A QUALITATIVE ANALYSIS OF THE PROCESS OF DEVELOPING AND IMPLEMENTING DO NOT RESUSCITATE AND DEGREES OF INTERVENTION POLICY IN LONG TERM CARE SETTINGS IN BRITISH COLUMBIA

by

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ABSTRACT

This descriptive qualitative study examines the process of developing and implementing policies on two types of advance directives, Do Not Resuscitate (DNR) and Degrees of Intervention (DI), in Long Term Care (LTC) facilities in British Columbia.

Thirty-three participants from twenty-three LTC facilities engaged in face to face or telephone interviews. The facilities were randomly selected to represent four regions of the province. The semi-structured in-depth interview format was comprised of questions pertaining to the policy process particularly in relation to the impact of the 1989 provincial guideline documents "Death and Dying in Long Term Care Facilities".

A thematic analysis of the qualitative data illuminated several findings. Respondents identified feelings of uncertainty, fear of legal sanctions, concern for resident rights to self-determination and the desire for residents to die in place as problems related to DNR and DI prior to the release of the 1989 guidelines.

Consequently, the respondents described a process of first clarifying these problematic situations and then defining specific procedural and moral circumstances that required action. The definitive problems which emerged involve not only unwritten agency policy, but unclear doctor's orders, absent and existing legislation, divergent value perspectives on resident autonomy and the meaning of death in LTC facilities.

For all the facilities in the study, the process of developing and implementing agency policy on DNR and DI was enhanced by the information provided in the 1989 provincial government guideline documents. Additionally, individual attitudes, group perspectives both internal and external to LTC facilities, and structural and functional components of the LTC organization were identified as influences on the policy development process. Five distinct types of policy paths that led to development of DNR and DI policy were evident. Eventual approval of a DNR or DI policy in a LTC facility resulted from a process of consensus encompassing many different perspectives.

The respondents described a number of unique factors which influenced implementation of DNR and DI. These include individual styles of communicating the policy issue, the amount of time available to discuss the policy, and the degree education (basic and inservice) of care staff and doctors around issues related to DNR and DI.

This study underscores the significance of public policy-making in local units and the importance of practitioners as policy-makers in the policy development process. Future research directed toward illuminating policy networks between nurses practicing in LTC settings would be beneficial. Finally, studying the impact of implementing DNR and DI policies on care staff, residents and families would provide insight into the realities of resident choice, informed consent and discretionary decision-making.

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DEDICATION

It is with great honour, love, respect and sadness that I dedicate this thesis to my daughters, Keri, age 13 years, and Kelsa, age 11. You are my world!

You learned to adapt to a new home, life-style, school and gained wisdom, maturity and many good friends. You packed, re-packed, and battled ferry line-ups with grace and never complained. I treasure our time together and always wish for more, but realize that you have given me the most wonderful gift of all, unconditional love. I hope you will always remember:

"Life begets life.
Energy creates energy.
It is by spending oneself
That one becomes rich.

Sarah Bernhardt

CHAPTER I

INTRODUCTION

During my years of nursing elderly people who were dying, I have been unable to accept organizational policies which do not recognize a person's right to autonomy to choose an appropriate death rather than survive with machines and tubes. This frustration has led to a desire to assist in changing the direction of policy-making from a top down organizational approach to a more bottom up practice approach. The driving force behind my commitment stems from nursing experiences of assisting in the resuscitation of individuals where this procedure was clearly contrary to the person's desire or who I knew had not been given the opportunity to discuss their wishes.

Without direction from clients as to their wishes or legislation which facilitates a process for determining the clients desires, health care providers are faced with making decisions that may not be in the client's best interests. It has been suggested that people who live the latter part of their lives in long term care (LTC) facilities will likely face such events unless the facility has developed policies or standard procedures which are based on the principal of autonomy and self-determination. My own belief that bedside nurses can shape the policy process and that a person's autonomy is an essential requirement of organizational policies, led to my desire to

uncover how resuscitation policies are made in organizations which care for long term residents.

Background

In Canada we treasure our freedom as individuals to make our own decisions, however senseless they might seem to others. This devotion to the principle of autonomy (from the Greek "autos" meaning self and "nomos" meaning rule) is apparent in our legal system as well as in a variety of social rules that direct our daily lives. The most supreme exercise of this principle occurs when individuals consent to or refuse life sustaining treatments, such as cardiopulmonary resuscitation (CPR) (President's Commission, 1982). Difficulties arise, however, when we lose, either temporarily or permanently, the ability to make our own decisions. To preserve a person's autonomy in such situations advance directives such as Do Not Resuscitate (DNR) orders, Living Wills, Degrees of Intervention (DI), or Supportive Care plans have been created. These documentary notices allow competent persons to extend their autonomy into the future by discussing and recording choices for resuscitation and care plans for a time when they are no longer able to make those decisions (Danis et al., 1991).

Advance directives for resuscitation and care preferences have been advocated internationally as a guide for enhancing resident autonomy and the quality of decision making by people who live the last days of their lives in care facilities (Brunetti, 1990). In the United States advance directives have been legalized in forty states, leading to their increased acceptance in LTC facilities (Danis et al., 1991). This has

prompted an increasing prevalence in LTC facilities of policies on advance directives such as DNR, DI and Living Wills. Brunetti (1990), found substantial variation in the content of these policies and suggested that the quality of these policies and thus resident decision making could be enhanced if LTC facilities incorporated uniform criteria outlined in their model. Earlier, Miles and Moldow (1984) studied the influence of the Minnesota State Medical Association model policy and guidelines for DNR and other advance directives and inferred that they were of critical importance in the rapid rise in development of advance directive policies in hospitals.

Canadian decisions and policies on advance directives have been cautious; we have no legislation on living wills or other types of advance directives. From my nursing experience documents indicating future care preferences such as DNR orders, Living Wills and "no blood transfusion cards" have often been accepted by members of the care team. Despite the lack of legislation a practice standard has evolved through other means: a) statements by single and joint groups of professional organizations (Joint Statement on Terminal Illness, 1984), b) case law (Malette v. Shulman; Fleming v. Reid), and c) an abundance of multi-disciplinary literature. Our cautious approach to legalizing advance directives is supported by Bardach (1978) who suggests that governments should implement different policy instruments that centralize the goals and allow decision makers in local settings to choose the means.

This notion is the basis behind a provincial policy instrument, originating in British Columbia, to establish a standard for advance directives. The needs of staff in LTC facilities for DNR and advance directive policies influenced the Continuing

Care Division of the British Columbia Ministry of Health to produce "Death and Dying in Long Term Care Facilities: A Report and Operational Guidelines" (Province of British Columbia, 1989) in September 1989. These documents provide information on the content of a policy on DNR orders and DI. In addition to recognizing the need for policy content information, the provincial government focused on implementing a non-coercive policy instrument which allowed facilities the autonomy to formulate and implement this type of policy.

There is limited information available on who chose to use the provincial government guideline documents and formulate DNR or DI policies. The available nursing literature is extensive on the need for policies regarding advance directives in LTC organizations in Canada. However, our knowledge is limited to anecdotal reporting on specific advance directive formats (McPhail, 1981; Continuing Advisory Sub-Committee, 1989) and absent on the organizational process of making such policies. Although public policy literature provides rich information on the ideas, structures and processes of policy-making at the federal, provincial and municipal government levels in the field of health, the literature is lacking on the evolution of policies in the LTC sector or in the policy area of dying and death.

Pal (1992) believes that policy-making is contextual and needs to be understood in terms of structural factors, individual behaviour and what the situation means to the actors involved. By examining the patterns of regularities across a policy sector (e.g. long term care) or a policy area, (e.g. advance directive policies) it is possible to uncover that a policy may "require certain types of policy process in

order to function efficiently" (p. 114). If the goal of an advance directive policy in LTC facilities is in fact to enhance resident autonomy and to improve the quality of resident decision making, it is necessary to gain a more thorough understanding of if and how those policies are made, if at all, and what influenced the process. In order to determine the variation in policy-making as well as forces affecting such acts, those individuals involved with advance directive issues in long term care facilities should be heard.

Problem Statement and Research Purpose

The problem statement for this thesis is: What is the policy process in long term care settings regarding advance directives? Particular emphasis is placed on a careful examination of how the documents "Death and Dying in Long Term Care Facilities: Report and Operational Guidelines" influenced DNR and DI policies.

The overall purpose of this investigation was to examine the process of developing and implementing DNR and DI policy in LTC facilities in the province of British Columbia.

CHAPTER II

LITERATURE REVIEW

The public policy process relevant to long term care and the practice of nursing are just beginning to be addressed in the literature. This chapter reviews diverse aspects of the literature to enhance the concept of policy as it is currently understood in the fields of public policy, public administration, health, gerontology, and nursing, focusing on the Canadian context. The review is divided into four major sections:

(a) Policy - Definitions

(b) Policy - Categories

(c) Policy - Instruments in Canada

(d) Policy - Process

This review is intended to provide a sufficiently broad and detailed backdrop against which to view the policy process on advance directives in long term care settings in British Columbia.

Policy Definitions

Policy is a construct which is not a self evident term and is pervasive in almost every area of study. As Feldman (cited in Jackson & Jackson, 1990, p. 581) has noted "no term in social science has suffered more ambiguity and abuse." The conclusion of a host of writers is that the definition of policy depends on the context.

In the context of political science and public administration, a wide range of definitions of policy exist (Easton, 1953; Jackson & Jackson, 1990; Pal, 1992). Doern and Phidd (1989), define Canadian policy as ideas and the power to actually realize them in a world of organizations faced with various influences. From a health perspective Ottoson and Green (1987) summarize many policy science scholars (Derthick, 1972; Smith, 1973; Elmore, 1976; Titmuss, 1972; Dewey, 1976) and define policy as a proposal for change, shaped by ideals, expectations and values, assembled by choice or interaction, which must be understood in connection with its implementation and modifications in practice. As is frequently present in Canadian and British public administration and political science definitions of policy, the influence of values and processes is prominent in their definitions.

From a nursing perspective, authors define policies in different ways: a) as non-negotiable rules producing an organized, concise and user-friendly policy manual which in law is seen as binding (Katz & Green, 1992); b) official statements of the organization outlining responsibility and action for a given situation (Ellis & Hartley, 1991); c) acceptable activities to accomplish goals (Marriner-Tomey, 1992); d) and as standardized outcomes from a quality management process (Katz & Green, 1992; Marszalek-Gaucher, 1992). Policies can also be implied practice rituals, expressed orally or written (Marriner-Tomey, 1992), or a label for every wish and rule (Katz & Green, 1992). Specific to the Canadian nursing context, Baumgart and Larsen (1988, p. 199) state, "policy is generally understood to mean the broad guidance developed to ensure the successful formulation and implementation of management strategy as

defined in legislation and within organizations or by corporate and departmental goals." Thus, the nursing definitions of policies as guides to manage activities is not congruent with public administration, policy studies, or health promotion perspectives whereby values, ideas or processes are central tenets. The historical development of hospitals as organized bureaucracies and the practice based education of nurses in these settings may have influenced nursing's view of policy. Furthermore, the nursing perspective focuses on policy as an exclusive product of government or management which establishes rules for governing.

In the context of the present study, the definition of policy by the Continuing Care Division of the B.C. Ministry of Health is not explicit in available documents. This division is responsible for most long term care facilities in the province and develops and distributes a 'policy' manual to all government funded service providers. Within the manual there is no written definition of policy, although the following statement implies several elements of policy:

> The Continuing Care Act came into force on July 1, 1990. The Act gives the Minister of Health the authority to designate Continuing Care services; to protect clients by establishing certain operating and program standards; to determine levels and amounts of payments to Service Providers; and to intervene in crisis situations. (Province of BC, 1991R.4)

Hence policy flows from legislation and guides management activities. This definition relates very closely to the nursing definition of policy and is also related to a hierarchical organization process. Furthermore, management activities and control are accented over values and ideas.

The definition of policy then takes on diverse and distinct attributes. Some policy scholars note the value based web of decisions (Easton, 1953), others focus on change, process and practice (Ottoson & Green, 1987) and still others focus on the priorities of policy-makers (Fulton & Sutherland, 1988). Definitions of power in the context of nursing are centred on legal, text based manifestations of policy (Katz & Green, 1992) and as a management tool to direct staff in attaining goals of quality care (Marriner-Tomey, 1992). Additionally, policy can be viewed as a political construct to administer legislation (Baumgart & Larsen, 1988; Province of B.C., 1991R). Regardless of discipline, policy appears to be expansive and dependent on context.

Policy Categories

Several categories of policies are discussed in the social science literature. In examining the principles behind a policy process in long term care facilities the following types of policies appear to be most significant:

a) public policy

b) social policy

c) health policy

d) long term care policy

Public Policy

No universally accepted definition of public policy exists in the academic literature. Pal (1992, p. 2) surveyed several definitions and concludes that public

policy is "a course of action or inaction chosen by public authorities to address a given problem or interrelated set of problems". Public policies stem from governments or the public sector who have legitimate authority within a political system (Bullock et al., 1983). Public authorities are not only elected, appointed or salaried government officials but can be elders, chiefs, administrators and public service workers or "street-level bureaucrats" (Bullock et al., 1983; Lipsky, 1980). As such, a circuitous linkage between public authorities as "street level bureaucrats" and nurses employed in government funded LTC facilities is notable.

A relatively new development in the nursing literature is the appearance of the term public policy as an element within the concept of nursing power. Some suggest that public policies which concern nurses can be influenced and changed by applying organized group pressure to political and government policy-makers (Baumgart & Larsen, 1988; Kerr & MacPhail, 1991; MacPherson, 1987; Milio, 1984). In that context, Baumgart and Larsen (1988, p. 384) define public policy as "whatever governments choose to do or choose not to do, the values espoused, and the initiative funded" (p. 384). While Baumgart and Larsen (1988) and others (Kerr & MacPhail, 1991; MacPherson, 1987; Milio, 1984) focus attention on the macro political scene, there is no indication in their review that they consider a practice setting as a political system where staff nurses can apply knowledge of public policy to influence policies, shape practice and improve services. Although Sullivan and Decker (1992) suggest that a nurses work setting is a political system whose policies can be influenced to improve care, they describe policies related to providing more money or staff.

Whereas, nurses are increasing their awareness of public policy concepts and pressure group strategies to influence government policy, for example briefs, position statements, representation on government committees, they have yet to extend this awareness to establish policies to guide public policy from experts at the practice level.

Social Policy

The definitional boundaries of social policy are slippery, ever-shifting and expansionary due to the social, economic, political and cultural ideas and values that permeate all public policy fields (Doern & Phidd, 1988; Rice & Prince, undated). Wharf (1984) and Yelaja (1987) both build on the work of Titmuss, a renowned British social policy scholar, and provide clarification of the meaning of Canadian social policy. They indicate that social policy is concerned with the public administration of services based on socially recognized needs of survival, individual identity, participation and community. This type of policy focuses on processes, transactions and institutions by government, voluntary organizations, business, labour, industry, professional groups, public interest groups and churches.

At each of these levels, action or non-action influences the direction in which choices are made to obtain humanitarian goals and discourage individual alienation. Thus, the concept of social policy clearly recognizes the ideas and values of community, consensus, quality of life, and choice. As Wharf (1984, p. 32) suggests, for practitioners at all levels "policy is all about establishing purpose and a sense of direction," in unclear circumstances, where positions are polarized, and "where

opinions are deeply held and cherished." Further categorization of social policy is based on the scope of ideas, values, and issues (Doern & Phidd, 1988; McPherson, 1990). Hence, there can be overlap and diffuse boundaries.

Social policy is not a term found to date in the nursing literature. Splane and Splane (1991, p. 364) imply the notion of social policy in their examination of the conditions to achieve health for all by stating that:

> Action begins at the grassroots level in conveying the principles and providing the aid needed to enhance self-help and individual responsibility. It extends to reformulating the policies and changing the practices over the entire range of social services. It focuses on governments, provincial and national with jurisdictional responsibilities for social services, income support, income re-distribution, and the economy in general.

The social service policies noted by Splane include an economic dimension and focus on "governments, provincial and national". Similar to nursing definitions of public policy, involvement in the policy process at the nursing practice setting is unclear in this statement about social policies.

Writing in 1987 MacPherson argued that nurses need to understand social policies and the underlying values and structures which affect nursing practice. MacPherson (1987) borrows from Gil, a scholar in social policy, and delineates social policies as guiding principles or action plans, embraced by any unit of individuals, which may or may not stem from legislation that address "the intra-societal relationships among individuals, groups, and society as a whole" (p. 13). Possibly, the thrust of political action by nurses towards macro level public and social policy-

making needs to be extended to policy-making in the practice setting as this is where value laden policies can affect the day to day connection between nurses and clients.

Health Policy

As with all policy fields, the definition of health policy is contextually based. In Canada, definitions of health policy vary according to jurisdiction and unit of actors. These may include: a) the federal government, b) provincial governments, c) municipal governments, d) professional health care organizations, and e) citizen collectives concerned with health issues. Siler-Wells (1988) writes that generally health policy "is public and corporate policies and practices, both explicit and implicit, that determine the nature and quality of these environments" (p. 8). Health is a relationship between individuals and their environment which Siler-Wells (1988) perceives can be influenced by policies and procedures. Health policy in this context includes overlapping fields of public policies, as well as private policies, both implicit and explicit.

Lomas (1990) contends that Canadian health policy can be defined according to three levels of decision-making: a) legislative, administrative, and clinical (Table 1). He points out that these levels are synonymous to terms of governance, service, and practice.

Table 1 - Levels of Canadian Health Policy

Legislative health policy

- organizes overall health services for province or federal government.
- equity, the role of government, individual liberty are most important
- scrutinized by the public, e.g. Health Act.

Administrative health policy

- implementing policies, providing resources for health policies that have been legislated by others
- managers may not accept or value, e.g. provincial abortion laws, hospital and facility user fees.

Clinical policy

- client centred therapies and issues which are established by practitioners at all levels of an organization
- not scrutinized by the public, e.g. admission policy, medication policy

In the context of this study, DNR and DI policies fall into Lomas's category of clinical policy. While Lipsky's (1980) work supports this notion, he has concentrated on professional discretion and the day to day decisions and practice of human service workers which become policy. On the other hand, Lomas (1990) concentrates on the values embedded in different institutional health settings which are exhibited through their policies. He articulates that in the past, health professionals have had shared values such as "life over death" and beliefs about the medical model which led to a consensus on clinical policies that were often implicit and only open to brief public scrutiny. This is changing as the values of various health professions have become polarized which Lomas (1990) argues is due to a new

breed of practitioners "whose values lie less in the guild than in the broader society." If in fact as some authors have suggested, nurses are influencing broad public and social policies, an insight on improving clinical policies could come through understanding the values and attitudes which nurses hold on client centred issues.

Lomas (1990) contends that a gap is developing between the public who value accountability and participation in clinical policy development and those health professionals who have a long valued professional autonomy and accountability. He perceives that health policies are beginning to originate at the clinical or practice level. This supports the work of Lipsky (1980) who describes health workers as an example of street-level bureaucrats. He believes that street-level bureaucrats interact directly with citizens granting them access to government programs and services and who make decisions which become agency policies that represent the hopes of citizens for fair and effective treatment by government. Lipsky's suggestion that public policy can originate in local units of publicly funded service workers alludes to a multi-faceted definition of political systems and public authorities which is in distinct contrast to those who would view policy arising only from the government.

The bottom up approach is not however prominent in the nursing literature. One of the first nursing scholars to write about health policy was Milio. Writing in 1984, Milio concludes that:

> Nurses in leadership positions are better situated for influencing policy than the vast majority of nurses who hold staff positions. Nurse leaders have influenced certain aspects of health care policy and will continue to do so in the future - if not by their actions, then by their inaction (p. 23).

Thus health policy according to Milio (1984) is a process that can be influenced, and one in which nursing leaders "are better situated for". It is an elitist viewpoint based on the assumption that health policy originates from the top down and that nursing power is situated in those with resources, information, and flexibility to organize political activities.

Additionally, this perspective is noted in Baumgart and Larsen's (1988) discussion of Canadian public policy and nursing. They borrow from Presthus's book "Elite Accommodation in Canadian Politics" and detail the socioeconomic (money, education, prestige of individuals) and psychopolitical (self-esteem, expertise, prestige of group) resources needed by nursing groups who wish to ensure success in influencing public policy that affects health. Involvement of nurses in the health policy process is therefore viewed at a macro political level as an activity involving influence, power and prestige.

A different approach is taken by MacPherson (1987) who examined the values underlying nursing involvement with American health care policies and sought to expose that nurses have not critically analyzed the dominant values of individualism, competition, and inequality behind those policies. She believes that improving the quality of life and human relations in a society can be accomplished by nurses if they analyze a health care policy for its "overt or covert value premises" (p. 10). Macpherson (1987) concludes that the dominant values of collectivism, cooperation, and equality need to underlay nursing's involvement with health care policy, as well as nursing theories, research, practice, and education.

Long Term Care Policy

Definitional pluralism exists in the field of long term care policy as in all other policy fields. The context of long term care policy is shaped by the jurisdiction, the various actors and to some extent historical events. Historically long term care policies have valued a medical model of care and considered long term care institutions as housing for dependent people (Chappel, 1987). McPherson (1990) notes these principles have guided development of policies on long term care facility construction and resulted in a 'warehousing' effect. However, he provides a summary of viewpoints that agree on the change of values in Canadian society and that adopt a social model of care for long term clients. Policies based on this model emphasizes a continuum of coordinated services and programs to ameliorate social and community problems. Hence, the control over the long term care system by the medical profession in some jurisdictions has diminished. Schwenger (1987) articulates that the western provinces have progressed further than most by adopting this model of long term care and making a commitment to the value of long-term care needs.

Policy Instruments in Canada

The literature review thus far has included an overview of various definitions of policy and a discussion of the characteristics of public, social, health and long term care policy. The third major policy concept which will be discussed is policy instruments. The concept is well developed in the political science, public administration and policy studies literature, yet still evolving in the literature on health care administration, gerontology and nursing.

Instruments as the means to bridge policy problems, goals, and outcomes is a central tenet of a policy design and process. They are used to coerce and change private behaviour and include: a) self-regulation (e.g. nurses, doctors, lawyers), b) regulation (e.g. statutes, taxation), c) paid services or subsidies (e.g. Pharmacare, pensions, home care) d) public ownership (school and hospital boards), or e) information (Canada food guide, health promotion ads) (Pal, 1992; Doern & Phidd, 1988). Although governments have a menu of choices to obtain democratically desired behaviours, Doern and Phidd (1987, p. 112) conclude "the chosen instrument reflects the policy content, context and the government's normative values on coercion".

Pal (1992) suggests that any degree of coercion on constituencies is likely to produce resistance due to concerns about the integrity of the policy content, design or process. In the context of this research, the B.C. Government choice to use "guidelines" as a policy instrument to influence behaviour in long term care facilities. Hence, insight of the power and effect of this type of instrument can come through understanding the essential nature of guidelines.

Doern and Phidd (1988) place guidelines at the coercive end of policy instruments as a regulation; Pal (1992) perceives guidelines to be a non-coercive instrument under an exhortative category; and Doern, Prince and McNaughton (1982) view guidelines as a type of regulation which are flexible and fluid depending on the circumstances. Hence there are divergent notions of what criteria underlay the policy instrument labelled as a guideline. The intent behind guidelines can be as

enforceable regulations or standards because of scientific uncertainty or controversy (Doern, Prince & McNaughton, 1982). or as standardized information for professionals to safely practice (Leape, 1989; Woolf, 1990; Brennan, 1991). Doern, Phidd and McNaughton (1982, p. 14) conclude "as if this distinctions were not confusing enough to the layman, they do not complete the picture. The fact is that 'standards' are often in reality applied flexibly and 'guidelines' are often obeyed as if they were standards."

Physicians have established practice guidelines yet according to Harvey and Roberts (1987) and Clements (1990) some doctors do not follow practice guidelines because they do not insulate them from malpractice suits the way legislation and court decisions would. Therefore some doctors disapprove of guidelines as rules for behaviour because they are not supported by legislated regulations or the rule of law. This rejection of an informal and discretionary means of obtaining policy goals has been seen as the reason for government to step in with legislated coercive rules (Bardach, 1978, p. 377).

Bardach (1978) claims that governments step in with coercive regulatory instruments because a society is not well ordered and people are unwilling or unable to take responsibility for self protection against the injustices and threats of everyday life. He adds that since 1970 in the United States new social regulations have tripled in numbers and budget expenditures. This plethora of American regulations is evident in their statutes related to issues on death and dying. According to a recent study (Areen, 1991) forty-two states have legislated living wills, forty states have a

statute which allows for a proxy decision maker or durable power of attorney and eighteen states now have a mechanism for family decision making in the absence of advance directives. However, abundant literature from the disciplines of medicine, law, sociology and ethics supports the view that statutes which regulate decision making on life sustaining treatment issues have been ineffectual (Snider, 1991; Thornton & Winkler, 1988; Emanuel, 1988).

The Canadian choice of means to provide direction on advance directives, such as DNR and DI have been extremely conservative. Since 1984 policy direction has been in the form of the Joint Statement on Terminal Illness which was developed by major health care provider organizations across Canada and sets out guidelines for their members to follow when a treatment or non-treatment decision has to be made in cases of terminal illness. By 1989 only Nova Scotia had legislated very limited aspects of advance directives.

From personal nursing experience Lindsay (1991) writes that the life saving treatment decision that she feels is most often a dilemma for nurses and care providers in long term care facilities is "do we resuscitate in the event of a cardiac arrest without knowing the resident's wishes?" This became a central issue for many service providers and in response the B.C. Ministry of Health researched the topic and produced a report and operational guidelines "Death and Dying in Long Term Care Facilities". These two documents where intended to provide a framework for long term care agency policies that allow residents to discuss and choose treatments or non-treatments in advance of life threatening events. It is very clear in the

introduction by the Executive Director of the Continuing Care Division that the documents "should not be construed as 'recommended policies' but, rather, as a vehicle for stimulating thoughtful discussion on this timely topic." Thus, the provincial government introduced a non-coercive governing instrument which relied on information and individual choice.

There have been limited studies on the use of guidelines as a policy instrument to shape health behaviour in Canada (Doern, McNaughton, & Prince, 1982) and to date no studies have been located in the field of long term care policy. Our cautious approach to legislated regulatory instruments is supported by Bardach (1978). He argues that we undermine personal choice by establishing instruments which make governments responsible for moral decision making. Alternatively he suggests that governments should establish principles and overall policies which allow decision makers in local settings to choose the means. Pal (1992) confirms that the latest trend in Canada is a gradual move to instruments which rely on voluntary behaviour and a mix of instruments in large part to restrain government and reduce costs to public budgets. However, the flexibility which guidelines can offer as a policy instrument are reflective of the underlying political and normative values that recognize voluntary behaviour, diversity of values, and that circumstances can be different.

In summary, three concepts of policy have been examined including; policy definitions, policy categories, policy instruments. To complete an understanding of how policy is made and implemented the policy process will be examined.

Policy Process

If the policy goals, instruments, content and underlying principles are variable, is there a core to the process which can be studied and understood? To understand the answer to this question several aspects of the development and implementation of policy will be examined.

Phases of the Policy Process

One of the earliest writers to influence the thinking on the policy process was Lasswell. As cited by Nakamura (1987), Lasswell's perspective to the policy process relies on abstraction and system theory with no attachment to the policy environment of actors and institutions. Lasswell's categories have been reformulated by many scholars (Barrett & Fudge, 1981; Doern & Phidd, 1988; Hill & Bramley, 1986; Pal, 1992). In examining the principles behind a policy process the works of Pal (1992) appear to be most significant. He established a framework with which to view the policy process in Canada and looked at the influence of values in the political, social, and structural environment on this process. Although the framework for the policy process was presented by Pal with elected governments in mind, it can be utilized to examine any political system involved with delivering public services.

Pal is quick to forewarn that it is inaccurate to think that the policy process has a clear beginning, middle and end and is an objective process starting from one point. Instead he describes the process as cyclic, subjective and contingent on windows of opportunity. In order to illuminate the elements or "benchmarks" of any policy process, Pal lists three phases which need to be examined. These are:

a) Agenda-setting and Problem identification

b) Policy Development

c) Policy Implementation

Agenda-Setting and Problem Identification

The elements at the beginning of the policy process are agenda-setting and problem definition. This phase is based upon an approach to setting an agenda where problems affecting the community are responded to by government or legitimate political system. In the words of Pal (1992), "problems are defined by that community, or they are not defined at all" (p. 323). Hence the agenda is not independently or precisely defined by one set of issues or actors in an exclusive political environment. The basic agenda of the political system does not shift but the main priority or problem that receives inconsistent attention by policy-makers changes. Thus the basic characteristics of this primary phase are an agenda, the issues or problems that receive attention, and their priority.

Pal suggests that agenda setting is influenced by structural pressures, institutional processes, and unpredictable events. Subsequently, in recognizing that in a given policy-making system, "everything is in flux and motion" (p. 125) and in any policy area, a stream of ideas, arguments, and proposals can be recognized, Pal set out three elements identified by Kingdon (1984) which clarify the process of agenda-setting:

1) Problem recognition - This involves a process where our attention is drawn to a situation or context and we become circumspect. Pal discusses three ways in

which attention is evoked: a) a change in accepted indicators - the rise or decline of deaths, accidents, complaints, for example, b) a focusing event, most often unpredictable, that compels notice and sometimes action, and c) through feedback from people or evaluations of policies, programs or procedures.

2) Solutions within policy communities - Pal notes that people advocating a problem may have a commitment to a specific solution because they are convinced of the benefits of that solution or offered the solution first before the problem was well defined. For example, in the context of advance directives, some physicians in Canada have resisted writing DNR orders and accepting Living Wills until these acts are legalized (Clements, 1990).

3) Political element - This component focuses on what Pal identifies as the "mood" of an organization or community, along with the introduction of new policy-makers and information that focus attention and pressure groups. The political component also incorporates the structural and institutional influences which have been mentioned earlier in this section.

When these elements converge, Pal articulates that they open a "'policy window'" for action by policy-makers. However, policy-makers must be willing and ready when a window of opportunity opens. Hence, setting a policy agenda is dependent on timing. Pal concludes that the particular mix of problems, solutions, and political events are unique to each policy issue and political environment and, which, does not guarantee that a particular vision and policy design will be chosen by another political system.

Upon establishing these elements of the agenda-setting and problem recognition process, Pal went further to explain the nature and definition of problems. He establishes two categories of problems: a) impediments to our desired actions or goals and b) attacks on broadly held values of what is right, moral, just, or fair. Thus, defining problems depends on some blend of objective stimuli and personal view that alters a situation from usual into something that impedes or affronts us. Pal concludes that problems that impede us are much easier to sell than those that are categorized as affronts to our values.

In summary problems in the real world are complex and so are there attributes. Neither exist as objective entities waiting to be discovered. As Dery (1984, p. 5) states "we make a choice about how we want to formulate a problem". If our formulation is wrong, the policy solution may not address the problem as it exists. Thus, the way the problem is defined is crucial for the rest of the policy process.

Design or Development Phase

During this phase goals, objectives and decisions are made which lead to the choice and publication of a policy. Pal believes that individual and collective decisions, choice and development of a policy intervention are influenced by 1) a matrix of organizations, and 2) the policy content.

Organizations and Policy Development

Similar policy issues can be processed in many political systems in a variety of ways because of the difference in organizational structure and capacity. Pal (1992) argues that a matrix of institutions affect the policy process and include governments and policy communities. He defines policy communities as actors in a specific sector who may be in disagreement but who are committed to the policy area, have expertise or familiarity with the terms of discourse, and interest in that domain. These actors can include: a) government actors at all levels, b) key associations or umbrella groups both labour and professional, and c) interested individuals.

Pal also believes that policy is developed in a certain sector where there is a stable set of actors that have a "real set of connections" (p. 111), that can then debate the issues and make decisions. Thus, policy sectors and communities influence the policy agenda and the problems which need policy solutions. To further understand the influence of institutions and process on policy, Pal suggests that policy communities need to be examined to discern the patterns of relationship between actors. Moreover, he claims that examining how different policy sectors process policy may lead to an understanding "that some areas of policy require certain types of policy process in order to function efficiently" (p. 114).

Yanow (1987) extends the matrix of political institutions that influence the policy process downward to include any unit of organization which implements policy. Thus small units of organized actors would be included, such as long term care facilities. Yanow (1987), in analysing public policy processes in organizations, has

developed a "policy culture" framework which is presented in Table 2. In this context Yanow describes the characteristics of a policy culture as the values and beliefs about a policy issue, transmitted through policy language, which implementors then interpret and act on. Thus, values and beliefs of an organization structure the policy process. Yanow's framework consists of "lenses" that combine four sets of concepts commonly used to analyze behaviours in an organization and six organizational levels, both inter- and intra-levels.

Table 2 - Policy Culture Framework for Analyzing the Policy Process

1. **Human relation lens**

   - analysis of roles, character traits
   - behavioural change required
   - impact of enforcing compliance

2. **Political lens**

   - degree of power, influence, coalition-building, negotiation and bargaining

3. **Structural lens**

   - task allocation, lines of authority
   - spans of control, discretion to implement policies

4. **Systems lens**

   - policy goals, coordination, communication, and societal forces

Thus, if the values, beliefs and ideas on a policy issue, such as resuscitation in long term care facilities, are varied among the actors in policy communities and organizations in British Columbia, then there is a need to focus on the meanings which they make of the policy process.

A political institution at any level promotes certain beliefs and constrains the choices of individuals. This approach to understanding the policy process assumes that individual actions are based on what is appropriate rather than on self interest. Pal (1992) speaks of appropriate action as "norms" which "set benchmarks of behaviour and are internalized by actors" (p. 101). Thus this approach places an additional emphasis on examining the policy actors ideas and meanings they hold on a specific situation or policy content in a specific organization.

Policy Content Related to DNR and DI

Pal (1992) perceives policy content as key concepts, theories and thinking which are the guiding ideas behind the policy issue. Hall et al. (cited in Hill and Bramley, 1986, p. 149) perceive the policy issue as the "'image' which influences its progress within the system". People, organizations and the larger policy community influence this image. Pal (1992) articulates that "intellectual frameworks" will more closely resemble the types of problems to be defined in the course of determining the appropriate policy. In this study the policy substance is Do Not Resuscitate and Degrees of Intervention for long term care clients. The following ideas and concepts related to this issue are examined in order to understand how they become framed as problems requiring a policy solution.

Advances in medical technology have allowed death to be delayed for almost any life-threatening condition (Gordon & Hurowitz, 1984) and cardiopulmonary resuscitation (CPR) is one such dramatic intervention which has made death a matter of human choice (Murphy et al., 1988). This procedure was first adopted by the medical profession as an efficient means of reviving a select group of patients (Editorial, 1962). The American Heart Association developed standards and trained teams of professional groups in basic and advanced CPR techniques (Snider, 1991), hospitals developed policies and protocols for resuscitation and expanded the population receiving CPR to any patient regardless of underlying illness (Blackhall, 1987).

This practice was soon expected in long term care facilities although various professional and research organizations had recognized earlier that most persons could not be saved even in the ideal setting of a hospital, but promoted CPR based on the belief that this intervention may save some peoples lives (National Academy of Sciences National Research Council, 1966). The tendency for medicine to aggressively adopt new technologies without in depth research is supported by Snider (1991) who believes that doctors would rather intervene than be defeated by death. The history of resuscitation suggests that the practice of medicine along with pressure from allied interest groups, shaped health care policies which facilitated the routine use of CPR.

The widespread use of CPR led Gordon and Hurowitz (1984, p. 743) to state that indiscriminate application of this technique may "reflect poor clinical judgement".

The obligation to use CPR to prolong life for elderly residents with chronic and debilitating illnesses has been a concern to physicians, nurses, ethicists and the public (Glasse & Murray, 1984; Gordon & Hurowitz, 1984). There are few studies which have examined the outcomes of CPR specifically on elderly populations and only a scant number done in long term care settings (O'Donnel, 1990; Taffet et al., 1988). Past research which has studied groups of elderly people and their response to CPR have generally confirmed that age alone is not critical to a successful outcome (Gulati et al., 1983; Bayer et al., 1985; Murphy et al., 1989; Scheidermayer, 1988). Scheidermayer (1988) views age as a clinical marker that helps us identify ill elderly patients who may be in the poor survival group. He believes that physicians with this perspective would prompt ongoing sensitive discussions with the patient, family and health care providers about the use of CPR and other lifesaving technologies.

The decision to resuscitate can not be based only on the objective medical facts, but must consider if resuscitation best serves the person's own values and goals. It seems that these values and goals are best determined by discussing the issue with the person, yet there are diverse perspectives in the medical literature. Some scholars note that many patients feel uncomfortable with making this decision and ask the physician to do whatever is best (Snider, 1991); others feel the decision must be an informed one and that health care providers must be honest about prognosis, risk and benefits of various treatment options or non-treatment choices (Snider, 1991); and still others see that some patients with a terminal illness would be needlessly

harmed if a detailed discussion of CPR procedures and risks occurred (Spencer, 1979). Miles and associates (1982) believe that although doctors and family find the topic difficult and the time emotional they often underestimate the patient's ability to handle such a discussion and participate in the decision. Thus resuscitation decisions can occur on a continuum from patient determined to resolution by a physician.

Although the right of a competent patient to refuse life sustaining treatment is well established in ethics (Thornton & Winkler, 1988), in U.S. law (Emanuel, 1988), and is most likely guaranteed under sec. 7 of the Canadian Charter of Rights and Freedoms (Ferguson, 1988; Clements, 1990), the right to be informed and to choose treatment in advance for the end of life is not legal in Canada. Hence, for residents in a long term care facility this right is affected by government and institutional policies and the practice of their health care providers.

Winslade and Ross (1986) in their book, "Choosing Life or Death", suggest that attempts to provide public policy guidance on this issue have been sporadic and ineffectual. This view is supported by the scant literature on hospitals and long term care agencies that have successfully established clear and specific policies on when and how life saving treatment decisions are made, especially for elderly clients.

There is considerable confusion in the literature as to the precise meaning of the DNR order. The view of the President's Commission (1983) is that a DNR order means not summoning a team of health providers to revive a patient who has had a cardiac arrest. Their underlying premise is that death of a patient in hospital can not

occur unless CPR as been performed, except where a DNR order has been written by a physician. Evans and Brody (1985) studied three teaching hospitals and found that medical staff varied in their interpretation of a DNR order. For health care providers in nursing homes a DNR order could also mean, do not hospitalize or do not treat (Besdine, 1983). Thus DNR orders were established to prevent unnecessary application of CPR.

Hospitals which pioneered DNR policies began to appear in 1976 in the U.S. (Rabkin et al., 1976) and three years later in Canada (McPhail et al., 1981). The prevalence of written DNR policies nationwide is unknown. Fisher (1989), in speculating on the situation in Canada suggests that there is a great deal of variation in the availability of CPR and the implementation of a DNR policy. This supports his concern that transferring acute care policies to a long term care setting does not promote the goals of resident care.

Fisher (1989) suggests that more suitable guidelines should address a range of therapeutic treatments that allow for flexibility of resident choice and care. This was the purpose behind the British Columbia, Ministry of Health 1989 guidelines Death and Dying in Long Term Care Facilities which adapted a flexible range of treatment choices developed as levels of intervention by Levinson et al. (1987) and labelled them "Degrees of Intervention." Levinson and associates believed that residents in their nursing home needed to be involved in discussions of their wishes for the end of life and that the health care team needed to be assisted to make rational treatment decisions in the event that terminal care or resuscitation was needed.

Hence a protocol was developed for their American based facility. No further literature has been located to date which evaluates Levinson's (1987) protocol or describes the process of developing or implementing flexible levels of intervention for care at the end of life in long term care facilities.

In summary, the policy content related to DNR and DI is based on the emergence of CPR for use in hospitals. This treatment is based on the assumption that people in care facilities must all be resuscitated unless otherwise ordered. This presumption has been transferred to LTC facilities despite the very low long-term survival rate of the elderly following CPR. However, the decision to resuscitate is an ethical and legal right of competent residents. Thus health care providers have an obligation to determine the residents preferences in advance of the need for CPR. Communication with residents and/or family has been identified as a factor which is crucial in determining residents wishes yet is often difficult for doctors based on their values and ideas.

Hill and Bramley (1986) in examining the policy process discuss three criteria which influence the progress of policy issues:

1) Legitimacy - which is concerned with the ideologies within the system and opinions of people and groups external to the system that affect the policy-makers decisions to consider the policy issue.

2) Feasibility - of a policy issue which is determined by the structure and distribution of knowledge on the topic. Feasibility is based on judgments about resources, collaboration and administrative capacity to carry though with the policy.

3) Support - of the policy which involves the balance between those who are discontented and those who are satisfied with the change in power, influence, status or values that the policy will create.

Doern and Phidd (1988) suggest that while political systems can express their concern about, and support for an issue through policies, they may have no capability to carry through development in terms of money, personnel, time or enforcement. Thus, even with identifying a problematic situation, consensus on the problem and goals, further development and implementation of a policy may not be complete.

Policy Implementation

The final phase of the policy process identified by Pal (1992) is implementation. He states

> Implementation is an intriguing problem. No policy can ever be designed in such a way as to contain every conceivable or important administrative detail. It is the trickiest phase in the policy-making process. (p. 172)

The complexities of implementation are also reflected in the variety of approaches to implementation analysis found in the literature. Similar to the broad range of policy definitions, according to Linders and Peter (1987) implementation has become a popular social science concept that has lost its clarity and meaning by being used so often.

Palumbo (1987) in reviewing the work of many scholars summarizes the diversity in approaches to policy implementation (Mazmanian & Sabatier, 1981; Bardach, 1978; Pressman & Wildavsky, 1973). He articulates his perspective on

implementation as a stage in the policy process. Elmore (1979) and Lipsky (1980) both advocate that those at street level are more familiar with problems in practice therefore, can find more effective ways of implementing policy in the organization. Yanow (1987) believes policies are interpreted by all involved in the process and hence the values, history and culture surrounding them must be examined. Love and Sederberg (1987) view policy as a seamless web, where many voices are aiming to structure the environment from within and beyond. Thus, policy implementation in organizations can be understood by utilizing a number of approaches from the top, bottom, inside, outside, all around and through.

From the literature reviewed, the work of Love and Sederberg (1987) seems most useful to this study. Love and Sederberg in studying underdeveloped countries, found that rational government plans have little relation to actual processes and performance in the field. They abandon the idea that policies succeed or fail and instead consider policy as a seamless web that reflects the continuous nature of the process. Further, Love and Sederberg focus on interdependencies and illuminating the differences between individuals who may play a role in policy development as well as modifying the policy over time. They found that the third world environment is very fluid and can not be easily captured by theoretical approaches to policy implementation which assume a natural organized environment. Moreover, Love and Sederberg suggest that their approach to implementation may be useful in understanding any relatively turbulent environment. Thus, this approach can be

useful in analyzing the policy implementation in long term care facilities where policy-makers may be policy implementors in an ever changing environment.

The approach which Love and Sederberg propose makes the assumption that a gap always exists between the policy and the world which is being controlled by that policy. This policy world contains pre-existing, multi-layered and dynamic structures which can help to explain the different forces and influences on implementation. These environmental levels are:

1) Formal policy level

2) Informal policy level

3) Informal organization level

4) Ecological level

Formal Policy Level

At any given time an organizations plan for implementation may be altered due to rapidly changing demands in the organization which can not be quickly abandoned or those bound to them may resist change. Further, the implementation plans may exceed the resources of the organization and can not be completed. Love and Sederberg found that implementation can also be influenced by policy actors speaking with different voices at the same time, each advocating their own policy preferences. In their study the third world service organization was caught between conflicting policy directives from two larger more political organizations. Thus, the policy as developed may be articulated by any number of individuals, possibly at the same time, and with different agendas, that may change over time.

Formal Organizational Level

"Policy must be carried through by organization whose performance is already governed by formal and informal explanatory directives" (p. 165). These directives include, authorized structure, procedures, and the character and capabilities of the organization which may be taxed with introduction of a new policy. Love and Sederberg found that policy implementation at this level involved change in personnel, physical design, and funding arrangements. They concluded that there will be gaps between the policy and the selected environment and the greater the turbulence in the environment, the greater will be this gap.

Informal Organizational Level

This involves informal hierarchies, procedures, and dispositions which may reinforce or undercut formal operations. Although these characteristics are difficult to identify, any policy which challenges these implicit structures and procedures will not likely meet with success. Included in this level are relationships between policy actors, degree of competition, change in vested interest, reasons for emphasizing the problem and not the policy solution. Love and Sederberg suggest additional characteristics of organizations which may influence implementation such as: communication problems, inadequate training, decreased morale, unrealistic goals given constraints on personnel and financial resources, maintaining reactive management style versus proactive planning. Thus, these three levels which view the formal policy, formal and informal organizational structure and processes comprise a group of circumstances that affects the course of implementation.

Ecological Level

The final level includes elements outside the organization which have an explicit impact on the implementation process. The pre-existing exterior environment may either resist or facilitate those policies being carried out. Love and Sederberg identify that resistance to change is based on the patterns or "culture" that the unit of organization has developed and wishes to retain along with a high degree of social and economic integration of individuals in that organization.

In summary, as Love and Sederberg articulate the complexity of policies in highly-charged policy arenas can be interpreted by an explanatory level approach. It shares certain elements of organization theory but with a greater focus on complexity, different perspectives, infinite number of solutions, and mutual aspirations. Using this approach, both policy development and implementation are not only influenced by internal administrative ability, resources and political power, but dependent on the compatibility of the policy with established dispositions and tendencies internal and external to an organization. Hence, if a policy is incompatible, the process adapts with the conflict and moves forward or becomes baffled and policy is never fully developed or implemented.

Summary of Literature Review

The public policy process has been, and continues to be, a key interest of many political, administrative, gerontological and nursing scholars. A variety of concepts and frameworks exist to explain both the attributes of policies and the process of making and implementing policy. Of these perspectives, Pal's model of

the Canadian public policy process offers a general guide by which publicly funded organizations can gauge their specific situation. According to Pal (1992) the four elements most commonly referred to are: a) agenda setting and problem recognition, b) problem definition, c) policy development, and d) policy implementation.

All of those involved in the policy process are not isolated from the general historical and value context of the policy they are developing and implementing. Thus, multiple meanings exist and need to be interpreted when the policy process is examined in any organization.

The gap between policy intention and implementation can be explained by an interpretive approach which views different levels external and internal to an organization. According to Love and Sederberg (1987) the characteristics of this approach are: a) pre-existing formal policy directives within the organization, b) formal organizational processes and structures, c) informal organizational relationships, processes and structures, and d) external environmental forces.

The ideas, values, and beliefs of medical and nursing professionals on Do Not Resuscitate and Degrees of Intervention suggest that there is diversity in perspectives on this policy content. This notion supports the need to uncover and understand the reality of multiple interpretations in long term care facilities of government policy instruments and the impact on their execution of a policy. Further, multiple meanings of this policy issue within a variety of organizational environments needs to be examined to illuminate the barriers and successes of the policy process in this setting.

Research Questions

In order to understand the policy process for specific advance directives, DNR and DI, in British Columbia, three major research questions were posed:

1) What were the problems related to advance directives in LTC facilities prior to the release of the provincial guidelines and report "Death and Dying in Long Term Care Facilities" in 1989?

2) Since release of the provincial guidelines and report "Death and Dying in Long Term Care Facilities" in 1989, what was the process of DNR and DI policy development in LTC facilities?

3) Since release of the provincial guidelines and report "Death and Dying in Long Term Care Facilities" in 1989, what was the process of DNR and DI policy implementation in LTC facilities?

CHAPTER III

METHODOLOGY

This study examines the process of policy-making on issues related to advance directives in long term care settings in British Columbia. The primary purpose of the study is to understand the process of developing and implementing DNR and DI policies in long term care settings and to determine the impact of the provincial guidelines Death and Dying in Long Term Care Facilities, (Province of B.C., 1989) on this process. Thus a descriptive approach was chosen as the most congruent design for this inquiry. Specific methodological approaches were drawn from qualitative research (Morse, 1991) and policy research (Putt & Springer, 1989).

This chapter outlines an overall discussion of the research process including: a) the study design, b) a description of the research setting and study participants, c) a discussion of the development of the interview guides, d) the method of data collection, and e) approaches to data analyses.

Methods

Research Design

This policy research study utilizes a descriptive qualitative design. The purpose of policy research is to obtain information on a problem through a multi-method and human-centred inquiry which leads to actions which improve or benefit

a human condition. A descriptive qualitative research design was selected as it provides detailed information on the current status of phenomena of interest. The comprehensive nature of this research design and ability to provide first hand information from practice settings supports the purpose of this study.

Research Setting

The research was carried out in the province of British Columbia in the natural settings of facilities which provide shelter and care for a group of two or more long term residents. Site locations were chosen to facilitate face to face interviews for data collection. In B.C. there are over 25,000 people who live in 400 facility settings. The residents vary in age, require diverse levels of nursing and personal care and receive a range of government funding based on need and personal income. The residences vary in size, funding, and governance; and can be called a group home, boarding house, facility or hospital. There are some facilities which are governed by one umbrella organization yet maintain separate physical structures scattered throughout different areas in the province.

The internal organizational structure and function of a facility is shaped by several provincial legislative Acts and policies. The variety of organizational structures in long term care facilities in B.C. can be categorized according to provincial legislation, funding source and profit or non-profit status. All LTC facilities in the province of British Columbia fall into one or more of the following categories found in Table 3.

Table 3 - Categories of LTC Facilities in British Columbia
by Legislation, Funding Source, and Operating Status

Category A

Facilities which are:

a) regulated by the Community Care Facility Act
b) funded by the Continuing Care Division
c) operate as a business for profit

Category B

Facilities which are:

a) regulated by the Community Care Facility Act
b) funded by the Continuing Care Division
c) operate as a non-profit society

Category C

Facilities which are:

a) regulated by the Hospital Act (Part 1)
b) funded by Hospital Programs
c) operate as a non-profit society

Category D

Facilities which are:

a) regulated by the Hospital Act (Part 2)
b) funded by the Continuing Care Division
c) operate as a business for profit

Category E

Facilities which are:

a) regulated by the Community Care Facility Act
b) receive no government funding
c) operate as a business for profit

Research Participants

The population of interest for this study included residential facilities who were sent a copy of "Death and Dying in Long Term Care Facilities: Report and Operational Guidelines" (Province of B.C., 1989) from the B.C. Ministry of Health, Continuing Care Division at some point since September 1989. Each of these facilities provides a geographically defined unit which was considered a potential contact institution for this study. The government distributed the guideline documents to facilities which: a) fall into Category A, B, C, or D, (see Table 3), and b) if funded by the Continuing Care Division, have greater than 15 beds. There are approximately 340 settings which fit this criteria and were sent the report and guideline documents since the Fall of 1989. Although each of these facilities were sent documents, there are approximately 44 facilities excluded from this study population because they are satellite sites of a larger organization and have no administrative functions for developing DNR/DI policy. Thus the total study population was 296 facilities.

Sampling Technique

The B.C. Ministry of Health made available databases from which two lists were created that categorized the facilities according to whether they were: funded by the Continuing Care Division or funded by Hospital Programs. These lists were generated from computerized funding information and were considered accurate by government officials independent of this study.

Each list contained the facility name in alphabetical order and were numbered from one to two hundred and ninety-six. A table of random numbers was used to select the sample size of thirty. This was approximately ten percent of the population to be studied and was practical to survey. Each facility in the sample had an administrator who was contacted by letter (Appendix A) and invited to participate in the study. Following acceptance, the administrator indicated by mail, fax or phone the staff person within the organization who would act as an informant for this study. This person was sent an information package (Appendix B) and consent form (Appendix E), then interview dates and times were arranged.

Human Subjects and Informed Consent

Each participant in the study was asked to sign an informed consent form; their signature was a requirement for inclusion in the study. The form included the nature and purpose of the research, an explanation of what was required of them if they agreed to participate, a guarantee of anonymity, and reassurance that they could withdraw their consent at any time without any prejudice on the part of their employer, the University of Victoria, the researcher, or the B.C. Ministry of Health (see Appendix C). The study was approved by a Human Subjects Committee at the University of Victoria and by Mr. Brian Ethridge, a lawyer for the B.C. Ministry of Health.

Instrumentation

Individual In-depth Interview Guide

The in-depth individual interviews were exploratory and semi-structured. The interview guide was developed by the researcher utilizing the multiple concepts derived from an interdisciplinary literature review and informal interviews with key individuals involved with long term care facilities. Concepts related to policy development, implementation, impact analysis, dying, and death in long term care facilities, were identified. A policy process framework evolved and an in-depth interview guide (Appendix D) was developed.

The questions in the interview guide were developed for the purpose of gaining a description of the policy-making processes related to dying and death that have occurred in various types of long term care facilities and determining factors which have influenced this process. The questions for the interviews set the context for the interaction and were semi-structured in order a) to gather information across common areas and b) to facilitate the generation of perspectives and observations unique to each individual participant.

Initially, content validity of the interview guide was maximized by utilizing concepts which are prevalent in the literature. In addition, two independent faculty members trained in questioning techniques examined the interview guide to establish face validity and to assess question structure and development. The interview guide was pilot tested with Directors of Nursing from three facilities in Victoria who were included in the study population, but not in the sample. The questions did elicit

coherent answers and the respondents indicated they felt the questions were clear and unambiguous. Responses from the participants in the pilot test indicated the integrity of the interview questions and further supported the content validity of the interview guide.

Demographic Data Profile Schedule

The participants provided information about their facility, including: a) regional location, b) size, c) governing and funding category, d) ethnic or religious affiliation, and e) present stage of DNR and DI policies. The participants also provided personal information about their educational preparation, number of years in practice, number of year present in their facility, area of responsibility, and involvement with policy-making. (See Appendix E for a copy of the Demographic Profile Schedule).

Data Collection

Data collection occurred during individual in-depth face to face and phone interviews. I was the sole interviewer of the participants. Data were collected in twenty-three facilities from thirty-three participants with interviews lasting an average of one and a half hours per facility. The interviews took place in a four week period between August and September 1992.

Data collected from the in-depth interviews was self-report qualitative data. A brief demographic profile schedule was utilized to collect further information about the informants and participating facilities. The data were number coded in such a

way as to not identify the participants or their facility. Face to face interviews took place with twenty-five study participants on site at sixteen facilities. Of these facilities, nine facilities had single informants, five facilities had multiple informants who chose to be interviewed together, while two facilities had multiple informants who chose to be interviewed individually. A further seven interviews were conducted by phone with eight participants.

Following introductions, I delineated the purpose of the study, estimated the time involved for the session and my role in monitoring the time progression. For the face to face interview participants, the use of a tape recorder including the handling of transcription and the erasure of the tape, was discussed. At this point the face to face interview participants each read and signed a letter of informed consent.

The phone participants had each received a copy of the demographic profile schedule and a letter of informed consent two weeks before and returned a signed copy of the consent prior to the interview. At the time of the phone interview, the consent was reviewed with them and they were given an opportunity for discussion. Extensive notes were taken during the phone interviews and completed in detail immediately following. These conversations were not tape recorded.

The initial questions of each interview were related to the demographic profile schedule so as to begin to develop an understanding of the specific characteristics of the facility, a sense of its organizational culture and set a relaxed informal tone for the interview. Next, I began with the interview questions and followed the interview guide to prompt the participant to discuss varying aspects of the facility's policy

process related to the government guidelines on dying and death. I used probes to encourage recall of situations and expansion of ideas and opinions. Probes such as: "Can you expand on that?" "How do you think it affected your situation?" are examples of those used. The interview also involved empathetic responding, rephrasing and clarifying concerns. Throughout each interview written notes were taken.

Data Analysis

Preliminary data analyses occurred immediately following the in-depth interview(s) from each participating facility. These analyses included a process of examining the written notes from the interview and discovering the themes, assumptions and processes. Summary notes where made on index cards corresponding to each theme within a major interview question.

The audio tapes of each face to face interview were transcribed verbatim by the researcher within four weeks of completion of all the interviews. Where two or more participants from one facility site were interviewed separately, the transcriptions were combined into one document to represent the experiences within the participating facility. Each document representing a facility was then assigned a protocol number. If more than one individual interview was obtained from a facility, each individual interview was also assigned a letter. The document was then formatted into WordPerfect 5.1 to support entry into Text-base Alpha (Tesch, 1992) a computer software program for data analysis.

The data from the phone interviews were extensive hand written notes made during and immediately following the interview session. As with the taped interview transcripts, each document was assigned a protocol number. There was only one multiple interview from those participating facilities interviewed by phone. The field notes were not transcribed and therefore could not be analyzed by the computer program.

Data analyses proceeded and generative themes were identified congruent with a qualitative evaluation approach (Tesch, 1990). First the taped interview transcriptions were converted into the Text Based Alpha (Tesch, 1990) computer program and segmented chronologically by responses to interview guide questions. Computer files were generated for each question within each taped interview. Next the data in each interview were examined to identify key themes, events, phrases, concepts and processes. These segments were categorized according to topics and the questions that guided the interview, then marked by the computer, coded and transmitted to files organized by a category code. Owing to the large amounts of data in each interview transcription, elaborate lists of category codes were generated from the first transcripts which were later refined as the analysis process continued.

Following completion of categorizing the interview transcripts, eight sets of field notes from the phone interview were analyzed. The analysis involved extracting phrases or sentences pertinent to the essence of the phenomena and categorizing them by meaning. This was done by reading each set of field notes several times, listing statements that identify themes, concepts or events and coding them in a

similar process to the interview transcripts. The phone interview field notes and face to face interview transcripts were treated as one data set for the results. Therefore, the results are based on twenty-three responding facilities.

After segmenting all of the interview data sets, the most relevant categories were selected and then assessed by members of the thesis committee for consistency of coding and for the inclusion of relevant themes. The researcher then analyzed specific interview questions. Due to the quantity of data which was obtained, the researcher chose to analyze specific questions. The first two sections of questions in the interview guide which related to the facility's policy process were analyzed as these questions most closely approximate the main purpose of the study. They included questions which were the most general (When you first saw the guidelines how did you think they would help your situation?) and the most specific (What was the most important thing that would have helped you at that time?). Additional information was drawn from the bulk of the interview data to further describe and articulate themes which were relevant to these questions.

This process resulted in analysing five main questions and their sub-questions related to the government guidelines and concepts of the policy process. They included: 1) Prior to 1989, what do you recall where the issues or problems related to Do Not Resuscitate and decision making a the end stages of a resident's life? 2) Did you find the guidelines useful? 3) Could you draw or explain for me the process you went through, including lines of authority, in order to have a policy related to this issue developed in your organization. 4) What do you think has or will

delay or promote successful development of your policy? 5) What do you think has or will delay or promote successful implementation of your policy?

Following selection of questions for final analysis, recontextualization (Tesch, 1990) was completed by the researcher. Recontextualization involves: "assembling everything that belongs in one category in one place, so that the researcher can read in a continuous fashion about the pool of meanings" (p. 130) and "looking to see whether any interesting patterns can be identified; whether anything stands out as surprising or puzzling" (p. 91). Strauss and Corbin (1990, p. 96) identify this type of procedure as axial coding, "whereby data are put back together in new ways after open coding by making connections between categories". Categorization and recontextualization of data continued until consistent patterns emerged.

As an external reviewer, one of the thesis committee members, Dr. Laurene Sheilds, provided guidance and feedback during qualitative data analysis. As themes and categories were identified, Dr. Sheilds provided both critique and confirmation of the emerging patterns.

Limitations and Delimitations

Several potential limitations of the study are important and relevant to consider. The research design of this policy study is exploratory in nature and consequently the findings must be regarded as groundwork. While exploratory policy studies systematically summarize the major variations found among a group, they are valid only for the participants of the study. However, the detailed experience provided by the participants will begin to establish a record of concerns, interactions,

and influences to aid health care administrators and care providers who need information on the policy process in publicly funded health organizations.

The study population was identified through a combination of government databases that could, potentially, have been incomplete. Two alphabetized lists of the facility names were generated, examined for repetitive names and multiple sites of one organization, and then merged. Although potential errors are possible, no evidence was discovered that a facility had been excluded from the sampling frame.

The facilities were invited to participate through a letter form the Director of Residential Services (Ministry of Health) and a letter from the university researcher. Although the information provided stressed the voluntary nature of the study, some respondents may have based their decision to participate on perceived organizational pressure. Additionally, the nature of the study, the independence of the researcher, the connection with the university, and the aims and design of the study may not appeal to a specific segment of the sample being recruited. Some facilities may have felt obliged to participate due to the fact that they receive government funding. Historical, social, political and demographic factors may also have influenced participation.

The interview guide was developed by the researcher and must be examined within the context of the literature review. The interview questions were exploratory and historical in nature which required the study participants to have a certain degree of insight and ability to recall experiences within the organization prior to 1989. The

open ended questions and direct probes may have influenced both the quantity and quality of the participants' responses.

Data collection was completed entirely by the researcher which may have provided consistency to the process. However, limitations may occur in the process of the interview related to the selection of probe questions and the depth of probing. To minimize the bias, I consistently followed the major categories of the indepth interview guide and attempted to maintain a consistent time frame with each interview.

The location of the interview and the time commitment are further potential limitations. Additionally, the use of a tape recorder may have influenced some participants' responses.

Some LTC facilities had two respondents who chose to be interviewed at the same time and respondents may have felt inhibited to participate fully due to their positions or personalities. Aside from the same limitations as the indepth interview, the data collected from the telephone interviews was affected by my inability to observe non-verbal cues and to develop the same kind of rapport with the respondents.

The study utilized self report data. Although, the respondent(s) were selected by the facility administrator or owner to represent them, the respondent(s) provided their perspective on events and experiences in the facility which limits the degree of facility representation. It must be remembered that the study respondents will be mostly in management or nursing positions which may influence their perceptions of

other health professionals involved in the policy process. Additionally, the subject matter may have aroused personal and past experiences which may be intertwined with experiences in the present LTC setting, therefore, affecting the validity of the results.

There are some further limitations associated with data analysis. To maximize validity, data were coded by listening to the taped versions of the face to face interview as well as reading the verbatim transcript. The phone interviews were not taped although extensive field notes were taken. Combining two types of interview data with different degrees of inclusiveness into one data set for analysis could affect the validity of the results. Although the qualitative research method of this study is intended to allow categories to emerge from the interview questions and the data itself, images of other categorization schemes invariably shape the results. Qualitative analysis is an ongoing process and thus will continue to evolve as the researcher works with the data. The data analysis in this study must be examined in light of the specific interview settings, methods of data collection and the current knowledge on the public policy process related to the issue of DNR and DI.

CHAPTER IV

RESULTS

The purpose of the study is to understand the process of developing and implementing policies on advance directives in LTC facilities in the province of British Columbia. This chapter is broadly divided into subsections, each corresponding to the specific research questions posed in Chapter II. First, a description of the study facilities and respondents is provided. Second, the pre-1989 problems related to advance directives are examined. Third, the development process of DNR and DI policy post 1989 is detailed. Finally, the implementation process of DNR and DI policy post 1989 is examined.

Portrait of Study Facilities and Study Participants

Study Facilities

Twenty-three of the thirty LTC facilities randomly selected responded to the invitation to participate in the study. Although the facilities vary in funding arrangements, governing regulations, and size (see Appendix F for complete data) they are remarkably representative of LTC facilities in British Columbia. The size, setting, and classification of the participating LTC facilities are summarized in Table 4. The facilities are situated throughout the four physical quadrants of British Columbia: a) Northwest, b) Northeast, c) Southwest, and d) Southeast. The majority of facilities have between fifty (50) and one hundred and fifty (150) beds, are situated

in urban areas, and classified as an intermediate care facility. Two facilities are operated by non-profit ethnic associations; two facilities by religious groups; and two by non-profit social organizations.

Table 4 - Number of Responding Facilities in Study by Size, Setting, and Association with Groups

Size[1]		Setting[2]	
Small (<50 beds)	5	Rural	8
Medium (50-150 beds)	13	Urban	15
Large (>150 beds)	5		
Group Association[3]	Ethnic 2	Social 2	Religious 2

The facilities are further characterized according to parameters of governance and funding found in Table 3 in the methodology chapter. In this chapter Table 5 summarizes the number of participating facilities by category of governance.

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[1]General categories used by the Continuing Care Division, Ministry of Health, Victoria, B.C. (Butler, A., 1992. Personal Communication)

[2]Refers to 1986 Canada census definitions of: a) rural - places having a population of < 1000, and b) urban - places having a population of 1000 or > with a density of 1000 per square mile (cited in The Rural Community).

[3]Corresponds to facilities which operate through elected Boards of Directors from non-profit societies in the community, e.g. Catholic Church, Association of German Canadians, Kiwanis, or Downtown Eastside Association.

Table 5 - Number of responding facilities by category of governance and funding		
Category A	(Facility Act, profit)	4
Category B	(Facility Act, non-profit)	11
Category C	(Hospital Act, non-profit)	6
Category D	(Hospital Act, profit)	2

Of the eight facilities that declined to participate, four are Category A, three are Category B, and one is a Category C facility. Some administrators or owners of these facilities mentioned their reason for not volunteering for the study, these include: "our administrator left", "we have a new Director", and "we have no need for DNR, people here don't die".

Study Respondents

The study participants consist of staff members who were selected by the facility administrator as the person most knowledgeable about their DNR/DI policies. Following the recruitment period, thirty-three (33) staff members from the twenty-three (23) facilities participating in the study were interviewed. The respondents varied in terms of the position they held in the organization, length of time in that role, and years in a long term care setting, however, over half are nurses in a position as Director of Resident Care or Nursing. The demographic and professional characteristics are presented in Table 6.

Table 6 - Demographic and Professional Characteristics of Study Respondents from LTC Facilities in the Study

Length of Time in the LTC facility	
< 3 months	0
3 mo but < 1 yr	4
1 yr but < 2 yr	5
2 yr but < 5 yr	9
5 yr and >	15
Present Title	
Administrator/CEO	7
Owner/Operator	1
Director of Resident Care	17
Director of Nursing	2
Unit Manager/Head Nurse	3
Clinical Nurse Specialist	1
Social Workers	2
Length of Time in Present Role	
< 3 months	2
3 mo but < 1 yr	5
1 yr but < 2 yr	5
2 yr but < 5 yr	12
5 yr and >	9
Highest level of education completed	
Graduate Degree	6
Undergraduate Degree	10
College Diploma	17
Proportion of Facility policies written by respondent	
All - 2	Some - 29 None - 2

Most notable is the high education level among the respondents. All of the respondents have completed a college diploma program and further education levels ranged from ten respondents with completed baccalaureate degrees to six with completed graduate degrees. Of the thirty-three respondents, fifteen have worked in the participating facility for greater than five years and twenty-one respondents have been in their present position for greater than two years. All but two of the respondents have been, or currently are, involved in the development of policies in their facility.

Identification of Problems Pre-1989

Each facility was asked to describe the problems or issues related to DNR/DI and advance decision-making for the end stage of a residents life they had experienced in their facility prior to the guidelines in 1989. Three major themes emerged from the data as being significant elements in the problem identification process. A further analysis of the data supports a reduction of the information within each theme into a framework which focuses upon twelve sub-themes which are presented in Table 7. These sub-themes represent common views and opinions and, as such, provide a concise representation of the findings.

Table 7 - Elements of the Problem Identification Process

1. Initial perception of problem by:
    - i) Care staff
    - ii) Residents
    - iii) The Organization
    - iv) Doctors
2. Nature and type of problems
    - i) Uncertainty
    - ii) Lack of resident autonomy
    - iii) Residents unable to die in place
    - iv) Fear of legal and regulatory sanctions
3. Clarification of the problem
    - i) Absent or unclear doctor's orders
    - ii) Unwritten agency policy and process
    - iii) Absent legislation
    - iv) Existing legislation and external policies

Initial Perceptions of Problems

The first question of every interview asked: Prior to the guidelines in 1989, what where the problems or issues related to Do Not Resuscitate and advance decision-making for the end stage of a residents life. All of the respondents perceived their problems in 1989 in relation to somebody or something. These were: care staff, residents, the organization or doctors. One Director of Care responded that "the nurses began to feel very uncomfortable, feeling in the middle and starting to question why are we doing this?". Close to one half of the respondents spoke of

nurses experiences in their facility. A Head nurse responded: "One of our residents collapsed, was admitted to hospital and put on all kinds of support and died in 2 weeks. We [care staff] felt terrible". Similarly, over half of the respondents described problems as situations experienced by residents: "Residents heard about how another resident was kept alive by machines and started to say, I don't want that to happen to me".

Other respondents first spoke of the problem in terms of the organization. The stimulus was perceived as either "we had no policy which directed staff to determine resuscitation status from the doctor" or as another respondent states: "Our DNR policy was too black and white and did not encompass all the situations we faced". The undesirable situation began for some with a stimulus external to the organization "the coroner slapped our hands. We felt that we were not judged right."

Occasionally the respondents described their problems in 1989 as situations involving doctors. "The major problem was noncompliance from the doctors, they were and are not committed to discussing the topic or signing an order." Yet a Head Nurse from a rural setting describes their problem as: "Doctors were leaving the decision up to the nurses." Thus problematic situations involved the doctors methods of decision-making on the issue of resuscitation and advance choices for residents. In all but one facility, the respondents recalled that prior to 1989 they experienced problems related to resident resuscitation and decision making at the end of life.

Nature of the Problem

Whatever the initial experience of nurses, residents, administration, or doctors in the facility, all of the respondents recalled their problems in 1989 as an uncomfortable condition or situation. Although differences existed four types of problems emerged from the data, including: 1) health care providers uncertain about the resident's wishes and physician orders, 2) lack of resident autonomy, 3) residents unable to die in place, and 4) health care providers fear of legal and regulatory sanctions.

Perceptions of Uncertainty

All of the respondents in the study discussed situations where a care provider was in doubt as to what to do or was uncertain about what decision to make when a resident was dying or had collapsed. Repeatedly, respondents would comment that "nurses often asked we are not sure what we should be doing when a resident collapses or has a cardiac arrest". This situation exemplifies the uncertainty experienced by the staff which respondents reported.

Occasionally respondents stated that doctors were uncertain about resident resuscitation and decision-making. A Clinical nurse specialist discloses "the new doctors call me all the time and say "'I don't know what to do with this old person, everybody is old and dying"'. Physician uncertainty was reflected in statements by three respondents who mentioned that prior to 1989 doctors expected nurses to "walk slowly" to resuscitate long term care residents because they "couldn't decide".

Nine respondents spoke of uncertainty as excessive nursing discretion. While more than half of these respondents are from rural areas, all of them discuss nursing discretion as making judgements, making choices to act or not act, within professional, legal and moral rules. One Director of Care clearly perceives discretion as a problem: "I see the problems they face in nursing practice. The nursing dilemmas they have when a person collapses and they have to use their own discretion as to what should be done, they find that very difficult sometimes, especially with some people here who they become so attached to." Further, these situations are also uncomfortable for administration. "I didn't feel it was fair to leave nurses on a limb and just let them make a decision". Directors of Care from rural settings were concerned with casual staff "in a situation to make critical decisions without guidelines" and with only care aides on nights, they "are in no man's land, with no where to turn". Conversely one Director of Care had a policy which gave nurses the power to use their discretion. She found that "nurses resisted that they had the judgement skill to make a decision when the resident was dying".

Lack of Resident Autonomy

Close to one half of the respondents in the study had experiences with residents who had no choice or say in decision-making for their care at the end stages of life. While an overwhelming number of these respondents are from rural settings, all of the respondents discuss that "There was the typical no codes being written with no consultation with the family and/or resident". Some respondents also described that nurses "want the residents to have a choice and feel "badly" when this does not

occur. For a few respondents the lack of resident autonomy is not perceived as a problem. They voice that "we are the best people to make the decision for the resident". As one respondent stated: "nurses, doctors and families in this facility don't value the rights of the aging individual to choose". Although the lack of resident autonomy to make resuscitation and treatment decisions is considered by the majority of respondents to have been a problem in 1989, there is a small number of respondents who did not perceive the lack of resident autonomy as a problem.

Unable to Die in Place

The third situation which one-half of the respondents identified as a problem for them in 1989 was the inability of residents to die in their facility. Unlike the previous situation of resident autonomy, described most often by respondents in rural settings, the inability of residents to die in one place was clearly a problem for facilities in urban settings. This difference is discussed by several respondents from rural settings as being directly related to the lack of other long term care beds in their communities which can be utilized.

The experience of moving a patient to die in another facility was felt to have a negative impact on residents, and care staff. One Director of Care who had been a staff nurse in the facility in 1989 remembered that "residents begged us not to send them to hospital to die. But we sent them and they had a bad experience, died there and we were sad that they had to go through that in their last few days. We felt we were abandoning some of the residents who had lived here for up to 7 and 8 years." Even in a hospital with both acute and extended care beds this feeling prevailed: "we

love this patient, we have had him/her for so long, it seems a shame to have to send them up the hall". Consistently the depth of the impact was associated with the staff-resident relationship that had developed.

Health Providers Fear of Legal and Regulatory Sanctions

Finally, in addition to perceiving problems as situations related to uncertainty for health care providers, the lack of resident autonomy, and the resident's inability to die in place, most of the respondents had a sense of fear of legal and regulatory sanctions. Although this condition is closely associated with the previously described situations, one half of the respondents at first clearly articulated their problem as a "fear of being sued". "It seemed to be a general feeling at the time of legal liability. The respondents mentions that this fear was experienced by nurses, doctors and administrators. Several respondents mentioned situations where the Board of Directors were "very concerned with their moral legal responsibilities".

The respondents have all described multiple complex situations or conditions which they now recognize in retrospect as problems they faced in 1989 related to Do Not Resuscitate and advance decision-making for the end stages of a residents life. These problems include: uncertainty as to resident wishes or doctors orders; lack of resident autonomy; residents unable to die in place; and fear of legal or regulatory sanctions.

Clarification of the Problem

Whatever the uncomfortable situation or condition, the respondents inevitably discuss specific circumstances which further define their problems. The circumstances which emerged in all of the interviews focused on procedural conditions that obstructed the respondents actions or those of their care staff. Four themes emerged and include: 1) absent or unclear doctor's orders, 2) unwritten agency policy and process, 3) absent legislation, and 4) existing legislation and external policies.

Absent or Unclear Doctor's Orders

The first procedural condition, absent or unwritten doctors orders for DNR were a specific problem for eleven respondents. In the words of one respondent: "The problems really where lack of clarity. If there had been a decision for Do Not Resuscitate, it was not having it documented in the physicians order". Absent or unclear doctors orders are discussed as a problem almost exclusively by respondents in urban settings.

Unwritten Agency Policy or Process

Although thirteen out of twenty-three respondents indicated they had a DNR policy, some respondents stressed that problems were related to the lack of clearly defined roles in written policy. Prior to 1989, the respondents indicated they had not heard of Degrees of Intervention. However, five respondents discussed having a formal process for discussing care and treatment for the end of life with residents and/or their families. Hence, the lack of written policies and processes within the

facility was another key circumstance which fuelled the problems related to advance directives prior to 1989.

Absent Legislation

The third procedural circumstance is the absence of legislation on advance care directives identified by twelve respondents in the study. "One of the problems we have in today's society legally is the acceptance in a formal sense of the living will." Another respondent states: We have had some very difficult situations, and legislation would help. There were no checks or balances to ensure that people's rights were protected. While some respondents understood that their fear of civil negligence and liability stems from our common law system, many felt legislation would prevent nurses and doctors from being sued.

Existing Legislation and External Policies

The final procedural problem which a small group of respondents mentioned was existing legislation that governs B.C. ambulance drivers and the Coroners Service. Speaking about the ambulance service, one administrator states: "they won't take a dead person from here without a doctors order, or only takes them and resuscitates them, which is a bit hard if they have been dead for a while. Thus,the perceived problems related to DNR and advance decision making in long term care facilities, involve procedural circumstances with internal or external policies and processes.

The findings related to perceived problems in 1989 associated with Do Not Resuscitate and advance decision making for residents in long term care facilities

have been articulated. The respondents identified a variety of problematic situations for staff, residents and their families, doctors and administration. In recognizing their problems, the respondents all proceeded through a process of clarifying the circumstances of the situation in order to understand the procedural elements of the problem requiring action. In the following section, the policy development process will be examined.

Factors Which Influence the Policy Development Process

The second area of inquiry focused upon development of policies on DNR and DI in the participating facilities and factors which influenced this process. Results correspond to the following interview questions: a) respondents perception of the B.C. Ministry of Health, 1989 report and operational guidelines titled "Death and Dying in Long Term Care Facilities", and b) other factors which may have influenced the development of DNR and DI policies in their facility. Following analysis, seven themes emerged and are presented in Table 8.

Table 8 - Factors Which Influence the Policy Development Phase

THEMES

1. Perception of provincial guideline documents "Death and Dying in Long Term Care Facilities"
2. Attitudes of individuals
3. Perspective of groups internal to the organization
4. Perspective of groups external to the organization
7. Physical, structural and functional components of the organization

Perception of Provincial Guideline Documents

"Death and Dying in Long Term Care Facilities"

After identifying and discussing the problems and situations related to DNR/DI prior to 1989, the respondents in the study were asked: What helped your situation at that time? Over one-half of the respondents replied that the Ministry guidelines on Death and Dying assisted them to develop a policy solution. The degree to which the guidelines helped was different between the respondents. However, the respondents all discussed the documents with words such as functional, practical, valuable, and worthwhile. Not all of the respondents in the study saw the guidelines at the same time or from the same source. Four facilities had never seen the guideline documents until contacted for this study and nineteen respondents had

first hand knowledge that the guidelines were available in their facility prior to or during the development of their policy.

To further articulate the impact of these guidelines, I asked the respondents a two part question: "Were the guidelines useful? what do you like about the format?" Seventeen of the nineteen respondents who had access to the guidelines, found them useful. These respondents describe the guidelines as a useful document for several reasons. First, the guidelines were discussed as the "catalyst" which promoted discussion and the policy process, "when we got the publications from the Continuing Care Division it acted as a catalytic event in our lives. We then formed a committee, went through over a period of time the contents of the publications and came out with a set of draft policies". Secondly, respondents reported that the guidelines were an authoritative influential government document. "Certainly the guidelines that were written in black and white, were an authority which motivated people to start talking about this issue and doing something about getting a policy developed." Respondents also reported that the guidelines directed facility staff by providing background information, a framework and a checklist for discussion and development. Finally, the guidelines were proactive and well researched which provided a valid, credible document for facility staff. As one respondent stated: "That document has the potential to change some things, a proactive approach, who is this person, where are they at, the goals. I thought it was a credible document. The degrees of intervention are phenomenally sound, really clear".

The preceding themes were evident throughout the interviews, however, differences between rural and urban respondents surfaced. For example, a greater proportion of urban respondents perceived the guidelines to be useful because they were an authoritative government document, whereas rural respondents more often described the guidelines to be useful due to their informative nature. As one Director of Care from a rural setting states the guidelines are "a good overview of solutions, and gave us direction." While these were the common themes that emerged, additional responses indicated that the guidelines were also effective because; 1) they were a non-coercive document; 2) they confirmed respondents beliefs and values; and 3) they reflected reality.

Only two respondents reported that they did not find the guideline documents useful. One respondent emphatically stated: "I don't agree with the ideas that the guidelines refer to". Further she mentions that they do not have a DNR/DI policy. The other respondent explained that "I did not feel that they would help. We were already doing a lot of what was described in there. I saw another type of policy from a peer facility and liked how they dealt with degrees of intervention which I prefer over the guidelines." Therefore the guideline documents were considered by a greater majority of respondents to provide "valid" information in a manner which directed them in developing policies on DNR/DI.

Ten respondents mentioned the format of the guidelines. They described the documents in terms of "easy print size", "simple layout", "easy to follow" and "good content". On the other hand, four respondents described the guidelines as using

"excess paper and space", and being "too lengthy". Only one respondent mentioned that the guideline documents are "poorly written". Thus the respondents in the study generally perceived that the document was well formatted. When asked how the guideline documents could be more useful, thirteen respondents provided various suggestions (Appendix G). One respondent summarizes the usefulnes of the guidelines expressed by many respondents: "Before the guidelines came out we were all tiptoeing around this issue."

However, the guideline documents were initially perceived, at some point in time the respondents moved from a stage of problem identification to a stage where a policy was developed then implemented. Statements from respondents focusing on the influences on policy development illuminated a further five themes:

Individual Attitudes

For all the respondents in the study, certain individuals connected with their organization exhibit attitudes directly related to behaviour which influenced the development of their policy on DNR/DI. These include: Director's of Care/Nursing, Medical Coordinator's/Director, nursing care staff, resident's or family members. For all of the respondents the attitude of an individual in a management role promoted policy development. One hospital Director of Nursing states: "I promoted it because it needed changing to reflect the resident's rights."

Conversely, all of the respondents perceive that policy development on this issue is delayed or impeded most often by the attitudes of family physicians associated with their organization. There was no differences between urban or rural

respondents. In the words of one respondent "the doctors were very patronizing, they tried to humour administration out of developing our policy". Another respondent from a rural setting perceived that the "a majority of our doctors have an attitude and value of long term care facilities" as a "dumping ground for nurses who can't make it in acute care". Policy development on DNR/DI is delayed by the attitude and behaviour of physicians. Further, this attitude is influenced by their beliefs and values of long term care facilities, staff and residents.

Individual physicians were perceived to promote DNR/DI policy development if they were either a Medical Coordinator or Medical Director or when there are fewer of them to serve a facility, they live in the community and they "value this organization and will help in any way possible".

Respondents consistently discussed the attitudes of individual nurses and care aide staff as a positive influence on developing a policy on DNR/DI. Sixteen respondents discussed how their DNR/DI policy was "pushed up the priority list" because of the attitudes and actions of select nursing staff.

> The most influential in promoting our policy were our registered nurses. It is them in the middle of the night who make the decision. It was their strength and need of being by themselves in the middle of the night that pushed it along to be developed.

Interestingly, respondents only spoke of resident/family attitudes in the context of promoting policy development. One quarter of the respondents, most from facilities in rural settings, describe some residents and families as "being more informed of this topic and aware of their rights" and "asking about the facilities policy and process". Some respondents spoke about residents who "on their own pressured

the doctors to agree to our policy." Resident attitudes promote policy development by influencing key individuals involved in the policy process.

In summary the attitudes of individual management staff, nursing care staff, doctors, residents, and family members have a positive influence on the development of policies on DNR/DI. However, respondents do perceive that policy development on this issue is delayed or impeded most often by the attitudes of general physicians associated with their organization.

Perspective of Groups Internal to the Organization

The perspective of a group is directly related to their behaviour or action which influences the development of policies on DNR/DI. While the composition and the role of the groups are varied, all of the respondents in the study discuss at least one experience with a group which influenced development of their DNR/DI policy. Groups internal to the organization which influenced policy development include: 1) Board of Directors, 2) Management, 3) Medical staff committees, and 4) Resident councils.

The group which was described most often as influencing policy development is the Board of Directors. Seventeen of the respondents in the study are from facilities with Boards of Directors. Thirteen spoke of their Board as having a "positive attitude and wanting us to develop a policy on DNR/DI". Moreover Board members of facilities in rural settings "volunteer in the facility", "have family members or neighbours in the facility", or "have lived in the community for a great length of time". Hence board members who value resident choice, have a personal connection

to the community and/or facility and have board experience relates directly to Board decisions to promote DNR/DI policy development. One Director of Care spoke at length of her experiences with her Board of Directors who "vetoed the idea of such a policy. The majority of our board are from a certain ethnic group. I think it is tied to the fact that they are scared that the facility will turn into an institution and they want it to be a home." Thus conflicts between a groups beliefs of resuscitation as an institutional process and the values of the organization as a "home" inhibited the Board to develop this policy.

Sometimes respondents described an 'organizational attitude' which influenced policy development. While the depth and form of this 'organizational attitude' varied among the respondents, all the respondents discuss to some extent the values and beliefs which the management and board together expressed as being significant in providing an environment and giving care to residents. For example, respondents discussed a mission statement, facility culture, belief statement or an organizational philosophy which originated from management. Seventeen respondents stated they have a mission statement and thirteen of those respondents also described an additional policy statement on resident rights. For ten respondents the perception existed that the philosophy of their facility promoted the implementation of their DNR/DI policy. As one administrator voices: "it's getting people on board who believe deeply in a different long term care approach. It's very protective of the rights of the residents, when you get those attitudes married to process then your bang on." Another respondent describes the organization as being very open with the

staff about death and do not resuscitate. "We believe that choice is not only for degrees of intervention, death and dying, but for everyday life. So on a bigger scale the degrees of intervention are just another part of life."

Concurrently only two respondents felt that the organization's "philosophy" acted as a barrier to implementing a policy on DNR/DI. For both of these respondents the facility was considered like a "home" and dying was described as "a natural event" which led them to believe that "we don't need to ask anyone about resuscitation or degrees of intervention, we just provide good supportive care until the end."

To recap, the influence of group culture internal to the organization was critical for all of the respondents in the study. Respondents describe the attitudes and beliefs of their Board of Directors as having the greatest influence on DNR/DI policy development. Moreover, for the study participants, internal group values underlying the purpose of their facility act as a major force in determining the priority of this policy issue.

Perspective of Groups External to the Organization

In the respondents discussions of group perspectives influencing policy development on DNR/DI, the second category which was evident was groups external to the facilities in the study. External groups included:

a) Other health care facilities in the community - These where described by half of the respondents as a factor which promoted them to develop their policy on DNR/DI. "We went to the acute care hospital in the area and got what they are

doing, the ECU there. They already had something established then that our doctors were using there." Hence, sharing between different types of organizations within a community made policy development easier. In a dramatically different way one Administrator spoke directly of the pressure she felt from the community to change her policy: "Now everybody around here is expecting it [DNR, DI] and it is getting thrust upon us. The hospital is phoning wanting to know what the wishes of the resident where when they were here. You know I was sort of giving in to the community pressure, but in my heart I was sort of saying, why am I asking these people what they want. We do not resuscitate here. Other health organizations in a community can apply pressure to long term care facilities to change. However, the attitude of facility administration can be divergent and block new policy development.

b) Regional Director of Care Group - This group is composed of people who normally function in the role of Director of Care in a community care facility. One half of the respondents clearly voiced that this group of external peers is "our lifeline", "supportive", "avenue of information", "the nuts and bolts, we share, pass on policies, etc, what have you done, how. The group is informal, its great networking and information sharing".

c) Long Term Care Associations - These include the British Columbia Hospital Association (BCHA), the British Columbia Association of Community Care (BCACC), and the British Columbia Association of Private Care Facilities (PRICARE). Almost one half of the respondents felt that their specific health care association assisted them in some way to develop their DNR/DI policy. Some

respondents mentioned that at that time (1989) supporting information from "BCHA got stuck" in the administrators office, "it was never filtered down, I had to go asking for it". Thus the lack of access to information from external associations and communication paths to respondents hindered policy development.

d) Government bodies - Half of the respondents perceived government officials to be unavailable or inaccessible when assistance is needed on policy development issues. Some respondents spoke of "not knowing who to call" or getting "tangled up in bureaucratic run around". One-third of the respondents spoke of government in terms of delaying their development of DNR/DI policy due to the provincial government's turbulent relationship with doctors over a "work to rule" campaign. This conflict between two groups external to long term care facilities delayed the process "because the doctors in this city were not participating in any hospital or facility meetings". A respondent from a rural hospital found the same problem, "so there have not been any meetings which made our Board balk at approving this policy without their approval." Thus the values and behaviour of government and doctors at a provincial level directly affects the management and priorities of long term care organizations and hinders formulation of DNR/DI policies.

In summary, while the details of each respondent's experience with external groups varied widely, three groups were consistently described as a positive influence on policy development and they include: local community care facilities and/or hospital, 2) regional Director of Care groups, 3) health care associations. For some

respondents in the study the provincial government's actions toward physicians are a negative influence on the development of DNR/DI policy in long term care facilities.

Physical, Structural and Functional Components of the Organization

The fourth factor which respondents discuss as an influence on the development of DNR/DI policies are salient components of their organization. The actual organizational component which a respondent claims as an influence on policy development depends on their circumstances, their position in the organization, and their perception of the policy issue. Many of the respondents discuss more than one component of the organization as an influence on their policy. These components include:

a) The physical structure of the facility - in terms of its room design, overall facility design and bed capacity. For one-third of the respondents, renovations and additions to the facility structure were described as "major projects" which delayed policy-making. Conversely two-thirds of the respondents felt the lack of physical resources, such as "oxygen spaces", "bigger rooms", and "suction" in their facilities to resuscitate or provide care for a dying resident prevented them from "even developing a policy in the first place". Thus, the perceived impact of a DI policy on the existing facility structure and resources acted as a barrier to development.

b) Organizational structure - influenced policy development according to respondents in terms of management changes, and existing policies and routines. One half of the respondents believed that changes in management personnel delayed

their development, while the remaining spoke of changes in their ownership or administrative pattern which they perceived promoted the development of this policy. Existing facility policy on CPR was exclusively perceived by one-third of the respondents as a barrier to policy development. As one respondent articulates "if you develop a policy like this you can't veer from it and the nurses must maintain their CPR, that is mandatory which means nurses have to use their time, we'll only pay for the course which is an added expense we don't have money for". Hence, to change their policy and require staff to have CPR would place a greater demand on their resources. DI policy was also delayed because of "the union". According to the union, the proposed changes in policy would alter the nature of the work of care aides and the union expected the facility to "provide paid time and course fee". Thus the real and potential political and economical impact of a DI policy on existing policies acted as a barrier to development.

c) The role and function of the organization - relates to facility as a place where residents live 24 hours a day. A hospital respondent states: "We had a real change in the patients coming in, we are not getting these elderly dying patients as much. Also our organization is getting out of the business of extended care so maybe our administration delayed the policy development due to lack of future need." A respondent from a rural multi-level facility mentions that the role of their organization in providing "care until the final moments of death" promoted them to "fast-track" their DNR/DI policy. Combined hospital and extended care units articulated that "We didn't have that type of [DI] policy in ECU because of the

influence of acute care, it is so close just across the hall". The physical ease of transferring dying residents within the facility to a higher level of care resources delayed the need for a Degrees of Intervention policy. The role of the organization can delay or promote policy development.

The respondents also speak of these organizational components as having an impact on their time management and the "priority" for developing a DNR and DI policy. As one Director of Care lamented, "we ended up with a lot of stuff and issues to deal with and it [DNR policy] seemed to fall down on the priority list". One half of the respondents spoke of priority in terms of "not enough time". This policy "is something we want to get done, but between January and now we just haven't had time." This concept of priority was articulated by one respondent as meaning "getting the policy on the agenda".

Implicit within an organization which cares for long term care residents are existing physical structures, organizational structures, policies, and routines that all impact on time and priorities which influences the development of policies related to DNR and Degrees of Intervention. Important subcomponents of these factors include: the absence of a CPR policy; characteristics of the facility structure and resources which affect care of dying residents.

Policy Paths

Whatever the factors which promoted or delayed development of DNR/DI policies, all but one respondent in the study has begun to formulate a written policy document on either Do Not Resuscitate and/or Degrees of Intervention. In fact,

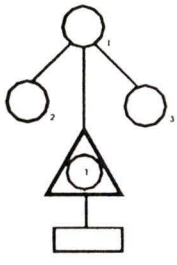
seventeen respondents had completed policy documents on Do Not Resuscitate in September 1992, while three respondents had draft documents. Two respondents incorporated their DNR policy into the Degree of Intervention policy. In relation to the Degrees of Intervention policy, fifteen respondents had a completed document and four where in a drafting stage. Only four respondents had not begun any work on a DI or similar policy.

The respondents in the study were asked to draw or explain their path of policy development. Differences existed between the respondents detailed descriptions of their "path" and the time involved in developing the policy to date. All of the "paths" were diagrammed and five patterns emerged. Figure 1 provides a pictorial overview of the five patterns and includes the number of facilities which described that policy path and the status of their policy to date.

Figure 1: Patterns of Policy Development on DNR/DI in LTC Facilities in British Columbia

Category A: Single Person Initiates Policy Development

A single person initiates a policy then drafts the policy.
A second person provides input before policy goes to the Board/Owner.
This path occurred for one facility in the study and was vetoed by the Board/Owner.

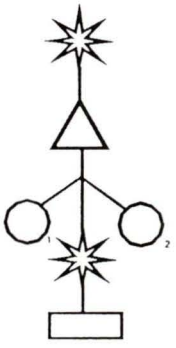


A single person initiates a policy then obtains advice from others.
A single person drafts the policy before going to the Board/Owner.
This path occurred for two facilities in the study and one was completed.

A single person initiates a policy then obtains advice from a Committee.
A single person drafts the policy before going to the Board/Owner.
This path occurred for seven facilities in the study and six were completed.

Figure 1: Patterns of Policy Development on DNR/DI
In LTC Facilities in British Columbia (cont'd)

Category B: Group or Committee Initiates Policy Development



A Committee or Group initiates a policy then drafts the policy.
Single people provide advice before policy goes back to the Committee.
Committee representative presents policy to the Board/Owner.
This path occurred for three facilities in the study and two were completed.

A Committee or Group initiates a policy then a single person drafts the policy.
A Committee provides advice before going back to the single person who takes policy to the Board/Owner.
This path occurred for nine facilities in the study and seven were completed.

KEY:

 Individual

 Drafter

 Board/Owner

 Committee

These five patterns fall into two categories related to the initial source of policy development: 1) a single person initiates policy development, or 2) a group or committee of people initiate policy development. Eight of the respondents fall into the first category whereby a single person initiated DNR/DI policy development. Six out of the eight respondents identified their Director of Care or Director of Nursing as the 'single' person who initiate development of the policy. Two respondents mentioned that the Administrator initiated the development process.

The majority of respondents fall into the second category. Fifteen respondents indicated that the development of their policy was initiated by a group or committee of individuals from within the organization. Among these respondents there is variation in group composition, however, six respondents from rural settings all speak of nursing care staff as the group which started the development of DNR/DI policy. On the other hand respondents from urban settings described their groups or committees as management staff or staff from multiple disciplines within the organization such as social workers and theologians. Rarely, residents and family representatives were included as members of the group which initiated policy development. Thus the type of facility setting directly relates to the composition of a group or committee which begins the work of developing a policy on DNR/DI. Each of these two categories are further broken down into sub-categories based on the method of assistance that is engaged to prepare the policy prior to final approval by a Board of Directors, Owner or Administrator.

There is a wide variation between the five patterns in regards to the number of facilities utilizing a path and the completion of a policy document. Facilities where a committee initiated the development and was involved throughout the process (pattern 5) has the highest completion rate (7/9). Facilities where one person initiate the process and sought committee advice also has a high completion rate (6/7). Only one facility described a singular, non committee path which resulted in disapproval from the Board.

Aside from the details, all of the respondents consider the sequence of events, number of people involved, and points when decisions were made. Any one or combination of these components delayed the policy development process but did not relate to a failure to produce a policy document. Fifteen respondents talked about "co-operation", "consensus", "educate, inform and involve" as methods which advanced DNR/DI policy development. For example, one Director of Care speaks of educating all care staff "as the first priority of the plan for the development of this policy." We felt that was going to be what was going to make it successful or not as far as staff was concerned. Respondent's from rural setting often spoke of methods that encouraged both resident and family representation on a policy committee. For others "The policy development process was successful for us because it was a multi-disciplinary committee with real feeling. We wanted a general practitioner on the committee because there is no use writing, if they are not part of it, nursing, social work, padre, community and board members." Thus the involvement of a front-line

workers and a wide range of people affected by this policy is directly related to a perception of successful policy development.

To summarize, the findings related to the development phase of the policy process related to DNR/DI policy have been articulated. Factors which influence this phase have included: the perceptions of the government guidelines "Death and Dying in Long Term Care Facilities", and other factors, namely, individual attitudes, internal groups, external organizations, and components of the facilities physical and organizational structure, and function. Hence, factors which influence DNR/DI policy development provide a basis for determining its priority.

Furthermore, these factors relate directly to the respondents ability to proceed along a path of policy development. In this study five distinct paths of development on DNR and DI policy emerged and can be classified in two categories according to the initial source of the process; a single person or a group/committee. Important elements of the process to completion are; the model of decision-making that is chosen; the number of people involved and the method of presentation to the approving body. The responses from sixteen facility representatives in the study indicate that obtaining approval of a policy document on DNR/DI is obtained through committee involvement. Approval of a policy related to the issue of death and dying is the direct result of a process involving consensus among many different perspectives.

Factors Which Influence the Policy Implementation Process

The final area of inquiry in this study centred on the implementation phase of the policy process related to DNR and DI policies in long term care facilities. The transition point from development and approval of a DNR or DI policy to the actual implementation of the policy in practice were obvious for all of the respondents. Eighteen of the respondents had actual experiences with implementation of their policy, whereas five respondents had not implemented a policy and therefore discussed the potential process of implementation they would undertake. Differences existed between the respondents descriptions of the chain of events in their facility. However, aside from the variances, all of the respondents discuss a process of informing their residents, families, staff and doctors, before a form was actually used.

To determine what influenced the process of implementation, I asked the respondents two questions. The first question states: What do you think did or will delay the implementation of your policy? The second question asked: What do you think did or will promote the implementation of your policy? The responses to these questions were extremely varied and in several ways are consistent with the pattern that emerged in the answers on the policy development process questions. What was perceived as a negative influence for one respondent was often perceived as a positive influence for another respondent. However, six themes were defined from the data as being significant influences on the implementation process and are presented in Table 9.

Table 9 - Factors Which Influenced the Policy Implementation Phase

THEMES

1. Individual Attitudes
2. Influence of Groups External to the Facilities
3. Individual Styles for Communicating DNR/DI policy
4. Time to Discuss Issue with Residents and Family
5. Education of Health Care Providers; Basic and Inservice
6. External Government Regulations

Individual Attitudes

Similar to the findings indicated previously in the policy development phase, individual attitudes were perceived by respondents to have an influence on the implementation phase. These individuals include: doctors, care staff, residents and their families. Twenty-one respondents with actual policies or drafts all require a physicians signature on their DNR and/or Degrees of Intervention form which implies that a communication process had taken place between the family and/or resident and the physician. However, for some the process of communication is initiated by facility staff and the physicians signature will only indicate that they were aware of the residents decisions and have no opposition to their choice. Therefore, at whatever point in the process between development and implementation, the doctors are a critical element in implementation of a DNR/DI policy.

Two-thirds of the respondents perceived that doctors displayed an attitude which acted as a barrier to policy implementation. As one respondent clearly voices,

> I think they are the barrier, they will not come here at the best of times to visit or assess. They seem to have an attitude which is definitely the medical model of care, 'come if you have a problem that needs fixing, but don't ask me to think ahead, be preventative or make a decision in advance.' They are still very paternalistic in their thinking.

Another respondent described her recent experience with sending their new DNR/DI form to over 100 physicians.

> Several of the doctors were unwilling to complete the form. We had really bad, rude comments and I actually had some cases where doctors wrote 'just let them die'. It ticks me off that the doctors will not take the responsibility for doing this with their patients, the resident has the right and because of their attitude or fear, I don't think we should have to deal with their garbage.

On the other hand, one-third of the respondents perceived doctors as promoting the implementation of their DNR/DI policy. One respondent mentions that "the young doctors are really in the mode of multidisciplinary care, they are willing to consult and get assistance to help them make these difficult decisions." Another respondent voices: "we have developed a very good relationship with our physicians because they have been the same for years and years. Thus while doctors are a critical element in the implementation of a DNR/DI policy, an overwhelming majority of respondents perceived doctors to be a barrier to this process.

The participating facilities staff who provide nursing care vary in numbers, roles, education, cultural background, and their life experiences. It is notable that the respondents were split on their perceptions of care staff attitudes as a negative or

positive influence on policy implementation. This is quite different then the respondents views of nursing care staff in the policy development stage who where reported to be instrumental in promoting policy development. Respondents who felt their care staff acted as a barrier to implementation often cited their "cultural differences and values" as a factor. One Director of Care surmised that "my staff with a different cultural value may in fact subscribe to what we are doing but they may not feel good or comfortable about it." Some respondents perceived the care staff attitude as "all immediately thinking that people in ECU are going to die whatever illness they have and we do not want to resuscitate them, therefore we need a no code order.

On the flip side, attitudes of care staff promoted the implementation of their DNR and/or DI policy, as noted by many respondents. Our nursing staff are "strong advocates for recognizing and providing residents rights" when this issue "needs to be addressed and the form signed". One-third of the respondents described personal experiences they had with their own family members dying and how they came to value the importance of a persons right to autonomy of choice even in death. As one Director of Care cites "my life experiences with death makes it easier for me to understand how I believe people should be treated." Hence past personal or professional experiences with dying people was found to be a significant influence on staff who promoted the implementation process.

Influence of Groups External to Facilities

Similar to the policy development stage, external groups also emerged as an influence on implementation of DNR/DI policy, including other health care facilities in the community and the regional Director of Care groups. Without exception the thirteen respondents who mentioned these groups all discussed them in terms of promoting policy implementation. Several of the respondents discussed "learning from other's mistakes". They discussed the actions of their community group composed of individuals from the following sectors; ambulance, coroners, fire/police, acute and long term care facilities. These groups came together "to understand the issue and come to a consensus on implementing a policy that would work for all of us, you can't just work in isolation, we consider our facility part of the community." Thus community involvement and sharing information and beliefs promoted policy implementation.

Individual Styles of Communicating DNR/DI Policy

The third theme which was evident in all the interviews was the style of communicating to others about the DNR/DI policy. The respondents discuss being able or willing to talk in person with others, communicating the beliefs and events associated with the facilities policy on DNR/DI, or in the case of residents, discussing personal beliefs and feelings related to the event of death. Also, the level of comfort communicating DNR/DI policy is closely associated with the previous theme of individual attitudes. Within this theme several types of relationships between

individuals emerge as being critical; doctor to resident; staff to resident; resident to staff, and doctor to staff.

To some extent all of the respondents had personal experiences with at least one doctor who they believe was uncomfortable discussing issues related to DNR/DI with long term care residents. This is reflected by one Director of Care: "In so many cases the doctors are not capable of listening and discussing with individuals, they don't explain it right." Despite the similarity in experiences of all the respondents, those working in rural settings described doctors as being comfortable in talking to residents about this issue because "we only have one or two doctors in the community and they seem to understand the residents, the context of the social, cultural and physical environment we have here."

On the other hand, three quarters of respondents from urban settings mentioned that they "had a lot of problem with the doctors being uncomfortable discussing with a resident." In fact as one administrator states "the number one problem will be communication i.e. will the physicians discuss this with the residents or the family or both or will they just make that arbitrary decision on their own? I believe they are not comfortable with this stuff."

Three-quarters of the respondents were entirely opposite in their views on communication styles of professional nursing staff.

> I think nurses have a greater understanding of the total care needs of the resident and the interplay of the families. We don't just take on a resident we take on a family with all the problems and dynamics. I think we understand that the best and can guide them all through understanding this topic and through the grieving process at whatever stage.

As another respondent said, "we [nurses] spend the most time with them and are able to understand their wishes and desires in the event they begin to die". Thus respondents perceived the frequency and proximity between staff and residents as influencing the level of access to communicate the topic of DNR/DI.

However, there are five respondents who mentioned that many registered nurses in their facility were "unable or uncomfortable" discussing this issue with residents. "It's difficult to have staff with English as a second language and get them involved in helping residents understand and make decisions on DNR/DI. Of course there is also a great cultural difference and values too that sort of interfere." From another perspective, one Administrator speaks of staff with family backgrounds where there have been tragic deaths therefore "they are not accepting or able to communicate with residents". Thus cultural values, and past experiences of staff related to DNR and death influenced their style of communication and sometimes acted as a barrier to policy implementation.

Finally, the implementation of a DNR/DI policy depends to a large extent on the residents and/or families ability to discuss DNR/DI issues with nursing staff or doctors. All of the respondents expressed that residents experience variability in comfort and ability to discuss the issue depending on the following circumstances: a) mental competency, b) ethnic or religious values, c) length of stay in the facility, and d) relationship with their family and/or significant others.

A greater proportion of respondents from rural areas spoke of resident/family comfort level as a barrier to implementing their DNR/DI policy. For example, one

Director of Care explained that residents in her facility "don't want to discuss the issue", "they have very few have extended family in the area" and most of the residents want the staff to make the decision. In yet a different rural locale with a large network of extended families, one respondent describes the ethnic values of this community as a barrier to implementing their policy. This respondent discusses that "this ethnic group, values the adult children as decision makers", therefore a policy that residents have autonomy to choose resuscitation or degrees of intervention was not accepted by either the resident or their family.

Thus, discussing DNR/DI policy and subsequent issues is a factor which influences the process of policy implementation. The ability of doctors, staff, family and residents to communicate on this issue is influenced by attitude, mental capability, ethnic and religious beliefs, rural or urban settings, time in a facility, relationship with others, and past experiences.

Time to Discuss DNR and DI

Whatever a person's attitude about DNR/DI and their level of comfort discussing this issue, the respondents comment on the concept of time as an influence on the process of policy implementation. As with the policy development stage, time is most often discussed by the respondents as a barrier not a promoter of implementation. In fact, twelve respondents clearly articulated that they "did not have enough time to implement" their policy. "Not enough time" can mean time to implement; time to educate; but most often means time to discuss the issue with residents. A head nurse explained that doctors in their facility will "soon be o.k with

doing this, it just takes time to educate them, work out their fears, etc., its a very complicated issue for doctors and residents, a decision that cant be made instantly. Despite the lack of time, one respondent explained further that "it's still the time, but we have prioritized that issue [DNR/DI policy] and now it is part of our nursing care. Hence, the policy is important to nurses and meant making time to discuss this issue with residents. Similarly, the importance of the policy meant allowing time for residents to "digest and understand the DNR/DI concepts". Four respondents from rural settings clearly articulated this view and mentioned that "taking time to get to know the resident and discuss this issue over several weeks has really made a difference in getting DNR/DI directives on each resident and being successful."

The idea that time influences the implementation of a DNR/DI policy is found in many of the statements of the respondents. Over one half of the respondents clearly identified that the lack of time delayed policy implementation. A smaller proportion felt that the policy was important enough to make time to implement. Similarly, some respondents felt time was necessary to promote the understanding of the policy issue and achieve "successful" implementation.

Basic and Inservice Education

The theme of education which was present in each of the twenty-three interviews, involved both doctors and care staff and occurred on three levels: 1) personal experiences, 2) basic education or training, and 3) inservice education. Without exception when respondents discuss this issue they describe the "lack of" basic education or experiences related to DNR/DI, death, and dying as a barrier to

policy implementation. Despite the different personal and educational backgrounds of the doctors, nurses and care aides, all of the respondents discuss four areas of knowledge which they perceive are lacking in these groups, included are topics on: a) ethical principles, b) legal issues concerning advance directives, c) communication techniques, and d) concepts of aging involved with death and dying.

The group most often mentioned as lacking basic education on death and dying issues are the doctors. A common response is voiced by a Director of Care:

> we are in the process of implementing our policy so I will not say we are unsuccessful, but physicians really need some education in their programs related to care of dying geriatric patients. Both the medical coordinator and I feel they are just not well versed on the issue of geriatric medicine generally.

Ten respondents in the study discuss the basic education of care staff as a barrier to implementing their DNR/DI policy. Differences exist between the type of staff; long term care aide (LTC), registered nurse (RN) or psychiatric nurse (RPN), or licensed graduate nurse (LGN) and their educational programs. However, despite the differences the respondents all perceive to some extent that "the education of both aides and RN's is not adequate enough to deal with resident situations in terms of their knowledge about the ethical and legal situation. I would say that they have a lot to learn in that respect." A Director of Resident Care relates a resuscitation experience in her facility with new graduates from a long term care aide program who were "terribly upset and unhappy with our policy" because they had been "taught only CPR skills and not the legal or ethical principles of advance decision-making". Thus respondents have care aide staff in long term care facilities who lack basic

education, application of knowledge, and work experience which they perceive is a barrier to implementing their DNR/DI policy.

The findings indicate that inservice education is perceived as critical to promoting policy implementation. Inservice education is described as providing information on the policy; an opportunity to discuss the meaning; or outlining the process for residents/family, staff, or doctors who are linked with a long term care facility. "The education was the first priority of the plan for the development and implementation of this policy. We felt that was going to be what was going to make it successful or not as far as staff was concerned." Many respondents described the education of their "resident council on degrees of intervention which has resulted in their being no problems". However, respondents were not as descriptive about plans to educate doctors. Most respondents indicated that physician education was the responsibility of their medical coordinator who in some facilities had a "disappointing response" to education sessions.

In summary, while health care workers and residents vary in their knowledge base about DNR/DI issues in long term care settings, all the respondents in the study perceive the lack of knowledge on these issues as an impediment to policy implementation. Important knowledge components that were identified are: ethics, law, gerontology, and communication strategies. This knowledge is obtained at different levels including; personal life and work experience; basic education or training for doctors, nurses, and long term care aides; and inservice education offered by a facility for their residents/families, staff and doctors. While a pattern of the

need for knowledge emerged, inservice education is described as a vehicle which can provide this knowledge and promote policy implementation.

External Government Regulations

The final theme which emerged as an influence on the implementation of DNR/DI policies is a specific government regulation, the Community Care Facilities Act (CCFA). This Act governs seventeen facilities in the study and thus influences their internal policies and processes. Over one half of the respondents from facilities under the CCFA mention their lack of "clout to make physicians communicate with residents and fill in the form". They all compare this deficiency with their peers in hospital extended care units who are governed by the Hospital Act which they perceive "makes doctors comply". It can be further illustrated in the words of one respondent:

> we don't have the ability under our act to enforce medical staff bylaws, like hospitals do, so we have to work around that by developing standards for medical care and services which would include the stuff on DNR/DI. Now, I get remarks from doctors like "if you pay me to do all those things I will gladly do them.

Thus, the lack of a coercive Act to force doctors to communicate with residents and comply with resident wishes is as a barrier to implementation of policies related to DNR/DI.

This lack of an external regulation caused a few respondents to establish their own rule by making resident admission conditional on doctors communicating the policy. This is detailed by one Director of Care:

> The DOC at facility X, she made it a condition of their admission, if you don't fill out the form for DNR/DI then you cant get your resident admitted. Another facility in the area also did that. They (doctors) get a bit miffed, I have a lady here that missed 3 beds in extended care because the physician never had the forms completed. This makes the resident and family get on the physician.

The lack of external regulations can lead to innovative methods to promote implementation of a DNR/DI policy. This innovative method relies on sanctions for residents and family if they do not "harass doctors to fill in the form". Contrary to this method of changing physician behaviour, facilities under the Hospital Act can rely on medical staff bylaws which provide penalties if doctors fail to abide.

Summary

To conclude, the findings related to the process of implementing a policy on DNR/DI have been articulated. Factors which influence this phase have included: individual attitudes on the policy issue, external group influences, level of comfort communicating the policy, and time to discuss the policy issue. Furthermore, the level of basic and inservice education of care staff and physicians, and government regulations have also impacted on the process. Hence, factors which influence DNR and DI policy implementation provide a basis for determining how a policy will be sustained in practice.

CHAPTER V

DISCUSSION

The purpose of this study is to understand and describe the policy process in LTC facilities in British Columbia from a theoretical and practical perspective with particular focus on Do Not Resuscitate and Degrees of Intervention policy. Qualitative data from informants in LTC settings was analyzed to acquire an understanding of their policy processes. The literature suggests that the policy process encompasses three major phases: identification of problems, development of a policy, and implementation of a policy. The overall findings of this study indicate that the policy process in LTC facilities in B.C. incorporates those three phases. Additionally, the policy process in LTC settings was influenced by B.C. government guidelines contained in the document "Death and Dying in Long Term Care Facilities" (Province of B.C., 1989) as well as a multitude of other factors.

The findings of this study will be discussed according to the three phases of the policy process. First, the identification of problems in LTC settings in B.C. in 1989 will be discussed. Second, policy development that occurred in relation to DNR and DI will be described. Third, the process of policy implementation in these facilities will be presented. Fourth, the limitations of this study will be discussed. An application of the findings to nursing policy and practice will follow, then implications for future research will be addressed.

Problem Identification Pre 1989

The findings of this qualitative study demonstrate clearly that a diverse range of situations related to DNR and DI were problematic for various individuals involved with LTC facilities in 1989. The process of defining problems that emerged involved: a) the initial perception of a problematic situation, b) clarification of the nature of the problem and, c) identification of the specific circumstances that needed to be addressed. Similarly, Pal (1992) identified a three phase process that he termed: a) problem recognition, b) delimiting the nature of problem, and c) categorizing the problem.

Kingdon (cited in Pal, 1992, p. 126) believes problem recognition begins with attention to a situation that is evoked by a change in accepted indicators, focusing event, or through feedback from people. Further, he notes that becoming circumspect about a situation and recognizing a problem is a crucial step for policy-makers as they begin to determine their policy agenda and subsequent policies. The findings reported in this study supports Kingdon's viewpoint. In this study problematic situations in LTC in 1989 were identified by participants as: a) care staff uncertainty about resident wishes and doctors orders, b) residents lacked autonomy to make decisions, c) residents were unable to die in place, and d) care staff, management, and doctors had a fear of legal sanctions. Thus, the nature of the problematic situations involved feelings and processes.

According to Pal (1992) problems involving processes are procedural in nature and impede us from taking action, whereas situations that affront our values or

beliefs are moral problems. Several procedural problems are reported by respondents in this study including: a) absent or unclear doctors orders for DNR or DI, b) unwritten agency policy on DNR or DI, c) absent legalization of Living Wills, and d) existing legislation or policies which did not respect decision making in LTC facilities. Moral problems in this study were linked with the value of resident self-determination, the rights of residents to be informed, and the meaning of aging and death in LTC settings. Recognition of problems related to advance directives involves both moral and procedural circumstances.

Pal (1992) contends that policy problems can be framed according to relevant concepts and theories found in "intellectual frameworks", that is, policy specific literature. The problems identified in this study are not dissimilar to those described in the literature on aging, nursing, medicine, law and ethics. In this study the participants most often defined their problems as lack of resident autonomy and unwritten agency policy on DNR and DI.

Although nurses wanted to uphold the residents wishes for "no resuscitation", they felt uneasy in using their discretion to make a decision without an agency policy. However, it was reported that this feeling did not improve with an agency policy that gave nurses discretion to make DNR decisions. This finding may be explained by Pal (1992) and Yanow (1987) who suggest that in political institutions individual actions are based on what is appropriate rather than on self interest. It may be that nurses have accepted the belief that this type of decision is made only by physicians and/or requires legalization. Thus, as Pal (1992, p. 101) contends the norms encased in a

practice set the "benchmarks of behaviour and are internalized by actors" (Pal, 1992, p. 101). This type of behaviour is contrary to Lipsky (1980) who believes that health workers as street level bureaucrats use their discretion to make decisions which then become agency policy. This perspective is supported by a few respondents in the study in a very radical yet startling manner. Some respondents reported that they are the best people to make decisions for competent residents. Although these nurses took on the responsibility of making decisions, this view does not enhance or enable resident autonomy. Thus, practitioners values about residents in LTC facilities influences their discretion in decision making which may lead to policies that are not in the best interests of residents.

In this study respondents also report that in 1989 a major problem was the lack of clear doctors orders for DNR. This is supported by Besidine (1989) who reported that there is considerable confusion in the literature as to the meaning of the doctor's DNR order in nursing homes. Advancing medical technology and the advent of CPR has produced a cultural standard in health care facilities that resuscitation occurs unless there is a DNR order on the residents chart. However, application of CPR is considered to be unnecessary for LTC clients (Glasse & Murray, 1984; Gordon & Hurowitz, 1984) and can be avoided by physicians writing DNR, management making DNR policies, and government legislating advance directives such as DNR (Clements, 1990). The findings in this study indicate that this culture still exists in most LTC settings.

An opposite view was indicated by some respondents in this study who believed their facility was a home where death of elderly residents is expected and who assumed that resuscitation does not occur unless requested by a resident/family. While they did not have a problem with unclear DNR orders or policy, they had situations with external agencies such as ambulance, coroner's service and those with a mainstream cultural view, that became problematic. Thus the meaning of aging, death, and long term care settings held by respondents in the study shaped their view of the problem. As Dery (1984, p. 5) states "we make a choice about how we want to formulate a problem" and if our formulation is unconventional, the policy solution may not address the problem as it exists.

Levinson (1981) formulated the problem as being a need to clarify resident wishes and care situations for the health care team and that care situations should extend beyond DNR. His solution was to develop a "Degrees of Intervention" form which provided several options of care for the end of life. This idea was adopted by the B.C. Government in their guideline document "Death and Dying in Long Term Care Facilities". Thus the "intellectual framework" came from the medical literature and suggested that a DI form can increase resident autonomy and reduce uncertainty for health care providers in LTC facilities.

In summary, strong concurrence is found within the literature for identifying whose frame of reference is being attended to in order to understand how certain policies are designed as solutions. The participants in this study claim a multitude of DNR and DI related problems in 1989, that emanate from different value

perspectives, and diverse procedural or moral circumstances. Further, the medical literature provided an "intellectual framework" which the provincial government adopted as a policy solution.

Pal (1992) states that situations that affect a large proportion of the public, offend or affront public views or values, or are a result of another public policy are defined as public problems that are placed on the government agenda. These characteristics are highly evident in this study, therefore, the problems identified by participants in LTC facilities may be viewed as public policy problems which could be addressed in a number of ways.

One way to address public policy problems is through the use of policy instruments. Pal (1992) suggests that the latest trend in the public policy process in Canada is a gradual move to a mix of policy solutions including some which are non-coercive and rely on voluntary behaviour. However, the situation in 1989 in LTC facilities of diverse problems related to DNR and DI was identified by the respondents as a problem requiring more than a voluntary solution. The choice of actions that LTC facilities in B.C. had in 1989 for these problems was limited to: a) placing this problem on the government agenda for development of compelling laws on advance directives (Areen, 1991; Bardach, 1978; Clements, 1990), b) changing the cultural beliefs about CPR and DNR in LTC facilities, and/or c) developing a facility policy to give direction to staff and physicians for managing DNR and DI activities.

In this current study the greatest majority of respondents from LTC facilities adopted the latter action plan, to develop and implement a facility policy on DNR and DI. This action was encouraged and strongly supported by the B.C. Ministry of Health, through the Continuing Care Division. They recognized the problem in LTC facilities and chose to provide information in the guideline documents "Death and Dying in Long Term Care Facilities" to assist facilities who opted for developing and implementing their own policy. This action concurs with Pal's (1992) perspective that problems are defined by a community which government responds to. Doern and Phidd (1988) noted "the chosen instrument reflects the policy content, context and the government's normative values on coercion" (p. 112).

To reiterate, in this study respondents reported diverse problems, from a range of value perspectives, related to the policy content and context of DNR and DI. Thus, to influence the behaviour and practice of health care professionals in LTC facilities with pluralistic cultures, the government selected non-coercive guidelines which provided information on DNR and DI policy. This is supported by Bardach (1978) who concluded that governments should establish principles and overall policies which allow decision makers in local settings to choose the means.

The study respondents speak of the government guideline documents as an important influence on their policy development. In describing the impact of the guidelines the respondents placed a high value on the DNR and DI content as a catalyst for discussion, and as information which was authoritative, credible, and valid which influenced them to develop their DNR and DI policy. The quality of

information on a specific policy issue are central tenets of Hill and Bramley's (1986, p. 149) "image" of a policy matter which they believe influences policy development within a system. Hill and Bramley also postulate that the structure and distribution of knowledge on a topic determines the feasibility of developing a policy. Hence the study respondents image of the government guidelines as beneficial and functional may have influenced them to view DNR and DI policy as feasible to develop. On the other hand, those few respondents who envisioned the guidelines as authoritative government documents may have felt obliged to develop DNR and DI policies. This supports the view of Doern, Prince and McNaughton (1982, p. 14) who suggest that in practice, enforceable standards are often applied flexibly and "guidelines are often obeyed as if they were standards."

Public policy as a process occurs in several political institutions, most often originating in government and implemented by other institutions. This is supported by Milio (1984) and Baumgart and Larsen (1988) who believe that health policy originates from the top down and nurses can influence the policy process by organizing their political power to make changes. At the agency level, nurses consider policy to be rules developed and implemented by management, as defined in legislation (Baumgart & Larsen, 1988; Katz & Green, 1992).

However, as Lipsky (1980) and Elmore (1987) suggest, policy can be made and implemented as agency policy by "street level bureaucrats". Love and Sederberg (1987) concur and found in their study that government plans have little relation to processes in the field and, in fact, policy-makers may be policy implementors. The

respondents in this study reported that they developed and implemented policies on DNR and DI.

In attempting to describe their processes of policy development and implementation the study respondents spoke of diverse and complex factors which controlled their progress. They reported that many of the same factors influenced both the development and implementation phases of the policy process. This is displayed in the repetition noted in the literature between the fields of study on public policy and policy implementation. As Love and Sederberg (1987) argue the policy process is continuous in nature and should be considered as a seamless web. However, for ease of discussion, the development and implementation phases of the policy process will be presented separately and some repetition will be noted.

Factors Which Influence Policy Development

In this study the respondents spoke of many influences on the policy development phase including: a) attitudes of individuals, b) perspective of groups internal and external to the organization, and c) physical, structural, and functional components of the organization, d) time and priorities, and e) policy context related to DNR/DI. These factors are supported by Pal (1992), Yanow (1987) Love and Sederberg (1987) who reported that a matrix of institutions affect the policy process, that multiple values and beliefs on a policy issue exist in these institutions and that policy development can be made visible by examining these forces within and external to an organization.

For respondents in the study, the attitudes of the Director of Care or Nursing, Medical Coordinator, nursing care staff, residents or family members is crucial in promoting the development of DNR and DI policy. Most study respondents believed that the Director of Care or Nursing, Medical Coordinator and care staff valued and respected resident rights to choose their terminal care in advance. Additionally, respondents perceived that residents' attitudes towards advance decision-making and death was often intertwined with the family relationship, cultural beliefs, and attitudes on this issue. Conversely, all of the respondents describe the attitudes of family physicians as patronizing and devaluing long term care which they perceived delayed or impeded policy development.

A common theme throughout the literature is that values and beliefs reflected in individual attitudes and behaviour can promote or delay policy development. Harvey and Roberts (1987) and Clements (1990) discuss physician views on practice guidelines and believe they reject informal and discretionary guidelines in favour of legislated regulations and the rule of law due to their fear of being sued. The physicians attitude and commitment to a law on advance directives is supported by Pal (1992) who suggests that people advocating a problem may have a commitment to a specific solution because they are convinced of the benefits of that solution. Hence, if a person's perspective of a policy goal and solution does not fit with the policy being developed then their promotion of that policy is highly doubtful.

The second factor influencing policy development which the study respondents describe is the perspective of groups internal to the organization. It is a factor which

is very prevalent in the work of Yanow (1987) and Pal (1992). Yanow's construct of policy culture, views the policy process in an organization through multiple levels and various lens and concludes that the values and beliefs of policy actors and the organization, the meaning they make of an issue influences policy development and implementation. Pal (1992, p. 111), in describing policy communities as an influence on policy development, hypothesizes that policy is developed in a certain sector where there is a stable set of actors that have a "real set of connections".

For the respondents in this study, the policy community is most apparent in the groups of policy actors that exist within LTC facilities. The groups in LTC facilities which respondents identified most often as being influential in developing DNR and DI policy included Board of Directors, and management. Respondents from LTC facilities in rural settings best exemplified Pal's notion of a stable set of actors with "connections". The Board of Directors in these settings valued resident choice, had a personal connection to the facility and lengthy ties to the community and promoted a DNR and DI policy.

Likewise, management as a group was often considered by most study respondents to have an "organizational attitude" which promoted policy development. This "organizational attitude" was viewed by respondents to be the existence of statements on organizational philosophy, mission, beliefs, and resident rights. Pal (1992, p. 128) refers to these components as political elements, information that focuses attention and defines the "mood" of an organization. DNR and DI policy

development occurs for the respondents when groups in the organization feel attached and hold values and meaning that are congruent.

In this study respondents reported that groups external to the LTC facility also had a positive influence on policy development. These included: a) other health care facilities in the community, b) regional Director of Care group, and c) long term care associations. This provides additional support for the idea of an inter-relationship level between organizations which Yanow (1987) believes influences the policy process and, further, extends the boundaries of policy communities which Pal (1992) advocates as a factor in policy development.

Study respondents indicated that other components of their LTC facility had an influence on DNR and DI policy development. They characterized these components as the physical structure of their facility, the organizational structure and its role and function. The matrix aspects of Yanow's (1987) framework portrays the multiple forces on policy development described by the respondents. In this study characteristics of the physical and organizational structure contributed to the respondents belief that a DNR and DI policy would have an adverse economic impact. These included: a) need for physical room, equipment and supplies to care for dying residents, b) money and time for staff training and education on CPR, and c) pressure from unions to provide education if nature of care staff work was changed.

Thus, the economic impact of a DNR and DI policy was seen by respondents to be a barrier to development. This is supported by Hill and Bramley (1986) and

Doern and Phidd (1988) who reported that an organization may support the policy issue and need for solutions, yet policy development (and implementation) may not be feasible in terms of money, personnel, time or enforcement.

In this study respondents mentioned that the role and function of their organization also influenced policy development. Respondents from multi-level LTC facilities spoke of providing care until death which influenced them to "fast-track" a DNR and DI policy while other respondents moved a dying individual to a hospital next door, therefore, not needing a DNR or DI policy. This variance can be explained by Pal's (1992) notion of a policy window which does not open for everyone on the same issue at the same time. Structural pressures, and institutional processes are unique to each organization and do not guarantee that a particular vision and policy design will be chosen by another organization.

Pal (1992) viewed these unique organizational pressures and processes as a major factor in how the organization would prioritize policies for development. In this study the respondents described a barrier to development of DNR and DI policy as not enough time. For example, it was revealed that LTC facilities experience major renovations, projects and day to day management tasks that become the priority. Thus, the priority of DNR and DI policy for an organization determines its progression through the policy development phase.

Pal (1992) reports that there are a number of policy-making processes that differ across sectors, depending on the actors, history of past policies, the nature of the policy issue, and degree of opportunities for development. Coleman and

Skogstad (1990) have begun to explore networks of policy-makers at the federal level and have developed a collection of schematic diagrams which map the policy process in specific policy fields. They describe policy networks as either: a) many dissonant groups competing for agencies attention, b) agencies relying on groups for information, support, and allow them to participate in policy development, c) groups and agency both participating in policy formulation and implementation, d) agency and groups are equal partners in planning and policy development, or e) agency dominates policy process as group is weak and dispersed. Pal (1992, p. 113) strongly urges that "the state must be disaggregated and the policy process pluralized".

In this study the policy processes in LTC facilities described by respondents are diagrammed in Figure 1 (pp. 81-82). The majority of respondents reported that a group initiated the development of DNR and DI policy and in urban settings the policy group was most often composed of nursing managers or multi-disciplinary staff. This is not unusual in nursing since according to some scholars (Baumgart & Larsen, 1988; Ellis & Harltey, 1991; Katz & Green, 1992) policy is a management activity to guide action for a given situation. In a broader context Milio (1984) explored nursing's impact on public policy and boldly suggested that nurses in leadership roles are better suited to influence policy-making than staff nurses.

However, this does not explain that in rural LTC facilities respondents reported that groups of staff nurses initiated DNR and DI policy. Additionally, in rural settings the policy development group often included a mix of management, resident and family representatives. Noteably this diersity is absent in the makeup

of policy groups in urban settings. As earlier discussed rural LTC facilities have a stable set of actors who are well "connected" in the organization and community which may provide an encouraging and comfortable environment for staff nurses. Additionally, the ties to the local community may provide the foundation which Lomas (1990) believes allows clinical policy to be developed, based on values "less in the guild than in the broader society." Or as Lipsky (1980) suggests "street-level bureaucrats" make and implement policy. Of particular interest to note in this study is the inclusion of representatives from resident councils and/or families in the policy-making group. This adds a different slant to the work of Coleman & Skogstad (1990) and Lipsky (1980) who do not appear to include the recipients of government services as policy actors. Thus, in the policy field of long term care, policy networks of co-operative, consensus groups of agency and special interest actors worked together to formulate and complete DNR and DI policy.

Factors Which Influence Policy Implementation

Love and Sederberg (1987, p. 164) abandoned the idea that policies succeed or fail and considered policy as a "seamless web" reflecting the continuous nature of the process. They assume that a gap always exists between the policy and the pre-existing, multi-layered and dynamic environment which is being controlled by that policy.

Factors from multiple layers of an organizational environment can influence policy implementation and include: a) formal policy level - number of policy actors and degree of cacophony, b) formal organizational level - existing governing directives

and degree of turbulence or change, c) informal organizational level - extent that policy challenges the implicit hierarchies or structures, d) ecological level - external culture which has explicit impact on organizational units. The basic premise of this approach is that policy development and implementation are dependent on the compatibility of the policy with established dispositions and tendencies internal and external to an organization.

In this study respondents described their policy implementation as being influenced by factors from each level outlined by Love and Sederberg (1987). These included: a) individual attitudes, b) groups external to the facility, c) individual styles of communicating DNR/DI policy, d) time to discuss issue with residents and family, e) basic and inservice education, f) communication processes within facility. Emphasizing the continuous nature of the policy process and that respondents reported similar factors which influenced both policy development and implementation, only those identified as being unique to policy implementation will be discussed.

According to Love and Sederberg (1987) a policy which challenges or undercuts a pre-existing formal operation or implicit procedure will not likely meet with success. This is due to relationships between policy actors, degree of competition, or change in vested interest. In attempting to implement a DNR and DI policy the respondents in this study placed a high value on physician involvement in the process. The impact doctors had on policy implementation was evident in the respondents descriptions of procedures that required doctor's signature on DNR/DI

forms. Most study respondents expressed negative regard for doctors based on perceptions that doctors disregarded LTC facilities and retained a paternalistic attitude towards advance directives. Some respondents did indicate that young doctors or doctors known in a facility for a great length of time promoted policy implementation. There was an underlying sense that even with physician representation in developing a DNR and DI policy study respondents encountered physicians who valued their role as decision maker, and the facilities role to take direction and provide care.

Throughout the implementation literature it is assumed that policy developers are different individuals than policy implementors, that individual values and ideas can be conflicting, hence the potential exists for implementation failures. What seems to create an interesting situation in this study is that individuals in LTC facilities who develop DNR and DI policy are often from the same group of actors that must implement the policy. Most respondents indicated that care staff advance problems and develop policies related to DNR and DI but may be more inhibited in executing the final policy. Study respondents perceived that cultural backgrounds of care staff or their lack of personal experience with dying people inhibited policy implementation. This supports Love and Sederberg's theory that implementation is delayed by policy actors who speak with different voices at the same time, in this case advocating their own culturally based values on death and dying.

In this study the respondents report that communicating the DNR and DI policy to residents and their families is the key element of the implementation

process. The respondents identified that comfort and style in communicating, and time to communicate influenced the implementation of their policies. The ability of doctors, care staff, family and residents to communicate about this issue was further influenced by an individuals attitude, values, level of mental or professional competency, ethnic and religious beliefs, time in a facility, relationship with others, and past experiences. Study respondents indicated that physicians consistently appeared to have difficulty communicating this topic with residents. This view may be encouraged through the medical literature which suggests that people with a terminal illness would be needlessly harmed by a discussion of CPR procedures and risks (Spencer, 1979) or that people feel uncomfortable and doctors are asked to make a DNR or DI decision (Miles et al., 1982; Snider, 1991).

On the other hand, nurses in LTC facilities were described by respondents as having frequent, close and extensive relationships with residents and their families which influenced their access and ability to communicate on the topic of DNR and DI. This is supported by Splane and Splane (1991, p. 364) in their discussion on nursing power and policy who believe that nursing "action begins at the grassroots level in conveying the principles and providing the aide needed to enhance self-help and individual responsibility." Grundstein-Amado suggested that the process of making ethical decisions are different between doctors and nurses. She found that doctors valued patients' rights whereas nurses valued responsiveness and sensitivity to the patients' wishes.

Love and Sederberg (1987) suggest that policy is carried through by an organization whose effectiveness is already governed by formal and informal explanatory mandates. These mandates including authorized structure, procedures, personnel, and funding which can delay or promote policy implementation. The respondents in this study reported that the education of health care providers and the provincial government regulations impeded the implementation of DNR and DI policy. In terms of education, respondents identified that doctors, nurses and care staff all lacked either basic knowledge or experiences related to the issue of DNR and DI in four areas: a) ethics, b) legal issues, c) communication techniques, and d) gerontology. For example, care aide staff had been taught CPR skills but not the ethical, legal principles or policy goals behind DNR and DI policies which respondents believed caused care staff to be confused and impeded policy implementation.

In summary, I have analyzed the process of development and implementation of DNR and DI policy within the context of current knowledge related to the concepts of public policy, resuscitation and long term care facilities. The elements of the DNR and DI policy process and the salient influences on this process have been discussed and are substantially supported by current research. Moreover the basic premise of policy made from the bottom up which has occurred in LTC facilities may have important implications for an extended understanding of the public policy process. If the core assumption is of policy as values and ideas that the agency chooses to serve, made by people in those local situations then policy developed from

governing institutions at the top may in fact be rejected or sabotaged during implementation. While governing is a part of democratic societies, it does not mean that the diversity of cultures, values and ideas about resuscitation and death held by citizens in LTC facilities will be better served by an autonomous centralized government body making policy. In fact, for most of the respondents in this study the governments decentralized approach of providing information and allowing LTC facilities to choose to develop and implement policy had a positive outcome.

Implications for Nursing Practice and Policy

The process of developing and implementing DNR and DI policy in LTC facilities has implications for nursing policy in general. In particular, this study demonstrates the importance of grassroots, or bottom -up approach to policy-making and the power nurses have in influencing the policy process.

Policy-making from the bottom up is best characterized by Lipsky's (1981) term "street level bureaucrats". He contends that public policy can originate in local units of publicly funded service workers who grant citizens access to programs and services. For many in the field of policy studies, this was one of the first countervailing views and signified a notable change in the long standing perspective that policy stemmed from government and was implemented by others. In contrast, Lipsky's frame of reference regards service workers and the policy process as a symbiotic situation which provide policies that have an immediate and positive influence on the lives of citizens they serve. Inherent in this perspective is the notion that service workers are the experts and practice can influence policy.

Similarly, Lomas (1990) believes that health care practitioners at all levels of an organization may recognize client centred issues and establish "clinical policies". This view concentrates on the values embedded in different organizations which are reflected in their policies. Health professionals have become polarized due to some groups switching from highly valued professional goals to valuing broad health goals for society. Thus, the "street level" approach to the policy process is much more decentralized and addresses the local community needs of those receiving public services. Moreover the policy process is seen as entailing the expertise of service workers and recognizing the influence of competing values within health service organizations. These competing values are also culturally based and given the diversity of cultures among staff and residents in LTC facilities, the environmental context will influence the policy path.

These characteristics are in many ways congruent with the policy process related to DNR and DI in LTC facilities in this study. The elements of the policy process in B.C. LTC facilities, not only involved nursing administrators, but most often staff nurses, other multi-disciplinary professionals and sometimes residents or family representatives. It is from this collaboration and group activity over time that most DNR and DI policies were developed, approved, and prepared for implementation. Thus a strong congruency exists between the concept that policy can originate from the "street level" and the policy paths and processes as experienced by respondents in the study. Additionally, this study points out that the "street level"

in LTC facilities also includes the recipients of services (residents and their families) as policy actors.

Nursing scholars (Baumgart & Larsen, 1988; Kerr & MacPhail, 1991; MacPherson, 1987; Milio, 1984) define public policy and the policy process as something which nurses can influence. They suggest that the application of organized group pressure on political and government policy-makers will influence the policy process and may lead to changes. For example, regional, provincial and national nursing associations have used their "political power" and organized pressure to influence public policies at various levels on mental health, smoking, healthy communities, and medicare. Milio describes "nurse leaders" as those in management positions and best suited to gain "political power" to influence government social and health policy development. This view devalues the ability of staff nurses to become political and contribute to making changes in policy and practice.

Thus, much of the focus has been directed to influencing government policy by nurse leaders, and has yet to be extended to staff nurses influencing and changing policies in places where they work. Although Sullivan and Decker (1992) have recently noted that nurses are influencing policies in the workplace, these policies are described as affecting the nurses work life and resources. Policies that directly involve clients (patients, or residents) and impact their care are most often developed by management.

While undoubtably some government public policy goals have been influenced by nursing power and pressure groups, there is a growing recognition that nurses have

expertise in practice, understand policy problems from different perspectives, and need to design policy that reflects the values and concerns of local communities and organizational units. It is the paradigm shift underlying the drive toward staff nurses' knowledge of the policy process and influencing factors which is congruent with the impact nurses made on the process of developing and implementing DNR and DI policy in LTC facilities. Moreover, nurses at the practice level in LTC settings had a positive influence on the policy process by their: a) attitudes towards resident rights and choice, b) close relationship with residents and families, c) style of communicating the issue with residents, and d) strong support and guidance from peer network.

The experiences of respondents in this study suggest that nurses can initiate, develop and implement public policies using a multi-policy actor approach which recognizes resident and community values and ideas that will improve the quality of life for citizens in society.

Future Recommendations for Research

The public policy process in local publicly funded health organizations is poorly understood, therefore the opportunities for future research are extensive. From the findings in the current study future research may be directed toward further investigation and articulation of the connection between policy development, implementation and the final outcome of DNR and DI policy. Quantitative and qualitative data on the process of communicating advance directives to individuals in facilities should be part of research studies that examine the experiences and

viewpoints of residents and family. Policy evaluation from this perspective may offer some very significant insights into the realities of resident choice, informed consent, and policy implementation.

The respondents who participated in the study are from LTC facilities that include both residents and care staff from diverse ethnic, religious and social backgrounds. They identified that individual values, attitudes and experiences influenced the process of developing and implementing DNR and DI policy. Therefore, it would be informative to examine the relationship between cultural beliefs and the policy process. Furthermore, policy processes may be examined in conjunction with religious beliefs that may be reflected in health care organizations managed by church boards.

One of the influences that respondents perceived to be essential to their progression through the DNR and DI policy process was peer group support. Additionally, there was a pattern of family/resident involvement, community support and policy development. Thus the scarcity of knowledge of policy networks in long term care facilities also warrants further investigation.

Conclusion

In conclusion, the purpose of this study was to analyze and understand the process of developing and implementing DNR and DI policy in LTC facilities in the province of British Columbia. The respondents in the study described the situations they encountered in 1989 which included procedural problems based on unwritten agency policy and problems which provoked respondents beliefs and values on aging, death and resident autonomy. From recognizing problematic situations, the respondents moved into a development phase which was influenced by a variety of forces. The British Columbia government choice to distribute guideline documents "Death and Dying in Long Term Care Facilities" had a major, pivotal, and beneficial impact on the development of DNR and DI policies for respondents. Other influences on the policy development process included: a) the attitudes of individuals connected with LTC facilities, b) internal and external group perspectives, and c) components of organizational structure and function.

In addition to these factors, the implementation phase of DNR and DI policy was found to be influenced by: a) individual styles for communicating DNR and DI issues, b) lack of time to discuss DNR and DI with residents and families, c) variable amounts of basic and inservice education for health care providers, and d) external government regulations. The findings were supported and discussed in the context of current scholarly work on public policy and nursing. Additionally, the findings are examined in the context of resuscitation, advance directives and gerontology.

Perceptions from participants working in LTC facilities of their experience of the policy process, contributed additional information to the current literature. These contributions included a better understanding of policy-making from "the bottom-up" and an illumination of factors which influence the process of establishing policies that are affected by incongruent values and ideas. Policy-makers in LTC facilities have experience and understanding of the policy process that may be viewed as a rich and valuable resource. If this study has demonstrated anything, it reveals how nurses at all practice levels have much to contribute to the policy process.

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APPENDIX A

Administrator/Owner's Letter of Invitation to Participate in Study and Return Form

xxxxxx 1992

Administrator
LTC facility
xxxxxxxx
B.C.

RE: CONTINUING CARE DIVISION, MINISTRY OF HEALTH RESEARCH PROJECT ON DEATH AND DYING GUIDELINES

Dear

I am interested in your facilities experience with the 1989 provincial guideline documents titled **"Death and Dying in Long Term Care Facilities: Report"** and **"Death and Dying in Long Term Care Facilities: Operational Guidelines"**. It is hoped that information from this study will help government, care facilities and British Columbians to better understand how policies can be developed which respect a person's values, dignity and rights to choose care at the end of life.

Participation in this study is voluntary. Your facility is under no obligation to participate and even if you choose to participate you may withdraw from the study at any time. The relationship that you and your staff have with the Ministry of Health will in no way be affected by your decision to participate or not participate.

This project is being conducted as part of my "co-operative work term in the Masters in Policy and Practice in Human and Social Service program" and is approved by the University of Victoria. I will ask questions about the experiences, concerns and needs related to receiving and using the guideline documents in your facility, which will take approximately one hour. The three basic questions I will be asking are:

1) Since the guidelines were distributed, what policy development process has taken place in your facility on this issue?

2) What impact have these guideline documents had on policy development in your facility?

3) What further direction and assistance on policy and practice issues related to advance decision-making and resuscitation orders do you and your facility need?

Participants who are interested will be sent a summary of the results upon completion of the study.

I have enclosed a Letter of Information and Informed Consent form for the participant(s) from your facility.

If you have further questions or concerns regarding the study, please do not hesitate to call me at the Continuing Care Division Ministry of Health, 387-6408, or my university supervisor, Dr. Howard Brunt (721-7963).

RETURN FORM FOR PARTICIPATION IN RESEARCH STUDY

TO: DIANE LAUGHLIN
CONTINUING CARE DIVISION
MINISTRY OF HEALTH

FAX # 387-2548

Title of the Study:

Guidelines for Death and Dying in Long Term Care Facilities:
The Process of Implementation from Government to Facility

Investigator:

Diane Laughlin, R.N.

ID # FOR THE FACILITY _____

Name of contact person(s): Telephone number:

a) _____ _____

b) _____ _____

c) _____ _____

PLEASE CHECK ONE:

[ ] **YES,** I would be interested in having our facility included in the interview group of your study.

[ ] **NO,** I would not like to have our facility included in the interview group of your study, but we would be willing to complete a brief questionnaire.

[ ] **PLEASE DO NOT CONTACT US** for either the interview or questionnaire sections of your study.

PLEASE RETURN THIS FORM BY JULY 30TH, 1992
BY FAX TO: 387-2548

APPENDIX B

Research Participant's Outline of Study

UVIC LETTERHEAD
LETTER OF INFORMATION

(For the staff person(s) identified by the facility administrator as the respondent for the study).

My name is Diane Laughlin. I am a Registered Nurse and currently a student in the Master of Arts in Policy and Practice in Health and Social Services program at the University of Victoria. For the next six months my co-operative work term will be with Mr. Andrew Butler, Director of Residential Care Services in the Continuing Care Division, Ministry of Health. I will be conducting a research project which will examine the process of implementing the government guidelines titled **"Death and Dying in Long Term Care Facilities: Report"** and **"Death and Dying in Long Term Care Facilities: Operational Guidelines"**. Your administrator has identified you as the person in your facility that I may contact regarding this project.

This letter is an invitation for you to participate in this study. It is hoped that the information provided will help government, care facilities and British Columbians to better understand how policies can be developed which respect a person's values, dignity and rights to choose care at the end of life.

Participation in this study is voluntary. You are under no obligation to participate and if you choose to participate you may withdraw from the study at any time. The relationship that you or your facility have with the Ministry of Health will in no way be affected by your decision to participate or not participate.

If you are interested in sharing with me your experience with these two guideline documents, I would like to meet with you in your facility in August or early September. The interview will last for approximately one hour. I will ask questions about your experiences, concerns and needs related to receiving and using the guideline documents. Participants who are interested will be sent a summary of the results upon completion of the study.

The interview will be tape-recorded so that I may listen closely to what you are saying without having to take notes. The tapes will be numbered so that your name and that of your facility will not appear on them or any written information arising from this study. You may request erasure of taped information at any time and at the completion of the study all tapes will be destroyed in accordance with the Document

Disposable Act. Access to the data will be limited to my thesis advisors, my typist and myself, although we can not deny a request that may be made under the provincial Freedom of Information Act for any records related to this study.

I will be calling you shortly to determine if you are interested in participating in the study. If you have further questions or concerns regarding the study, please call me at the Continuing Care Division,387-6408, or my university supervisor, Dr. Howard Brunt (721-7963). I look forward to meeting with you.

Sincerely,
Diane Laughlin, R.N.

APPENDIX C

Research Participant Consent Form

CONSENT FORM

Title of the Study:

Guidelines for Death and Dying in Long Term Care Facilities:
The Process of Implementation from Government to Facility

Investigator:

Diane Laughlin

NOTE:

This project subscribes to the ethical conduct of research and to the protection at all times of the interests, comfort and safety of participants. This consent form and the information it contains are given to you for your own protection. Your signature on it will signify that you have received the written description of this project, that you have received adequate opportunity to consider the information in that description, and that you voluntarily agree to participate in the project.

I, _____, have read the Letter of Information for this research project and understand the purpose of the study is to identify the implementation process and impact of the government's death and dying guidelines on policy development in our long term care facility _____, and to provide recommendations to government on our needs related to this issue. I understand that I will be interviewed on one occasion for approximately one hour, by Diane Laughlin.

I understand that I may refuse to answer any questions and may withdraw my consent at any time without any risk to the relationship I or my facility has with the Ministry of Health. I understand that the interview will be taped and that my name and that of my facility will not appear on the tape, transcript or any information presented to others. Although the transcripts from this study will not be published I understand that the Ministry of Health can not deny a request made to them under the provincial Freedom of Information Act for any records connected with the study.

If I have any concerns, questions, or complaints about the study, I understand that I may contact Diane Laughlin (387-6408) or her supervisor, Dr. Howard Brunt, (721-7963) a professor in the Faculty of Human & Social Development at the University of Victoria.

I acknowledge receipt of a copy of this consent form and attached Letter of Information.

_____ _____

Participant Signature Date

_____ _____

Interviewer Signature Date

APPENDIX D

Interview Guide

I would like to interview you over the next hour. I am going to be responsible for the time and if we get into an issue that I feel we don't have time for, I will mention this and move on to the next area. There are two sections to my questions. The **first section** deals with events in the past, i.e. the process you went through when you received the guideline documents and the impact these documents had on you and policy development in your facility. The **second section** will deal with your future needs in relation to death and dying issues and how you feel the Ministry of Health may best assist you in this area.

SECTION ONE - POLICY DEVELOPMENT

1. Prior to 1989, what do you recall where the issues or problems related to Do Not Resuscitate and decision making at the end stages of a resident's life.

2. What would have helped at that time?

3. When you first saw the guidelines how did you think they would help your situation?

4. Could you draw (or explain) for me the process you went through, (or must go through) including lines of authority, in order to have a policy related to this issue developed in your organization.

5. In your opinion, what events, people, and other factors have influenced the development of your policy?

    a) Considering these factors (repeat them) which one or two do you feel have been most significant.

    b) Can you describe the factors that have delayed your policy development?

POLICY IMPLEMENTATION

1. Have you implemented your policy?
   .....If YES

   Have you been successful in implementing your policy?

   Why?

   Why not?

   ..... If NO

   What do you think will promote successful implementation?

   What do you think will delay implementation?

IMPACT OF THE GUIDELINE DOCUMENTS

1. Where the guidelines useful? Why?

   (What would have been more useful?)

2. Can you explain what you liked about the format?

   What you did not like?

SECTION TWO - NEEDS ASSESSMENT

1. In your facility what are the pressing issues related to death and dying? Why have these become so prominent?

2. What is it that you need to solve these issues?

3. How can the Ministry of Health best help you with these issues?

APPENDIX E

Demographic Profile Schedule

CODE _____
01FACE 02PHONE

RESEARCH PROJECT

IMPLEMENTATION ANALYSIS OF MINISTRY OF HEALTH GUIDELINES ON "DEATH AND DYING IN LONG TERM CARE FACILITIES"

DEMOGRAPHIC DATA SCHEDULE

The following schedule contains information I presently have on your organization. Would you please review this data schedule so that during our interview on _____ _____ the information can be verified or changed. Please keep in mind that your name will not be on this schedule.

A. ENVIRONMENT

HEALTH UNIT _____

LOCATION 01 URBAN _____ (> 1000 people and density of 1000/sq.mile)
02 RURAL _____ (1000 or less)

B. FACILITY

TYPE: 01 PROFIT _____ 02 NON-PROFIT _____

HOW LONG HAS YOUR FACILITY BEEN IN OPERATION

01 < 1YR _____
02 1YR AND <4YR _____
03 4YR AND <10YR _____
04 10YR > _____

WHO IS YOUR LICENSING AUTHORITY?

	01 COM. CARE FACILITY ACT _____
(acute hospitals)	02 HOSPITAL ACT PART 1 _____
(private hospital/profit)	03 HOSPITAL ACT PART 2 _____
(rehab or ECU)	04 HOSPITAL ACT PART 3 _____

WHICH OF THE FOLLOWING CATEGORIES BEST REFLECT YOUR LICENSE:(Check more than one if applicable)

01 Intermediate Care _____
02 Extended Care _____
03 Acute Hospital _____
04 Mental Health Boarding Home _____
05 Multi-level Care _____
06 Private Hospital _____

GOVERNMENT FUNDED LTC BEDS _____

TOTAL # OF BEDS IN FACILITY _____

AS OF JULY 31, 1992, WHAT ARE THE # OF PATIENTS IN YOUR FACILITY ACCORDING TO THE FOLLOWING CARE LEVELS

01 PC _____ 02 IC1 _____ 03 IC2 _____
04 IC3 _____ 05 EC _____

IS YOUR FACILITY AFFILIATED WITH OR OPERATED BY ANY OF THE FOLLOWING TYPES OF ORGANIZATIONS

01 RELIGIOUS _____
02 ETHNIC _____
03 SERVICE OR COMMUNITY _____
04 GOVERNMENT _____
05 OTHER _____
06 NONE _____

YOU HAVE A MEDICAL COORDINATOR 01 YES _____ 02 NO _____

YOU HAVE HAD A MEDICAL COORDINATOR ON STAFF

01 < 1YR _____
02 < 2YR BUT > 1YR _____
03 < 5YR BUT > 2YR _____
04 > 5YR _____

WHICH ONE OF THE FOLLOWING CATEGORIES BEST DESCRIBES YOUR MEDICAL COORDINATOR:

FAMILY PHYSICIAN _____
GERONTOLOGIST _____
INTERNIST _____

WHAT # OF SESSIONS ARE ALLOTTED FOR YOUR MEDICAL COORDINATOR?

_____/YEAR

WHAT PERCENTAGE OF THOSE SESSIONS ARE USED FOR

CLINICAL TIME _____%

ADMINISTRATIVE TIME _____%

DOES YOUR FACILITY HAVE A COMMITTEE OR PROCESS THAT DEALS WITH ETHICAL PROBLEMS? 01 YES _____ 02 NO _____

Code_____

RESEARCH PROJECT

IMPLEMENTATION ANALYSIS OF MINISTRY OF HEALTH GUIDELINES ON "DEATH AND DYING IN LONG TERM CARE FACILITIES"

DEMOGRAPHIC DATA SCHEDULE

Would you please complete the following schedule prior to our interview on _____. Please keep in mind that your name will not appear on this schedule.

C. INTERVIEWEE

HOW LONG HAVE YOU WORKED FOR THIS ORGANIZATION

01 <3 MONTHS _____
02 >3MO BUT < 1YR _____
03 >1YR BUT < 2YR _____
04 >2YR BUT < 5YR _____
05 5YR AND > _____

WHAT IS YOUR PRESENT TITLE(s)

01 ADMINISTRATOR/CEO _____
02 OWNER/OPERATOR _____
03 DIRECTOR OF CARE _____
04 DIRECTOR OF NURSING _____
05 UNIT MANAGER/HEAD NURSE _____
06 CLINICAL NURSE SPECIALIST _____
07 OTHER _____

WHO DO YOU REPORT TO

00 BOARD OF DIRECTORS _____
01 ADMINISTRATOR/CEO _____
02 OWNER/OPERATOR _____
03 DIRECTOR OF CARE _____
04 DIRECTOR OF NURSING _____
05 UNIT MANAGER/HEAD NURSE _____
06 OTHER (Please explain) _____

HOW LONG HAVE YOU BEEN IN THIS POSITION

01 <3 MONTHS _____
02 >3MO BUT < 1YR _____
03 >1YR BUT < 2YR _____
04 >2YR BUT < 5YR _____
05 5YR AND > _____

PLEASE CHECK HIGHEST LEVEL OF EDUCATION COMPLETED

01 GRADUATE DEGREE _____
02 UNIVERSITY DEGREE - specify _____
03 COLLEGE DIPLOMA - specify _____

WHAT ASPECTS OF THE PROPOSED GUARDIANSHIP LEGISLATION ARE YOU CONCERNED ABOUT IN TERMS OF DEATH AND DYING ISSUES?

I am not sufficiently aware of the proposed legislation to comment

_____

I am concerned about _____

D. POLICY PROCESS

WHAT PROPORTION OF THE POLICIES DO YOU WRITE FOR YOUR FACILITY?

ALL _____ SOME _____ NONE AT ALL _____

PRIOR TO SEPTEMBER 1989, WAS THERE A POLICY IN PLACE FOR:

Do Not Resuscitate Orders	01 YES _____	02 NO _____
Process for communicating to residents about their wishes and rights	01 YES _____	02 NO _____
CPR Certification for staff	01 YES _____	02 NO _____

AT PRESENT, DOES YOUR FACILITY HAVE A WRITTEN POLICY ON:

Resident Rights?	01 YES _____	02 NO _____
Do Not Resuscitate Orders?	01 YES _____	02 NO _____

Process for communicating to residents about their wishes and rights?	01 YES _____	02 NO _____
Degrees of Intervention	01 YES _____	02 NO _____
CPR Certification for staff?	01 YES _____	02 NO _____
Mission Statement	01 YES _____	02 NO _____

HAVE YOU SEEN THE MINISTRY OF HEALTH DOCUMENT:

1) "Report on Death and Dying Guidelines for Long Term Care Facilities"?

   01 YES _____ 02 NO _____

2) "Operational Guidelines "Death and Dying Guidelines for Long Term Care Facilities"?

   01 YES _____ 02 NO _____

   .....IF YES,

   When did you first see this report? (mo/yr) _____ / _____
   Did you use the documents to develop your policy?

   01 YES _____ 02 NO _____

   .....IF YOU BELONG TO PRICARE

   Did you see their guideline documents?

   01 YES _____ 02 NO _____

   Did you use their documents to develop your policy?

   01 YES _____ 02 NO _____

WHAT OTHER MATERIALS ARE YOU FAMILIAR WITH ON THIS TOPIC?

_____

Did you use these to develop your policy?

01 YES _____ 02 NO _____

REGARDING THE POLICIES FOR: DO NOT RESUSCITATE AND/OR DEGREES OF INTERVENTION:

Were you the primary author?

01 YES _____ 02 NO _____

Did you develop the policy with a group?

01 YES _____ 02 NO _____

GUIDELINES ON DEATH AND DYING RESEARCH PROJECT

FACILITY INTERVIEWS
AUGUST 13 - SEPTEMBER 18, 1992

Interview Sequence	Quadrant of Province	# Interviewees	Interview Length (hr)	Facility Type	Profit	# Beds	Funding	DNR Policy	DI Policy	Strata	Interviewer Saw Guidelines	Used Guidelines	Used Peers/ Assoc. Literature
1	SW	2	1.5	ic	yes	113	cc	d	d		no	no	yes
2	SW	3	2.5	ic/ec	no	108	cc/hp	yes	yes	R	yes	yes	
3	SW	2	1.5	ic	no	159	cc	d	d		no	no	yes
4	SW	1	2.0	ic	no	155	cc	yes	yes	r	yes	yes	
5	SW	2	2.0	ic	yes	65	cc	yes	yes		no	no	yes
6	SE	1	1.5PH	ec	no	35	hp	yes	yes	R	yes	yes	
7	SW	1	1.5	ec	no	15	hp	yes	yes		no	no	yes
8	SW	1	1.75PH	ec	no	8	hp	yes	yes	R	yes	no	yes
9	NE	1	1.5PH	ec	no	54	hp	yes	yes	R	yes	yes	
10	SE	1	1.75PH	ic	no	32	cc	yes	yes	eR	yes	yes	
11	SE	1	2.0	ic	no	196	cc	yes	yes	r	?	no	yes
12	SW	1	2.0	p/ic	no	91	cc	d	d	e	yes	yes	
13	SW	1	1.5	ec	no	71	hp	yes	no		yes	no	yes
14	NW	2	1.25PH	ic	no	17	cc	yes	no	R	yes	no	yes
15	SW	3	3.0	ic	no	131	cc	yes	yes	s	yes	no	yes

GUIDELINES ON DEATH AND DYING RESEARCH PROJECT

FACILITY INTERVIEWS
AUGUST 13 - SEPTEMBER 18, 1992

16	SE	1	1.5	ic	no	157	cc	yes	yes		yes	yes	
17	SW	1	1.25PH	ic	no	67	cc	no	yes		yes	yes	
18	SW	1	1.5	ic	no	102	cc	yes	no	s	yes	no	
19	SW	2	2.5	ic	yes	85	cc	no	no	R	yes	no	
20	SW	1	1.5	ec	no	10	hp	yes	yes	R	yes	no	yes
21	SE	2	2.0	ic	yes	74	cc	no	d		yes	no	yes
22	NE	1	1.5PH	ml	no	100	cc	yes	yes		yes	no	yes
23	SW	1	1.5	ml	yes	85	cc	yes	yes		yes	yes	

KEY

ic - intermediate care
ec - extended care
p - personal care
ml - multi-level

R - rural
e - ethnic
s - social
r - religious

cc - continuing care
hp - hospital programs
PH - phone interview
d - draft

SE - Southeast
SW - Southwest

NE - Northeast
NW - Northwest

APPENDIX G

Recommendations by Respondents for Guideline Improvement

1. Provide an example of an actual facility policy.

2. Provide in-service education strategies for staff, residents and family.

3. Promote the content of the guidelines more in the public and professional media.

4. Apply the guidelines to organizations other than long term care facilities.

VITA

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Title of Thesis:

A QUALITATIVE ANALYSIS
OF THE PROCESS OF DEVELOPING AND IMPLEMENTING
DO NOT RESUSCITATE AND DEGREES OF INTERVENTION POLICY
IN LONG TERM CARE SETTINGS IN BRITISH COLUMBIA

Author: [redacted]
Signature

Diane Laughlin
DIANE LAUGHLIN

August 6, 1993
August 6, 1993