A DESCRIPTION AND ANALYSIS OF THE FUNCTION AND MEANING OF HOSPICE:

A COMMUNITY DEVELOPMENT STUDY

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ABSTRACT

The Mid-Island Hospice Society is a registered, non-profit society in Nanaimo, British Columbia. It was organized at the community level by local people (including the writer) between November 1979 and December 1981.

The objective of this study is to describe and analyze the development of the Mid-Island Hospice Society, and its efforts to change the health care system in Nanaimo. The study utilizes Jack Rothman's (1974) social reform model as a guide.

The application of the Rothman framework in Chapter 5 makes it clear that the purposes of the study are to (a) describe and analyze how the Mid-Island Hospice came into being, and to (b) elucidate its efforts to change health care for the terminally ill.

This study is based on various printed data as well as interviews with the two persons closely associatated with the writer during the Hospice's organization and implementation period.

It was found the overall contribution of the Mid-Island Hospice Society was to humanize the dying process. The Nananimo hospice group identified the sources of the terminally ill person's dehumanization--physical pain, emotional and psychological discomfort and social isolation. For each of these problems, the hospice organizers proposed solutions: for the problem of physical pain, they brought in a

medical expert to educate the local physicians and nurses, and they facilitated a closer working relationship between the hospital team and home-care nurses. For the problem of psychological pain and social isolation, they set up the hospice volunteer visiting service made up of interested and sharing members of the community. To ensure that these humanizing measures continued, the hospice organizers educated the local community-at-large about the plight of the dying person.

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This thesis is dedicated in memory of my husband, Harvey C. Tomasson, and to the many people who volunteered their time and effort unstintingly to the Mid-Island Hospice Society, especially the wonderful one-to-one volunteers who put hospice principles of caring into practice.

TABLE OF CONTENTS

Abstract i

Acknowledgement iii

Table of Contents iv

Chapter I INTRODUCTION
- Statement of Problem and Purpose 1
- Background of the Problem 2
- Significance of the Study 2

Chapter II REVIEW OF THE LITERATURE
- Framework and Literature Review 4
- Terms Surrounding Community Development Practice 5
- Assumptions underlying Community Development Practice 6
- Methods of Community Development Practice 6

Chapter III JACK ROTHMAN: FOUR METHODS OF COMMUNITY DEVELOPMENT PRACTICE
- Locality Development Method 13
- Social Planning Method 14
- Social Action Method 16
- Social Reform Method 17

Chapter IV DESIGN OF THE STUDY
- Theoretical Framework 20
- Data Sources and Collection 23
- Data Analysis 25
- Limitations 28

Chapter V NANAIMO HOSPICE
- PART I - Perceptions and Assumptions Surrounding Social Structures and Problem Conditions 29
- PART II- Basic Change Strategy 34
- PART III-Characteristic Tactics and Technqiues 43

Chapter VI Perceptions about the terminally ill in death and dying literature related to perceptions about the terminally ill among those involved in organizing the Nanaimo hospice. 62

Chapter VII Function and Meaning of the Hospice 68
- Recommendations 69
- Further Considerations 71

Bibliography 72

Appendix 'A' 74

Appendix 'B' 75

Appendix 'C' 76

CHAPTER I

Statement of Problem and Purpose

The community-based volunteer hospice is a local organization registered as a charitable, non-profit society. It is organized at the community level, by local people, to promote better and more comprehensive care for the terminally ill person. The local organization is part of a larger contemporary Western movement known as the hospice movement. The hospice concept involves a concept of total care -- physical, social, emotional and spiritual -- for the terminally ill person (those for whom no current treatment is effective), and care and support for their families.

Typically, the local hospice quickly and successfully organizes a programme to train and supervise volunteers to provide emotional support. However, the course of organizational activity is unique to each local community, and hospices vary in terms of the auspices and services provided. In order to ascertain the development and contributions of the Mid-Island Hospice, it was analyzed as a community development programme.

Background of the Problem

The local hospice usually comes into existence and proceeds with few guidelines. Generally action and planning intertwine so spontaneously that the exact methods to achieve total care are not explicit or clearly identified. Consequently, once the volunteer component of providing emotional support is established, the direction of future planning remains uncertain. For example, in the Nanaimo hospice, some of the people involved in future planning and decision-making saw the hospice as a social service; others felt that the function of the hospice was different, but could not articulate the exact nature of that function.

Significance of the Study

There is to date, no full, formal description and analysis of a Canadian community-based volunteer hospice. I could find only one study, an American one, of a community-based volunteer hospice (Mudd, 1982, pp. 11-13). The study describes only the service of volunteers. In addition to uncovering the essential nature and function of the hospice, this study provides:

1. a formal documentation of the organization's activities;
2. a raising of consciousness about the essential nature and function of the hospice;
3. useful information to those in decision-making roles regarding hospice;
4. a potential prototypical framework for the analysis of similar

organizations;

5. a review of community development which may be valuable for understanding the nature of the community.

CHAPTER II

Framework and Literature Review

There is no single community developmental theory. The practice of community development relies upon concepts borrowed from social science, and on the insights developed in practice. Jim Lotz (1979) comments on the lack of a body of practice theory:

> Community development does not seem to have achieved those prerequisites of a scientific discipline a coherent body of theory and a close relationship to reality. There is a pervasive feeling in the writings on community development, that community development is not academically responsible (because it lacks a body of substantive theory) and also that community development does not work as a technology (because so many disasters in development have been identified as community development projects). On the other hand, when a vogue for community development appears in a country, as is the case in Canada at the present time, the representatives of established disciplines appropriate the field of community development and claim it for their own (pp. 386-88).

Historically, the field of education made the initial step by identifying community development with adult education or with basic education. The field of social work views community development as an excellent vehicle to expand the expression of their philosophy and organizational methods, equating community development with community social welfare, while sociologists and social anthropologists, with their interest in the processes and techniques of social change, see community development as an applied field of their respective disciplines (Cary, 1970).

The literature on community development is confusing and difficult to find. Brian Wharf (1979) elaborates this aspect:

> the literature...accurately reflects the state of the art in practice. The literature is composed of hard to-find agency reports, articles in journals, which often have considerable merit, but are essentially unrelated to each other, and pragmatic, how-to-do monographs and pamphlets instructing neophytes on the ABC of community work (p. 10).

To Wharf's observation might be added the difficulty of sorting out the audience the writer addresses.

Terms Surrounding Community Development Practice

In the literature, community development is variously referred to as community organization, community development, community work and community planning. Professional practitioners are variously referred to as community developers, social planners, community organizers, enablers, catalysts, animators, advocates and community psychologists. These terms reflect types of employing agencies as well as general philosophies about community development itself. This will be elaborated more fully later in this section of framework and literature review. In the present study, the terms 'community organization' and 'community development' will be used interchangeably, chiefly because this seems to be the practice in community development literature. There will be no reference to a professional practitioner because the Nanaimo hospice did not employ anyone in this capacity (though there were many non-professional "practitioners").

Assumptions Underlying Community Development Practice

Community development, in all its forms, is concerned with bringing about change. Those who engage in community development believe that deliberate, planned change is possible, desirable and leads to social betterment. This is illustrated in a United Nations publication which states that:

> Community development...[is] ...designed to create conditions of economic and social progress for the whole community with its active participation and the fullest possible reliance on the community initiative (Cary, 1964, p. 48).

For some writers, community development is the expression of a dedication to the ideal of social betterment. Thus the 1948 Cambridge Conference on African Administration characterized community development as

> designed to promote better living for the whole community with the active participation, and if possible, on the initiative of the community, but if this initiative is not forthcoming, spontaneously, by the use of techniques for arousing and stimulating it in order to secure its active and enthusiastic response...it embraces all forms of betterment (Cary, 1964, p. 49).

Generally, however, the practice of community development to bring about planned change takes a neutral, scientific form (Cary, (1964): 49).

Methods of Community Development Practice

A central figure in community development practice, Murray G. Ross (1955), favours the practice of community development based on the participation of a broad cross-section of the community working toward solving commonly-held problems. Ross argues that rapid urbanization around the world creates imbalances, tensions, and the consequent loss of community that must be addressed:

> The processes of urbanization have almost destroyed man's feeling of belonging to a community...the problem of developing and maintaining common or shared values (the basic ingredient for cohesion) is made vastly more difficult by industrialization and urbanization...the tendency for large subgroups to develop cohesion as separate entities in the community produces social tension, potentially dangerous in any community ... democracy will weaken, if not perish, unless supporting institutions are supported and new institutions (to meet new ways of living) are developed (p. 29).

Ross stresses that the practitioner should function as an enabler to stimulate individuals and groups in local communities to determine and identify common felt needs. He hypothesizes that the community, in a process of identifying common felt needs, will build common values and consensus on common goals. Ross anticipates resistance from individuals and community groups who wish to preserve the status quo. However, the role of the enabler is to initiate processes to overcome these feelings, facilitating and encouraging co-operation and participation. Ross considers this kind of change more likely to last than imposed change.

Like Ross, William Biddle and Loureide Biddle (1975) advance community participation as a technique to stimulate the local community to determine and identify common felt needs. They stress that what happens to people psychologically and socially is the essence of the process of effective change, and state that:

> it is a social process whereby human beings can become more competent to live with and gain some control over

local aspects of a frustrating and changing world (p. 46).

Local initiative is stressed, also, in Arthur Stinson's model. Stinson (1979) argues that even in the weakest community some kind of positive relationship among people persists. It is the job of the animator to stimulate the community. By searching out an object for which there is some motivation, raising awareness surrounding the object, and guiding the community toward competence in dealing with the problem, confidence and ability grows. Stinson calls this the 'transforming process'. He argues, too, that an animator needs autonomy from institutional restraints to practice this kind of community development. For this reason he sees true community development as being distinct from social planning, government planning and institutional outreach.

In contrast to models that allow and encourage broad participation by the community -- with the community defining its own need -- is the social planning model. From this approach, the practice of community development incorporates an approach that is for the most part administrative in nature. J. P. Belshaw (1953) suggests that it is a principle that 'is not inherently democratic...(but) makes a contribution to democracy...because this country is democratic' (cited in Wileden, 1970, p. 75). A social planning model is constructed by Robert Morris and Robert Binstock (1966) in which the planner focusses on a delimited problem within the prevailing system. Successful practice involves developing administrative devices to promote more effective co-ordination of existing programmes, as well as introducing new programmes for new needs. The planner, who is usually employed by the prevailing system, uses his expert understanding of cause and effect relationships to select a goal which guides subsequent decisions and actions. Morris and Binstock concentrate on power and conflict in their model, anticipating that there will be resistance to implementing change; however, the effective planner finds resources to overcome the resistence to change.

Saul D. Alinsky's (1962) model is another that illustrates power. The approach to practice, however, differs from the Morris and Binstock model. In Alinsky's (1962) model, the advocate for those oppressed by bureaucracy, big business, or society-at-large, works with the oppressed to wrest control from the oppressor. The practitioner seeks to engage the disadvantaged members of the community in the decision-making process both to overcome apathy and estrangement and to cultivate skills in problem-defining and goal setting. A clash-of-interest strategy is usually employed to bring about change. Alinsky describes such a group in action:

> [the] conflict group has as its sole reason for coming into being...waging war against all evils that cause suffering and unhappiness. A people organization is the banding together of multitudes of men and women to fight for those rights which insure a decent way of life...a war is not an intellectual debate...in the war against social evils...there can be no compromise (cited in Rothman, 1974, p. 30).

With knowledge of the rules and technicalities, the practitioner is an advocate for the consumers of social welfare services, building a constituency to organize and exercise its own power.

Jack Rothman's 'Three Methods of Community Organization Practice' (1974)

Because approaches to community development vary greatly considerable confusion exists about its nature and function. Jack Rothman (1974) made the first advance in unravelling the confusion. In his article, 'Three Methods of Community Organization Practice', Rothman (1974) denies that any one method brings about change. Rothman (1974) believes that "in empirical reality, there are different methods of community organizational practice to bring about different kinds of change" (23).

In his article, Rothman (1974) identifies three methods of community organization practice in the writings of community development theorists since 1955. He believes that these three methods apply equally to rural, urban, American and overseas development. Rothman names the methods locality development, social planning and social action, but cautions against interpreting these terms literally. Rather, the terms designate orientations to practice.

Rothman (1974) hypothesizes that methods of community organization reflect certain presuppositions about problem conditions and social structure. On the one hand, the locality development method (which Rothman (1974) sees as the mode of Ross (1955), Stinson (1979) and the Biddles (1975)) presupposes that the local community is apathetic and needs stimulation to work towards self-initiated change as a solution to social problems. On the other hand, the social planning approach presupposes a complex environment which needs expert planners to guide complex change. The Morris and Binstock approach (1966) incorporates this social planning approach. Rothman (1974) identifies the Alinsky (1962)method as social action. He argues that it presupposes that a power structure informs the community structure -- bureaucracy, big business, society-at-large -- and systematically oppresses islands of powerless, weak people.

Rothman (1974) advances another orientation which he designates as 'social reform'. The social reform method combines social planning and social action. Like social action, it assumes that a segment of the population is oppressed and disadvantaged. However, like the social planning approach, it assumes that the problem is also substantial. In the social reform method, as in the social action method, organizing takes place outside the formal system. But rather than organizing the oppressed members, those concerned organize to act on behalf of those members.

Rothman (1974) argues that methods do not stand in opposition to one another. Instead, he asserts that the method employed depends upon a group's problem and its own relationship to the social structure. The community development scholar, Brian Wharf (1974), supports Rothman's (1974) argument in the following illustration:

> a neighbourhood association working under the assumption that common problems affect all living in the neighbourhood and that, in a democratic society, all groups have an equal change of being heard by decision-makers, will naturally turn to consensus-oriented strategies, such as filing briefs and holding meetings. By contrast, a Native Indian Band, convinced that it has been consistently ignored by white dominated society, may very well resort to tactics of

> disruption and confrontation (Wharf, 1979, p. 244).

The neighbourhood group which perceives the social structure to be an effective part of the solution to the problem, will employ different strategies than the Indian Band who perceives the social structure to be part of the problem. Consequently, the neighbourhood group employs tactics and techniques which reflect their belief in the effectiveness of their society's processes, while the members of the Indian Band -- who are suspicious of the social structure -- employ tactics and techniques which reflect their disillusionment and frustration with society's processes.

CHAPTER III

Locality Development, Social Planning, Social Action, Social Reform

As seen in Chapter II, Rothman (1974) hypothesizes that there are four methods of community development practice. He synthesizes and describes these methods in a set of eleven variables, which are used to characterize different practices. Practice characteristics operate, with more or less regularity, depending on the method of practice. The profile is sketched for each method of practice.

Locality Development Method

1. Goal Categories: In locality development the focus is on 'process goals' such as stimulation of wide interest and participation among individuals and community groups.
2. Assumptions regarding community structure and problem conditions: the community is seen as overshadowed by the larger society. People are isolated, lack problem-solving skills and understanding of democratic processes. Disillusionment and a lack of feeling of belonging results, creating apathy.
3. Basic Change Strategy: This variable is characterized by an effort to get a wide range of community people involved in identifying felt needs and moving to solve their own problems.
4. Characteristic change tactics and techniques: The essential technique is to organize as wide a range of people as possible to discuss and to consider action alternatives.

5. Practitioner roles and Medium of change: The practitioner is frequently referred to as an 'enabler' or 'encourager' who helps people to express their discontent, their problems, and finally, to begin a process of problem-solving. The medium of change may be small groups.
6. Orientation to power structure: the power structure is part of the solution of the problem; working towards a solution is a common venture.
7. Boundary definition of the community client system: the total community is the client system.
8. Assumptions regarding interests of community subparts: interests of various groups and factions are seen as basically reconcilable.
9. Conception of the public interest: the conception of public interest characteristic of the locality approach is rationalist/ unitary in which a broad cross-section of the community focusses on general welfare, utilizing co-operative decision-making.
10. Conception of the client population: clients are considered to be normal citizens needing the services of a practitioner to help them focus and release inherent capabilities.
11. Conception of client role: clients are viewed as active participants.

Social Planning Method

1. Goal Categories: social planning stresses task goals (i.e. the focus is on completing a concrete task, or on solving a delimited problem concerning the functioning of a community social system).

2. Assumptions regarding community structure and problem conditions: the social planning approach focusses on the social problem. It sees the community as comprised of numerous substantive social problems upon which experts deliberate and plan.
3. Basic Change Strategy: in social planning, the strategy is to gather facts and then decide on a feasible course of action.
4. Characteristic change tactics and techniques: social planning technique is fact-finding and analysis, moving to tactics of conflict or consensus, depending on the practitioner's analysis of the situation.
5. Practitioner roles and medium of change: the practitioner as planner is the expert fact-finder who implements programs and deals with bureaucracies.
6. Orientation to power structure: in the social planning model, the power structure is usually the planner/practitioner's employer.
7. Boundary definition of the community client system: in social planning, the client system can be a total geographic community, or some area, function, or subpart.
8. Assumptions regarding interests of community subparts: there is no pervasive assumption about the degree of intractability of conflicting interests in social planning. The approach is pragmatic, oriented toward the particular problem and actors. The planner is not expected to be attuned to all factions within complex organizations.
9. Conception of the public interest. The conception of public interest characteristic of the social planning approach is

idealist-unitary in which the power to identify the public good lies in knowledge, rather than in political influence or popular mythology.

10. Concept of the client population: clients are thought of as consumers of services.
11. Conception of client role: In social planning, clients are active consumers, but not involved in determining or setting policy or goals.

Social Action Method

1. Goal Categories: the social action method incorporates either task or process goals.
2. Assumptions regarding community structure and problem conditions: the social action approach advances the idea of fundamental change in major institutions or community practices.
3. Basic Change Strategy: social action is organized to eliminate the oppressor. Issues are crystallized, the legitimate enemy is identified, and pressure is brought upon selected targets.
4. Characteristic change tactics and techniques: the social action technique mobilizes people for action, moving to tactics of either campaign strategies when there are differences among parties or contest and confrontation if the external group refuses to recognize needs or opposes change.
5. Practitioner roles and Medium of Change: the practitioner's role is advocate and activist. The practitioner's expertise is available exclusively to serve client interests: organizing the

disadvantaged members and creating a potential for mass organization.

6. Orientation to power structure: the power structure is seen as an oppressive form.
7. Boundary definition of the community client system: The client is a community subpart or segment which suffers at the hands of the broader community.
8. Assumptions regarding interests of community subparts: in social action, there is an assumption that interest among community subparts are at variance and irreconcilable. Those who hold power or privilege and who profit from the disadvantage of others do not easily give up their own advantage.
9. Conception of the public interest: the conception of public interest characteristic of the social action approach is realist-individual in which special interest groups confront others.
10. Concept of client population: in the social action model, clients are viewed as victims of the system.
11. Concept of client role: The clients are peers and co-partisans of the practitioner.

Social Reform Method

1. Goal Categories: in the social reform method of community development, task goals -- the solution to a delimited problem pertaining to the functioning of a community social system -- are stressed.
2. Assumptions regarding community structure and problem conditions:

social reform approaches the situation assuming that the problem is substantial. It is also assumed that a segment of the population is oppressed and disadvantaged.

3. Basic change strategy: in social reform the basic change strategy involves seeking out others interested and concerned with the problem, and organizing them into a coalition.
4. Characteristic change tactics and techniques: the social reform technique mobilizes the people for action, moving to campaign strategies, to resolve issues and differences among parties.
5. Practitioner roles and Medium of change: the practitioner's role is to manipulate voluntary associations and legislative bodies to bring about change in a community social system.
6. Orientation to power structure: in the social reform model, the power structure is viewed in 'gatekeeper' terms as a centre of decision-making that can be influenced through persuasion or pressure.
7. Boundary definition of the community client system: the client system is defined as a population at disadvantage or risk.
8. Assumptions regarding interests of community subparts: in social reform, community subparts may be either reconcilable or in conflict. Subparts may be reconcilable based on common interest or common concern with a problem. On the other hand, interests may be at variance and irreconcilable, if power or privilege is threatened.
9. Conception of the public interest: the conception of public interest is realist-individualist in which a special interest group confronts others.

10. Concept of the client population: in this approach, the client is viewed as a victim.
11. Conception of client role: in the social reform approach, the clients are potential consumers or recipients.

Following Rothman, several other frameworks have been constructed. One such framework is the Robert Perlman and Arnold Gurin model (1971). This framework attempts a more integrative approach. This study, however, was concerned with ordering and clarifying organizational activity more explicitly. As a result, the Rothman (1974) framework was selected to uncover the function and nature of the hospice. Furthermore, in an empirical check of the Rothman model by Canadian community development practitioners, Brian Wharf (1979) noted that as an ordering and clarifying device, the Rothman framework was a classic in the literature.

CHAPTER IV

Design of the Study: Theoretical Framework

As stated previously, all community development practice aims to bring about change. Jack Rothman hypothesizes that all community development is practiced from one of four approaches: locality development, social planning, social action or social reform.

Locality development practice approaches community development with a goal of working towards stimulating wide community interest and participation, thereby identifying common problems or common needs. By organizing a wide range of people to express problems and discontent, a process of problem-solving will begin. Clients are considered normal citizens and active participants who need the services of a practitioner to help them focus and release inherent capabilities. The power structure is part of the solution to the problem.

The remaining three models, social planning, social action and social reform focus on a particular social problem rather than on the community. However, all three models are not alike in practice. In social planning, the power structure is usually the planner's/ practitioner's employer. The practitioner as planner is the expert fact-finder who implements programs and deals with bureaucracies. Clients are thought of as consumers of services but are not involved in determining or setting policies or goals.

In the social action approach, the practitioner organizes disadvantaged members to confront those who hold power or privilege and profit from others. The clients are peers and co-partisans of the practitioner. Differences between those who hold power and the victims are irreconcilable and the power structure must be destroyed and taken over, generally by those presently victimized.

In the social reform model, the power structure is viewed as a centre of decision-making that can be influenced through persuasion or pressure. The social reform approach to community development organizes itself outside the formal prevailing system. In this way it is like social action. However, unlike social action which organizes disadvantaged community members to act on their own behalf, social reform organizes to act on behalf of what is perceived to be a disadvantaged community group. Clients are thought of as potential consumers.

The method or practice that was most relevant to this study was social reform. The hospice society was organized outside the system (the formal health care system), and the group was organized to act on behalf of what was perceived by them to be a disadvantaged community group (the terminally ill).

Rothman identified eleven variables common to the four community development models; however, the characteristics constituting each variable are different for each model. Three of the eleven practice variables are important to the social reform model, and consequently this study treated these variables in great detail. These variables and characteristics of practice are as follows:

Variables	Characteristics
2. Assumptions about problem conditions and social structure	Substative social problem and disadvantaged populations.
3. Basic change strategy	Organizing a coalition of concerned interests.
4. Characteristic change tactics and techniques	Campaign tactics -- the employment of facts and persuasion to apply pressure on decision-making bodies; resolving differences and issues among parties.

Rothman (1974) argues that the assumptions and perceptions of those involved in community organization are most accurately and consistely apparent in the variables of strategy, tactics and techniques (this argument was set out earlier in this paper together with Brian Wharf's (1979) supporting illustrations). In other words, the strategy, tactics and techniques adopted result directly from the group's assumptions and perceptions about the relationship between social structure and problem conditions.

Furthermore, two of the characteristics of these three variables (nos. 2 and 4), subsume characteristics of seven of the eight other variables. The one remaining variable (no. 5) was not treated because hospice did not employ a professional developer. Instances of 'overlap' are as follows (See Appendix A for the outline of the model):

Variables to be studied	Areas of Overlap with other Seven Variables
2. Assumptions about problem conditions and social structure: SEGMENT OF POPULATION DISADVANTAGED AND OPPRESSED; SUBSTANTIVE SOCIAL PROBLEM.	7. Boundary of client system: COMMUNITY SEGMENT DISADVANTAGED OR AT RISK. 10. Client population:VICTIMS. 11. Conception of client role: POTENTIAL CONSUMERS OR RECIPIENTS.
4. Change tactics and techniques: CAMPAIGN TACTICS-THE EMPLOYMENT OF FACTS AND PERSUASION TO APPLY PRESSURE ON DECISION-MAKING BODIES; RESOLVING DIFFERENCES AND ISSUES AMONG PARTIES.	9. Conception of public interest: SPECIAL INTEREST GROUP CONFRONTS OTHERS. 8. Assumptions regarding interest of community subparts: COMMUNITY SUBPARTS MAY BE RECONCILABLE BASED ON COMMON INTEREST. 6. Orientation toward Power Structure: POWER STRUCTURE VIEWED AS A CENTRE OF DECISION-MAKING THAT CAN BE INFLUENCED THROUGH PERSUASION OR PRESSURE. 1. Goal categories of community action: A SOLUTION TO A DELIMITED PROBLEM PERTAINING TO THE FUNCTIONING OF A COMMUNITY SOCIAL SYSTEM.
3. Basic Change Strategy: ORGANIZING A COALITION OF CONCERNED INTERESTS.	

Data Sources and Collection

Data collected from the fall, 1979 to December 31, 1981 and particularly from the fall, 1979 to December, 1980 were used. This implementation period was the focus of this study because as Carol H.

Weiss (1972) argues:

> we know that implementation is a critical juncture between the best-laid plans of program developers and the 'gang aft agley' of operation. Understanding what happens in the political and social complexities of broad-aim intervention programs may well be a priority order of business if we are to learn how to develop programs more realistically, to reduce the slippage between intent and action, and to address social problems with greater effect (pp. 96-97).

The study used five kinds of printed data: first, the minutes of the monthly meetings of the Mid-Island Hospice Society; second, prepared speeches which disseminated information from the group to the public; third, newspaper interviews which reported both the questions asked on behalf of the general public and the answers offered by the organization; fourth, newspaper clippings which reported the public dimension of the organization; fifth, miscellaneous sources such as letters, printed proposals, volunteer training materials, newsletters, records of client referrals, and personal memos. Finally, an interview was conducted with two persons closely associated with the Nanaimo hospice to corroborate the interpretation of printed data (and/or for data leading to other views).

The Minute Book of the Mid-Island Hospice Society, which recorded the monthly meetings of the society, was at the Society's office, 1225 Grant Street, Nanaimo, B. C. Letters, proposals, volunteer training materials, newsletters, records of referrals were also on file at the society's office. All other printed data was in my possession. I received verbal authorization from the physician/

president of the Mid-Island Hospice Society to use all the material at the office.

The personal interviews were conducted July 18 and July 19, 1985, one in person, one by telephone.

Data Analysis

Analyzing the data, I drew upon my practical experience in, and knowledge of theories about, community development. Both were equally important to this study. My practical experience, on the one hand, involved me in

(a) organizing the Nanaimo community members to act on behalf of the terminally ill person;

(b) planning and implementing events to introduce the hospice concept to the community;

(c) interacting with the segments of the present system surrounding the dying person;

(d) researching and drawing together educational materials for the training of volunteers.

On the one hand, my knowledge of community development theories led me to choose the Rothman social reform model for interpreting my data. Using any model to interpret a set of data, however, always raises problematical methodological questions. To answer these questions I turned to Marion Lundy Dobbert, who in her book, Ethnographic Research, argues the following:

> the use of theory in organizing data is often misunderstood, with the data items conceived as standing, by themselves, on one hand and the theory on the other -- two separate entities which are then brought together in a study. Clearly, this is not true...specific...theories are no more than tightly organized, often better-tested organizing schemes. Thus, to distinguish between the data...the descriptive case study...and the interpretive theory is to create a false dichotomy and merely succeeds in obscuring the actual organizing scheme utilized in gathering and writing the data up (Dobbert, 1982, p. 276).

Theories, it seems, often develop out of provisional organizational schemes and, consequently, are not easily separated from the data to which they are applied. For this reason, general categories suggested by the data themselves can introduce a theoretical order and coherence into what would be otherwise confusing or unmanageable:

> analysis of data by use of the general...categorical approaches...in conjunction with theory...usually proves most powerful in establishing the adequacy or inadequacy of previous knowledge and gives greater depth of interpretation (Dobbert, 1982, p. 276).

Within community development theory, then, the three core variables of Rothman's social reform model functioned as categories, and hence were a way to gather, analyze and organize data. Functioning as a category, each variable suggested questions, data sources, and procedures.

Part I

ASSUMPTIONS AND PERCEPTIONS

QUESTION	DATA SOURCE
How are the terminally ill, as a community group, perceived by those involved in hospice organizational activity, in relation to the social structure?	Prepared addresses Newspaper interviews Newspaper clippings

Procedure

Read through data for a general theme. In the final report, I described and analyzed similiarities and differences of perception among those involved in organizational activity toward the terminally ill as a community group in terms of (1) the system surrounding the dying and (2) the larger community.

Part II

BASIC CHANGE STRATEGY

QUESTION	DATA SOURCE
What was the process of organizing community members?	My own notes Minutes of monthly board meeting Newspaper clippings

Procedure

Read over my own informal notes, checked my own recording of organizing the group against the formal records and against newspaper clippings reporting the public dimension. The final written report is a fairly straightforward account of the chronological development of organizing community members in terms of the actors.

Part III

CHARACTERISTIC CHANGE TACTICS AND TECHNIQUES

QUESTIONS

How did the hospice group campaign on behalf of the terminally ill? What were the 'tactical' characteristics of the campaign in relation to the system surrounding the dying and in relation to the larger community?

Procedure

Obtained a framework of activities between fall, 1979 to December 1981, by

(1) Reading over my own notes, fall, 1979 to April, 1980.

(2) (a) Enlarged and supplemented the activities by reading the public recording of activities in newspaper interviews, newspaper clippings.

(b) Read through the correspondence file of the society enlarging upon records of correspondence recorded in the minutes.

(c) Read through the prepared addresses, to enlarge upon records of public addresses recorded in minutes.

The final written report describes and analyzes the group's activities in terms of interaction with (1) the system presently surrounding the dying and (2) the larger community.

As I was reading through the data, in addition to parameters set to research questions, the overall consistency of the group focus was considered.

Major conclusions are reported at the beginning of each section; however, as pointed out by Dobbert (1982), the descriptive case study is in itself a set of conclusions based on generalizations that stay very close to the data (Dobbert, 1982, p.277).

Finally, major conclusions, relative to the function and meaning of the hospice society were verified in an interview with two persons, Lynn Green and Marion Sylvester, who had worked closely with me in organizing Mid-Island Hospice during the period under study. One interview was conducted in person; one by telephone. Eight questions were devised using major conclusions as a guide. The interviewees have been quoted in the body of the study. (See Appendix B for the interview guide).

Limitations

Because the thesis has been undertaken by one of the founders of the hospice, a certain lack of objectivity may have influenced the selection, ordering and interpretation of data. To address this major limitation, this study employed, whenever possible, the observations, opinions and information of other hospice members, which in turn have been supported by published authority (books and articles). Some features of the Rothman model did not apply to the Nanaimo case study. First, the hospice did not employ a professional developer; second, the model did not account for trained volunteers adjoined to the prevailing system.

CHAPTER V

Nanaimo Hospice

In Chapter four, I argued that Rothman's social reform model was the one which most closely described the Nanaimo hospice organizational process. As well, I argued three variables in particular - perceptions and assumptions of the problem, basic change strategy and characteristic tactics and techniques - formed the core of community development practice and would most clearly uncover the nature and function of that practice. It is, then, with these variables that I organized, described and analyzed the raw data of the Nanaimo hospice development.

Part I

Perceptions and Assumptions Surrrounding Social Structure and Problem Conditions

In the Rothman social reform model, it is assumed that a segment of the community is disadvantaged and that it is a substantial social problem. Those who act on behalf of this group focus their reforms on the social system surrounding the disadvantaged group. The Nanaimo Regional Health District, which extends from Cowichan to Alberni, serves a population of 169,845. The numbers of deaths for the district in 1984 was 1,164 (Central Vancouver Health Unit Annual Report, 1984, pp. 12-15). The Nanaimo hospice group overwhelmingly agreed that terminally ill persons suffered dehumanization in the process of their dying and that the health care system was the biggest problem. Physicians were blamed for inadequate physical pain control, for taking little time to be with the patient and for lack of clear, open communication with the patient and family about treatment. The hospital also came under attack as a less-than-desirable environment for the dying person. Standardized routine rather than personalized care seemed to predominate, adding to the suffering of the person who was ill. Lastly, it was felt that society at large avoided and isolated the dying person. The dying person was a pariah both to the institution where people were sent to die and to the larger society.

Among the hospice organizers, perceptions about the source of patients' dehumanization varied. Some felt that the professional training of medical staff was responsible for the existing situation; that scientifically-oriented training led to viewing a person as merely a 'body', ignoring that person's integrity. Lynn Green, a nurse actively involved in the Nanaimo hospice, commented

> As a nurse, over the past seventeen years, I have often felt frustration in caring for the terminally ill. The physical needs are met, but emotional, spiritual and social needs of patients...are handled poorly...doctors are trained to diagnose, cure and prolong life...(address, Ladysmith Registered Nurses Association, September 25, 1981).

Others noticed that physicians were reluctant to approach and be with the dying person in an honest, open manner. The way in which facts were given about treatments often made it difficult for the persons and their families to make appropriate decisions and then to receive support for those decisions. For the physicians the battle against death seemed to become more important than the dying person. The nurses involved in some of the training of volunteers expressed their concern about issues surrounding therapeutic treatment. One home-care nurse dealt with the rights of the patient, educating volunteers about patient rights. The hand-out she provided to volunteers, 'A Dying Person's Bill of Rights' (which was created by nurses at Wayne State University, Detroit, June 12, 1976), stated that patients have a right not to be treated in an atmosphere of mystery, often knowing their own condition only vaguely; that the patient has a right to clear, honest information, and that the patient has the right to refuse treatment. These were all issues of care directly related to the doctor/patient relationship. Another member of the training team, Fran Dykes, a hospice volunteer and a board member of the society, referred to the Bill of Rights in the context of her own experience:

> the first two lines of the Dying Person's Bill of Rights says 'I have the right to be treated as a living human being until I die...' 'I have the right to have my questions answered honestly.' In the two and one-half years of my husband's illness, not only him, but myself were shoved aside with the well-meaning words 'Don't worry, everything will be alright'. All the time, everyone knew everything was wrong (Volunteer training session, October 28, 1981).

While doctors were sometimes less-than-open with the patient, this was not the only source of dehumanization. Green exprssed a larger dimension:

> there are fewer visits from doctors and nurses, leading to feelings of isolation and rejection when a person needs to feel secure and comfortable...(address, Ladysmith Registered Nurses, September 25, 1981).

Green felt that hospital staff generally found caring for the terminally ill person a distasteful task.

Canon Paul Chidwick, an Anglican clergyman addressing the hospice public informational meeting, eloquently stated the plight of institutionalized dying people, who were victims of a rigid system:

> dying is a very dehumanizing experience...because of the workload in hospitals, patients often feel the centre of a conspiracy of silence...and fear that they will be considered nuisance patients. It prevents them from asking for relief from one of the major physical conditions of the terminally ill -- pain. Until there is relief from pain, no other needs can be met ("Hospice ideals bring new hope for dying," 1984, September 24, Nanaimo Times, p. 3).

Chidwick perceived that inadequate physical pain control was part of a system that gave standardized rather than individual care. It produced an atmosphere that discouraged patients to ask for and to receive relief from physical pain. In this system, the dying patient 'is treated like a vegetable...saying, just lie there and behave yourself'(address, September 23, 1980). Chidwick implied that all professionals, as part of a dehumanizing system, were caught up in and contributed to the dehumanization.

Concerning the problem of physical pain, I shared Canon Chidwick's perception. This was touched on in my address to the Cowichan group:

> my husband was very uncomfortable following surgery, as well as having discomfort from the disease itself. Sometimes the medication did not hold the pain during the night and I would go to the desk and ask for medication. I was always told it was too soon, that we must wait for the four hours to be up...(O. L. Tomasson, notes from speech delivered May 12, 1981).

Like my husband, many patients were victims of a system that adhered to standardized rather than personal care, including adequate physical pain control.

The family may also be neglected by the hospital staff. Families often felt excluded and unwelcome. My own experience was related in an address to the public informational meeting of the

Cowichan hospice group:

> I was asked to speak to you this evening to tell a very personal story of what happens to a person and their family when they are faced with a terminal illness. My husband died from lung cancer one and a half years ago. I took care of my husband during the time he was ill and from that experience I learned that many of the needs of a person in a life-threatening illness go virtually unrecognized...at the Vancouver General Hospital after an unsuccessful attempt to remove my husband's lung...I sensed very strongly that he needed very much that I be with him. I told the staff that I would be staying all night as long as he wanted me there. They were non-commital. One staff member questioned how long I planned to keep this up...for the next eight nights I slept by my husband's bed, pushing two wooden chairs together, scrounging an extra pillow and blanket... eventually we returned to Nanaimo...three months later my husband contracted pneumonia, and it was impossible for him to remain at home longer. The morning my husband died, I was told by the nurse, in the elevator, that my husband was not at all well. I went to his room, found him alone, having difficulty breathing. I requested that he not be left alone, and asked that the doctor be called. I spoke briefly to the doctor...then went and sat in a little room down the hall. I called my children to come to the hospital. No-one came to tell me my husband was near death...nor were we asked if we wanted to be with him. I wish someone could have given us the support to be there (O. L. Tomasson, notes from speech delivered on May 12, 1981).

From my experience, I perceived that rigid hospital structure took precedence over humane care. I also saw that staff were unaware that the dying person and the family, as a unit, were mutually bereaved, both in need of support and care.

The physician/president of the hospice society, believed that hospitalizing dying persons contributed to their misery, chiefly by hindering their social well-being. He argued that isolating the dying person from something familiar and comforting was destructive to the person. In a press interview, Dr. Cameron talked about the need for alternative care:

> The hospital is not the best place for people who are dying. They are better off at home with people they know and are more comfortable with than in the hospital surrounded by strangers. One of the aims of the society is to establish a pool of volunteer helpers who are able to offer assistance to the families of terminally ill patients and patients families in the familiar surroundings of their home. ("Local Hospice will go it alone," 1980, September 25, Nanaimo Free Press, p. 2).

Cameron (1980) argued that the custom of removing the dying person to hospital needed changing; and that keeping the patient at home was more desirable and better both for the dying person and for the family.

Part II

Basic Change Strategy

In the Rothman social reform approach to community organizing, basic change strategy aims to bring about change on behalf of a disadvantaged community group by organizing a coalition of concerned interests, outside the system surrounding the problem. The Nanaimo group reflected this characteristic. I will describe the chronology of events from November, 1979 to December 31, 1981, the organizational period under study.

November, 1979

Laying the groundwork to bring together a group began at a meeting in the office of the hospital administrator at the Nanaimo Regional General Hospital. Those present at the meeting included the hospital administrator, the hospital chaplain, a local Anglican clergyman, a hospital nurse and the writer. Aware of the writer's efforts to create community interest in better care of dying persons and their families, the Anglican clergyman had arranged the meeting.

The hospital nurse, Lynn Green, addressed the meeting, citing how difficult it was for hospital staff, with myraid demands on their time, to give personal care to the dying person. The need for alternative forms of care was discussed and plans to investigate the degree of community support and interest were outlined to the administrator. He requested that notifying the media be postponed until there was an opportunity for him to investigate the hospice concept further.

January, 1980

The hospital administrator was again contacted and advised that there would be a press release. He was invited to become part of a community group to investigate ways and means to implement better care of dying people. He declined, saying that some of his staff were already involved (the hospital chaplain and the administrator of an intermediate-care facility under the jurisdiction of the Nanaimo Regional Hospital had joined the group). The Anglican clergyman also declined an invitation to join because of a heavy schedule of work in his parish. However, both the administrator and the clergyman acccepted a later invitation to be part of an advisory group to the main body. In this way, the hospice maintained contact with both the hospital administrator and community clergy.

The local cancer society was informed of plans underway to find community support for better care of the terminally ill. Efforts to involve the cancer society were unsuccessful. They did, however, accept a later invitation to meet and exchange information about respective programs (minutes of meeting, Dec. 8, 1981).

At this juncture of organizing a community group, group members (with the exception of the writer), were all affiliated with the hospital. I felt there was a need for broader community representation in the group. Lynn Green felt ambivalent about broadening the base to include other community members. On the one hand, as a hospital nurse, she was anxious to work towards change within the hospital and, on the other hand, was concerned that the hospital setting would not implement all that was necessary for comprehensive care of dying people. Green speaks, retrospectively, about her concern:

> hospitals get hung up in logistics of unions and health care regulations and for those reasons all would not get done that needed to to be done. (interview, July 19, 1985).

The hospital chaplain perceived that the hospital was the appropriate place to begin changes in the care of terminally ill persons, hence he was even less supportive of a broader community base. The other member of the group, representing intermediate care, did not express an opinion about group direction.

<u>March, 1980</u>

Lynn Green attended a two-day workshop in Victoria, sponsored by a Victoria hospice group, and brought back valuable information. About this time, a friend brought me some literature from St. Christopher's hospice in London, England. The literature provided information about the successful knitting together of hospital, home-care, volunteers, physicians, nurses and home-help. As well, the literature described new and innovative means of physical pain control. My earlier perception that our group ought to have larger community representation was confirmed by reading hospice literature.

I telephoned the chaplain to voice my concern for larger community representation. He provided me with the name of the wife of the college president, who herself had called him to ask about local efforts in hospice care. I arranged to have lunch with her. My meeting with Marion Sylvester was fruitful insofar as her background in home-care nursing provided support for including this dimension of care. She agreed to become part of the group, bringing with her 'the necessary home-care perspective and the need to incorporate that aspect' (interview, Lynn Green, July 19, 1985). Following my meeting with Sylvester, Lynn Green approached the supervisor of the local home-care nurses, a relatively new segment in the health care system. Home-care became enthusiastic supporters and participants. (A two thousand dollar personal donation to the group by the supervisor of home-care nurses indicated the degree of support given by the home-care segment of health care). Green also contacted the executive director of home-maker services -- a non-profit society and community social service -- that aids people in their homes. Its executive director joined the hospice group.

Representatives from physicians' groups also joined our group.

The chairman of the local general practitioners' group was giving a noon-hour guest lecture to students at Malaspina College. I made a point of attending the lecture, hoping to have an opportunity to speak to him. Following the lecture, I introduced myself to the physician guest speaker, indicating that our group would like to address a monthly meeting of general practitioners. An invitation was subsequently extended to address their group. Following that address, a general practitioner offered to represent his group on the hospice board. The intermediate-care director contacted the doctors' 'specialists' group by telephone, inviting their participation in our group. A local internist joined to represent his group on the hospice board.

At this point in the organizational process, the hospital, home-care nurses, homemaker services and local physicians were represented. I was the only 'lay' representative. I telephoned the hospital administrator (who had agreed to become part of the hospice group's advisory board) asking his suggestions about business community representatives. He advised me to contact local lawyers and accountants. I telephoned my own lawyer, inviting him to join the group. He declined, but offered to do (and did) any necessary legal work without charge, should our group incorporate as a non-profit society. I contacted a banker and businessman, both of whom consented to become part of the hospice group.

April 30,1980

Twelve people met at the Nanaimo Regional General Hospital in a room adjoining the cafeteria, to discuss the problems of the terminally ill person and various ways of dealing with these problems. The group consisted of nine representatives from various segments of the formal health care system -- two physicians, two general-duty nurses, an intermediate-care administrator, the director of home-care nurses, the executive director of home-makers, a hospital chaplain, the director of hospital volunteers. The remaining three persons, a banker, a businessman and the writer were from the larger community.

The group agreed that a formal structure was necessary to act on behalf of the disadvantaged community group. A local internest was elected chairperson. The group agreed to apply for incorporation as a non-profit society (minutes of meeting, April 28, 1980). This group, which became the decision-making board of the society, remained intact until the spring of 1981.

May, 1981

The hospital chaplain, the director of hospital volunteers, the general practitioner and the administrator of home-care nurses resigned, all leaving because of work-load committments. The general practitioner and the home-care nurse suggested colleagues to replace them. Instead the chaplain and the director of hospital volunteers were replaced by a primary school supervisor and a community director of senior citizens. These replacements on the board decreased hospital representation and increased community representation. As well, a move was made out of the hospital where we had been meeting, further separating the hospice group from the hospital. Yet even though hospital representation on the board had been reduced, and the group's meeting place moved from the hospital, a good working relationship with hospital administration was retained. The chaplain was invited to remain part of the training team for volunteers. Green believed this helped retain communication with hospital administration:

> we retained liaison with the hospital. I think the chaplain felt good to be asked to be part of the training programme. He felt that his expertise was being called on (interview, July 19, 1985).

I also kept in touch with the hospital administrator. I continued to call him occasionally, 'just to keep in touch'. When the hospice president asked the administrator that hospice volunteers be allowed to visit any time the patients requested a visit, his request was granted. This round-the-clock access to the hospital was an unprecedented granting of privileges to a group of non-medical persons.

Until March, 1980, the group consisted primarily of representatives from the hospital segment of health care. In March, 1980, the group began to expand, bringing in representatives from home-care, physicians, home-makers and the business community. Lynn Green perceived that the presence of the business community was influential in preventing the group from being absorbed into any segment of health care:

> I think the presence of the business community representatives balanced out other dimension. It gave it a community base, outside any part of the health-care system. The business community added expertise that health care professionals don't have. They (the business community) were esential to the smooth running of the group so it did not become totally health-oriented (interview, July 19, 1985).

Marion Sylvester also felt the presence of lay, business representatives kept the society outside the prevailing system:

> the group had a community-oriented feeling. The people that were there were people from the community. It also helped to get wider community support - from the Rotary Club, for instance (interview, July 18, 1985)

The business community, then, was an important element in broadening support beyond the health care system.

In May, 1981, the hospital chaplain and the co-ordinator of hospital volunteers resigned simultaneously. Marion Sylvester saw a relationship between these resignations and the direction in which the group was moving:

> the hospital contingent was a powerful group that wanted hospice inside the hospital...when that didn't happen, they left (interview, July 18, 1985).

She was convinced that there was a desire on the part of hospital representatives to keep the hospice group inside the hospital. She talked about her contact with the chaplain when she first telephoned him to inquire about hospice care in Nanaimo:

> I had not heard of your [the writer's] efforts until I telephoned the chaplain. Having recently moved from Vancouver, I wondered if anything was happening in this area, particularly in home care...He told me there were two women but he wasn't sure I would want to be involved in their efforts. He said their idea was to start hospice in the community. I got the impression

> he had doubts about the approach. (interview, July 18, 1985)

The resignation of the two hospital representatives, then, highlights the movement of the hospice group toward establishing itself outside the prevailing system surrounding the dying person. With this, the hospice group in Nanaimo became a group outside the health-care system to advance better care of terminally ill persons and their families.

Part III

Tactics and Techniques

In the Rothman social reform model, characteristic change tactics and techniques aim to bring about change on behalf of a disadvantaged community group by bringing pressure to bear on decision-makers. The decision-makers here are, of course, the professionals in the health-care system who administer to the dying person. The Nanaimo hospice group pressured the medical community in two ways: first, it persuaded members of the health-care system that alternative methods of care for the dying person were necessary and pressing; second, it encouraged the community-at-large to pressure the medical profession to acknowledge this need and to allow the implementation of an alternate method (i.e. hospice care). I will deal with this two-part process -- persuasion from within and pressure from without -- in the following section.

1. Persuasion: Bringing together segments of the prevailing system in a common effort

A. The hospital administration

Because dying -- at least in our society -- is handled primarily by medical professionals within a formal health care system, Lynn Green and I assumed that the idea of hospice would be threatening to the system surrounding the dying person. Green touched upon this assumption in address to a local community group

> we worked for several months...quietly speaking to
> hospital administration and community groups ...
> attempting to remain non-threatening...
> (address, Nanaimo Steps to Maturity, May 27, 1981)

The first segment approached was the hospital administration, because in Nanaimo, like most other communities, the hospital is the established institution to care for the dying person. And again, like other communities, Nanaimo has a well-established, well-regarded hospital. (In fact, most members of the community see the hospital as the place to go to die; this was illustrated when the writer was asked by a lay person if it were legal to die at home). Given these facts, the hospital administrator's co-operation with, and support for, the hospice was essential to its acceptance and legitimization.

There was initial resistance to the hospice concept, however. The hospital administrator appeared non-committal during the first meeting with hospice organizers, and asked that notifying the media about hospice be postponed. It was the writer's impression that in this request the hospital administrator sensed the tacit criticism that the existence of a hospice could bring to the health care system and that the media could bring this criticism out. As I documented in Part II, the organizers complied with the administrator's request, and waited two and one half months before going to the local press (February, 1980). This delay was a conscious tactic on the hospice organizers' part: by delaying, it was hoped that the administrator would acknowledge that the hospice meant to be non-threatening.

Yet, even after this gesture of good-will, the hospital administrator hesitated to be associated publicly with the hospice group. Perhaps he felt that if he did, he would be criticizing the very system he ran and represented. He therefore declined the invitation to come on to the hospice board (February, 1980). Four months later, however, after much positive press coverage and the striking of the hospice board, the administrator accepted a position on the hospice's advisory board. This group was made up of experts in various fields (health care, clergy, education and so on), and was a courtesy position formally acknowledging the members' expertise. It is the writer's impression that the hospital administrator accepted this position for two reasons: first, that the media coverage did not openly critize the health care system; and second, that the position itself was much less 'politically' contradictory of his position as hospital administrator. Approximately one year later, he returned the hospice organizer's initial gesture of good-will and granted hospice volunteers round-the-clock visiting privileges, allowing them direct and legitimate access to the dying person. This presence of supportive, caring volunteers resolved one of the hospice's aims: visiting rights were an important step towards humanizing the system.

Another employee of the hospital, the hospital chaplain, resisted the hospice concept more openly. In several conversations with him (November, 1980; February, April, 1981), hospice organizers felt that he actively discouraged plans to begin training hospice volunteers, and encouraged hospice organizers to direct their efforts towards fund-raising for a hospice site and building. It was writer's impression that the chaplain, being the head of hospital volunteers, didn't want agencies outside the hospital system to train people for the health-care field. (This impression was supported by Marion Sylvester's comment on the chaplain's reservations about hospice quoted in Part II). Despite this verbal resistance, the chaplain accepted an invitation to join the hospice board (April, 1980). Yet it was a further five months later, after the success of the public informational meeting, that the chaplain was more overtly supportive of the hospice's progress. Sensing his ongoing reserve, the hospice organizers consciously moved to invite him to become a member of the training team for hospice volunteers (spring, 1981). Even after his formal resignation from the board (spring, 1981), the organizers encouraged him to continue as one of the volunteer trainers. As Lynn Green pointed out (quote in Part II), the chaplain 'felt good' about being asked. Here again, then, the hospice organizers strove to be conciliatory with a facet of the hospital system.

B. Health Care Professionals

i. The Physicians

Because doctors are the central experts in the care for the dying person, the hospice organizers knew that it was essential to elicit the interest and support of the local physicians. Knowing that some doctors are sensitive to nurses' suggestions about medical treatment, I approached the local medical society - as a non-medical person - (Lynn Green, another hospice organizer was a nurse)- to address one of their monthly meetings. In my address, I focussed primarily on the value of the hospice approach to care. The text of the address included a brief summary of my own experience of the dying person and his family, followed by a comprehensive outline of the history, concept, and philosophy of hospice. Thus, on two levels - the choice of speaker and the presentation of topic - the hospice organizers consciously chose to approach the doctors in a non-threatening manner.

In the final analysis, this was the best approach. After the address, the numerous questions I received indicated the degree of interest in both the hospice concept and in the local efforts to promote it. When I indicated to the audience that we were anxious to have a representative from the medical group on our hospice board, a general practitioner in the audience offered to represent his profession on the executive. Even more importantly, a local internist became the president of the hospice board (April, 1980). His election was another tactic on the hospice organizers' part: to have a doctor represent hospice would incrase its credibility in the community, assuring people that this group was both accepted and supported by the established medical system. Both Lynn Green and Marion emphasized the importance of this tactic. Green said

> it was very important to have a doctor as chairperson of the society. People still regard the doctor as an important figure (interview, July 19, 1985).

ii. The Nurses

In dealing with the nursing staff, the hospice organizers sensed that the most potentially successful hospice representative would be another nurse. For this reason, Lynn Green, a nurse and founding member, spoke to her colleagues. And again, the mode of presentation was a conscious tactic: Lynn spoke to them about her feelings of frustration with traditional hospital care:

> when I speak to nurses' groups, I always talk about my own frustration as a nurse not doing what I know should be done for the terminally ill person and their family. I often saw persons in the audience nodding their heads (interview, July 19, 1985).

The nurses' empathy for the hospice concept was demonstrated by their numerous requests for other speaking engagements (Ladysmith Registered Nurses; District meeting of Registered Nurses; Parksville Home Care Nurses). Even more importantly, the Registered Nurses Association (Nanaimo Chapter) moved to endorse formally the Nanimo hospice only a month after Green addressed it. It is the writer's impression that most nurses were more openly and immediately responsive to the hospice concept for two reasons: first, they see the dying person on an often hourly basis (versus the doctor or hospital administrator, for example) and are, therefore, more practically aware of the patients' pain and isolation; second, the nurses are 'secondary' figures in the medical team and, therefore, would not receive the brunt of public criticism (versus the doctor, for example). Because their position in the medical hierarchy is not so volatile, the nurses can afford, 'politically', to be more critical of the system in which they work.

iii. Health-Care Professionals in Hospice

The doctors and nurses who came together in the hospice group were, by and large, exceptions in their professions. They saw a pressing need to humanize direct care of the terminally ill person. For example, the local physician who became the chairperson of the hospice board acted on a number of issues: he approached the hospital administrator to get round-the-clock visiting rights for hospice volunteers; he arranged to have a guest lecturer speak to hospital nurses and other physicians on physical pain control in terminal diseases; and, from time to time, he acted as a liaison between families and their own physicians when specific problems of care arose. These actions, in the writer's view, were ones which demonstrated tactics to pressure the medical system from within.

As well, the hospice organizers chose a Victoria medical doctor with a special expertise in physical pain control to speak to the local physicians and nurses (November, 1981). This was a conscious and radical move: education on strictly medical matters was normally handled by the doctors' and nurses' own education groups. But the hospital administrataor gave his consent, even though the hospice had no formal connection with an official health-care body. And further, the hospice organizers decided that the speaker address the physicians and the nurses separately. It was felt that the optimal professional education could be provided by eliminating any potential confrontations between the two groups. Once again, then, the hospice organizers chose to be non-controversial in their pressuring of the medical system.

C. Home-Care Nursing

The home-care nursing service in Nanaimo was the facet of the health care system most supportive of hospice. There were two reasons for this: first, home-care (like hospice) was relatively new in Nanaimo, having been established only six years; second, and perhaps more importantly, hospice's tactics of non-confrontation and gradual integration into the existing system were close to home-care's own philosophy.

A few examples of the home-care service's response demonstrate their support of the hospice concept. After accepting a position on the hospice board, the nurse representing the home-care department requested that one home-care nurse be allowed to take the volunteer training programme each time it was offered. Even though the course was officially restricted to board members and volunteers, the board granted her request because it was felt that this would promote interest and expand knowledge about hospice within the health-care system. As well, a film promoting hospice education was loaned to the home-care nurses for their further education. And, as I documented in Part II, the home-care representative herself made a personal donation to the hospice fund drive of two thousand dollars.

Though home-care nursing was part of the health-care system, it operated under a different administrative umbrella than the hospital itself. The system limited the nursing service's usefulness, making it difficult to work effectively with hospital doctors and nurses. For example, home-care nurses could enter the home of an ill person only after a requisition had come from the attending doctor. Further, when the ill person needed to be hospitalized, contact with the home-care nurse was lost if the doctor did not re-order the service. This awkwardness within the system was compounded, too, by some physicians' resistance to the home-care nursing concept. Because doctors are not conditioned to the idea of home-care, they are naturally apprehensive about it, preferring to see the patient themselves. From a more critical perspective, doctors may resent giving up some of their control (and prestige) within the hierarchy of the health care system. As it is now, doctors control virtually all facets of examination, prescription, and medical judgement. The result: many terminally ill patients and their families were uninformed about the home-care nursing service.

This was the situation that hospice volunteers became aware of in their home visits. Because the ill patients were not informed, they believed that if they needed nursing care, their only choice was to be hospitalized. Seeing this as a source of misinformation, the hospice volunteer <u>tactfully</u> began to inform families about home-care nursing, who in turn requested the services from their doctor. Though the hospice volunteer acted as a catalyst between existing facets of the health-care system, the hospice organizers advised that the volunteers act unofficially. No criticism of the awkwardness between home-care and the hospital system was to be voiced. In this way, hospice organizers and volunteers indirectly persuaded -- without promoting conflict -- two segments of the prevailing system to work for the benefit of the terminally ill person.

2. Pressure: Bringing together the community-at-large to pressure the health-care system.

While the hospice organizers used various tactics to persuade the health-care system of the need for hospice, they sensed that public information was the most effective technique for persuading the community. Information about the hospice concept and local efforts to promote it came in three forms: media reporting, a public informational meeting, and speaking engagements to local organizations.

A. The Media Coverage

Pressure on the health-care system by the media was indirect, that is, its coverage of the hospice's founding, establishment and development was a constant reminder to the health-care professionals that a community group was addressing certain weaknesses in their system. While all three local media -- newspaper, radio, and television -- duly promoted hospice as a community activity, the press became the mainstay of hospice's ongoing educational drive.

The hospice organizers employed a number of tactics to ensure that the hospice concept be introduced to the community in a positive and non-adversarial manner. First, one of the organizers approached a freelance writer to see whether the hospice organizers could edit a feature story on hospice <u>before</u> it was submitted for publication. It was felt that a freelance writer would be receptive to this unusual request because of the greater freedoms -- time, choice of material, writing style -- that a freelance writer (versus a daily reporter) has. The writer agreed, and a full front-page feature story was published on February 15, 1980. The Victoria Colonist published the feature story later that month. Part of the feature was devoted to a definition of the word 'hospice'. It was felt that once the community understood the historical significance of the concept, the local and present-day effort would become meaningful:

> In medieval times a hospice was a resting place for weary pilgrims seeking a spot to rest and be replenished on their long journey. Today a new type of hospice is becoming more common -- a place of special support for a person suffering from a life-threatening illness...two women are busy putting their energies into getting a non-profit society set up which will provide volunteer support to patients and families faced with a serious illness...Mrs. Tomasson's interest in hospice grew out of her experience of lack of adequate support when she was taking care of her husband...Green, a nurse, said she has often experienced frustration of not being able to meet the needs of patients and their families...they are hoping to bring others together in Nanaimo, who may have felt the same need in the community (Nanaimo Times, February 15, 1980).

This full, front-page story promoting hospice -- a fledging organization -- indicated the newspaper's unusual interest and support. Marion Sylvester attributed the press support to the positive qualities of the group's approach to community education:

> I think the word 'hospice' took hold -- they [the press] got to know what the word hospice means (interview, July 18, 1985).

Second, the hospice organizers consciously held off any further press releases for six months, until September, 1980. Though the hospice board had been struck in April, it was felt that introducing the hospice board members to the community would be most effective if announced in conjunction with the date of the public informational meeting in September, 1980. Here again the newspaper's co-operation was enlisted. A hospice organizer approached the editor of the local public events column and asked whether a reporter would be willing to accept editing of the press release. In a front page article (together with a picture of the board members), the community was formally introduced to this new society. The article, entitled 'Hospice -- Compassion for the Dying', outlined the society's plans to hold a public informational meeting:

> the society will host an informational evening open to the general public, September 23, at Malaspina College's choral room, at which time a film called 'The Last Days of Living' will be shown. Canon Paul Chidwick, a director of Hospice Windsor, Ontario, will be guest speaker. (Nanaimo Daily Free Press, September 9, 1980).

Third, the hospice organizers invited the local press to photograph and chat with the guest speaker, Canon Chidwick, for half an hour before the public informational meeting. It was felt that this courtesy would be appreciated by the press reporters, and that their interest in and understanding of the hospice concept and its potential importance to the Nanaimo community would be heightened. This tactic proved itself. On the day after the informational meeting, the bi-weekly paper, the Nanaimo Times devoted a one page feature story to the meeting. The reporter wrote the following:

> dying with dignity and care for the terminally ill was the topic which drew over 200 people to Malaspina College Tuesday night to hear how Nanaimo can initiate a hospice programme to care for cancer victims...the hospice provides an alternative to hospital care for terminally ill people...giving them, in the words of guest speaker, Canon Paul Chidwick, 'a chance to die with dignity...staffed mainly with both professionals and lay volunteers, the hospice provides round-the-clock care for patients and provides access to family and even family pets to those who would otherwise feel isolated and alone...following Chidwick's address, the

> audience viewed the National Film Board production, 'The Last Days of Living', a poignant and often uplifting look at those who have accepted the end of the life span on earth...the meeting sponsored by the Mid-Island Hospice Society obviously achieved what it set out to do, raise the consciousness of those attending to the essential need for alternative care for the terminally ill (Nanaimo Times, September 24, 1980).

The other local paper, the Nanaimo Free Press, not only covered the meeting, they also took the initiative to have a personal interview with the hospice president, a local internist. This interview was published two days after the informational meeting, and provided further information about hospice: first, it re-emphasized that a physician was involved as chairperson (this had been documented in the press release on the hospice board) and that he was a spokesperson for the hospice group; second, that the hospice concept was being advanced in other centres in the province; and third, that the Nanaimo group was a local rather than a provincial or federal government effort.

Finally, the organizers arranged with the local television station to interview Canon Chidwick. This half-hour segment was shown the week following the meeting, when public interest was high. Each of these points was important in itself, but for the next stage of hospice's development (fund-raising and volunteer training), the last point -- that hospice was a local effort -- was particularly crucial. Thus at three junctures, introducing hospice to the community, informing it about the public informational meeting, and covering the meeting, the hospice organizers consciously employed the press to serve as the community's educator in a constructive and non-critical manner.

B. The Public Informational Meeting

To elicit the widest public interest possible, the hospice organizers decided that a public informational meeting must be held. Several factors were considered in order to ensure that the meeting would be well attended and well received. The meeting was held in September (1980), but planning for it began a full three months earlier. Three factors were especially important: the choice of speaker, the choice of setting, and the invitation of civic and medical authorities. The hospice organizers chose Canon Paul Chidwick, founder of the Windsor hospice, to be the guest speaker. This choice was deliberate: he would speak as a non-medical person; he was an authority on the hospice concept and its implementation; and he was a non-controversial figure outside the Nanaimo community. The choice of setting, too, was calculated. The hospice organizers chose Malaspina College rather than the hospital or a health-care related building because they felt it was essential for the community to be introduced to the hospice in a public rather than a medical forum. Finally, the invitation of the central civic authority, the local mayor, was felt to be important. His presence would reinforce the impression that the organizers wanted to create about hospice: that it was to be a community, non-medical, and civic effort.

These tactics were very successful. Over one hundred and fifty people, a capacity audience, attended the meeting; a very strong interest was voiced by the audience through its questions and comments; and the mayor's private endorsement that evening became a public one immediately afterwards. He gave a personal donation to the hospice fund and, in his capacity as mayor, authorized further monies from the city. Furthermore, he obtained office space in the same building as the local home-care nursing service, thus demonstrating civic support for the hospice.

Finally, public interest generated from the meeting was strong and enthusiastic. Donations to the hospice began to come in. The hospice's finances over one year illustrate the strong community support: in December, 1980, there was a balance of $2,165.47 in the hospice account; by December 31, 1981, after expenses were paid, there was a balance of $12,178.54 (Treasurer's Annual Report, December, 1981). As well, even before the hospice settled into its office, people from the community began requesting to become hospice volunteers. The requests for training outnumbered the capacity of the programme. A waiting list of prospective volunteers was drawn up to accommodate the growing public interest in the hospice.

The hospice organizers' tactics, then, were highly successful. Both the community and the mayor responded to the hospice's appeal for support and did so in the same positive and non-adversarial manner in which the hospice concept was presented to them.

C. Speaking Engagements

Requests for speaking engagements came in quickly after the public meeting. Three hospice organizers -- the president and local internist, the nurse and myself -- divided these numerous invitations. During the following year, the hospice responded to approximately twenty invitations (though most of the hospice's efforts went into volunteer training). Here, again, tactics were employed. Lynn Green, the nurse, spoke to the several nurses groups (Ladysmith, Parksville and Nanaimo Nurses Associations), again outlining her frustrations as a nurse to appeal to her colleagues and their trainees. The doctor (and hospice president) usually spoke to the local service clubs (Kiwanis, Rotary, and so on) in the capacity of a medical authority and hospice spokesperson. It was felt that his professional position would appeal best to the audience: their financial support was needed by hospice and a conservative approach by an 'established' professional would be most readily accepted by them. To other associations -- clergy, women's groups, educational groups, community open-line radio programme and television programmes -- the hospice organizers went as a panel to provide the viewpoints of physicians, nurses and laypersons. These decisions seemed to have been the best. Most groups spoken to gave donations, as well as personal donations. (A successful ten dollar membership drive and unsolicited <u>in memoriam</u> cheques also demonstrated the community's support). A further tactic, one which was implemented after the first trained volunteer went out into the comunity (May, 1981), was to have the volunteer speak in conjunction with a hospice organizer. This method of community education was particularly powerful: a citizen from the community speaking at a practical level about extending non-medical support to terminally ill people and their families. These volunteers were concrete proof that the hospice's actions which were both successful and non-threating to the existing health care system. The first trained volunteer, Mrs. DeJong, told her listeners about her work. A local reporter present at a meeting recorded Mrs. DeJong's talk:

> we should realize that dying is as much a part of life as being born. Birth we greet with joy and happines. Death is met with grief and sadness. To deal with the emotions, the fear, the anxieties...that dying patients and their relatives experience in different degrees and at different times during the illness, we need people who care...if we could all help in making dying a process of growth -- of living fully until death -- of giving the dying person the respect, love and care every individual human being deserved, we would have a highly rewarding experience (Nanaimo Free Press, September 24, 1981).

DeJong elaborated on the larger dimension of hospice:

> ideally a team of doctors, nurses, clergy, relatives and hospice workers should work together to give full care to the patient and his family. By full care, I mean physical, spiritual and psychological care. Of course, the hospice volunteer is not going to prescribe medication or intrude on the personal conviction of a patient...our work is to serve the patient and his family (Nanaimo Free Press, September 24, 1981).

The trained lay volunteer was a highly effective method to pressure for hospice care of the terminally ill person. Green expressed her perception of the volunteer in the community:

> the trained volunteer told both professionals and the community what could be done. It's great to say what should be done, but if you don't come up with the

> goods, it doesn't hold. We had to offer something -- to start somewhere. The volunteer was tangible evidence of what could and should be done for terminally ill person and their families (interview, July 19, 1985).

Sylvester saw the trained volunteer as an embodiment of hospice principles:

> the type of volunteer that came in...they were such down-to-earth, caring, supportive non-professionals. By word of mouth they gained alot for the hospice group (interview, July 18, 1985).

Speaking engagements, then, as well as the earlier tactics of the hospice's community education technique -- media coverage and the informational meeting -- were crucial steps to introducing hospice to the community and gaining its support without threatening the prevailing health-care system.

In summary, Chapter III outlined the eleven variables of the social reform model. Under 'characteristic change tactics and techniques', it listed Rothman's criteria: 'the social reform technique mobilizes the people for action, moving to campaign strategies, to resolve issues and differences among parties'. The Nanaimo hospice organizers employed both tactics -- which I will define here as 'a conscious plan agreed upon by a group (here, the hospice organizers) to be used in what it perceived as a potentially hostile situation (such as meetings with the hospital administration, the physicians, and so on)' -- and techniques, which I will define 'as an approach or method that does not involve a potentially hostile response by the target group (such as the technique of educating the community about hospice)'. In my opinion, the Nanaimo organizers exhibited each of Rothman's criteria under his tactic and technique variable. In bringing the hospice board together, the organizers 'mobilize[d] the people for action'. In approaching the media, setting up the public informational meeting, speaking to community groups, and training hospice volunteers, the organizers 'move[d] to campaign strategies'. And, finally, in bringing segments of the prevailing health care system together in a common effort, the hospice organizers began 'to resolve issues and differences among parties'. Both Lynn Green and Marion Sylvester observed this bonding. Green felt the technique of educating about the hospice concept had united segments of the system:

> I'm sure it did something to unite the system, to create a bond. It was a new idea...it wasn't blatant criticism (interview, July 19, 1985).

Sylvester believed the technique brought about co-operation among health-care workers, leading to better care, not only for the dying person, but also care for family members:

> with hospice, everyone learned...hospice was to help the families, the terminally ill person...but it also helped the care-givers to learn about support to one another. It was a total thing (interview, July 18, 1985).

CHAPTER VI

Much literature has been written about the problems of terminally ill persons and, in particular, their dehumanizing treatment at the hands of the health-care system. Dr. Eric Cassels, Dr. Elizabeth Kubler-Ross, and Robert Veach have discussed these problems: the tendency to treat patients as objects, to withdraw emotional support, to see the dying person as a failure because of doctors' need to defeat death, to give insufficient or unclear advice about treatments. And on a more practical level, they cite inadequate training. These same concerns were shared by all members of the Nanaimo hospice group, though not all agreed on the exact source of the dehumanization.

Writing in the New England Journal of Medicine, Dr. Eric Cassels argues that less-than-satisfactory medical care treats patients as objects rather than as persons. Though doctors and nurses generally have a more-than-average concern for human welfare, their medical training is insufficient for the care of dying persons. This situation calls for the awareness of the wider psychological and social framework of the patient's condition:

> the patient's emotional reaction to surgical disfigurement or disability, his disrupted domestic environment and his failure to understand his predicament...can lead to feelings of oppression (Cassels, 1982, p. 649).

Consequently, patients feel intimidated, or worse, that they are helpless victims of events. Canon Paul Chidwick expressed a similar sentiment in his address to the public informational meeting at the Malaspina College in Nanaimo, September 23, 1980. He stated:

> dying is a very dehumanizing experience...because of the workload in hospitals, patients often feel the centre of a conspiracy of silence...and fear that they will be considered nuisance patients... [the dying patient]...is treated like a vegetable...saying, just lie there and behave yourself. ("Hospice ideals bring new hope for dying," 1980, September 24, Nanaimo Daily Free Press, p. 2).

One of the first professionals to write about dying persons, Elizabeth Kubler-Ross voiced concern about abandoning the terminally ill. In her best-selling book, On Death and Dying, Kubler-Ross (1969) exposed the avoidance behavior of hospital staffs: how the beds of dying persons were placed furthest from the window, their bell answered last, and their visit from the doctor reduced to approximately two minutes per day. Even the nurses, who spend a greater proportion of their time with patients, had similar responses. In a study done by nurses, 'How Do Nurses Feel When Patients Suffer', a typical reaction was documented:

> She [the patient] wanted desperately to live. She was in a tent, and when you went near the bed she would grab you by the wrist. She hadn't energy to eat by herself but her grip was unbelievable. She kept saying, 'I don't want to die. I don't want to die.' I couldn't go in anymore after I knew she was going to die. I did anything I could just to get out of going into her room (Davitz & Davitz, 1975, p. 118).

In my address to the Cowichan hospice group, I spoke of my concern finding my husband alone when he was near death:

> The morning my husband died, I was told by a nurse, in the elevator, that my husband was not at all well. I went to his room, found him alone, having difficulty breathing. I requested that he not be let alone (O. L. Tomasson, notes from speech delivered May 12, 1981).

Dr. Cassels claims medicine's fundamental basis of strict analytic thought can mean depersonalization:

> Medicine is founded in strict analytic thought. It is the thought mode in which discoveries about the body were made and therefore the kind of thought required to understand the result of the discoveries. Physicians learn to think in body terms and see disease as altered units of structure or chemistry. When dealing with a dying patient, the physician bases his definition of dying upon the prognosis of the disease, in other words, he is basing the definition upon his own ability to cure (Cassels, 1982, p. 649).

Cassels suggests that it is medicine's thought mode in which the physician is strictly steeped, that labels persons. In the Nanaimo group, Lynn Green saw this labelling as a lack of interest in a patient no longer 'curable'. She perceived physicians looked upon dying people as a failure.

In Dying, Death and the Biological Revolution, Robert Veach (1976) concluded doctors have a higher-than-normal desire to defeat death and likely tend to misjudge what is in the person's best interest. Veach argued that inappropriate treatments are being indiscriminately administered. As a result of new medical discoveries and new technology, hospitals are becoming science centres (with physicians engaged in a life and death struggle). Veach poses the question 'Is morality becoming immoral?':

> even if we conclude that it is still morally acceptable to die in a technological age...still we must ask whether a particular death -- a particular way of dying -- is moral. Some will die through starvation, war...some because they cannot obtain needed care...still others will do their dying in an atmosphere of mystery knowing their own condition only vaguely or are given medical treatment they or their

> agents are desperately trying to refuse (Veach, 1976, p. 7).

Furthermore, Veach argues physicians are confused about ethical norms relating to prolonging life:

> physicians may feel that they have a special moral duty...a duty that is codified in the medico-moral folk tradition...life is to be prolonged at all costs (it is not incorporated into any formal code of medical ethics) (p. 7).

Bound by such norms, physicians may systematically reach various conclusions about what is ethically required of them.

Home-care nurses involved in the Nanaimo organization expressed concern about treatments being administered; about patients and their families lacking information to make choices about treatment or to refuse treatments; and about lack of clear, open information generally. Fran Dykes, a hospice volunteer and board member, recounts her own experience in relation to inadequate, unclear information:

> the first two lines of the 'Dying Person's Bill of Rights says 'I have the right to be treated as a living human being until I die.' 'I have the right to have my questions answered honestly'. In the two and one half years of my husband's illness, not only him, but myself were shoved aside with the well-meaning words, 'Don't worry, everything will be alright.' All the time everyone knew everything was wrong (address, Volunteer training programme, October 23, 1981).

Dr. Cassels (1982) reports on lack of adequate training in relation to non-physical suffering:

> shockingly, non-physical suffering is understandable to lay people, but not the the physician...the problem of human suffering, the concrete, inner lived experience of the person who is ill, is not directly addressed in medical education. When physicians were challenged to think about suffering, they were surprised how

> little thought they had given it. Medical students, on the other hand, were unsure of the relevance of suffering to their work (Cassels, 1982, p. 649).

Lynn Green suggested inadequate training partly was responsible for the failure to provide adequate care. In her address to the Ladysmith Registered Nurses Association she states:

> the physical needs are met, but emotional, spiritual and social needs of patients...are handled poorly...doctors are trained to diagnose, cure (address, September 25, 1981).

Dr. Sylvia Lack, Medical Director of Hospice of New Haven argues for home care:

> the home is the natural place to die. Here a patient is surrounded by loved ones and cherished possessions. The dying can gain much by being care for in this familiar environment. They are better able to maintain their dignity and their individuality and avoid the anonymity that is devastating to the dying hospital patient... (Lack, n.d., n.p.).

Dr. Howard Cameron, president of the Nanaimo group also argued for home care of the dying person:

> the hospital is not the best place for people who are dying. They are better off at home with people they know and are more comfortable with than in the hospital surrounded by stranger. One of the aims of the society is to establish a pool of volunteer helpers who are able to offer assistance to the families of terminally ill patients in the familiar surrounds of their home (Nanaimo Daily Free Press, September 25th, 1980).

Dr. Lack does not, however, minimize the need for good, hard-headed practice of medicine:

> if people are cared for with common sense and basic professional skills, with detailed attention to self-evident problems and physical needs, then patients and family themselves cope with many of their emotional crisis. Without pain, well nursed, with bowels

> controlled, mouth clean, and a caring friend available, the psychological problems fall into manageable perspective (Lack, n.d., n.p.).

Canon Chidwick and I both perceived that little can be done for the dying person until physical needs are met. In his public informational address in Nanaimo, he stated that 'until there is relief from [physical] pain, no other needs can be met' (September 23, 1980). I recounted my personal experience of inadequate attention to physical pain control:

> my husband was very uncomfortable following surgery, as well as having discomfort from the disease itself. Sometimes the medication did not hold the pain during the night and I would go to the desk and ask for medication. I was always told it was too soon, that we must wait for the four hours to be up (address, Cowichan hospice group, May 12, 1981).

Unless proper physical pain control and a decent standard of nursing care is present, little can be done to help patients' psychological problems.

As shown, the Nanaimo hospice group members shared the concerns of those authorities writing about terminally ill people in the health-care system. Both professionals and lay people have seen that most health-care professionals have inadequate training to cope with the medical, psychological and social needs of these patients, and that unless the health-care system changes its structure and policy radically, terminally ill patients should be (if possible) taken out of hospitals to die at home in the security and comfort of their homes.

CHAPTER VII

The Function and Meaning of the Hospice

The objective of this study was to describe and analyze the development of the Nanaimo hospice and its efforts to change the health-care system in Nanaimo.

In my opinion, the overall contribution of hospice is to aid in humanizing the dying process. Like many other hospice organizations, the Nanaimo group identfied the sources of the terminally ill person's dehumanization -- his physical pain, his emotional and psychological discomfort and his social isolation. For each of these problems, the hospice organizers proposed solutions on his behalf: for his physical pain, they brought in a medical expert to educate the local physicians and nurses; and they facilitated a closer working relationship between the hospital team and home-care nurses. For his psychological pain and social isolation, they set up the hospice volunteer visiting service made up of interested and sharing members of the community. To ensure that these humanizing measures continued, the hospice organizers educated the local community-at-large about the plight of the dying person. Once the community was made aware of this, the responsibility for his humane treatment rested with both the health-care professionals and community members.

While the function of the hospice is readily apparent, its meaning is much less so. At the most profound level, the Nanaimo hospice expressed a cultural value implicit in the hospice movement and

Western society generally -- the value of the individual. Cecily Saunders, who spearheaded the hospice movement in London, England in the 1960's, expresses this value as the essence of hospice:

> We fail to understand what patients with terminal disease ask of us. They are commonly too realistic to expect that we can take away the whole, hard, thing that is happening to them; instead they ask for concern and care for their distress and symptoms. *Above all, they ask for our total awareness of them as people* [my italics]. At no time in the total care of the patient is this of greater importance (Saunders 2, 1978, p. 2).

In speaking to the Duncan hospice group in 1981, the writer expressed it this way:

> I have an uncompromising belief that the last hour of life is as important as the first. (address, Cowichin hospice group, May, 1981).

One of the hospice volunteers speaking to a local group in Nanaimo, expressed her feelings about the dignity and worth of the individual:

> If we would give the dying person the love, care and attention every individual human being deserves, we would have a richly rewarding experience. (Nanaimo Daily Press, September 15, 1981).

At its deepest level, then, the hospice was a cultural expression.

Recommendations

Uncovering the cultural assumptions of hospice is essential to restructuring and planning the health-care delivery to terminally ill persons. The hospice movement is a wide-sweeping phenomenon in the Western world. On Vancouver Island alone, since 1981, four local hospice groups have formed. As pressure increases both from without and within the system to implement changes in the care of the terminally ill person, hospitals and local groups will pressure for diminishing health-care dollars to restructure the present system.

However, restructuring the system alone is insufficient. Medical education of health-care professionals will need as careful assessment as the restructuring of the system. Dr. Daniel Hadlock observes:

> The common concept in our society [is] that the only valid goal of medicine is to cure the patient. But this in only part of the purpose of medical care. The more complete definition, found on a monument in memory of Trudeau and anonymously written in the fifteenth century, is: 'The role of medicine is to cure sometimes, relieve often, comfort always ' (Hadlock, 1980, p. 42).

Present day 'cure-oriented' medical training is narrow and leads to misconceptions about the true role of medicine. Hadlock feels to correct such misconceptions will take time, education and humility:

> Both physician and patient are alike in terms of their mortality and their fallibility...the physician should bear in mind that he himself is not exempt from the common lot, but subject to the same laws of mortality and disease as others, and he will care for the sick with more diligence and tenderness if he remembers that he himself is their fellow sufferer (Hadlock, 1980, p. 43).

Those who work with the terminally ill need the right temperment and training. Without it, change in the care of the dying will remain more superficial than lasting.

Further Considerations

Though not addressed directly, this study touched on how society encloses certain of its members within a system and then discourages public scrutiny and input. Further studies could include: the Ministry of Health Hospital Programs and its control of health-care delivery in British Columbia; the delivery of mechanisms that allow one to die at home and the public education programmes needed to encourge this; the attitude of acute care medical doctors and nurses and why the ignore the needs of the dying and their families. Finally, much more research is needed into the relationship between proliferation of systems in contemporary society, and social values. Several questions could be considered: Is there a relationship between proliferation of systems, and society's obsession with efficiency? Does the social value of efficiency, masking itself as professionalism, prop up and expand systems? Who is most vunerable to control by systems in the society -- is it the professional caught up in the system, or society's weakest members (the sick, the elderly, children) or both? Research to uncover the more tacit values of the society is difficult, but if present-day society is to achieve meaningful self-renewal, clarifying values surrounding social organizations is essential.

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APPENDIX 'A'

SOCIAL REFORM MODEL

Variables	Characteristics
1. Goal categories of community action	Of a task nature-solution of a delimited problem pertaining to functioning of social system
2. Assumptions concerning community structure and conditions	Substantive social problem and disadvantaged populations
3. Basic change strategy	Organizing a coalition of concerned interests.
4. Change techniques and tactics	Campaign tactics-the employment of facts and persuasion to apply pressure on decision-making bodies; resolving differences and issues among parties.
5. Salient practitioner role	Manipulation of voluntary agencies and legislative bodies.
6. Orientation toward power structure	Power structure viewed neutrally in gate-keeper terms as centres that can be influenced through persuasion or pressure.
7. Boundary defintion of community client system	Community segment termed as a population at disadvantage or risk
8. Assumptions regarding interests of community subparts	May be reconcilable or in conflict
9. Conception of public interest	Realist-individualist--special interest group confronts others
10. Client population	Victims
11. Conception of client role	Potential consumers or recipients

APPENDIX "B"

THREE VARIABLES AND CHARACTERISTICS DEALT WITH IN STUDY

Variables	Characteristics	Nanaimo Hospice
2. Assumptions concerning community structure and social conditions	Substantive social problem and disadvantaged populations	Hospice organizers assume the terminally ill are dehumanized in the process of dying, and that it is a serious social problem.
3. Basic change strategy	Organizing a coalition of concerned interests	Community members brought together to form a non-profit society to act on behalf of the terminally ill person.
4. Change techniques and tactics	Campaign tactics-the employment of facts and persuasion to apply presure on decision-making bodies;	-public informational meeting. -speaking to community groups -use of media to inform community about hospice
	resolving differences and issues among parties	-representatives of segments of health-care system come together, as a hospice board, to promote, among their collegues, hospice principles of networking and support.

APPENDIX 'C'

INTERVIEW GUIDE

1. It seems to me that the chief reason for the group's coming together was to campaign for better care of the terminally ill. Would you agree with that or do you have another interpretation?

2. Remaining outside the health care system was a tactic to be in a position to pressure the system for better care of the terminally ill. What do you think?

3. Included in the group were representatives from the hospital, home-care, physicians, nurses and homemaker service. I see that as a tactic to unite the health-care system surrounding the dying person in a common effort. Would you agree or do you have another interpretation?

4. Having a doctor as chairman of the society and having an office donated to the group in a health-care facility gave credibility to the trained volunteer in the community. Do you see it that way?

5. The group received alot of support from the community through the media and through money donations. Why do you think the group was so well supported by the community?

6. Educating about the hospice concept and philosophy (professionals and the community) was the central technique in the campaign. Would you agree with that assessment?

7. Having lay representatives from the business community ensured that the group would not be part of any segment of the health-care system. What do you think?

8. In May, 1981, both the hospital chaplain and director of hospital volunteers simiultaneously resigned from the board. Why do you think this happened?

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A Community Development Study

[redacted]

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April 21, 1986.