are combined to represent agree. The end of this section contains a brief summary of Albertans' responses to end-of-life health care alternatives.

CANCER SCENARIO

For the following six dependent variables (accept suggested treatment, refuse all treatment, consider ending life, prefer hospital care, prefer home care, and prefer to die at home) respondents were asked to "Suppose you have just found out that you have cancer and you have been told you have less than a year to live. How much would you agree or disagree with the following statements?" (1 = strongly disagree & 7 = strongly agree).

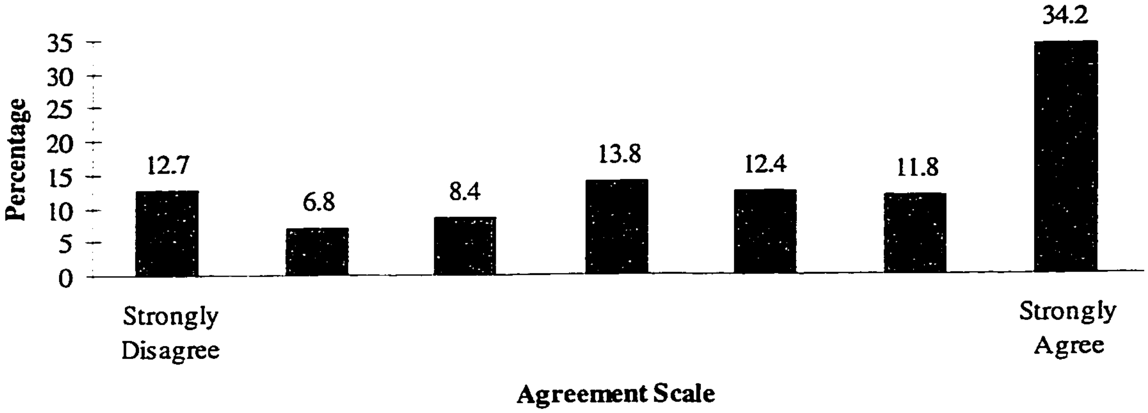
ACCEPT SUGGESTED TREATMENT

The response statement was "I would accept whatever medical treatment is suggested by my doctor", and was used to illicit attitudes about autonomy and end-of-life health care decisions.

Descriptive Analysis

From the seven-point likert scale, the mean level of accepting suggested treatment presented by the doctor was 4.8 thereby showing that most respondents agree with the statement "I would accept whatever medical treatment is suggested by my doctor". Overall, 58% of respondents agreed and 28% disagreed. The percentage of respondents falling in each of the seven categories is shown in Figure 4.1.

Figure 4.1: Accept Suggested Treatment if Cancer Develops



Bivariate Analysis

Bivariate crosstabulations of this dependent variable and selected independent variables were also done. A summary of all chi-square tests and p-values are presented in Table 4.3. Accepting suggested treatment was statistically significant with five of the ten independent variables - sex, age, education, region, and religiosity. The crosstabulation with sex indicated that 30% of males and 26% of females disagreed with this alternative. The bivariate relationship with age indicates that elderly respondents (72%) are more likely to agree to the doctor's suggested treatment when compared to respondents aged 18-29 (59%). In addition, respondents with a university education (40%) are more likely to disagree with this alternative compared to respondents who have not completed high school (24%). The crosstabulation with region revealed that respondents living in rural areas (67%) and towns or villages (64%) were more likely to agree with this alternative than respondents living in cities (58%), Calgary (53%) or Edmonton (55%). Although the relationship between accepting treatment and religiosity was statistically significant, results indicated that the majority (58%) of respondents who had strong religiosity and the majority (58%) of respondents who had not very strong religiosity agreed with the acceptance of treatment alternative. Furthermore, the majority (58%) of respondents that indicated somewhat strong religiosity also agreed with this alternative. Consequently, individuals who are elderly, and/or have less education, and/or live in rural areas are more likely to "accept whatever medical treatment is suggested" by their doctors.

Table 4.3: Summary of Chi-Square and P-Values, for Terminal Cancer and Frail Old Age Scenarios

Independent Variables

Cancer Scenario	*Sex*		*Age*		*Marital Status*		*Number of Members in Household*	
	χ^2	p	χ^2	p	χ^2	p	χ^2	p
Accept Suggested Treatment	14.018	.029*	34.376	.011*	12.301	.422	27.770	.270
Refuse all Treatment	11.233	.081	27.729	.066	4.071	.982	26.600	.323
Consider Ending Life	11.712	.069	30.739	.031*	12.831	.381	23.248	.505
Prefer Hospital Care	7.838	.250	101.944	.000**	32.060	.001**	35.808	.057
Prefer Home Care	20.731	.002**	60.353	.000**	32.666	.001**	25.929	.357
Prefer to Die at Home	17.520	.008**	46.317	.000**	28.417	.005**	33.451	.095

Frail Old Age Scenario	χ^2	p	χ^2	p	χ^2	p	χ^2	p
Family Care	42.882	.000**	100.304	.000**	59.312	.000**	45.534	.005**
Professional Home Care	28.062	.000**	49.218	.000**	16.308	.178	55.438	.000**
Move to Care Facility	21.812	.001**	99.061	.000**	48.265	.000**	35.240	.065
Prefer to Die Than Be Dependent	15.753	.015*	31.794	.023*	12.543	.403	21.018	.638

Note: ** is statistically significant at .01 and * is statistically significant at .05

Table 4.3 (Continued)

Independent Variables

Cancer Scenario	*Health Compared to Others*		*Education*		*Income*		*Region*	
	χ^2	p	χ^2	p	χ^2	p	χ^2	p
Accept Suggested Treatment	19.009	.088	74.900	.000**	47.005	.104	38.344	.032*
Refuse all Treatment	12.340	.419	46.284	.004**	31.797	.669	41.593	.014*
Consider Ending Life	9.008	.702	28.196	.252	30.319	.735	40.963	.017*
Prefer Hospital Care	10.081	.609	57.416	.000**	68.470	.001**	30.296	.175
Prefer Home Care	17.181	.143	48.961	.002**	45.629	.131	35.798	.057
Prefer to Die at Home	8.308	.761	48.350	.002**	48.796	.076	31.332	.144

Frail Old Age Scenario	χ^2	p	χ^2	p	χ^2	p	χ^2	p
Family Care	12.033	.443	46.414	.004**	34.941	.519	18.444	.781
Professional Home Care	12.387	.415	35.380	.063	54.538	.024*	29.865	.189
Move to Care Facility	3.774	.987	64.150	.000**	47.336	.098	34.669	.073
Prefer to Die Than Be Dependent	12.885	.377	51.392	.001**	26.981	.861	32.699	.111

Note: ** is statistically significant at .01 and * is statistically significant at .05

Table 4.3 (Continued)

Independent Variables

Cancer Scenario	*Religiosity*		*Depression Scale*	
	χ^2	p	χ^2	p
Accept Suggested Treatment	22.166	.036*	22.716	.202
Refuse all Treatment	18.446	.103	6.436	.994
Consider Ending Life	30.166	.003**	133.766	.000**
Prefer Hospital Care	12.130	.435	21.799	.241
Prefer Home Care	23.524	.024*	19.090	.386
Prefer to Die at Home	19.421	.079	11.514	.871

Frail Old Age Scenario	χ^2	p	χ^2	p
Family Care	17.424	.134	19.002	.392
Professional Home Care	18.899	.091	30.228	.035*
Move to Care Facility	9.687	.683	17.061	.519
Prefer to Die Than Be Dependent	19.258	.082	16.556	.554

Note: ** is statistically significant at .01 and * is statistically significant at .05

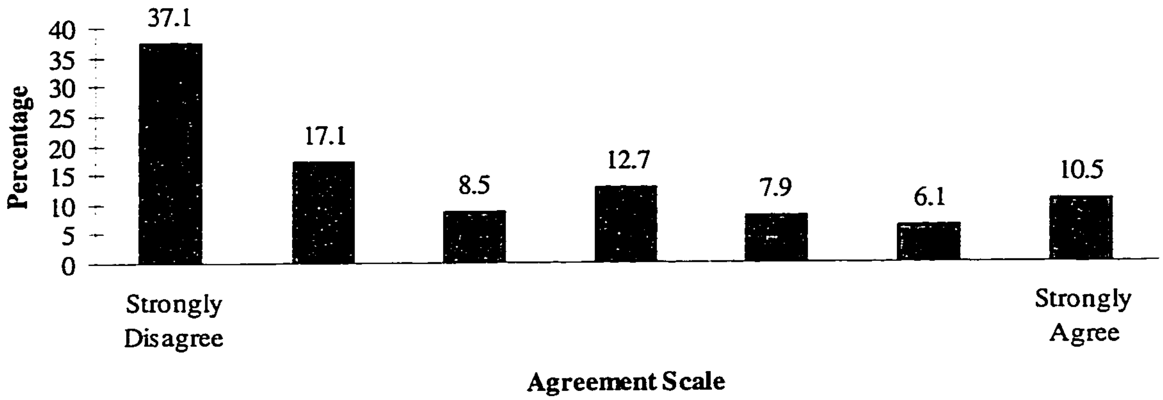
REFUSE ALL TREATMENT EXCEPT PAIN MEDICATION

The response statement was "I would refuse all treatment except pain medication", and was used to illicit attitudes towards palliative care.

Descriptive Analysis

When offered the alternative "I would refuse all treatment except pain medication", respondents had a mean level response of 3.0 indicating that the majority did not agree. Results show that 63% disagreed while only 25% agreed with this palliative care alternative. Figure 4.2 denotes percentages of respondents falling in each of the seven response categories.

Figure 4.2: Refuse All Treatment if Cancer Develops



Bivariate Analysis

Bivariate relationships using crosstabulations revealed that the refusal of treatment alternative was statistically significant with both education and region. Within the education crosstabulation, 68% of respondents graduating from university disagreed whereas 57% of respondents without high school education disagreed. Hence, it appears that respondents with less education are more likely to agree with palliative care. Respondents in different regions also disagreed with this alternative. Overall, 56% of rural residents disagreed, and 64% of town residents, 70% of urban residents, 62% of Calgarians and 63% of Edmontonians disagreed with this alternative. Hence, it appears that rural residents are more likely to agree to palliative care when compared to individuals living in cities, towns and/or villages. Overall, respondents with less education and/or living in rural areas are more likely to agree with palliative care. That is, these groups of individuals are more likely to "refuse treatment except pain medication".

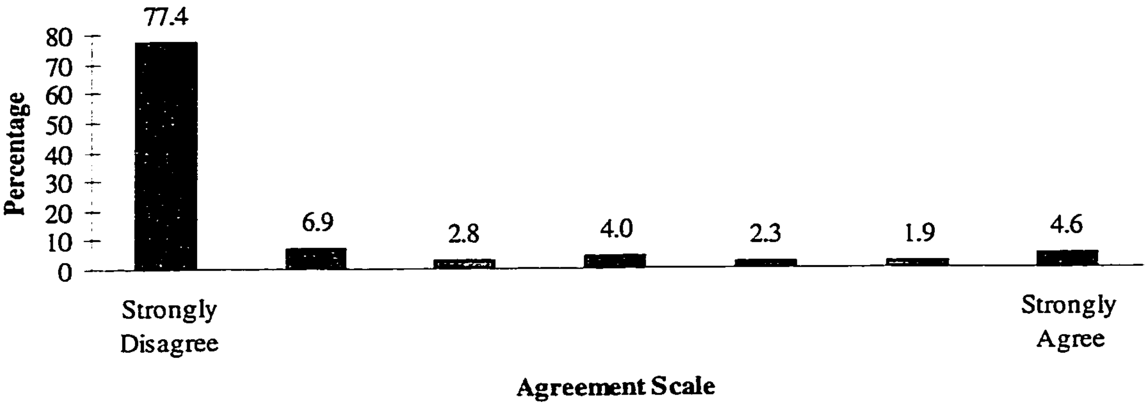
CONSIDER ENDING LIFE

From the cancer scenario, the response statement for this dependent variable was "I would seriously consider ending my own life". The variable was used to determine attitudes towards suicide when individuals were confronted with a terminal illness.

Descriptive Analysis

When asked "I would seriously consider ending my own life", the majority (87%) of respondents disagreed and the mean level was 1.7. Percentages of respondents agreeing and disagreeing on the seven-point scale are indicated in Figure 4.3.

Figure 4.3: Consider Ending Life if Cancer Develops



Bivariate Analysis

Four independent variables, age, region, religiosity, and depression showed statistically significant correlations with this alternative (See Table 4.3). Generally, elderly individuals (13%) were more likely to agree with this alternative in comparison to young ones (aged 18-29 - 8%). Despite being statistically significant, it appears that there are no substantive differences within the regional crosstabulation. For example, 85% of rural residents, 92% of town residents, 90% of urban residents, 87% of Calgarians and 84% of Edmontonians disagreed with this alternative. Consequently, there is no clear division between rural and urban responses. In addition, respondents with strong religiosity (90%) were more likely to disagree than respondents with not very strong religiosity (83%). Crosstabulations with the depression scale indicated that 33% of extremely depressed respondents agreed and only 6% of respondents who were not at all depressed felt that they would consider ending their life if they had cancer. Hence, these results show that elderly individuals, extremely depressed individuals, and/or individuals without strong religiosity are more likely to consider ending their lives if diagnosed with cancer.

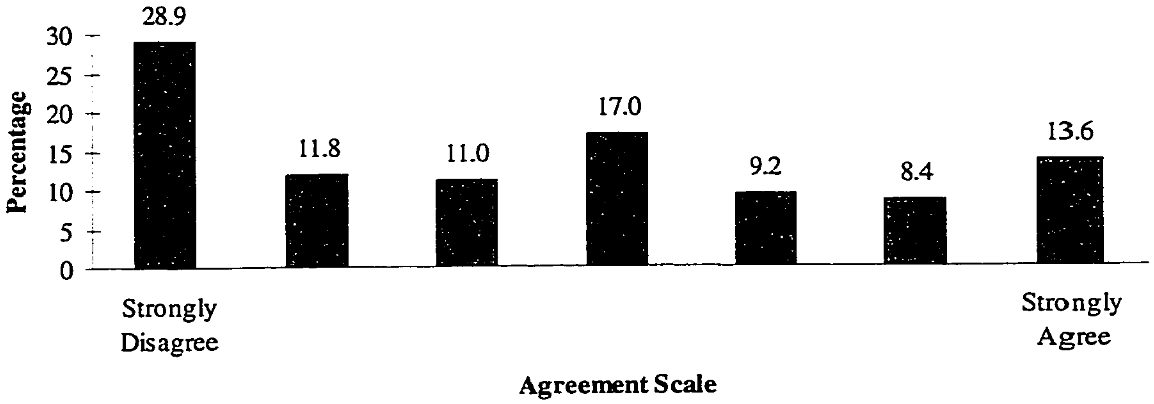
PREFER HOSPITAL CARE

"I would prefer to be cared for in a hospital" was the next response statement for the cancer scenario. It was used to determine public opinion attitudes towards hospital care at end-of-life.

Descriptive Analysis

The mean level of preferring hospital care was 3.5. Overall, respondents were more likely to disagree (52%) than agree (31%), and percentage frequencies for each of the seven categories are indicated in Figure 4.4.

Figure 4.4: Would Prefer Hospital Care if Cancer Develops



Bivariate Analysis

Bivariate crosstabulations show that preferring hospital care is statistically significant with four independent variables - age, marital status, education, and income. A large difference existed between the young and old. That is, 67% of respondents 18-29 disagree with this alternative whereas only 31% of individuals 65 years and older disagree. Respondents who are single (62%) are more likely to disagree with this alternative, followed by the married (51%) and the separated, divorced and widowed (45%). The majority of University graduates (60%) did not prefer hospital care and 44% of respondents without a high school education disagreed. Respondents who earn less than $6000 (53%) a year are more likely to prefer hospital care compared to only 28% of individuals who earn over $60,000. Consequently, individuals who would reject hospital care were more likely to be young, single, highly educated and/or have a household income over $60,000.

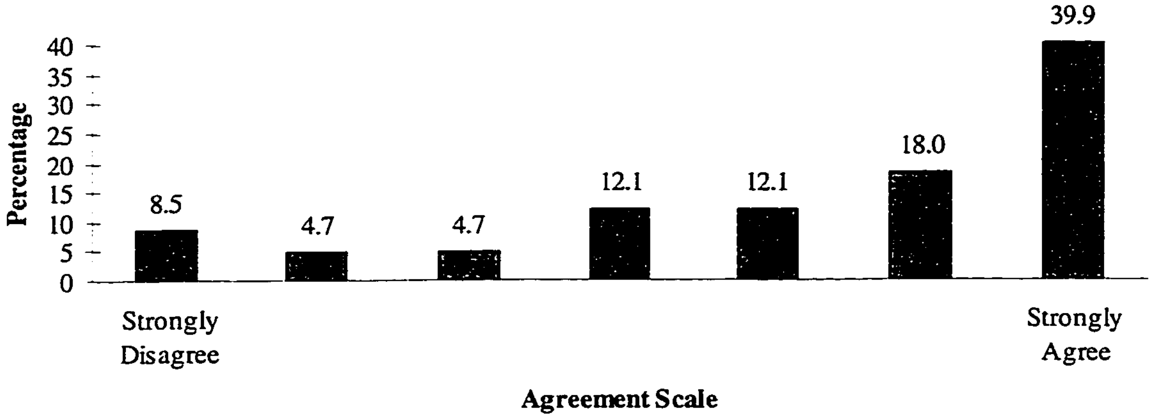
PREFER HOME CARE

The response statement was "I would prefer to be cared for in my own home" and was implemented to determine Albertans' preferences for home care at end-of-life.

Descriptive Analysis

On a seven-point likert scale, the mean level of preferring home care was 5.3 which indicates a strong preference for home care. Furthermore, 70% of respondents indicated a preference for home care. Only 18% of respondents disagreed with this option. Figure 4.5 shows the percentages of responses ranked from strongly disagree to strongly agree for this question.

Figure 4.5: Would Prefer Home Care if Cancer Develops



Bivariate Analysis

Bivariate analysis, using the seven point likert scale, indicates that a preference for home care is related to five independent variables - sex, age, marital status, education, and religiosity. Overall, 70% of females and 70% of males agreed with this alternative, but females (45%) were more likely to strongly agree when compared to the percentage of men (35%) who strongly agree. The majority (81%) of respondents 18-29 years of age indicated a preference for home care whereas only 58% of elderly respondents 65 years and older agreed with this alternative. Both never married (75%) and married (72%) of respondents indicated a preference for home care. Respondents (60%) who were separated, divorced or widowed were less likely to prefer home care when compared to the other marital groups. Overall, respondents (76%) who have graduated from

University preferred home care more than respondents (66%) without high school completion. In addition, respondents (72%) with strong religiosity indicated a higher preference for home care than respondents (68%) with not very strong religiosity. Altogether, female, young, never married or married, highly educated, and/or strongly religious respondents are more likely than their respective counterparts to prefer home care. Table 4.3 shows a summary of the chi-square values and p-values for each of these statistically significant relationships.

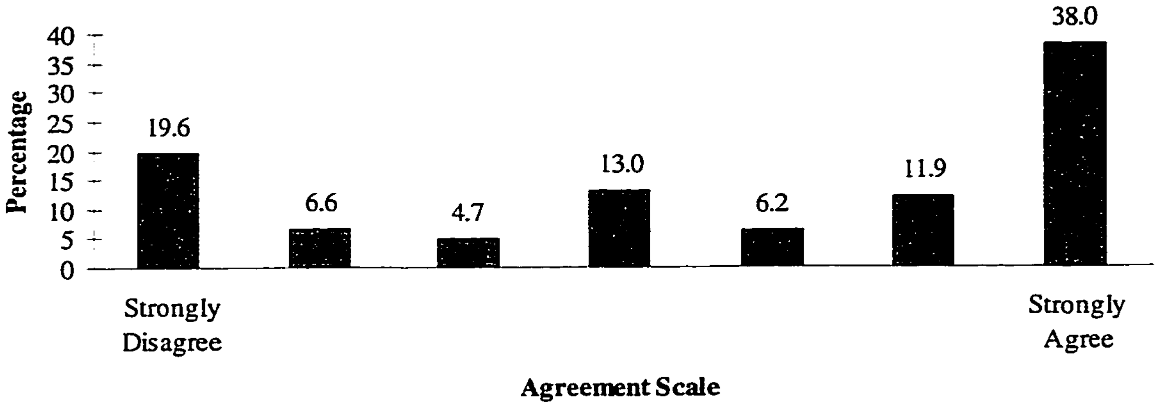
PREFER TO DIE AT HOME

"I would prefer to die at home" was the last response statement in the cancer scenario and was used to once again determine preferences for home care.

Descriptive Analysis

On average, respondents scored 4.7 on the seven-point likert scale when asked "I would prefer to die at home". Furthermore, 56% of respondents indicated a preference to die at home. The frequencies of the responses are illustrated in Figure 4.6.

Figure 4.6: Prefer to Die at Home if Cancer Develops



Bivariate Analysis

Bivariate crosstabulations reveal that this variable has a statistically significant relationship with sex, age, marital status, and education (See Table 4.3). Females (58%) were more likely to prefer to die at home when compared to males (54%). Among the elderly, only 47% agreed that they prefer to die at home. On the other hand, almost two-thirds (65%) of respondents aged 18-29 indicated a preference to die at home. Almost two-thirds (64%) of never married respondents preferred to die at home, and only 55% of married and 54% of separated, divorced and widowed respondents agreed to this preference. In addition, 60% of university graduates preferred to die at home and 52% of respondents without a high school education prefer to die at home. Consequently, female, young, never married and/or more educated respondents are more likely to prefer to die at home.

OLD AND FRAIL SCENARIO

For the remaining four dependent variables (family care, professional care, move to care facility, and prefer to die than be dependent on others), respondents were asked to "Suppose you have become old and frail. You live alone and can no longer care for yourself. Still using the seven point scale, please tell me how much you agree or disagree with the following alternatives for your care."

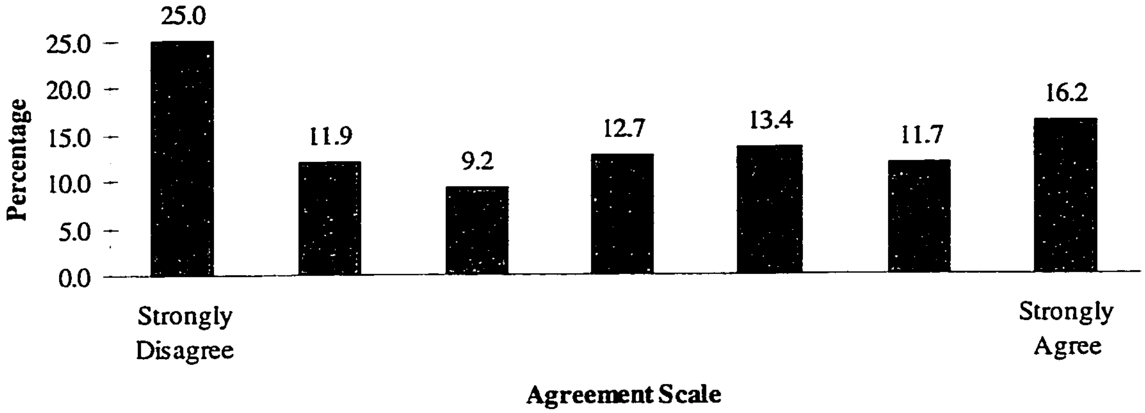
FAMILY CARE

The first response statement was "My family would care for me", and was used to discriminate between those preferring informal versus formal care.

Descriptive Analysis

When asked "My family would care for me" in the old and frail scenario, respondents averaged 3.8 indicating an even split between those who agreed and disagreed. Results from frequencies also indicate a polarization between individuals who agreed (41%) and those who disagreed (46%). Figure 4.7 shows the response frequencies for each of the seven categories.

Figure 4.7: Family Would Care for Me if Old and Frail



Bivariate Analysis

Bivariate analysis using crosstabulations revealed statistically significant relationships that exist between family care and sex, age, marital status, education, and number of members in the household. Males (47%) were more likely to agree with this alternative than females (35%). Moreover, 61% of respondents aged 18-29 agreed with this option, but only 23% of the elderly agreed. The crosstabulation with marital status indicated that never married respondents (50%) were more likely to prefer family care whereas 42% of married and only 28% of separated, divorced, and widowed individual agreed. More educated respondents (47%) were more likely than less educated individuals (41%) to agree that family would care for them when old and frail. Almost half (49%) of the respondents with five or more individuals living in the household indicated that they agree with family care if they become old and frail whereas only 35% of individuals who live alone agreed with this alternative. Consequently, male, young, never married, highly educated, and/or respondents with more members in their household are more likely to agree that their family would care for them if they became old and frail.

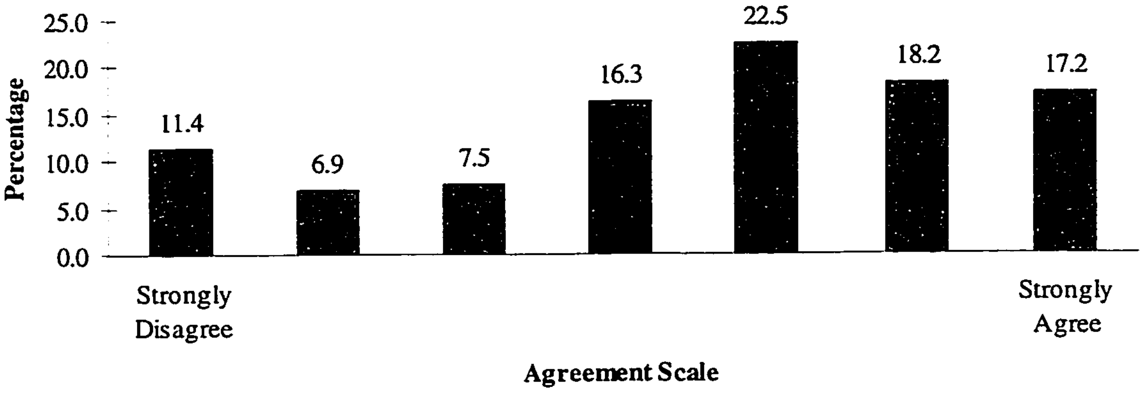
PROFESSIONAL CARE IN MY HOME

The response statement was “Professional care givers would come to my home”, and determined Albertans’ preferences for home care.

Descriptive Analysis

The mean level response was 4.6 when respondents were asked “Professional care givers would come to my home”. Statistics indicate that 58% of respondents agreed and 26% disagreed with professional care givers coming into their home. Figure 4.8 illustrates frequency percentages for this dependent variable.

Figure 4.8: Professional Home Care if Old and Frail



Bivariate Analysis

Crosstabulation statistics reveal that this variable has a relationship with sex, age, income, number of members in household, and depression. Sex differences are apparent since 62% of females and 54% of males agree that professional care givers would come to the home. In addition, elderly (63%) are more likely to have care givers come to their home when compared to respondents 18-29 years of age (54%). Respondents (61%) who had a household income of $60,000 or more and only 44% of respondents who had a household income less than $6,000 agreed to this health care alternative. Furthermore, 62% of respondents who lived alone and only 54% of respondents living in households consisting of five members or more agreed that they would have professional caregivers come to their home. In addition, respondents who were extremely depressed (75%) were more likely to have professional home care when compared to their not at all depressed counterparts (58%). Hence, individuals who were more likely to have professional home care are often female, elderly, depressed, live alone, and/or have higher household incomes.

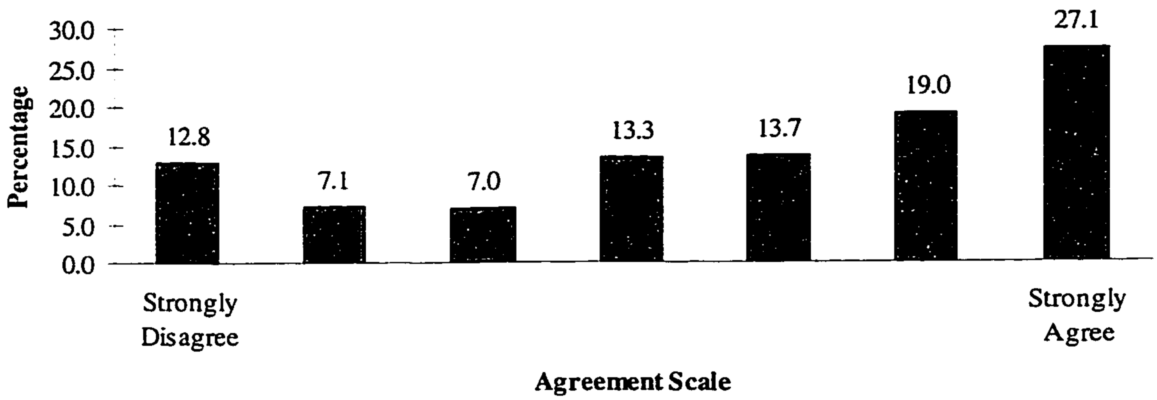
MOVE TO A LONG-TERM FACILITY

"I would move into a long-term facility (e.g. nursing home)" when I become old and frail was the next statement. This response was also used to determine the preference for informal care givers; Although it indicates a preference for formal care givers in an institutional setting such as a nursing home.

Descriptive Analysis

On average, respondents scored 4.7 when asked "I would move into a long-term facility (e.g. nursing home)". Almost two-thirds (60%) of respondents agreed to this alternative and only 27% disagreed. Percentage frequencies for each of the seven response categories are illustrated in Figure 4.9.

Figure 4.9: Would Move to a Care Facility if Old and Frail



Bivariate Analysis

Bivariate crosstabulations reveal statistically significant relationships between moving to a care facility and sex, age, marital status, and education. Females (63%) are more likely than males (57%) to expect to move to a long-term facility. Three-quarters of the elderly would move to a long-term facility whereas only one half of respondents aged 18-29 would. Married individuals (63%) were most likely to move to a care facility followed by separated, divorced, and widowed (61%), and never married persons (47%). Crosstabulations with education revealed that only half of university graduates (48%)

were willing to move to a care facility, while 64% of high school non-graduates agreed with this alternative. Hence, females, elderly, married or previously married, and/or less educated individuals were more likely to move to a long-term facility.

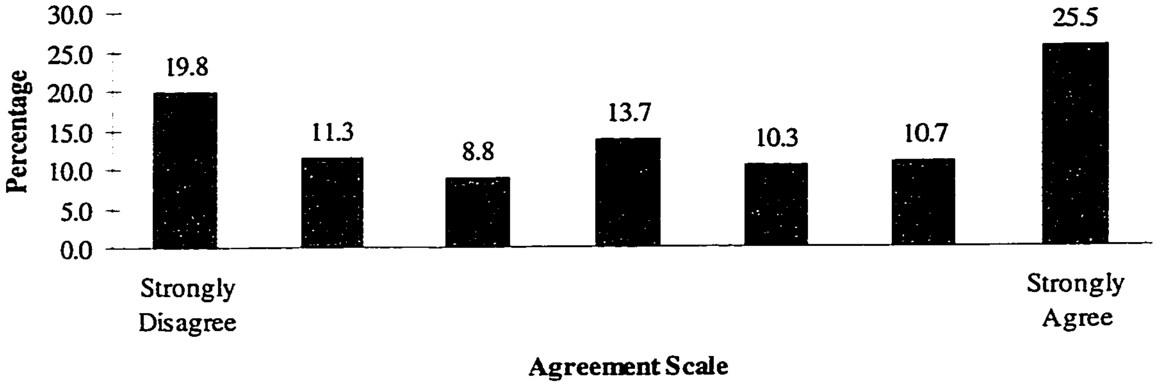
PREFER TO DIE THAN BE DEPENDENT

The final dependent variable is from the statement "I would prefer to die rather than become dependent on others." This statement was used to determine preferences for ending life when faced with a frail old age scenario.

Descriptive Analysis

When respondents were asked "I would prefer to die rather than become dependent on others", respondents overall were quite neutral scoring 4.2, and 47% of respondents agreed with this alternative while another 40% disagreed. Figure 4.10 shows the various response percentages for this alternative.

Figure 4.10: Prefer to Die Rather Than Be Dependent



Bivariate Analysis

A relationship between preferring to die and sex, age and education were revealed during bivariate crosstabulation analysis. Females (49%) were slightly more likely to prefer to die when compared with males (45%). Just over half of the elderly (55%) agreed with this alternative whereas only 40% of respondents aged 18-29 agreed. Crosstabulations with education reveal that the more educated (36%) were less likely to agree to preferring death than high school non-graduates (51%). Consequently, female, elderly and/or less educated individuals were more likely to agree that they would prefer to die rather than be dependent on others.

Summary of Albertans' Responses to End-of-Life Health Care Alternatives

Table 4.4 shows the frequency distributions of responses for the two scenarios regarding terminal cancer and frail old age. While Table 4.4 shows all seven response categories, in this summary, categories 1-3 are combined to represent disagree, 4 represents a neutral response, and categories 5-7 are combined to represent agree. In the first scenario, when respondents were asked to suppose they had found out they had cancer and had been told they had less than a year to live, the majority (58%) agreed to the response option that they would accept whatever treatment was suggested by the doctor. In addition, 63% of respondents did not select the palliative care alternative (refusing all treatment except pain medication). Furthermore, only a small minority (9%) indicated that they would seriously consider ending their own life. Responses also indicated a preference for home care rather than hospital care. That is, 70% of respondents preferred home care whereas only 31% preferred hospital care. Consistent with this result, when asked if respondents preferred to die at home, the majority agreed (56%).

When respondents were asked to suppose they had become old and frail, lived alone and could no longer care for themselves, less than half (41%) felt their "family would care for me". A majority (58%) wanted professional care givers to come to their home, and 60% thought they would "move into a long-term facility". While 47% agreed that they would prefer to die rather than become dependent on others, 40% did not feel this way.

Table 4.4: Percentage of Responses to Statements Describing Alternatives for Care, for Terminal Cancer and Frail Old Age Scenarios

	Percentage of Respondents Disagreeing or Agreeing with Statements Describing Alternatives for Care								
	Strongly Disagree					Strongly Agree		Total	
	1	2	3	4	5	6	7	%[1]	n
If Terminal Cancer									
Accept suggested treatment	13	7	8	14	12	12	34	100	1225
Refuse all treatment except pain medication	37	17	9	13	8	6	11	101	1205
Consider ending own life	77	7	3	4	2	2	5	100	1224
Prefer hospital care	29	12	11	17	9	8	14	100	1216
Prefer home care	9	5	5	12	12	18	40	101	1225
Prefer to die at home	20	7	5	13	6	12	38	101	1195
If Old and Frail									
Family Care	25	12	9	13	13	12	16	100	1225
Professional home care	11	7	8	16	23	18	17	100	1230
Move to care facility	13	7	7	13	14	19	27	100	1228
Prefer to die rather than become dependent	20	11	9	14	10	11	26	101	1213

[1] Differences from 100 are due to rounding error.

Overall, bivariate crosstabulations suggested that age, sex, and education had more significant effects on the subjects' responses for end-of-life health care preferences. More specifically, age was significant with nine dependent variables, and education was statistically significant with eight dependent variables. In addition, sex was statistically significant with seven dependent variables. Hence, it appears that age, sex, and education influence end-of-life health care preferences.

STATISTICAL ANALYSIS: Serious Illness and Elderly with a Serious Illness Scenarios for Edmontonians

Responses given by the Edmonton only sample on the serious illness and elderly with a serious illness scenarios will be used to supplement the Alberta analysis. Each of the specific questions is detailed in the following paragraphs and general frequency results are presented. Bivariate analysis with crosstabulations suggested only three statistically significant relationships, and hence, did not warrant further discussion.

Table 4.5 shows the frequency distributions of responses from Edmontonians for the two scenarios posed on developing a serious illness and being elderly with a serious illness. More specifically, respondents in the serious illness scenario were asked: "If you were to develop a serious illness please tell me how much you would agree or disagree with the following statements - I would rather leave the major decisions to my doctor, I would be in favor of donating my organs after death for transplanting to others, and it is important to leave written instructions ('living will') in the event I am no longer able to make important health decisions." Although almost half (48%) of respondents felt that they would not leave major decisions to the doctor, 40% did indicate that they would. In addition, a large majority (70%) agreed with organ donation and 90% of respondents agreed that a living will is important. Hence, it appears that individuals tend to favor self-involvement in their own treatment decisions.

For the last scenario, respondents were asked "imagine you are elderly with a serious illness, how much would you agree or disagree with the following: I would want to have my life prolonged regardless of its quality, even if my mind failed permanently, I would want my life prolonged indefinitely, and I would want to know about all the possible outcomes from my illness so I could provide treatment directives for doctors and others." When respondents were asked to imagine that they were elderly with a serious illness, the majority (75%) did not want their life prolonged regardless of its quality. Furthermore, 85% did not want their life prolonged indefinitely if their mind failed permanently. A majority (84%) of respondents wanted to know about all possible outcomes from their illness so that they could provide treatment directives for doctors and others. Consequently, these responses indicate that, in general, individuals do not want to have dying extended or they do not want to be a vegetative state at the end-of-life. Moreover, these responses indicate that individuals are generally inclined to make autonomous decisions and to take an active role in their treatment planning.

Table 4.5: Percentage of Responses to Statements Describing Alternatives for Care, for Serious Illness and Elderly With Serious Illness Scenarios

	Percentage of Respondents Disagreeing or Agreeing with Statements Describing Alternatives for Care								
	Strongly Disagree 1	2	3	4	5	6	Strongly Agree 7	Total %[1]	n
If Develop Serious Illness									
Leave Major Decisions to Doctor	27	11	10	12	13	12	15	100	315
In Favor of Donating Organs	11	3	3	13	7	14	49	100	310
Have a Living Will	2	1	2	5	7	21	62	100	314
If Elderly with a Serious Illness									
Want Life Prolonged, Regardless of Quality	46	21	8	9	6	4	6	100	317
Even if Mind Failed, Would Want Life Prolonged Indefinitely	65	15	5	7	1	3	3	99	317
Want to Know About All Possible Outcomes to Provide Treatment Directives	2	2	2	10	10	22	52	100	312

[1] Differences from 100 are due to rounding error.

RESEARCH QUESTION #2: Has the basic direction of health care restructuring in Alberta been consistent with public opinion regarding end-of-life health care issues?

ARE END-OF-LIFE HEALTH CARE PREFERENCES CONSISTENT WITH GOVERNMENT HEALTH CARE RESTRUCTURING?

In order to determine whether the basic direction of health care restructuring in Alberta has been consistent with public opinion on end-of-life health care preferences, frequency distributions from the cancer, frail old age, serious illness, and elderly with a serious illness scenarios are compared against Alberta Health's Annual Reports from 1989-90 to 1997-98. Alberta Health Annual Reports are the best source of information on health care restructuring and health care system planning. Two main reform goals relevant to this study were noted in the Alberta Health documents: increased home care and implementation of personal directives.

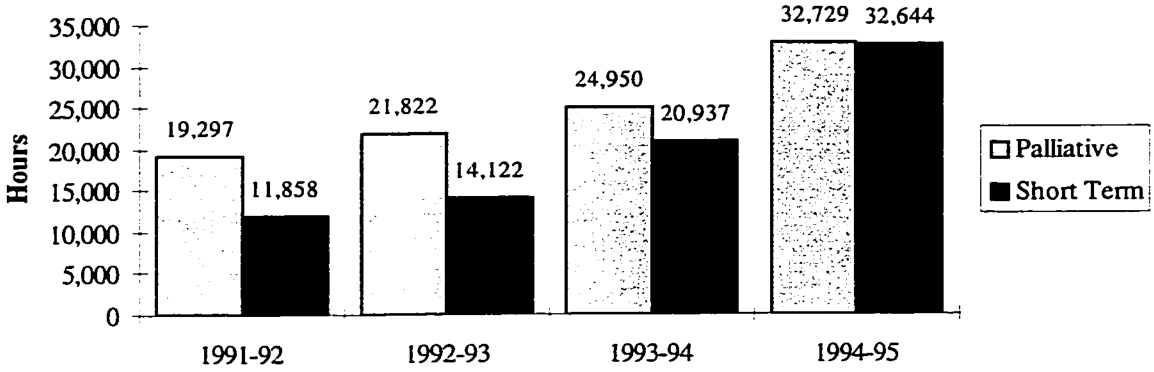
Home-Based Care Versus Hospital-Based Care

Government literature on health care restructuring demonstrated de-institutionalization and streamlining from institutionally-based care to community-based care as consistent themes (Alberta Health, 1994 & 1995a). In addition, annual reports filed by Alberta Health from 1989-90 to 1997-98 indicate this trend. Early annual reports filed in 1989-90 and 1990-91 did not contain conclusive figures on home care funding (Alberta Health, 1990 & 1991). Consequently, it is not apparent how much money was allocated to home care from 1989-90 to 1990-91. In the 1991-92 budget year, approximately 1.6% or $64 million was spent on home care in comparison to $4 billion total health care spending (Alberta Health, 1992). The following year, the 1992-93 Annual Report indicated that 1.7% or $72 million was spent on home care services (Alberta Health, 1993), and in 1993-94, approximately $87 million was spent on home care services across Alberta (Alberta Health, 1994b).

Beginning in the 1994-95 budget year, Alberta Health began to distribute $30 million of $110 million scheduled for community-based services (Alberta Health, 1995b). This strategy was executed to "provide new community care services to help people remain in the community and defer placement in long-term-care facilities as long as medically appropriate" (Alberta Health, 1995b: 24). In addition, this funding was used to "meet the needs of: people discharged from hospital at an earlier stage of recovery and needing rehabilitation, nursing, and/or support services; women requiring assistance because of early maternity discharge; people with long-term-care needs who would otherwise remain in hospital or who were waiting for a long-term-care bed; and people choosing to die at home rather than in the hospital" (Alberta Health, 1995b: 24). Furthermore, Alberta Health in the 1994-95 budget year reallocated a one-time transition fund of $800,000 to the Regional Health Authorities to assist them in supporting high-need home-care clients in the community. Unfortunately, the 1994-95 Annual Report did not state total home-care expenditures. It did however report the amount spent on community and home-based services for all Health Authorities ($151 million or 4.8% of health expenses).

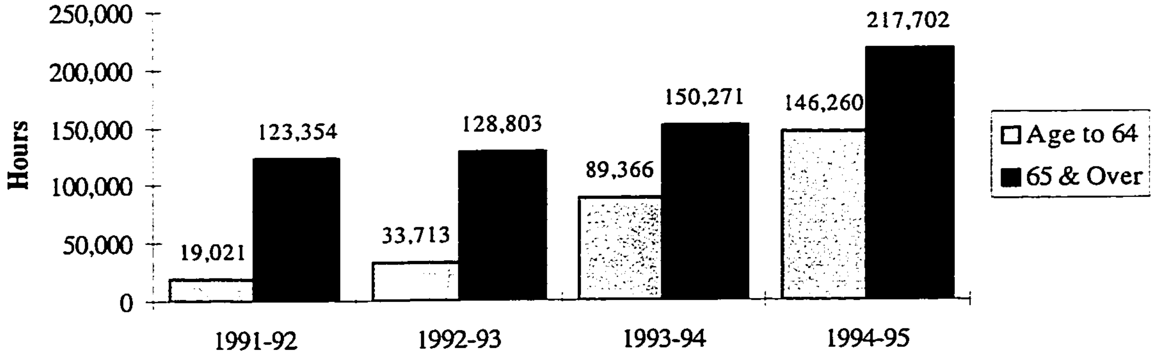
The 1995-96 Annual Report also indicates another $40 million in new funding to support the shift to community services (Alberta Health, 1996). Reallocating acute care funds to community-based acute, long-term, and palliative care services enhances the likelihood of availability of home-based care across Alberta. During this shift to more home-based care, the amount of acute care funding was being reduced. Acute care funding was decreased by the government in 1993 and 1994, and continued by the Regional Health Authorities in the following years. Approximately, 50% of the acute care beds closed in Alberta between June 1993 and the fall of 1996 were, as a result, redistributed to the home. For example, Alberta Health Annual Reports from 1991-92 to 1997-98 indicate increases since 1991-92 in palliative and short-term acute care and continuing care services in the home (Figure 4.11 & 4.12). In addition, the 1996-97 Alberta Health Annual Report indicates that the number of continuing care beds per 1,000 and the percent aged 75 and over in facilities has also decreased since 1991-92 (Table 4.6). Consequently, with regards to health care, a shift has occurred from institutional settings to homes and communities. Overall, the provincial cost of community and home-based services was approximately $174 million and represented 5.8% of 1995-96 budget year's total expenditure.

Figure 4.11: Acute Care Services in the Home, 1991-92 to 1994-95



Source: Alberta Health, 1996

Figure 4.12: Continuing Care Services in the Home, 1991-92 to 1994-95



Source: Alberta Health, 1996

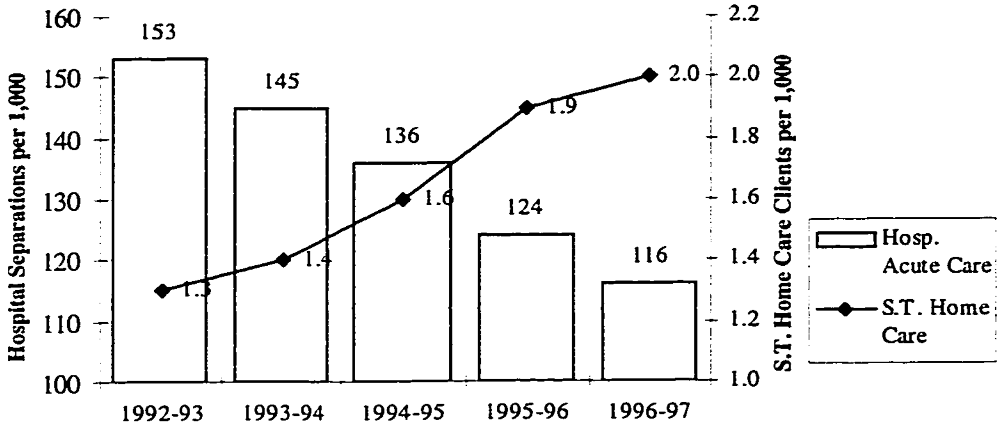
Table 4.6: The Use of Continuing Care Facilities, 1991-92 to 1995-96

	1991/92	1992/93	1993/94	1994/95	1995/96
Continuing care beds per 1,000	55.7	53.9	52.8	51.0	51.3
Percent aged 75+ in facilities	10.8	10.7	10.3	9.9	9.5

Source: Alberta Health, 1996.

In the budget years 1996-97 and 1997-98, Alberta Health reported a continuation of increasing short-term home care, and reduced average length of hospital stay (Alberta Health, 1997b; Alberta Health, 1998; see Figure 4.13 & Table 4.7). Annual Alberta Health reports indicated that a total of $188 million in 1996-97 and $210 million in 1997-98 were spent on community and home-based services, these figures represent 6.3% and 6.5% of annual expenses. Although overall trends indicate an increase in funding for community and home-based services, it is unclear what proportion of these expenses are for home-care. That is, community and home-based funding supports services which include everything from education classes and diagnostic services to respite and home care. Consequently, a precise indication of how much money was shifted to home care from hospital care is difficult to determine.

Figure 4.13: Trends in Utilization of Acute Care Hospitals and Short-Term Home Care, 1992-93 to 1996-97



Source: Alberta Health, 1998

Table 4.7: Average Length of Hospital Stay, 1992-93 to 1996-97

Measure	1992-93	1993-94	1994-95	1995-96	1996-97
Average Length of Hospital Stay (days)	6.9	6.6	6.1	5.6	5.7

Source: Alberta Health, 1998.

The previous reported analysis of frequency distributions of the 1990 All Alberta Survey questions on both the cancer and frail old age scenarios suggested a strong public preference for home care (see Table 4.4). In particular, in the cancer scenario, 70% of respondents agreed that they would prefer home care whereas only 31% of respondents preferred hospital care. Furthermore, females (45%) were more likely to strongly agree to prefer home care when compared to males (35%). In addition, 81% of younger (aged 18-

29) respondents and 76% of University graduates preferred home care. With respect to marital status, the never-married (75%) and married (72%) indicated a preference for home care as did 72% of the respondents with strong religiosity. Overall, results suggested that individuals who would reject hospital care are more likely to be young, single, highly educated, and/or have a household income over $60,000. Combining results from these two dependent variables ("I would prefer to be cared for in a hospital" and "I would prefer to be cared for in my own home") it appears that respondents most likely to favor home care over hospital care are often young, highly educated and/or single.

From the old and frail scenario, a majority (58%) of respondents indicated that they would want professional care givers to come to their home. Furthermore, female, elderly, and those who live alone are more likely to want professional care-givers in their home. When asked if their family would care for them, respondents were divided with 41% agreeing and 46% disagreeing. More specifically, individuals more likely to agree to family care were males, young, never-married and/or highly educated respondents. In addition, a long-term care facility, such as a nursing home, was considered to be an option for many respondents (60% agreeing). Female, elderly, married or ever-married, and less educated individuals are more likely to choose to move to a long-term facility. Hence, overall most respondents were in favor of non-hospital based care, especially female and elderly persons. Although more elderly respondents (65%) appeared to prefer home care in the old and frail scenario when compared to the cancer scenario (58%), the majority of elders did prefer home care. The youngest age group had more ambiguous results. More specifically, 81% of respondents aged 18-29 preferred home care in the cancer scenario, but only 54% agreed to home care in the frail old age scenario. Consequently, more research on preferences for home care and its relationship to age must be done. Nevertheless, these general findings are consistent with the 1993+ health system restructuring in Alberta.

Personal Directives

In December 1997, the *Personal Directives Act* was passed (Alberta Health, 1998). This Act legalized the use of advance directives in hospitals and other places of care, and gave individuals more autonomy over end-of-life decision-making. From the analysis of Edmontonians responding to the two scenarios on having a serious illness and being elderly with a serious illness, it was evident that most respondents had a preference for using advance directives to guide health care decision-making (see Table 4.5). For example, within the developing a serious illness scenario, results were divergent as to whether or not respondents wanted to leave major decisions to the doctor. Although a majority (48%) disagreed to this option, 40% of respondents did agree to the option of leaving major decisions to the doctor. Bivariate crosstabulations indicated that 81% of elderly (65+) respondents and 67% of respondents without high school completion agreed to leave the major decisions to their doctor. Consequently, age and education are relevant variables when considering leaving major decisions to the doctor.

Results from the other two responses in this scenario provide support for individuals wanting to indicate their end-of-life wishes. Overall, 70% of respondents were in favor of donating their organs, and, more importantly, 90% of respondents felt that it was important to leave written instructions (living will) in the event that they were no longer able to make important decisions. Results also indicated that young (69%) respondents aged 18-29 were more likely to agree to the donation of organs when compared to elderly (48%) respondents aged 65 and over.

Results from the elderly with a serious illness scenario, revealed a general preference to not having their lives prolonged regardless of its quality (75%) and if their mind failed (85%). In addition, 84% of respondents indicated that they would want to know all possible outcomes of their illness in order to provide treatment directives for doctors and others. Consequently, respondents in general appear to be willing to make their own decisions and provide written instructions indicating their care preferences. More specifically, younger respondents are even more enthusiastic about being involved in health care decision-making. These results are consistent with the implementation of the *Personal Directives Act* (1997) whereby individuals are able to indicate their end-of-life care wishes and thus preserve autonomous decision-making when they are no longer able to be involved in decision-making.

CHAPTER SUMMARY

General findings using univariate statistics such as frequencies, percentages, and means indicated what public opinions on end-of-life health care preferences existed prior to health care restructuring in Alberta. In addition, bivariate analysis using crosstabulations revealed that the most significant independent variables for end-of-life health care preferences were age, sex, and education. Hence, it appears that end-of-life health care preferences, such as home care and making autonomous decisions, are supported by the frequency distributions and crosstabulations.

The comparative/evaluative methodology used for the second research question yielded results consistent with health care restructuring in Alberta. For example, in general, Albertans tended to prefer home care to institutional care. In addition, consistent with Alberta's new health care agenda, Edmontonians felt that making autonomous end-of-life health care decisions were quite important in the event that they could no longer do so. This preference is consistent with the *Personal Directives Act* of 1997. In summary, these end-of-life health care preferences existing before health care restructuring were consistent with two of the Alberta government's health care restructuring strategies.

CHAPTER FIVE

DISCUSSION

INTRODUCTION

One of the reasons this study was conducted was to initiate an understanding of end-of-life health care preferences prior to health care restructuring in Alberta. In this chapter, the research findings presented in Chapter Four in relation to the research questions put forth in Chapter Three are summarized. Overall, this study addressed two main issues. The first issue was determining public opinion regarding end-of-life health care preferences prior to the deficit elimination strategy implementation and furthermore, what socio-demographics were related to end-of-life health care preferences. The second issue addressed in this study was to determine whether Alberta's health care restructuring beginning in 1993 has been consistent with public opinion regarding end-of-life health care issues.

This chapter is separated into two main divisions. The first division is a general discussion, and the second division indicates the limitations of this study and recommendations for further research. The first division begins the chapter with a discussion of the general research findings presented in the previous chapter. In addition, the discussion includes cross references to existing literature presented in Chapter Two, and the implications of this research for end-of-life discourse. The discussion is followed by the second division detailing the limitations of this study, and the chapter proceeds by offering recommendations for further research. A brief summary will conclude the chapter and the thesis.

DISCUSSION

This section is separated into four subdivisions. The first subdivision discusses public opinion regarding end-of-life health care preferences prior to health care restructuring in Alberta. This section is then followed by an explanation of the socio-demographic variables which influence end-of-life health care preferences. The next subdivision details an analysis of whether government restructuring has been consistent with public opinion regarding health care preferences. Concluding this section is a discussion of the implications of this study for continuing end-of-life discourse and future health system restructuring strategies implemented provincially and federally.

Public Opinion Regarding Consumer Preferences for End-of-Life Care Prior to the Onset of the Alberta Government's Deficit Elimination Strategy

Prior to this study, it was not evident what general end-of-life health care preferences existed prior to government-lead health system restructuring in Alberta. Current literature on end-of-life decision-making often focuses on terminal patients, the elderly, or individuals with disabilities (Anderson, Felsenthal, & Anderson, 1994; Bailly & DePoy, 1995; Cicirelli, 1997; Lewis, Pearson, Corcoran-Perry, & Narayan, 1997). More general literature indicates that public opinion regarding end-of-life decisions is often influenced by prognosis, religious activity, and age (Denk, Benson, Fletcher, &

Reigel, 1997; Genius, Genuis, & Chang, 1994; Singer et al., 1994). Moreover, existing literature was furthered by the statistical analysis in this descriptive/applied study revealing attitudes and preferences of the general public on end-of-life care.

Using data from the 1990 All Alberta Survey, some end-of-life health care preferences Albertans had prior to health care restructuring during 1993-1996 were determined. Results from the cancer scenario revealed that the majority of Albertans would accept treatment suggestions made by their doctor. In addition, most Albertans presented with the cancer prognosis scenario did not prefer palliative care. Furthermore, most respondents indicated that they would not consider committing suicide. Hence, it seems that given the situation of being diagnosed with terminal cancer, Albertans, in general, would continue to live their lives while accepting their doctor's treatment decisions, and at the same time, they would refuse palliative care, perhaps in the hope that the terminal cancer could be treated.

When examining preferences for home care versus hospital care, the cancer scenario once again asked relevant questions. General frequency results indicated that the majority of Albertans would prefer home care. Although respondents were not asked to choose between the two options (home care versus hospital care), each separate question indicated a preference for home-based care and a lack of preference for hospital-based care. Furthermore, the majority of Albertans also preferred to die at home. These results indicated general public preference for home care in Alberta prior to health care restructuring.

Additional confirmation of Albertans' preference for home care was found in the frail old age scenario results. Statistical analyses from this scenario disclosed that most Albertans, in general, did not expect family care and would prefer professional care in the home although many expect to move to a long-term facility. Consequently, Albertans did have preferences for end-of-life health care prior to government cutbacks, and the public opinion of Albertans that existed prior to health care restructuring favored home care over institutionalized care. The analysis of public opinion regarding end-of-life preferences prior to government cutbacks permits the discussion of which socio-demographic factors influence public attitudes on end-of-life care.

The Influence of Socio-Demographic Factors on End-of-Life Health Care Preferences

Few studies identify or describe factors influencing public opinion regarding end-of-life decisions (Denk, Benson, Fletcher, & Reigel, 1997; Genius, Genuis, & Chang, 1994; Singer et al., 1994). Moreover, recent research indicates that public opinion regarding end-of-life decisions may be influenced by patient prognosis (Singer et al., 1994). More specifically, when Canadians are given hypothetical situations whereby patient prognosis ranges from likely to unlikely to recover from the illness, they often support laws permitting decisions to forego life-sustaining treatment, assisted suicide, and euthanasia for patients who are unlikely to recover (Singer et al., 1994). Unfortunately, studies of preferences for home care or hospital care have not been published. Consequently, this descriptive/applied study fills the gap by revealing which socio-demographic factors influence end-of-life health care preferences (including home care versus hospital care and considerations of ending their lives) for Albertans.

Bivariate analyses using crosstabulations with the seven point likert scale revealed that age, sex, and education were the most significant variables in explaining end-of-life health care preferences. A summary of which dependent variables age, sex, and education were significant with is presented, and is then followed by three separate paragraphs detailing the specific nature of the significant relationships.

Overall, age was statistically significant with all dependent variables except the palliative care option in the cancer scenario. In addition, education was statistically significant with eight of ten dependent variables. More specifically, in the cancer scenario, education was significant with the following five dependent variables: accept suggested treatment, refuse all treatment, prefer hospital care, prefer home care, and prefer to die at home, and in the frail old age, education was significant with family care, moving to a long-term facility, and a preference to die rather than be dependent. Sex was also significant with all of the frail old age variables, but in the cancer scenario was significant only for accepting suggested treatment, preferring home care, and preferring to die at home. Consequently, it appears that end-of-life treatment decisions, especially ones concerning home versus hospital care and informal versus formal caregivers, are influenced by the unique age, gender, and/or educational level of the individual.

With regards to sex, females are more likely than males to prefer home care, professional home care, a move to a care facility, die at home and to die rather than become dependent on others, while males are more likely to expect to rely on family care.

Consequently, since informal caregivers are usually involved in each of these end-of-life care alternatives except family care, it appears that males, when compared to females, expect to rely on informal support during end-of-life care situations.

Analysis also indicated that more educated respondents preferred home care, dying at home, and having their family care for them. Less educated respondents preferred hospital care, and preferred to die rather than be dependent on others. Overall, these results reveal some ambiguous issues. For example, "home care" in the cancer scenario is not defined for the respondents. However, this distinction is clear in the frail old age scenario. Hence, some respondents may think the question is asking that their family would care for them at home and others may think that professionals would come into the home to care for them. Consequently, there is a confusion as to whether the home care support is formal or informal. This confusion or lack of definition may be a reason as to why more educated individuals prefer home care in the cancer scenario, but would have family care in the frail old age scenario. On the other hand, it may be that more educated individuals think that being old and frail may be a tolerable situation to have family members care for them whereas having cancer may be a circumstance too demanding and would need professional caregivers. Unfortunately, these ambiguities cannot be distinguished unless respondents were interviewed to expose what their definition of home care is.

Results from the age variable analysis also indicated some ambiguities. For example, elderly respondents were more likely to want professional care in the home in the frail old age scenario, but did not prefer home care in the cancer scenario. Once again, it is impossible to distinguish whether this difference is due to the scenario or due to the ambiguity of what “home care” entails. In addition, elderly were more likely than their younger counterparts to prefer hospital care, a move to a continuing/long-term care facility, and dying rather than being dependent. This ambiguity issue will discussed further in the limitations and recommendations section.

Current literature on end-of-life decision making usually focuses on either using or refraining from using medical technology to prolong life (Genuis, Genuis, & Chang, 1994; Singer et al., 1995; Wilson, 1997). Furthermore, existing literature shows strong effects of prognosis on public opinion regarding end-of-life decisions (Singer et al., 1995). Unfortunately, literature on general public preference for home care or hospital care and preferences of informal or formal caregivers is lacking. Results from this survey expand current literature by indicating general preferences for end-of-life health care, and exhibit some of the socio-demographic variables influencing these decisions. Consequently, when examining policies and procedures for end-of-life care, one should consider age, sex, and education as possible influencing factors.

Health Care Restructuring and Its Consistency with Public Opinion

Recent literature encourages public participation in the process of deciding health care issues (MacKean & Thurston, 1996; Yeo, 1996). Prior to and during Alberta’s deficit elimination years of 1993-96, the Alberta government expressed their objective of listening to concerns and views of Alberta’s residents. By implementing a health care restructuring strategy which focused on resource allocation, de-institutionalization, and indirectly the 'high cost of dying', one area the government ended up concentrating on was end-of-life treatment decisions. Therefore, combining public participation and end-of-life health care preferences places an emphasis on recognizing what end-of-life preferences existed prior to health care restructuring. Comparing these preferences with restructuring strategies that took place reveals whether health care restructuring has been consistent with public opinion. The comparative/evaluative portion of this study revealed that two health care restructuring concepts were supported by data from the 1990 All Alberta Survey: increased home care and implementation of personal directives.

An analysis of Alberta Health Annual Reports (1989-98) revealed that more public funds were allocated to home care services. Furthermore, frequency results indicated that, in general, Albertans had a preference for end-of-life home care. As mentioned in the previous section and chapter, age, sex and education differences existed in relation to preferring home care to hospital care. Nevertheless, although some ambiguities resulted with respect to age and education, overall frequency figures indicate that the majority of Albertans preferred non-hospital based care at the end-of-life. Likewise, even though there were percentage differences between young and old, female and male, and more educated and less educated, the majority within each respective category agreed to home care and to professional caregivers in the home. Therefore, since the majority of respondents indicated a preference for home care if old or dying, health care restructuring in Alberta has been consistent to some degree with public opinion.

Frequency analysis from the Edmonton-only sample revealed that respondents, in general, had a preference for using advance directives to guide health care decision-making. That is, the majority of respondents preferred to make autonomous decisions and wanted to provide written instructions indicating their preferences. The implementation of the *Personal Directives Act* in 1997 responds to these preferences by allowing individuals to indicate their end-of-life care wishes. Consequently, with regards to personal directives, health care restructuring in Alberta was consistent with public opinion.

Implications for Current End-of-Life Discourse and Health Care Restructuring in Alberta

Studying end-of-life care has been encouraged by discussions of an aging population, moral debates of 'quality of life versus quantity of life' and issues of the 'high cost of dying'. Research accomplished in this study contributes not only to end-of-life discourse, but also to literature on health care restructuring in Alberta. Furthermore, analysis conducted in this study revealed general preferences of what Albertans preferred regarding end-of-life care. Hence, results provide an extension beyond existing end-of-life literature. That is, preferences for individuals, in general, are presented, and this leads to further examination of socio-demographic factors which may have a bearing on their end-of-life health care preferences.

In addition, data analysis unveiled that age, sex, and education are influencing factors in end-of-life decisions. Knowing which variables contribute to end-of-life decisions aids the government when assembling focus groups and research teams. For instance, when looking for public input on end-of-life preferences and health care restructuring, one would want to have both men and women, old and young, highly educated and less educated individuals expressing their opinions. This will lead to a more representative examination of these topics, and will help provide beneficial information for administrators and politicians to utilize in their health system restructuring endeavors.

Moreover, this research will contribute to existing academic literature on health care restructuring in Alberta. Currently, some investigation has been conducted on Albertans' attitudes towards budget cuts in Alberta, the effects of health care restructuring on public sector employees, and the effects of cutbacks on seniors (Hughes et al., 1996; Maurier, 1996; Wilson & Kerr, 1998). This research expands the existing end-of-life literature by disclosing what end-of-life health care preferences Albertans had prior to these cutbacks, and details how some health system restructuring endeavor were consistent with these preferences. Consequently, the addition of this subject matter to existing provincial literature examining health care restructuring provides the government with beneficial documentation of what Albertans prefer.

From the current analysis of Alberta's health system restructuring and its consistency with end-of-life health care preferences of Albertans, it appears that with regards to home care and personal directives, the government's reform strategy was appropriate. Although there has been significant dissent about health system restructuring in the media, some obstacles may have been avoided if Albertans knew they had wanted increased funding for home care and increased opportunity for self-determination. Accordingly, government restructuring which involves public participation may be the optimal route to undergo when dealing with contentious issues of reforming government services. Hence, provincial and national governments may examine the societal implications of the Alberta deficit elimination strategy and imitate public participation in reform.

LIMITATIONS AND RECOMMENDATIONS

Based on the findings in this study, several limitations are recognized and recommendations for further research are offered. The use of a secondary data, cross-sectional quantitative survey research design inherently has methodological limitations. One constraint is the use of cross-sectional data which limits the ability to make legitimate claims about the causal directions in the associations observed. Consequently, this creates difficulties in building broad generalizations. In addition, the cross-sectional design cannot separate age and cohort effects.

Another deficiency of this study is the use of secondary data analysis. When using secondary data, one is restricted to the questions asked on the survey. Furthermore, one is restricted to the wording of the questions and the operationalization of variables. Consequently, some of the questions may not ask exactly what the researcher wants. For example, the use of the term "home care" in the cancer scenario did not clarify whether it entailed formal or informal caregivers. This created confusion as it is not possible to know what the respondent thinks "home care" is, and furthermore, this may lead to misguided responses by respondents. In addition, the terminology used in some of the questions may elicit extremist or non-extremist responses. For example, in the cancer scenario, the following two responses were asked: "I would accept *whatever* medical treatment is suggested by my doctor" and "I would refuse *all* treatment except pain medication". The words *whatever* and *all* turn the response into an extreme one. That is, responses given by individuals may determine that they are extremists or non-extremists, not their actual health care preferences for end-of-life alternatives. Hence, the use of secondary data may contribute to misinterpretations by future researchers or may elicit inaccurate responses by individuals being interviewed.

Another limitation of the 1990 All Alberta Survey data is the boundaries associated with the region variable. In this survey, region was separated in the following categories: city, town, village, rural area, Calgary and/or Edmonton. Since Alberta's health system restructuring created seventeen Health Authorities based on region, it is unfortunate that the regional boundaries used in 1990 do not and cannot be used to determine which of the seventeen regions each of the respondents belong. In future studies, it would be interesting to have respondents coded with respect to what Regional Health Authority they belong to. More specifically, researchers could examine whether end-of-life health care preferences differ depending on the availability of hospitals and/or home care facilities in their region. By separating respondents into their respective Regional Health Authority, comparing end-of-life health care preferences by region would be much more intriguing and hence, should be pursued in the future.

Using the 1990 All Alberta Survey data, a future researcher could further this study by combining some of the dependent, response variables into a scale. More specifically, preferences for home care over hospital-based care could be represented by creating a scale from the following three items asked in the cancer scenario: "I would prefer to be cared for in a hospital", "I would prefer to be cared for in my own home", and "I would prefer to die at home". That is, using factor analysis, one can create a scale for home care, and then examine the relationship of this scale with socio-demographic factors. The creation of a scale strengthens an analysis by examining the cases in terms of dimensions rather than each variable separately (Kim & Mueller, 1978). Consequently, existing data analysis from this study will be expanded upon, and end-of-life discourse will be extended.

Data from the 1990 All Alberta Survey had another deficiency built into the questions. Likely due to financial constraints, some of the questions were only asked of individuals living in Edmonton. This led to a small sample size for the Edmonton sample, and hence, reinforced the inability to generalize the results from the serious illness and elderly with a serious illness scenarios. Therefore, these scenarios were only used to supplement the Alberta analysis, and cannot be used to generalize beyond the Edmonton sample. Hence, although the use of secondary data offers the conservation of time and money, it does lead to some disconcerting issues.

The use of survey questions in this study did provide some advantages over other forms of public participation such as focus groups. For instance, the survey questions attempted to determine widespread public opinions and preferences by examining a random sample of respondents. Furthermore, survey questions may lead respondents' answers less than focus groups where an agenda is often in place prior to the subjects entering and participating. In addition, respondents are less likely to be swayed by the interviewer following a structured interview format whereas the possibility exists more in focus groups. Hence, focus groups are sometimes subject to manipulation and can be affected by the types of respondents selected. The use of a random sample survey promotes a type of public participation which elicits a more representative range of the public's knowledge base about the topics being discussed. Hence, a more representative sample leads to more generalizable results which can be used to supplement focus groups and other forms of public participation.

Additional limitations of this study occurred in the answering of the second research question regarding the consistency of health care restructuring in Alberta with public opinion. Due to the lack of available resources, it was difficult to tie the results from the survey to policy. Alberta Health Annual Reports did provide the best source for this, but since the questions were not designed to tie back directly to these reports, I had to determine which concepts asked in the questions were expressed in health care restructuring themes. This led to the discussion on home care versus hospital care and the discussion of personal directives. In addition, I was limited to the minute amount of information available on home care funding prior to the split into 17 Regional Health Authorities. Consequently, it was difficult to determine exactly how much funding was available for home care in the early 1990s. Furthermore, this study was limited to using the Alberta Health Annual Reports to indicate what health system changes and reform occurred.

In addition, discrepancies with respect to the preference for home care were noted. The preference for home care may be evidence of increased concern for quality of life whereby the comforts of home are often viewed as a more favorable location for end-of-life care. This idea is consistent with recent research conducted by Wilson (1998) whereby qualitative interviews revealed that the large majority of elderly citizens with caregiving experience felt that "the optimal place of end-of-life care and subsequent death was the home" (pp. 14). Although Wilson (1998) indicated finding a preference for home care among elderly individuals with caregiving experience, my results using the 1990 data indicated that the majority of elderly respondents favoring home care was not as significant for the cancer scenario when compared to the frail old age scenario. More specifically, approximately 58% of elderly favored home care in the cancer scenario, and almost two-thirds (65%) of elderly respondents favored home care in the frail old age scenario. Furthermore, the elderly were not in favor of dying at home in the cancer scenario. Consequently, these inconsistencies reveal the necessity to further examine what end-of-life health care preferences the elderly, in general, have at this time. That is, is there a change in the perception of home care for the elderly? Do the elderly prefer home care in some situations, but not in others? Since there is almost a decade spanning the two research endeavors (the 1990 All Alberta Survey, Wilson, 1998), it would be interesting to see if the elderly's preferences for non-hospital based care have changed. That is, attention in future research should be directed at determining what general preferences for end-of-life care elderly individuals have (quantitative surveys), and furthermore, combining these results with the use of qualitative studies to determine specifics regarding those preferences strengthens the research.

Future research on end-of-life discourse would definitely benefit by the combination of quantitative and qualitative designs. Goodwin and Goodwin (1984) promote the use of combining both qualitative and quantitative strategies in a single research design. Applying this method would enhance literature by revealing general preferences of end-of-life health care through quantitative designs and exploring specific, and personal accounts of end-of-life health care preferences through qualitative designs.

Other research can enhance this study through the use of qualitative designs. More specifically, follow-up interviews conducted on respondents who answered the 1990 All Alberta Survey may provide further insight into how respondents define "home care", and why the elderly may prefer home care when old and frail, but not to the same degree when they have cancer. In addition, since age, sex, and education influence end-of-life health care preferences, it is important to conduct in-depth interviews with individuals varying in these areas. That is, old, young, male, female, less educated and more educated individuals should *all* be involved in qualitative studies. Examining opinions for each of these groups of individuals would strengthen existing literature on end-of-life health care.

Another area requiring further examination is the effect of individual experience with hospitals. Currently, research exists on end-of-life preferences of seniors with caregiving experience (Wilson, 1998). A more detailed, qualitative inquiry into how an individual's prior experience with hospitals affects their end-of-life health care preferences is necessary. Such a study would broaden existing end-of-life discourse by adding a perspective which examines the effects of experience and possibly, life cycle effects.

One of the most important areas that requires further examination involves conducting a comparative analysis. Preferences regarding end-of-life health care that existed prior to health care restructuring were revealed in this study. Hence, a "before" picture of end-of-life health care preferences exists. Further research should embark on a more current study by repeating these end-of-life survey questions (or comparable ones) to Albertans. That is, a quantitative survey should ask Albertans these end-of-life health care preference questions as soon as possible in the new millennium. This would then provide an "after" picture, and therefore, a before and after comparative study could be done. These results would indicate whether any changes in preferences for end-of-life care have occurred since health care restructuring and after changes in health to the personal circumstances of the respondents. Consequently, research entailing the changes in end-of-life health care preferences which have occurred due to health care restructuring in Alberta and other life events would enrich not only academic research, but also government literature.

CHAPTER SUMMARY

In conclusion, this cross-sectional, secondary data analysis provided some evidence of what end-of-life health care preferences existed prior to health care restructuring. From the results, it is also evident that some socio-demographic variables, such as age, sex, and education influence preferences, and that health care restructuring in Alberta has been consistent to some degree with public opinion regarding preferences for home care and personal directives. The methodological limitations were outlined in this chapter, and were followed by recommendations for future research. Overall, this thesis implies that public participation could be an extremely important prerequisite of health system reform, and telephone surveys would enhance the existing use of focus groups and advisory boards. Furthermore, the massive overhaul of the Alberta health care system has had implications for Albertans, and current end-of-life opinions and preferences of Albertans must be examined in order to detail how restructuring itself affects these preferences. Hence, this study provides a preliminary discovery into Albertans' end-of-life health care preferences, and entices further research.

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APPENDIX A

DEPRESSION SCALE

A depression scale was created using the following questions from the 1990 All Alberta Survey:

1. I am going to read a list of problems and complaints that people sometimes have. In the past year, how much were you distressed by....

a) feeling no interest in things
b) feeling blue
c) feeling lonely
d) feeling hopeless about the future
e) feeling sad or depressed
f) feelings of worthlessness
g) thoughts of death and dying
h) thoughts of ending your life

Respondents were asked to answer on a scale of 1 to 5:
1 - not at all
2 - a little bit
3 - moderately
4 - quite a bit
5 - extremely

Overall, the scale had a reliability of $\alpha = .83$ and responses potentially and actually ranged from 8 to 40. Hence, respondents with a score of eight were not at all depressed and a score of forty indicated an extremely depressed respondent. Responses were then combined in four categories: 8-15, 16-23, 24-31, 32-40.