

WHAT CHINESE-CANADIANS PERCEIVE AS APPROPRIATE CARE FOR THEIR
DYING FAMILY MEMBERS: A PHENOMENOLOGICAL STUDY

By

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Abstract

This phenomenological study describes what Chinese-Canadians perceived as appropriate care for their dying family members. The unstructured interview was the method for data collection. Nine Chinese-Canadians who had a dying family member were interviewed. Data were analyzed using procedures adopted from Colaizzi's (1978) method. Three themes were conceptualized from what Chinese-Canadians perceived as appropriate terminal care: attentiveness, responsiveness, protectiveness.

Attentiveness was the description of Chinese families' perception that their dying family members required 24-hour attention and care for the satisfaction of their needs and for their comfort. In order to make the patient feel cared for, however, attentive care had to be delivered in a way that indicated caring to the patient. Responsiveness was the description of Chinese families' expectation for prompt and knowledge-based responses to the patient's physical problems. The Chinese families perceived that responsive care from health professionals could relieve the patient's suffering and maintain physical comfort in the patient. Protectiveness was the description of Chinese families' desire to protect the patient from emotional pain and/or from physical deterioration by maintaining silence around the issue of death, and/or by maintaining hope in the patient.

Attentiveness, responsiveness, and protectiveness were culturally constructed themes of appropriate terminal care, and their meanings had to be understood within the cultural context. Cultural meanings had significant influence on the way families reacted to and managed terminal illness. Moreover, the families' experiences of providing terminal care,

and the health care decisions that they made for the patient were shaped by complex social, political and economic factors. The illness experiences of terminally ill Chinese patients were embedded inextricably within a complex familial, social and cultural nexus.

Table of Contents

| | |
|---|----|
| Abstract | ii |
| Table of Contents | iv |
| List of Tables | ix |
| List of Figures | x |
| Acknowledgment | xi |
| CHAPTER 1: INTRODUCTION | 1 |
| Background to the Problem | 1 |
| Conceptualization of the Study | 3 |
| Problem Statement | 5 |
| Purpose of the Study | 7 |
| Research Question | 7 |
| Summary | 7 |
| CHAPTER 2: REVIEW OF SELECTED LITERATURE | 9 |
| The Concept of Caring in Nursing | 10 |
| Conceptualizations of Caring | 10 |
| Caring as a human trait | 10 |
| Caring as a moral imperative | 10 |
| Caring as an affect | 11 |
| Caring as an interpersonal intervention | 12 |

| | |
|--|----|
| Caring as a therapeutic intervention | 12 |
| Theories of Caring | 13 |
| Orem's Self-care Deficit Theory of Nursing | 13 |
| Watson's theory of Human Care | 15 |
| Leininger's Theory of Culture Care Diversity and Universality | 18 |
| Perceptions of Caring: Nurses' vs Patients' | 20 |
| Culture and Care | 23 |
| Caring in the Context of Death and Dying | 25 |
| Philosophy of Palliative Care | 25 |
| Nurse's Caring Role in Palliative Care | 26 |
| Caring for Dying Patients and their Families - A Cultural Perspective | 29 |
| Caring for Dying Chinese Patients and their Families | 30 |
| Summary | 33 |
| CHAPTER 3: METHODOLOGY | 35 |
| Introduction of the Methodology - Phenomenology | 35 |
| Assumptions | 37 |
| Assumptions in relation to the Phenomenological Method | 37 |
| Assumptions in relation to the Research Topic | 37 |
| Definition of Terms | 38 |

| | |
|--|-----------|
| Setting | 38 |
| Selection of Study Participants | 39 |
| Criteria for Selection | 40 |
| Recruitment of Study Participants | 40 |
| Characteristics of Study Participants | 42 |
| Collection of Data | 45 |
| Procedures for Data Collection | 45 |
| Ethical Consideration | 47 |
| Informed Consent | 47 |
| Confidentiality | 48 |
| Analysis of Data | 49 |
| Methodological Rigor | 50 |
| Credibility | 50 |
| Fittingness | 51 |
| Auditability | 52 |
| Confirmability | 52 |
| Limitations of the Study | 52 |
| Summary | 53 |
| CHAPTER 4: PRESENTATION OF THE FINDINGS | 55 |
| Attentiveness | 56 |
| Twenty-Four Hour Care and Needs Satisfaction | 57 |

| | |
|--|------------|
| Caring vs Uncaring | 70 |
| Responsiveness | 76 |
| Knowledge-based Responses | 77 |
| Protectiveness | 87 |
| Silence around the Issue of Death | 88 |
| Maintenance of Hope | 93 |
| Summary | 100 |
| CHAPTER 5: INTERPRETATION OF THE FINDINGS | 103 |
| Appropriate Terminal Care - An Interpretation from a Cultural Perspective | 104 |
| Attentiveness | 104 |
| Responsiveness | 106 |
| Protectiveness | 107 |
| Socio-cultural Construction of Illness Experience | 113 |
| CHAPTER 6: SUMMARY, CONCLUSION, AND IMPLICATIONS OF THE STUDY | 118 |
| Summary | 118 |
| Conclusion | 123 |
| Implications of the Study | 124 |
| Implications for Nursing Practice | 124 |
| Implications for Nursing Education | 125 |

| | |
|---|-----|
| Implications for Nursing Research | 125 |
| Implications for Nursing Administration | 126 |
| References | 127 |
| Appendix A Certificate of Approval for the Study | 135 |
| Appendix B Letter to the Nurse | 137 |
| Appendix C Information and Consent | 140 |
| Appendix D Information and Consent (Chinese) | 144 |

List of Tables

| |
|--|
| Table 1. Demographic Data of Study Participants and Patients |
|--|

| |
|----|
| 43 |
|----|

List of Figures

| | |
|--|----|
| Figure 1. Chinese-Canadians' perception of appropriate terminal care | 56 |
|--|----|

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CHAPTER 1: INTRODUCTION

Background to the Problem

Canada is made up of people of diverse ethnocultural backgrounds. Between 1981 and 1991, over 1.2 million people immigrated to Canada from other countries (Statistics Canada, 1994). In 1991, 19.5% of the population in the city of Vancouver in British Columbia reported Chinese as their mother tongue (Ministry of Health & Ministry Responsible for Seniors, 1993). Canadians whose countries of origin were outside Canada often have health beliefs and practices different from the mainstream population and from health professionals (Anderson, Waxler-Morrison, Richardson, Herbert, & Murphy, 1990). The present health care system in Canada, however, is based on the Western ideology of health and illness which inadequately addresses the health care needs of ethnoculturally diverse Canadians (Anderson, 1985). The British Columbia Royal Commission on Health Care and Costs (1991) recognized that members of ethnic and cultural minorities have historically been excluded from decision-making in the Canadian health care system, and that these people have had difficulty gaining access to appropriate health care and services because of language differences or other socio-cultural barriers. In order to provide all Canadians with the best care possible, regardless of their race and countries of origin, there is an urgent need to restructure the Canadian health care system.

Based on the report by the British Columbia Royal Commission on Health Care and Costs (1991), the provincial government in B.C. has developed New Directions for Health Care with the objectives to raise effectiveness and efficiency in health care delivery, to fill

service gaps, and to provide more appropriate and accessible health care to everyone (Vancouver Health Board, 1995). The restructuring of health care in B.C. also focuses on providing care 'closer to home', by creating and expanding community-based services to replace the more expensive in-patient hospital care ("Closer to Home", 1995). The Closer to Home initiatives have an impact across the continuum of care from maternity to palliative care. In palliative care, for instance, more community resources and health services are made available to support terminally ill patients who choose to stay at home and die in familiar surroundings (McIntosh-Newberry, 1995). Concomitantly, families are expected to take on the responsibilities of caring for their dying family members at home. Death and dying is a natural human experience. Nonetheless, the meaning of terminal illness and the perception and expectation of care for the terminally ill can differ across various ethnocultural groups. In order to provide a basis for making culturally sensitive health policies and to assist health professionals to plan and deliver culturally acceptable terminal care responsive to the needs of ethnoculturally diverse patients and their families, research findings pertinent to the experiences and expectations of terminal care by different ethnocultural groups are much needed. This study intends to fill part of this knowledge gap by describing from the perspectives of Chinese-Canadians, what they perceive as appropriate care for their dying family members.

Conceptualization of the Study

The major theoretical perspectives that underlie the conceptualization of this study are the *explanatory model framework* and the *disease/illness distinction* proposed by Kleinman, Eisenberg, and Good (1978).

Kleinman et al. (1978) argue that there are three structural domains of health care in society: professional, popular, and folk. The professional domain is comprised of health professionals such as doctors and nurses who practise in the Western health care system; the popular domain consists of the family, social network, and community; and the folk domain is comprised of non-professional healers (Anderson, 1987). Although the three domains may share some common values and beliefs, each of the three domains of health care has its own explanatory model of health and illness which may differ in terms of cognitive content, therapeutic values, expectations, and goals (Kleinman et al., 1978; Anderson, 1987). Through diagnostic activities and labelling, health care providers in each domain construct clinical realities and negotiate with patients about what is wrong and what should be done (Kleinman et al., 1978). Kleinman et al. (1978) have noted that the majority of health care in a society takes place in the popular domain. Moreover, decisions about when and where to seek care from the professional and/or folk domains, how long to remain in care, and how to evaluate treatment and care also occur most commonly in the context of the family within the popular domain (Kleinman et al., 1978).

Kleinman et al. (1978) further elucidate the discrepancy between the professional and the popular domains, and highlight the socio-cultural context of health and illness by

distinguishing between disease and illness. They (1978) hold that "disease in the Western medical paradigm is malfunctioning or maladaptation of biologic and psychophysiologic processes in the individual, whereas illness represents personal, interpersonal, and cultural reactions to disease or discomfort" (p. 252). In other words, illness and disease "do not stand in a one-to-one relation" (Kleinman et al., 1978, p.251). While health care providers in the professional domain focus on the treatment and management of diseases, patients suffer illnesses, or the "experiences of disvalued changes in states of being and in social function" (Kleinman et al., 1978, p. 251). The subjective experience of illness or the way that a person perceives, labels, evaluates, copes with and responds to symptoms and disease is influenced by the popular explanatory model, and by a complex system of social, cultural, economic and political processes (Kleinman et al., 1978; Anderson, 1987). Effective health care that is responsive to lay expectations and health care needs should be directed at both the curing of disease and the healing of illness (Kleinman et al., 1978).

Kleinman et al.'s (1978) explanatory model framework and the disease/illness distinction have relevance to all aspects of health care from maternity to palliative care. In particular, when palliative care is brought 'closer to home', health professionals are in partnership with ethno-culturally diverse families to provide care for terminally ill patients within the popular domain. Interactions between health professionals and patients and their families are transactions between different explanatory models of health and illness; the discrepancy in their explanatory models might even be greater when health professionals and patients come from different ethnocultural backgrounds (Anderson,

1987). Health professionals, therefore, cannot assume that the practice of palliative care, which developed within the Western ideology of health and illness, is universally expected and accepted by patients and families from all ethnocultural backgrounds. Moreover, within the context of the popular domain, the families play a predominant role in making decisions and evaluations regarding the care that their sick family members receive (Kleinman et al., 1978). In planning and providing care for terminally ill patients from different ethnocultural backgrounds, therefore, health professionals must take into account the families' perceptions and expectations of care for their dying family members. Such perception and expectation of care inextricably form part of the complex familial, social and cultural nexus within which patients experience their terminal illnesses.

Based on the theoretical perspectives provided by Kleinman et al. (1978), the present phenomenological study will describe, from the perspectives of Chinese-Canadians, their popular model of terminal care in terms of their perception of appropriate care for their dying family members.

Problem Statement

Despite technological advances and the comprehensiveness of health services, there is increasing dissatisfaction within our society with clinical practices and health services. Contemporary health care services, which are based on the Western biomedical model of health and illness, have been criticized as ethnocentric and unresponsive to the health care needs of clients from multicultural backgrounds (Anderson, 1985). Moreover, the medicocentric views of contemporary clinical practices disregard the socio-cultural context

of health and illness, and they are irrelevant to the solution of illness problems experienced by clients (Kleinman et al., 1978). The insensitivity to cultural differences and the inattention to illness by the contemporary health care system are in part responsible for inadequate clinical care, patient non-compliance, and patient and family dissatisfaction with professional health care (Kleinman et al., 1978).

Palliative care, a Western ideology of care which gained its momentum in England about three decades ago (Latimer & Lundy, 1993), should also be challenged in terms of its cultural sensitivity and its relevance to the experiences of terminal illness of ethnoculturally diverse patients. In my experience as a nurse in Canada, I have noticed clashes in beliefs and practices of terminal care between health professionals and some families from non-Euro-Canadian origins. While such clashes could be a reflection of the discrepancy between the professional and the popular models of terminal illness, they could also be the result of health professionals' lack of understanding about the perception and expectation of terminal care of ethnoculturally diverse clients, and their failure to negotiate with families a mutually acceptable plan of care for dying patients. Existing research data pertinent to the experiences and expectations of terminal care of different ethnocultural groups are scarce. Considering that the Chinese population makes up one of the largest ethnic groups in Canada, health professionals frequently interact with and provide care to dying Chinese patients and their families. It is therefore imperative to develop knowledge about the perception and expectation of terminal care from the perspectives of Chinese-Canadians.

Purpose of the Study

The purpose of this study is to describe, from the perspectives of Chinese-Canadians, what they perceive as appropriate care for their dying family members. It is hoped that the findings of this study will assist nurses to plan and deliver culturally acceptable care that is satisfying to dying Chinese patients and their families, and that will also enhance nurses' understanding of the decisions that Chinese families make in relation to the care of their dying family members.

Research Question

The research question for this study is, "What do Chinese-Canadians perceive as appropriate care for their dying family members?"

Summary

In this chapter, the background for this study was described in light of the multicultural composition of the Canadian population, and of the need to provide culturally sensitive and appropriate terminal care 'closer to home'. Kleinman et al.'s (1978) theoretical perspectives have provided directions for the conceptualization of this study in two major ways. First, interactions between health professionals and clients are transactions between different explanatory models of health and illness; the quality and efficacy of terminal care will depend on the ability of health professionals to elicit the discrepancies between the professional and the popular models of terminal care. Second, illness experiences are socio-culturally constructed; the illness experiences of terminally ill patients have to be understood within the complex social, cultural, and familial nexus. Existing research data pertinent to the popular model of terminal care of different ethnocultural groups are very limited. This study intends to fill part of this knowledge gap by describing, from the

perspectives of Chinese-Canadians, their perceptions of appropriate care for their dying family members.

CHAPTER 2: REVIEW OF SELECTED LITERATURE

Caring is an emerging central concept for nursing (Bottorff, 1991). In palliative care where the focus is on care and not cure, the nurse assumes the predominant caring and supportive role (Williams, 1982; Davies & Oberle, 1990). Studies on perception of caring have shown that intended caring by the nurse is not necessarily perceived as such by patients. Discrepancies in the perception and expectation of care between health professionals and clients could even be greater when they come from different ethnocultural backgrounds (Anderson, 1987). It is therefore important to elicit the discrepancies between the professional and the lay model of care, by understanding the perception of care from the perspective of clients (patients and families alike). In the area of palliative care, little is known about how clients from diverse ethnocultural backgrounds perceive care. The present study intends to fill part of this knowledge gap by describing what Chinese-Canadians perceive as appropriate care for their dying family members.

The following sections are the review of selected literature regarding first, the concept of caring in nursing, which includes the conceptualizations and theories of caring, and caring as perceived by nurses and patients; second, culture and care; and third, caring in the context of death and dying, which includes the philosophy of palliative care, the nurse's caring role in palliative care, and caring for dying Chinese patients and their families.

The Concept of Caring in Nursing

Conceptualizations of Caring

Caring has been described as the dominant and central focus of nursing (Leininger, 1984; Watson, 1988). It has also been suggested that nursing and caring have very similar meanings at root, which is 'to nourish' (McFarlane, 1976; Griffin, 1983). Although caring is an important concept that influences nursing practice, nursing research and theory development, the definition and conceptualization of caring remain diffuse. Morse, Bottorff, Neander, and Solberg (1991) have identified the following five conceptualizations of caring from existing nursing literature.

Caring as a human trait

Theorists in this category claim that caring is innate and is essential to human existence (Morse et al., 1991). Griffin (1983) contends that caring denotes a 'primary mode of being' in the world which is of significance in our relationships with others. Leininger (1988) argues that although there are diverse expressions, meanings, patterns, and modalities of caring which are culturally derived, people of all cultures are dependent upon human care for growth, survival, and to face death or disabilities. Leininger (1988) considers the human trait of caring as the motivator of nursing actions.

Caring as a moral imperative

Theorists who consider caring as a moral ideal are concerned about patient good and maintaining respect of patients as people (Morse et al., 1991). Watson (1988) asserts that caring as the moral ideal of nursing calls for a philosophy of moral commitment to protect

dignity and to preserve humanity. Carper (1979) considers caring as a professional and personal value which governs the actions and attitudes of nurses toward those they care for. Brody (1988) defines the virtue of caring as first, the desire and inclination of the nurse to act ethically and compassionately; second, the demonstration of caring actions which are reflective of the nurse's moral nature; and third, the ability of nurses to meet the moral obligations of the collectively defined role they have assumed. Fry (1988) argues that in order for caring to serve as an ethical standard for the practice of nursing, caring must be (a) viewed as an ultimate or overriding value to guide one's action, (b) considered a universal value and applied to all persons in similar circumstances, (c) considered prescriptive in that certain behaviors are preferred, and (d) other-regarding.

Caring as an affect

In this category, caring is described as an emotion or feeling of empathy for the patient which motivates nursing action (Morse et al., 1991). Caring, according to McFarlane (1976), signifies "a feeling of concern, of interest, of oversight with a view to protection" (p.189). Bevis (1981) considers caring to be a feeling of dedication of the nurse toward the patient that increases intimacy and mutual self-actualization. Forrest (1989) has conceptualized caring as a mental and emotional presence of the nurse that evolves from deep feelings for the patient's experience.

Caring as an interpersonal interaction

Theorists in this category signify caring as a mutual endeavor between the nurse and the patient (Morse et al., 1991). Benner & Wrubel (1988), for instance, define caring as the enabling condition of connection, concern and trust, with which help can be given and received in the interpersonal relationship between the nurse and the patient.

Caring as a therapeutic intervention

Theorists who view caring as a therapeutic intervention are patient-centered and task-oriented; they conceptualize caring as actions directed toward meeting the patient's goals (Morse et al., 1991). Gaut (1983) has proposed three conditions for an action to be described as caring: (a) S (the carer) has knowledge about X (the one cared for) to identify a need for care, and knows that certain things could be done to improve the situation; (b) S must choose and implement an action based on that knowledge, and intend the action as a means for bringing about a positive change in X; and (c) the positive change condition must be judged solely on the basis of a 'welfare-of-X' criterion. Since there is an emphasis on nursing competencies and skill related to caring as a therapeutic intervention, concrete actions such as listening and talking to the patient, touching, giving medications on time, and teaching the patient have been identified as nurse caring behaviors (Larson, 1987; Wolf, Giandino, Osborne, & Ambrose, 1994).

Morse et al. (1991) have concluded that the concept of caring is poorly developed and the theoretic link from nurse caring to patient outcome has remained inexplicit and tenuous. They argue that it is imperative to develop a conceptualization of caring with

theoretical preciseness, clarity and parsimony. Moreover, since research efforts on caring have focused on the nurse, there is a need to focus caring research on the patient so that the relevance of caring to the patient can be explicated (Morse, Solberg, Neander, Bottorff, & Johnson, 1990).

Theories of Caring

According to Morse et al. (1990), there are three major theories of caring for nursing, namely Orem's Self-care Deficit Theory of Nursing, Watson's Theory of Human Care, and Leininger's Theory of Culture Care Diversity and Universality. Although each of the three theorists have different conceptualizations of care and nursing, their theories have provided important direction for knowledge development and nursing practice.

Orem's Self-Care Deficit Theory of Nursing

Dorothea Orem (1991) has referred her Self-care Deficit Theory as a general theory of nursing which provides a descriptive explanation of the relationship between the action capabilities of individuals and their demands for self-care or dependent-care. The Self-care Deficit Theory assumes that human beings need continuous self-maintenance and self-regulation through self-care, and nursing is a response to human beings' incapability to care for oneself or one's dependents because of one's health state or health care demands of the care recipient (Orem, 1991). Orem's Self-care Deficit Theory of Nursing includes three interrelated theories of self-care, self-care deficit, and nursing system.

In the theory of self-care, it is maintained that in the context of day-to-day living, mature and maturing persons initiate and perform learned activities directed toward

meeting one's own needs or requisites for regulation of functioning and development (Orem, 1991). According to Orem (1991), there are three types of self-care requisites. First, universal self-care requisites represent those human actions that bring about the internal and external conditions necessary for human functioning and well-being. Examples of universal self-care requisites are the maintenance of a sufficient intake of air, water and food; the provision of care associated with elimination; the maintenance of a balance between activity and rest; and the prevention of hazards to human life, human functioning, and human well-being. Second, developmental self-care requisites involve those actions that bring about and maintain conditions for development and maturation, or actions that prevent or overcome deleterious effects of conditions that adversely affect human development. Third, health-deviation self-care requisites demand actions to restore normalcy when a person is sick or injured and becomes dependent on others for the needs to sustain life or well-being. Such actions may include seeking and participating in medical care for health deviations. Orem (1991) presupposes that human beings have the potential to maintain the motivation and to develop intellectual and practical skills for self-care and care of dependent family members.

In the theory of self-care deficit, it is recognized that human beings can be subject to health-derived or health-related limitations for engagement in self-care or dependent care (Orem, 1991). If care abilities of an individual are less than what is required for meeting a known self-care requisite, a deficit relationship between care abilities and care demand occurs. Nursing service is legitimized for persons with existing or projected care deficits.

Within the theory of nursing system, nurses are conceptualized to produce a system(s) of care/helping service to regulate the self-care capabilities of persons with health-derived or health-related care deficits and to meet those persons' self-care needs (Orem, 1991). According to Orem (1991), there are five helping methods: (a) acting for or doing for another, (b) guiding and directing, (c) providing physical or psychological support, (d) providing and maintaining an environment that supports personal development, and (e) teaching.

Although Orem's Self-care Deficit Theory of Nursing has been widely used in nursing practice, nursing research, and nursing education, it should be cautioned that the values inherent in this theory reflect those of Western society and may not be appropriate in other societies or congruent with other cultural values (Morse et al., 1990).

Watson's Theory of Human Care

Jean Watson (1988) regards nursing as an art and a human science committed to the study of the person as a whole and as an experiencing subject. She advocates that the major focus for nursing is the process of human care for individuals, families, and groups. According to Watson (1988), "caring is the moral ideal of nursing whereby the end is protection, enhancement, and preservation of human dignity" (p.29). Because our society is increasingly depersonalized, Watson (1988) views the preservation and advancement of human care as a critical issue for nursing today.

Watson (1988) argues that there are some requirements for provision of human care. First, the nurse acknowledges the value of human care and caring. Second, the nurse has a

will and a moral commitment to provide human care and to preserve humanity. Third, the nurse has knowledge of health-illness and environmental-personal interactions, knowledge of the nurse caring process, and knowledge of self and the other's power and transaction limitations. Fourth, the nurse carries out concrete action of caring based on the moral ideal of caring and on the individual's needs for care. Last but not least, the action of the nurse results in positive change for the welfare of others and contribute toward humanity. Watson (1988) has described a caring nurse as one who is responsive to a person as a unique individual, who perceives the other's feelings, and who distinguishes one person from another.

Central to Watson's Theory of Human Care is the concept of transpersonal caring. According to Watson (1988), human care or transpersonal care occurs when the nurse enters into the phenomenal field of another person, is able to detect the other's condition of being-in-the-world (spiritual-mental-physical), feels this condition with the person, and responds to the condition through means such as movement, gestures, looks, touch, sound, and procedures so that the person has a release of feelings, thoughts, and energies that are not conducive to his/her well-being. In the transpersonal caring relationship, the nurse uses his/her entire self as a resource. The nurse and patient are coparticipants in the intersubjective caring transaction, in which a spiritual union occurs between them. Watson (1988) believes that the union of feeling "can potentiate self-healing and discovery of inner power and control, and contribute to another finding meaning in his or her own existence" (p.68).

Watson (1988) has identified ten carative factors or caring interventions related to the human care process. These carative factors include humanistic-altruistic system of values; faith-hope; sensitivity to self and others; helping-trusting, human care relationship; expressing positive and negative feelings; creative problem-solving caring process; transpersonal teaching-learning; supportive, protective, and/or corrective mental, physical, societal, and spiritual environment; human needs assistance; and existential-phenomenological-spiritual forces. Watson (1988) argues that the more human care is actualized as an intersubjective moral ideal, the more potential caring holds for meeting human health goals, for preserving humanity, and for fostering spiritual evolution of humankind.

A few issues have been raised regarding Watson's Theory of Human Care (Morse et al., 1990). First, the broad gap between the human care process and clinical reality may have reduced clinical relevance of the theory to nursing practice. Second, factors such as short hospital stay, brief nurse-patient contact, and the conditions of patients may render the development of transpersonal caring relationship between the nurse and patient unattainable. Third, if Watson's theory accurately describes caring in nursing, one may question if those nurses who have not developed a transpersonal caring relationship with the patient are really nursing. Last but not least, Watson's Theory of Human Care has not discerned a unique caring role for the nurse.

Leininger's Theory of Culture Care Diversity and Universality

Madeleine Leininger is one of the nurse theorists who maintains that care is the essence and the unifying focus of nursing, and she considers nursing as a transcultural humanistic and scientific care discipline. Leininger (1991) argues that care is a transcultural phenomenon and care is culturally defined. Because all human cultures across the world have values, beliefs, expressions, and patterns of care that are specific to each culture, people of different cultural backgrounds have different expectations of care and different caring needs (Leininger, 1988).

Leininger (1991) has defined caring as those actions and activities "directed toward assisting, supporting, or enabling another individual or group with evident or anticipated needs to ameliorate or improve a human condition or lifeway, or to face death" (p.46). The purpose of the Theory of Culture Care is to discover human care diversities and universalities in relation to cultural and social structure dimensions, and to discover ways to provide culturally congruent nursing care to people of diverse cultural backgrounds (Leininger, 1991). The cultural and social dimensions that can influence human care patterns and expressions include worldview; biophysical state; religious or spiritual orientation; kinship patterns; cultural values and lifeways; the political, economic, legal, educational, technological, and physical environment; language; and folk and professional care practices (Leininger, 1991). Leininger (1991) maintains that these dimensions or influencers on care are inextricably and closely interrelated to each other, and an

understanding of the care phenomena of a specific culture requires exploration of each of the social and cultural dimensions from a people-based perspective.

In the Theory of Culture Care, three major modalities for guiding the provision of culturally congruent nursing care are proposed (Leininger, 1991). First, cultural care preservation or maintenance refers to those "assistive, supporting, facilitative, or enabling professional actions and decisions that help people of a particular culture to retain and/or preserve relevant care values so that they can maintain their well being, recover from illness, or face handicaps and/or death" (p.48). Second, cultural care accommodation or negotiation refers to those professional actions and decisions that help people of a particular culture to "adapt to, or to negotiate with, others for a beneficial or satisfying health outcome with professional careproviders" (p.48). Third, cultural care repatterning or restructuring refers to those professional actions and decisions that help clients "reorder, change, or greatly modify their lifeways for new, different, and beneficial health care pattern while respecting the client(s) cultural values and beliefs" (p.49). The nurse uses culture care knowledge and her professional care knowledge to act and make decisions with respect to the three modalities of nursing care. Leininger (1991) predicts that culturally congruent nursing care can lead to client wellness or health, or can assist the client to face disabilities or death.

One hundred and seventy-five caring constructs have been identified in fifty-four cultures from Leininger's Culture Care Theory research, which reveal that culture care meanings and action modes are more diverse than universal (Leininger, 1991). Although

Leininger's Theory of Culture Care has been criticized as lacking preciseness and encompassing a broad range of undelineated nursing activities, it has made significant contribution in alerting nurses to the need for cultural sensitivity in their practice (Morse et al., 1990).

The conceptualizations and theories of caring have been developed mainly from the perspective of nurses, and research efforts on caring have focused on the nurse rather than on the patient (Morse et al., 1990). It should not be assumed, however, that intended caring of the nurse is perceived as such by the patient. The following section is discussion of some of the research findings on the perception of caring from the perspectives of nurses and from that of patients.

Perceptions of Caring: Nurses' vs Patients'

Caring has been described as the most important and central focus of nursing. Leininger (1984) asserts that "caring is nursing, and nursing is caring" (p.83). Nonetheless, the findings of research studies have revealed that there are significant discrepancies in the perceptions of caring by care providers (nurses) and care receivers (patients).

In one of her studies on caring, Larson (1986) used the Caring Assessment Instrument to determine the most important and least important caring behaviors as perceived by fifty-seven registered nurses. By the forced-choice format, nurses in Larson's (1986) study have ranked expressive activities such as "listens to the patient", "touches when comforting is needed", and "allows expression of feelings" as the most important behaviors in making

cancer patients feel cared for. Conversely, activities such as "is professional in appearance" and "suggests questions for the patient to ask doctor" were perceived by those nurses as the least important caring behaviors. These findings by Larson (1986) were supported by Mangold (1991). By rating on the Caring Assessment Instrument, thirty senior student nurses and thirty professional nurses in Mangold's (1991) study have also ranked "listens to the patient" and "is professional in appearance" as the most important and the least important nurse caring behavior respectively.

The perception of caring from the perspective of nurses have also been studied by the phenomenological approach. In her phenomenological study with seventeen registered nurses, Forrest (1989) found that caring was perceived by those nurses as a mental and emotional presence that evolved from deep feelings for the patient's experience. While such involvement with patients motivated nursing actions, it could also increase the nurse's vulnerability with the potential to hurt (Forrest, 1989). Clark and Wheeler (1992), from their interviews with six registered nurses, found that the nurses placed a high focus on interpersonal aspects of care, and the significant components of caring for those nurses were "being supportive", and "communicating" their support and concern to patients through verbal and non-verbal means, including the giving of oneself. The quantitative and qualitative studies of caring as discussed above indicate the emphasis of nurses on the psycho-emotional aspect of care.

Brown (1986) has studied the experience of care from patients' perspectives. By asking fifty hospitalized patients to describe an experience in which they felt cared for by a nurse,

Brown found that those patients emphasized the professional competence of the nurse in meeting their physical and treatment needs; to those patients, the essential quality of a caring action was the patient's perception that the action taken by the nurse was congruent with and beneficial to his/her need. Cronin and Harrison (1988), by asking twenty-two patients who have had a myocardial infarction to rate on the Caring Behaviors Assessment, found that the nursing behaviors perceived as most indicative of caring by those patients focused on the monitoring of the patient's condition and the demonstration of professional competence, such as "know what they are doing", "know how to give shots, IVs, etc.". Nursing behaviors perceived as least indicative of caring by patients in Cronin and Harrison's (1988) study focused on the individualized aspect of nursing care, such as "ask me what I like to be called", and "ask me how I like things done". Findings from these studies indicate that patients emphasize the medical/physical aspect of care.

Discrepancies in how nurses and patients perceive caring are confirmed by two studies which compared nurses' and patients' perceptions of caring with the Caring Assessment Instrument. In Larson's (1987) study with fifty-seven registered nurses and fifty-seven patients with cancer, nurses have ranked behaviors in relation to "comforts" and "trusting relationship" whereas the patients with cancer have ranked behaviors in relation to "monitoring and following through" and "accessible" as the most important nurse caring behaviors. von Essen and Sjoden (1991), in their study with eighty-six hospitalized patients and seventy-three nurses, also found that while nurses perceived expressive/affective behaviors as most important, patients perceived behaviors such as

giving honest and clear information and showing competent clinical expertise as most important for constituting good nursing care.

The shown discrepancy in perceptions of caring between nurses and patients challenges the assumption that caring by the nurse is perceived as such by the patient (Brown, 1986; Larson, 1987; von Essen & Sjoden, 1991). It also points to the inadequacy of conceptualizing 'care' solely from the perspective of nurses. In order to increase patient satisfaction with care and to enhance the outcomes of care, it is imperative for nurses to study the perception of caring from the perspective of care receivers (patients and families alike), so that we can provide care in a way that is consistent with their "caring ideals" and expectations (von Essen & Sjoden, 1991).

Culture and Care

Culture is a universal phenomenon, and it refers to "the learned, shared, and transmitted values, beliefs, norms, and lifeways of a particular group that guides their thinking, decisions, and actions in patterned ways" (Leininger, 1991, p.47). The concept of culture is relevant to nursing practice in two important ways. First, health and illness "are socially and culturally constructed, and are not a given state of affairs" (Anderson, 1985, p.238). Illness is socially and culturally constructed in the sense that "how we communicate about our health problems, the manner in which we present our symptoms, when and to whom we go for care, how long we remain in care, and how we evaluate care are all affected by cultural beliefs" (Kleinman et al., 1978, p.252). Moreover, illness experience "is embedded in a complex cultural, family and social nexus" (Anderson, 1986, p.1277), and

it is "an intimate part of social systems of meaning and rules for behavior" (Kleinman et al., 1978, p.252). In order to provide effective nursing care and to assist individuals to acquire the knowledge and skills necessary for coping with their sickness, therefore, the nurse must attend to both the disease and illness aspects of sickness, and attempt to understand illness experiences from the perspectives of patients and their families (Anderson, 1985; Anderson, 1987). Second, nurse-patient interactions are transactions between two cultures, the professional culture of the nurse and the culture of the patient with their frameworks of knowledge (Anderson, 1987). Culturally relevant nursing care that is satisfying to patients (and their families alike) depends on the nurse's ability to elicit the discrepancies between the professional and lay explanatory models of health and illness (Kleinman et al., 1978; Anderson, 1990).

The concept of culture has overall and important relevance to nursing practice which is not restricted to providing care for patients of diverse ethnicity. Nonetheless, it is more likely for nurses to experience clashes in health beliefs and management of illnesses between themselves and patients of different ethnocultural backgrounds (Waxler-Morrison, 1990). These clashes call for the ability of the nurse to negotiate with patients a mutually acceptable plan of care (Anderson, 1987). Moreover, they challenge the nurse to step out from the ethnocentric professional framework, and to critically examine the values, beliefs, and "ideological structures" inherent in the professional health care domain (Anderson, 1986; Anderson, 1990).

Caring in the Context of Death and Dying

Philosophy of Palliative Care

Palliative care is a philosophy as well as a program or an institution. It is a humane and interdisciplinary approach to care, the primary concern of which is the comfort and caring support of dying patients and their families (Burns, Carney & Brobst, 1989; Van Bommel, 1993).

In palliative care, the basic unit of care is the patient and family (Priest, 1987). It is acknowledged that the patient's experience of his/her terminal illness is not a static phenomenon; rather, he/she is part of a system of family, friends, society and culture (Priest, 1987; Hudson, 1988). Dying patients and their families are encouraged to work together and, where possible, patients are allowed to die at home (Van Bommel, 1993).

Palliative care neither hastens nor postpones death (Hudson, 1988). Palliative care recognizes that dying is a normal part of living, and it aims at maximizing the quality of the dying patient's remaining life and supporting the health of surviving family members throughout the bereavement period (Burns et al., 1989). Fundamental to palliative care is its acknowledgment of patients' basic right to dignity, and its respect for patients as complete human beings with choices, means of expression, reactions, and physical and moral integrity (Hudson, 1988). As such, although open and honest communication is valued in palliative care, the specific information needs of patients and families and their cultural means for communicating about the impending death should be respected (Psychological Work Group, 1993; Jones & Pegis, 1994).

There are three major dimensions to the palliative care provided to dying patients and their families (Van Bommel, 1993). First, physical care includes pain and symptom control and maintenance of physical comfort for the dying patient (Burns et al., 1989). Second, psychosocial care is concerned with maximizing psychosocial support, maintaining emotional health, and facilitating emotional growth for both the patient and family (Burns et al., 1989). Last but not least, spiritual care involves assisting the patient and family in search for meanings in their experiences and encouraging their inner spiritual strength (Burns et al., 1989; Van Bommel, 1993). These dimensions of palliative care are interwoven. Together, they enable patients to live comfortably until they die (Saunders, 1983).

Nurse's Caring Role in Palliative Care

Caring has been described as the essence and the central focus of nursing (Leininger, 1991). Because palliative care focuses on care and not cure, it provides nurses with a preeminent opportunity to enact its caring role and functions.

Palliative care nursing involves intensive caring, in which high levels of skills and knowledge are required for providing humanistic care and for meeting the complex physical, psychosocial and spiritual needs of patients and their families (Rovinski, 1979; Dobratz, 1990). Hull (1989) has reviewed research studies that focused on family needs and supportive nursing behaviors during the terminal phase of a relative's cancer and she found a few consistent findings. First, families perceived clear and honest information about their dying relatives as their most important need. Second, families needed

assurance of the patient's comfort, and that the patient was pain free and receiving good nursing care. Third, families needed information on how to perform specific nursing skills in order to care for patients at home. Conversely, families considered their own emotional needs such as to ventilate their feelings as relatively unimportant. Some of the findings in Hull's (1989) review were supported by Kristjanson (1989). With a convenience sample of one hundred and twenty families of patients with cancer, Kristjanson (1989) found that those health care provider behaviors that the families have rated as most important to 'patient care' referred to the need for prompt and attentive medical care such as the relief of the patient's pain, whereas the behaviors rated by the families as most important to 'family care' referred primarily to their need for information. The caring behaviors of hospice nurses from the perspective of family caregivers have also been examined by Hull (1991). From the interviews with fourteen family members of dying patients, Hull (1991) found that 24-hour accessibility and availability, effective communication skills, accepting and nonjudgmental attitudes, and practitioner competence were the behaviors and qualities of hospice nurses that the family caregivers identified as a major source of caring support. Degner, Gow, and Thompson (1991), on the other hand, have identified seven nursing behaviors perceived as critical to the care of dying patients and their families from the perspective of nurse educators and palliative care nurses. These critical nursing behaviors were responding during the death scene, providing comfort, responding to anger, enhancing personal growth, responding to colleagues, enhancing quality of life during dying, and responding to the family.

Various authors have argued that the role of the nurse in the palliative care setting is one of a supportive care nurse. Williams (1982) defined the supportive role as "that set of role behaviors aimed at caring for the patient, supporting independent functioning, and easing pain and discomfort" (p.9). Seale (1991) found that when compared to conventional care nurses, hospice nurses were more likely to act in an advisory and supportive capacity. Davies and Oberle (1990) contend that support is a core concept in palliative care nursing, and they have identified valuing, connecting, empowering, doing for, finding meaning, and preserving own integrity as the six dimensions of the supportive role of the nurse in palliative care. Davies and Oberle (1990) argue that the nurse as professional cannot be separated from the nurse as person. The characteristics of the nurse as person, that is, "valuing" patients and families as human beings and as capable people and "preserving own integrity", are critical in "connecting" or establishing rapport and trust, in "empowering" patients and families to do for themselves, in "doing for" or providing physical care, and in helping patients and families in "finding meaning" in their experiences (Davies & Oberle, 1990). Davies and Oberle (1990) criticize the failure of other research on nurse caring to recognize the interaction between human characteristics and nursing behaviors, as a result of which conceptualization of the nurse's caring role has been incomplete.

Although research in the area of palliative care nursing has increased, little research effort has been exerted to examine the influence of cultural variations on adaptations to

terminal illness (Benoliel, 1983), and on the expectation and perception of care by dying patients and their families.

Caring for Dying Patients and their Families - A Cultural Perspective

Culture is an important concept to be considered in providing care to dying patients and their families because culture influences death concerns in many ways: it shapes the meaning of, and beliefs about causes of death; it affects assessment of comfort and caring needs and the kind of care dying people receive; it influences selection, perception and evaluation of health care givers and their methods; it determines funeral and burial rituals; and it patterns the emotional responses to death (Kalish, 1980; Ross, 1981).

The role of the family in palliative care cannot be overemphasized. Families are often the major caregivers and a source of support to dying patients (Chekryn, 1985). Families, as an essential structure within the lay health care domain, influence the illness experience of dying patients in different ways. First, families pass on from generation to generation many cultural attitudes and beliefs toward life and death; they therefore affect the perception of illness of their dying family member (Rosen, 1990). Second, the family's belief system and mode of operating influences expression and management of pain, suffering, and grief of the dying patient and other family members (Rosen, 1990). Third, families, influenced by their cultural backgrounds, vary in terms of their role expectation of family members, their seeking of and level of involvement in treatment regimens for the dying member, the decision-making process within the family, and their attitudes toward outside authority such as health professionals (Ross, 1981; Rosen, 1990). Last but not

least, families determine how they manage care, and how they perceive and evaluate professional and/or non-professional care for their dying family member (Nilchaikovit, Hill, & Holland, 1993). Working with the family is as important as working with the patient in palliative care (Trill & Holland, 1993). Moreover, the consideration and understanding of the complex socio-cultural context within which patients experience terminal illness is integral to the provision of effective and appropriate care to dying patients and their families.

Caring for Dying Chinese Patients and their Families

In North America, Chinese make up the largest group of Asian-Americans in the United States (Louie, 1985), and Chinese represent the third largest ethnic group in Canada (Tong & Spicer, 1994). The Chinese in North America are not a homogenous group. Rather, as China is made up of many races with different local/folk religions and cultures (Loong, 1987), there are intra-ethnic diversities in health beliefs and practices among North-American Chinese as a result of their origins from China, the number of generations or years they have been in North America, and their education and occupation (Louie, 1985; Germain, 1992). Similarly, attitudes toward death and dying are varied among the Chinese. Two of the major forces that shape the Chinese attitudes toward death and dying are religions and Chinese philosophies (Lai, 1990). Taoism, both as a religion and a school of thought, perceives death as equivalent to "rest" and as a simple process of change in nature (Lai, 1990). Buddhism, the religion that exerts the greatest influence on the Chinese' view of death, proposes that one has to bear the consequences of his/her previous

life, and what one does in this life will lead to what happens in his/her next life (Lai, 1990). These concepts allow Chinese Buddhists to attribute life-threatening illnesses to some misdeed of their previous life and to derive some solace by placing their hope in a better future in their next life (Lai, 1990). The Confucian, on the other hand, believes that personal destiny is decided by Heaven's will and everything is preordained (Lai, 1990). This Confucian view of fatalism prompts the Chinese to meekly submit to their fate and to accept their death or that of their loved one (Lai, 1990). Many of these religious and philosophical concepts and beliefs about life and death have become part of the Chinese culture, and they are adopted either consciously or unconsciously by many Chinese.

Because palliative care is a relatively new concept in China and Hong Kong (Morgan, 1986; Tsao, 1991), and because the subject of death is a taboo to most Chinese (Eisenbruch, 1984), relatively little is understood about the experiences of terminal illness of Chinese patients. In the limited literature on the behaviors of Chinese in the context of death and dying, it has been documented that Chinese-American patients tend to be stoic and fatalistic when faced with terminal illness and death (Eisenbruch, 1984). The silence surrounding terminal illness has also been recognized as a well-known behavior in the Chinese culture (Tong & Spicer, 1994). According to Tong and Spicer (1994), the Chinese do not promote open discussion of terminal illness and impending death because discussion of death is seen as wishing death upon the dying person, and the Chinese believe that the dying should be spared from any worry or distress and be allowed to have a calm, hopeful, and clear state of mind. As such, Chinese families often request doctors not to

disclose the diagnosis of terminal illness to their dying family members (Poliakoff, 1993). Moreover, the major role that families of the dying patients play in decision making is seen as the most remarkable difference in illness behavior between the Chinese and North American cultures (Tong & Spicer, 1994). In the Chinese culture, dying patients rely on their families for care and advice, and families commonly make crucial decisions about treatment of serious sicknesses on behalf of patients (Kleinman, 1980; Tong & Spicer, 1994). Kleinman (1980) has observed that in the Chinese culture, clinical communication in the context of terminal illness is in the form of practitioner-family and patient-family transactions rather than patient-practitioner transaction.

Although there is some literature on the behaviors and roles of Chinese families in the context of terminal illness, no research could be found on how Chinese families in North America perceive the terminal care provided to their dying family members. Knowledge about what Chinese families perceive as appropriate care will assist health professionals to understand the decisions that Chinese families make in relation to the care of their dying family members. Moreover, such knowledge is requisite for understanding the socio-culturally constructed illness experiences of dying Chinese patients, and for planning and negotiating a plan of care that is culturally acceptable and satisfying to these patients and their families.

Summary

Caring has been described as the essence and the unifying focus of nursing which provides important direction for nursing practice, nursing research, and nursing education (Leininger, 1991). Nonetheless, the definition and conceptualization of caring is poorly developed and elusive, and the theoretic link between nurse caring to patient outcomes has remained inexplicit (Morse et al., 1990; Morse et al., 1991). Study findings on caring have pointed to the discrepancy in the perception of care between nurses and patients, and they challenge the assumption that intended caring is perceived as such by clients. Further studies on perception of care from the perspective of clients are needed in order to increase our understanding of their expectation and experience of care.

The complexity in caring is intensified when the nurse and the patient come from different ethnocultural backgrounds (Anderson, 1987). Culture is not only a relevant but an important concept to caring because nurses provide care to patients whose illness experiences are socially and culturally constructed. Moreover, the nurse-patient interaction is a transaction between the nurse-professional culture and the patient's culture (Anderson, 1987). In palliative care where nurses assume a predominant caring and supportive role, nurses are challenged to provide care to dying patients and their families within the complex socio-cultural context in which patients experience their terminal illnesses. It is also recognized that families play a predominant role in influencing the care and the illness experience of their dying family members. This is particularly relevant to the Chinese culture in which dying Chinese patients may depend more on their families for

care and for making decisions than their counterparts in the Western culture (Tong & Spicer, 1994). Nonetheless, research data on how Chinese clients experience and perceive terminal care is lacking. The present study intends to fill part of this knowledge gap by asking the research question, "What do Chinese-Canadians perceive as appropriate care for their dying family members?".

CHAPTER 3: METHODOLOGY

Introduction of the Methodology - Phenomenology

Phenomenology was the research design for this study. Because the aim of phenomenology is to investigate and describe phenomena as they truly appear or are experienced and perceived (Omery, 1983), the phenomenological approach was chosen for this study to describe what Chinese-Canadians perceived as appropriate care for their dying family members.

Contrary to positivists who hold the tenet that the world is an ordered whole that can be understood in an objective way, phenomenologists such as Merleau-Ponty argued that the subjective view of reality is the only reality because consciousness is existence in the world through the body, and one can only experience and know the world through the subjectivity of being in the world (Munhall, 1989a; Oiler Boyd, 1993a).

According to phenomenology, human experience and human reality are always perspectival (Oiler Boyd, 1993a). In other words, at any point in time and for each individual a particular perspective exists. This perspective is based on the individual's biography, past experience, knowledge of the world, and other social and political facticities (Oiler Boyd, 1993a). Moreover, an individual's experience is shaped by the "natural attitudes", or those experiences and interpretations of the world by our predecessors which have become assumptions and unquestioned meanings about phenomena (Schutz, 1970). Reality is therefore constituted of individually interpreted experience and not pure experience (Oiler Boyd, 1993a).

According to Oiler Boyd (1993a), Merleau-Ponty stated that our experience of the world is lived through and discovered through perception. Perception is awareness of the appearances of phenomena, and the act of perceiving takes place through the body (Munhall, 1989a). By perceiving an experience in its totality, that is, by perceiving in the context of the experience with the overlays that form that experience, an individual lends an interpretation or gives meaning to his/her experience (Oiler Body, 1993a). One's reality, therefore, is defined by perception and his/her perspectives.

Because phenomenology is concerned with describing experiences as subjectively perceived and lived by individuals, the research methodology for phenomenological inquiry is descriptive rather than experimental (Knaack, 1984). Nonetheless, for the study to be truly of a phenomenological nature, one must not develop a set of steps but proceed as the direction of the experience indicates (Omery, 1983). The phenomenological method involves approaching the experience or phenomenon with no preconceived expectations or categories, and exploring the meanings of that experience from the perspective of the individual (Omery, 1983). As such, bracketing and intuiting are two of the essential operations in the collection and analysis of data for phenomenological inquiries (Oiler, 1982).

Bracketing is the process to set aside one's preconceptions and presuppositions in order to fully understand a lived experience and the meaning of the phenomenon to the individual involved in the experience (Knaack, 1984). The aim of bracketing is to peel away the layers of interpretation and meaning that we give to a phenomenon and to refrain from

judgments (Oiler Boyd, 1993b). Intuiting, on the other hand, is looking at the experience with wide-open eyes and with knowledge and facts set aside (Oiler, 1982). Spiegelberg described intuiting as utter concentration on the experience intuited without becoming absorbed in it to the point of no longer looking critically (Oiler Boyd, 1993b).

Assumptions

Assumptions are, "basic principles that are accepted as being true on the basis of logic or reason, without proof or verification" (Polit & Hungler, 1991, p.640). There are two sets of underlying assumptions in this study.

Assumptions in relation to the Phenomenological Method

1. Individuals are willing to disclose their experiences as subjectively lived.
2. Individuals are able to describe their perception or their original awareness of the appearances of the phenomenon under investigation.
3. Individuals are able to explicate the original meanings given in perception rather than the modified meanings given in subsequent analysis of their experiences.

(Adopted in part from Oiler Boyd, 1993b)

Assumptions in relation to the Research Topic

1. Human caring is a universal phenomenon, but the expressions, processes and patterns of caring vary among cultures.
2. The family plays a predominant and decisive role in decision-making and in evaluating the care that their dying family member receives.
3. Cultural values and beliefs are transmitted from generation to generation regardless of immigration.

4. Cultural meanings are not static, but change in ongoing interactions with other cultures.

(Adopted in part from Kleinman et al., 1978; Leininger, 1984 and Rosen, 1990)

Definition of Terms

1. **Chinese-Canadians:** Landed immigrants or Canadian residents of Chinese origin who can speak Cantonese and/or English.

2. **Dying family member:** Study participant's family member who is diagnosed as terminally ill, and who is receiving palliative care from health professionals either at home or in the hospital.

3. **Perceive:** The (conceptual) process by which an individual becomes aware of the appearances of phenomena in experience.

4. **Appropriate care:** This is to be defined by study participants according to their experiences and perceptions of care for their dying family members.

Setting

Because the aim of phenomenological research is to describe experience as it is lived, control over the research situation and variables is not only unnecessary but undesirable (Field & Morse, 1985). The settings in which phenomenological research takes place are naturalistic settings where the study participants normally operate (Brink & Wood, 1989). Naturalistic settings such as hospitals, villages and people's homes allow the researcher to get close to the study participants to really explore and understand a phenomenon from their perspectives (Polit & Hungler, 1991).

The preferred settings for this study were the homes in which the dying patients lived and were being cared for, recognizing that study participants might or might not live in the same dwellings. The homes of dying patients were the preferred settings for this study for two reasons. First, because both lay and professional care are provided to dying patients in their homes, homes are the naturalistic settings for exploring the phenomenon of care. Second, homes are one of the major settings in the "popular health care domain" within which family members interact and in which decisions regarding care and evaluation of care take place (Kleinman et al., 1978; Anderson, 1987). The student researcher could get close to the study participants in the home environment and explore their perception of appropriate care for their dying family members. In situations where it was inappropriate to interview study participants in the homes of the patients, interviews were held in a place mutually convenient to the study participant and the student researcher.

In this study, six interviews were conducted in the homes of the patients, two interviews were conducted in health care institutions, and one interview was conducted in the work place of a study participant.

Selection of Study Participants

The philosophy of phenomenology recognizes that there is no single reality; rather, each individual has his/her own reality which is subjective and unique to the individual (Burns & Grove, 1993). Because the goal of phenomenology is not to typify or generalize the phenomenon under study but to describe reality from the perspectives of individuals, two criteria suffice for selecting study participants in a phenomenological study (Colaizzi,

1978). First, the individuals have experiences with the investigated topic. Second, the individuals are willing and able to articulate their experiences.

Moreover, the number of study participants to be recruited for this study were not predetermined. When data saturation was reached, that is, when no new data added to the emergent themes, no more study participants were recruited. In this study, a total of nine study participants were recruited and interviewed.

Criteria for Selection

There were three criteria for selection of study participants in this study:

- (1) The study participant was a Chinese-Canadian;
- (2) The study participant had a dying family member; and
- (3) The study participant was willing to participate in the study.

Recruitment of Study Participants

A community health nursing agency was initially the only setting from which participants for this study were to be recruited. Nurses and the palliative care consultation team of the agency made home visits and provided palliative care to dying patients and their families at home. Nonetheless, because referrals of potential participants from the community health nursing agency was slow, the student researcher included a teaching hospital as a back-up setting for recruitment of study participants one month after the recruitment process had started. The palliative care unit in the teaching hospital provided in-patient palliative care to dying patients and their families.

Recruitment of participants for this study commenced after the student researcher received approval from the University of British Columbia Behavioral Sciences Screening Committee for Research and Other Studies Involving Human Subjects to conduct the present study (see Appendix A), and from the community health nursing agency and later from the hospital to access their terminally ill patients. Study participants were recruited through the nurses in the agency and through a clinical nurse specialist in the hospital. A letter was sent to all the full-time nurses and to the clinical nurse specialist (see Appendix B), asking for their cooperation to first, identify potential participants for this study based on the three selection criteria; second, to briefly explain to the potential study participants the purpose of this study; and third, to gain the verbal consent from the potential participants to be contacted by the researcher by phone. Because Chinese-speaking nurses in the agency looked after most of the dying Chinese patients in the community, the student researcher made telephone contacts with the majority of these nurses in order to enhance the recruitment of participants.

Upon obtaining permission to contact potential participants, a meeting was arranged at a mutually convenient time and place. At the meeting, the student researcher explained the purpose of the study to the potential participant, and answered questions about the study. Potential participants who agreed to participate were asked to sign an informed consent form (see Appendix C). The interview proceeded after the student researcher obtained an informed consent from the study participant.

In this study, the student researcher received twelve referrals from the community health nursing agency and none from the hospital. Among these referrals, one potential participant declined to participate in the study, another could not be reached by the student researcher by phone, and one potential participant refused to sign the consent form or to have the interview tape-recorded. As a result, a total of nine interviews were conducted with nine study participants respectively.

Characteristics of Study Participants

Out of the nine study participants, six were female and three were male. The ethnocultural background for all study participants and their dying family members was Chinese. All but two of the study participants lived under the same roof with their dying family members, and all study participants provided the majority or part of the care for their dying family members at home.

Except for one study participant who was reluctant to provide demographic data of herself and the patient, demographic data of the other eight study participants and their dying family members are summarized in Table 1 on the following pages. It should be cautioned that the table is intended to reflect the characteristics of the participants and the patients. It should not be taken as the basis for generalizing the findings of this study.

Table 1

Demographic Data of Study Participants and Patients

| Characteristics | Participant n=8 | Patient n=8 |
|-------------------|--------------------|----------------|
| Age | | |
| 31-40 | 2 | 0 |
| 41-50 | 3 | 2 |
| 51-60 | 0 | 0 |
| 61-70 | 1 | 2 |
| 71-80 | 2 | 3 |
| Over 80 | 0 | 1 |
| Country of origin | | |
| China | 3 | 3 |
| Hong Kong | 3 | 3 |
| Taiwan | 1 | 1 |
| Canada | 1 | 1 |

(table continues)

| Characteristics | Participant <u>n</u> =8 | Patient <u>n</u> =8 |
|------------------------------|----------------------------|------------------------|
| <hr/> | | |
| Years of residence in Canada | | |
| 1-10 | 0 | 2 |
| 11-20 | 2 | 2 |
| 21-30 | 3 | 1 |
| 31-40 | 1 | 2 |
| 41-50 | 1 | 0 |
| Born in Canada | 1 | 1 |
| Religion | | |
| Catholic | 2 | 2 |
| Buddhist | 1 | 0 |
| Atheist | 5 | 5 |
| Taoist | 0 | 1 |
| Language(s) spoken | | |
| Chinese only | 1 | 4 |
| Chinese and English | 7 | 4 |
| <hr/> | | |

Note. There were nine study participants; one declined to provide demographic data.

Collection of Data

Procedures for Data Collection

The philosophy of the phenomenological method is open, interpretive, and individualistic (Munhall, 1989b). As such, a phenomenological study should not be structured by a linear design (Munhall, 1989b). Open-ended and suggestive techniques rather than a definite design are appropriate for unfolding the experiences as subjectively lived by the study participants (Knaack, 1984).

In this study, the interview was the technique for data collection. One interview was conducted with each of the nine study participants. Six of the interviews were conducted in Chinese, and three of the interviews were conducted in English. All interviews were conducted by the student researcher who could speak both Chinese and English. The length of the nine interviews ranged from thirty to sixty minutes. Each interview was tape-recorded upon approval by the study participant, and it was transcribed verbatim within one week of the interview. Those interviews conducted in Chinese were translated by the student researcher into English during the process of transcription and prior to the analysis of the data. The trigger questions for the interview were, "What would good care for Mr/Mrs X look like to you?", or "What do you consider as good care for Mr/Mrs X?". No fixed structure was imposed for the interview. Instead, the experiences unfolded by the study participants directed the interview process.

The phenomenological method denotes that study participants are co-researchers with whom the researcher engages in cooperative dialogue (Knaack, 1984). As Anderson

(1989) argues, "the phenomenological tradition maintains that meaning is contextually constructed as an intersubjective phenomenon" (p. 20). In a phenomenological study, the success of the interview as an intersubjective dialogue depends on the interviewing skills of the researcher (Oiler Boyd, 1993a). The interview technique requires the researcher to be a good listener (Knaack, 1984). Moreover, the researcher must be able to formulate the right questions to tap the experience of study participants without telling them what to say (Colaizzi, 1978).

In this study, the student researcher has used various methods to aid the processes of interviewing, of disclosing the perception of study participants, and of unfolding the meanings that study participants have given to their experiences. First, the student researcher communicated to study participants her interest in understanding their experiences by listening attentively, by restating, clarifying, and reflecting on the participants' account of their experiences, and by maintaining appropriate eye contact with the study participants. Second, the student researcher asked open-ended, descriptive questions which encouraged the study participants to elicit in detail their lived experiences. For instance, "You mentioned that good care was being thorough and concerned about the patient. Can you talk about some of your experiences when you felt that the health professionals were being thorough and concerned in looking after your father?". Third, before each interview, the student researcher exercised "bracketing" by reminding herself to set aside any preconceptions and presuppositions about the research topic (Knaack, 1984). During the interviews, the student researcher asked questions and really wanted to

hear the study participants' description of their experiences (Oiler Boyd, 1993b). Last but not least, by "intuiting", the student researcher looked at the lived experiences of study participants with wide-open eyes and utter concentration and became absorbed in the phenomenon (Oiler, 1982; Oiler Boyd, 1993b).

It should be noted that in this study, the student researcher did not return to any study participant for a second interview. This was mainly because the student researcher did not wish to impose on the study participants who were already going through a stressful time in the face of impending death of their loved ones. Moreover, the deaths of some patients after the first interviews rendered the respective study participants unsuitable for second interviews.

Ethical Consideration

Ethical consideration involved measures taken to protect the rights of study participants in this study. It was recognized that human subjects in any study had the right to be free from physical and psychological harm and exploitation, the right to self-determination or to voluntarily decide whether or not to participate in a study, the right to full disclosure or to be given detailed description of the study, and the right to fair treatment and privacy (Polit & Hungler, 1991). In this study, the rights of study participants were protected by informed consent and confidentiality procedures.

Informed Consent

Informed consent was intended to protect study participants' right to self-determination and full disclosure (Polit & Hungler, 1991). It was also a validation of study participants'

agreement to be co-researchers in this study and to allow the researcher to enter into their worlds and share their experiences (Munhall, 1988). In this study, informed consent was obtained from each study participant before interviews were conducted. The informed consent included the title, purpose, explanation and procedures of the study; the rights of the study participant including his/her freedom to withdraw at any time; the measures to protect confidentiality of the study participant; and a statement that the study participant had the opportunity to ask questions (see Appendix C).

Confidentiality

A promise of confidentiality to study participants was the guarantee that the raw data provided by them would be accessible only to the researcher. In this study, the following procedures were used to ensure confidentiality. First, all identifying information was removed from the data and kept in a separate locked cabinet. Second, the names of study participants were coded with subject identities known only to the student researcher. Third, only the student researcher had access to all the transcript materials. Last but not least, research information was reported in the aggregate, and the identity of any study participant was disguised by fictitious names.

Munhall (1988) argues that from an ethical perspective, "the therapeutic imperative of nursing (advocacy) takes precedence over the research imperative (advancing knowledge) if conflict develops" (p. 151). Efforts to avoid any difficulties or harm to the subject, therefore, need constant vigilance from the nurse researcher (Munhall, 1988).

Analysis of Data

The goal of all phenomenological data analysis is to interpret data with faithfulness to the phenomenon (Knaack, 1984). In other words, all data were accepted as given, and the researcher analyzed the data with no preconceived notions, expectations, or frameworks (Omery, 1983). As such, the researcher was required to use bracketing and intuiting in order to accurately "see" and interpret the meaning of the experiences as lived by the study participants (Oiler Boyd, 1993b).

In this study, data collection and data analysis occurred simultaneously. The procedures of data analysis were adopted from Colaizzi's (1978) method for phenomenological data analysis. After an interview was transcribed verbatim, the transcript was read over once in order to acquire a feeling for the study participant's perception of care as a whole. The student researcher then read the transcript again more slowly, and delineated meaning units by identifying transitions in meaning in the described experience (Omery, 1983). The delineated meaning units might or might not directly pertain to the phenomenon of care. Nonetheless, the student researcher recognised that all meaning units had relevance to the study participant, and their identification was meaningful for understanding the study participant's experience as a whole.

Next, the student researcher reflected on and refined each meaning unit, using the words of study participants as much as possible, and retaining phrases that directly pertained to the investigated phenomenon of care. The refined meaning units were then reread, and collapsed into clusters. By creative insight, the student researcher formulated

meanings out of each cluster of meaning units while at the same time remaining faithful to the original data. These steps were repeated for each transcript. Formulated meanings in each transcript were compared to those in the other transcripts. After the formulated meanings in all transcripts were organized into clusters of themes, the student researcher validated the themes by referring back to the original data. The result of analysis was then integrated into a description of the investigated phenomenon.

Methodological Rigor

Guba and Lincoln have suggested that the criteria to evaluate methodological rigor of qualitative research are credibility, fittingness, auditability, and confirmability (Sandelowski, 1986).

Credibility

Credibility was the criterion against which the truth value of this study was evaluated. A phenomenological description is credible when it presents faithful interpretation of the experience as lived and perceived by study participants (Oiler, 1982).

In the processes of data collection and analysis in this study, the student researcher remained faithful to the perception and lived experiences of study participants by “bracketing” her own preconceptions and presuppositions about the investigated topic, and by “intuiting” and really “seeing” the experiences as lived by the study participants. Moreover, in the process of analysis, the student researcher validated the credibility of her interpretation by referring the conceptualized themes back to the original data. The faithful description of what Chinese-Canadians perceived as appropriate care for their

dying family members would be recognized by those who have actually or potentially experienced it (Sandelowski, 1986).

Sandelowski (1986) maintains that a major threat to the credibility of a qualitative study is the closeness of the researcher-study participant relationship. In this phenomenological study, however, the study participants were recognized as co-researchers; meanings were constructed through the intersubjective dialogue between the student researcher and the study participant. As Anderson (1989) maintains, "It is not as if the researcher is describing structures that are *out there and are independent of the researcher and informant*" (p.22). The student researcher would argue that this phenomenological description is credible if the description is faithful to the meanings constructed within the intersubjective dialogue between herself and the study participants.

Fittingness

Fittingness is the criterion against which the applicability of this study can be evaluated. There are two conditions for meeting the criterion of fittingness (Sandelowski, 1986). First, the findings of this study fitted the data from which they were derived. In other words, the findings were grounded in the lived experiences of study participants. Second, the findings of this study would fit into contexts outside the study situation, and readers would recognize the findings as meaningful and applicable in terms of their own experiences.

Auditability

Because phenomenological studies emphasize the uniqueness of human experience and do not expect duplicate behavior from duplicate data, the consistency of phenomenological findings is evaluated against the criterion of auditability instead of reliability in the quantitative sense (Omery, 1983; Sandelowski, 1986).

In this study, the student researcher has left a clear decision trail concerning the study from its beginning to its end. Auditability is established if another researcher could arrive at the same or comparable but not contradictory findings given the student researcher's data, perspective, and situation (Sandelowski, 1986).

Confirmability

Confirmability is the criterion against which neutrality of this study is evaluated. For qualitative research including phenomenological inquiries, confirmability refers to the neutrality of findings but not to the subjective or objective stance of the researcher. This study would meet the criterion of confirmability with the establishment of credibility, fittingness, and auditability (Sandelowski, 1986).

Limitations of the Study

There are four major limitations to this study. First, second interviews were not conducted with study participants. As a result, the findings of the study were not validated with the study participants. Second, what the families perceived as appropriate care for their dying family members might not reflect the actual caring needs of the patients. Although the findings of this study should assist health professionals to understand the

socio-culturally constructed illness experiences of dying Chinese patients and the decisions that Chinese families make in relation to the care of their dying family members, it should not be assumed that what the families perceived as appropriate care was necessarily perceived as such by the patients themselves. Third, the community health nursing agency was the only setting from which study participants were recruited. It should be recognized that families and patients in other settings such as hospital palliative care units could have different expectations, experiences and perceptions of care. Last but not least, the study had a potential problem of "elite bias", that is, those study participants who were willing to participate in the study were likely to be the most articulate, accessible, or high-status members of their groups (Sandelowski, 1986).

Summary

This is a phenomenological study which describes, from the perspectives of Chinese-Canadians, their perception of appropriate care for their dying family members. A total of nine study participants were recruited through nurses of a community health nursing agency, and each study participant was interviewed once by the student researcher. Six of the interviews were conducted in Chinese, and three of the interviews were conducted in English. There was no preset structure for the interviews; instead, the experiences of study participants guided how the interviews proceeded and what questions were asked.

Because the purpose of phenomenology is to describe experiences as lived by study participants, the student researcher used "bracketing" and "intuiting" to control the biases that she might have about the investigated topic, and to remain faithful to the original data

as described by study participants. Data analysis in this study was guided by Colaizzi's (1978) method. The final analysis was a description of what Chinese-Canadians perceived as appropriate care for their dying family members, which will be presented in the following chapter.

CHAPTER 4: PRESENTATION OF THE FINDINGS

Following from the data analysis discussed in Chapter 3, three themes have been conceptualized from what Chinese-Canadians perceived as appropriate care for their dying family members: attentiveness, responsiveness, and protectiveness. Although each of the themes might be seen as pertinent to a different aspect of care, implied within all the themes was the common goal of maintaining comfort in the patient.

In the following presentation of the findings, the three conceptualized themes will be described in relation to the lived experiences of study participants in caring for their dying family members at home. Specific emphasis was placed on revealing the perspectives of study participants and in explicating the meanings that study participants have given to their experiences. Moreover, the expectations and the preferences of study participants regarding where and from whom patients should receive care will be described in relation to their perception of appropriate terminal care, and to their perceived ability or inability to provide such care to their dying family member. The following is a schematic presentation (see Figure 1) and a detailed description of what Chinese-Canadians in this study perceived as appropriate care for their dying family members.

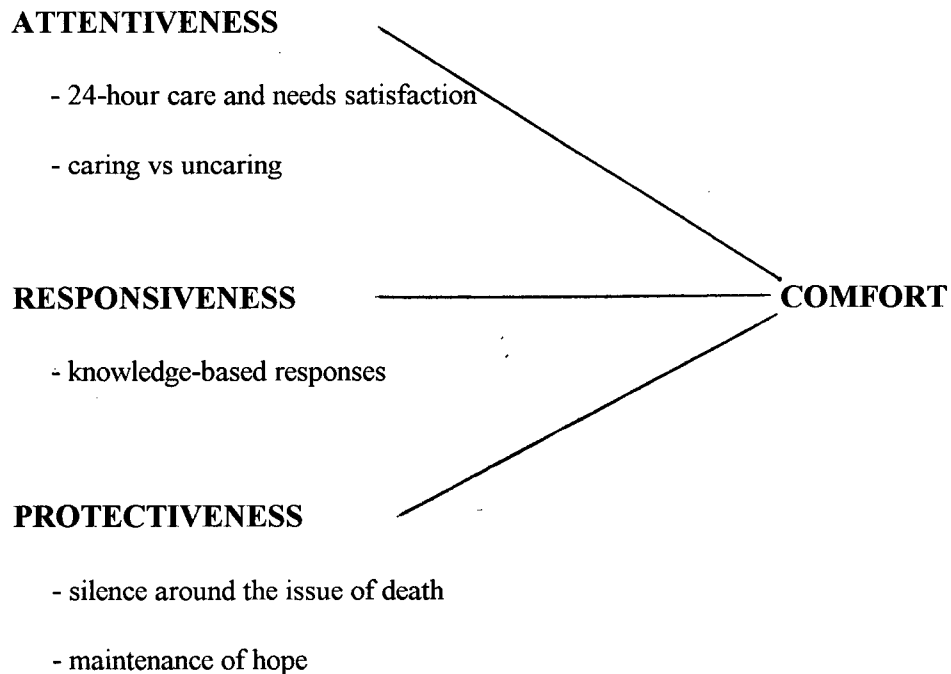


Figure 1. Chinese-Canadians' perception of appropriate terminal care

Attentiveness

Attentiveness was one of the three conceptualized themes of what Chinese families in this study perceived as appropriate care for their dying family members. Attentiveness signified the wholehearted attention that Chinese families expected their dying loved ones to receive. In the perception of these Chinese families, their seriously ill family members required attention or care day and night for the satisfaction of their needs. In order to

make patients feel satisfied and cared for; however, such care had to be delivered in a caring manner.

Because attentive care demanded 24-hour physical and mental attention from caregivers, some Chinese families in this study have spoken of the strain and difficulties in providing care for their dying family members at home. Such experienced difficulties could influence the families' decisions and/or expectations regarding where and from whom patients should receive care.

Language differences between patients and health professionals were also perceived by some Chinese families in this study as a barrier to attentive care and caring interactions. Language differences might not only affect the quality of care that patients received, it could also negatively shape the illness experiences of terminally ill Chinese patients. The following is a detailed account of the theme 'attentiveness' as perceived and described by the participants in this study.

Twenty-Four Hour Care and Needs Satisfaction

Some Chinese families in this study perceived that their dying family members required 24-hour attention and care for the satisfaction of their needs. In order to attend to the needs of patients whenever these needs arose, the caregivers had to be readily accessible and available to patients day and night. While the satisfaction of the patient's needs was necessary for maintaining comfort in the patient, it follows that delay or negligence in meeting these needs could inflict unnecessary suffering on the patient.

One study participant spoke of her preference for hospital care for her dying mother because of the availability of 24-hour nursing care to attend to the patient's needs. This study participant perceived that it was unrealistic to expect the family to provide the patient with day and night care without sleep. At home, when the family was not readily accessible nor available to the patient while they were asleep at night, the meeting of the patient's needs were inevitably delayed, and the patient had to suffer prolonged pain as a result, as the following conversation with one participant shows:

(P = Participant; R = Student researcher)

P: Sometimes when I am asleep, like last night, she complained of sore throat at 3 a.m., being asleep, she called me and I couldn't hear. That is, nobody can work the night shift.

R: That is she...

P: Just not possible, to tell you the truth.

R: I understand.

P: The younger ones were asleep, they were even harder to wake up. The elderly, old like me, also can't. Once asleep you won't know anything. She has to call for a long time, call you up before you know then give her some medications. This isn't possible. In the hospital there are nurses on shifts for 24 hours, at home there isn't.

R: So does it mean that you feel that in the hospital, because there are always somebody there all the time, so whenever the patient, like your mother, needs something, she can promptly get what she wants.

P: Right.

Another study participant perceived that good care was to meet every need of his dying wife and to give her the best possible satisfaction for her needs. Nonetheless, he saw that the care for his dying wife at home was inadequate because he was not readily accessible nor available to the patient while he was sleeping and therefore could not answer to nor attend to her needs promptly at night.

R: Care, what do you think good care should be like?

P: Care that is good? She, whatever she needs, try the best to care for what she needs.

(...)

R: So, in your experience, in your experience of caring for Mrs A, have you encountered any problems?

P: There are problems. Sometimes she, we sleep in different rooms, if she gets up from bed at night or whatever, separated (by the rooms), I am not too clear, being quite deaf, if anything happens to her, I wouldn't know.

R: That is not being able to hear her ...

P: Or if she gets out of bed, gets out of bed, maybe she gets dizzy or something, sometimes wouldn't know even if she falls, that's right.

R: Uh-huh, uh-huh. Are there any other difficult experiences that you have had?

P: Sometimes, she, sometimes if there is anything urgent at night, I won't be able to answer to her.

In the perception of this study participant, the availability of 24-hour care to attend to the needs of his wife was appropriate care. Since he saw himself as unable to be available to the patient day and night, the study participant opted for hospital care for his dying wife.

P: What I expect, of course, is to have appropriate care (for patient).

R: Appropriate care. For example, can you give me an example of what kind of care you would consider as appropriate?

P: Now, to go into hospital, it's best to be cared for in the hospital In the hospital, there is somebody there all the time. Because being here on my own, I have many other affairs to take care of, I can't put all my own affairs aside and not take care of them.

(...)

R: Let's say in the hospital, you, you, in your experience or in your observation, what do you think the hospital can give Mrs A that maybe is difficult to give her at home? What are those things?

P: ... In the hospital, there are nurses there all the time. That's right. In here, I can't be here all the time.

In order to attend to the needs of their dying family members day and night, the families might have to make sacrifices or to make some major changes in their lives. To some families, patients' needs and comfort seemed to take precedence over their own needs and well-being. A daughter spoke of her decision to temporarily leave her work in order to help her father to cope with the 24-hour care for her dying mother.

P: ... I have also taken half a year off to look after her at home.

R: Didn't go working?

P: Didn't go working, right. I was off from the fifth of December last year until the fifth of June this year. Because I saw that it was very hard on my father, he had to give her medications at night. Because she took the medications irregularly, took it once every four hours; then sometimes she, she, that is, one of which (medications) had to be taken every four hours, one of which had to be taken every twelve hours, she didn't, she didn't take them at the same time, that means that

sometimes having taken at 4 a.m., had to take at 6 a.m. again, my father couldn't get any sleep for the whole day then. During the day I sort of helped looking after her at home. Because my father's health isn't that good, he had an operation earlier.

At home, despite the effort of the families to provide for patients' needs day and night, not being readily available to patients especially at night was a common barrier preventing many families from providing all-time attentive care for their dying loved ones.

Negligence in meeting the patient's needs was perceived by some Chinese families as inadequate care for the patient. As such, this family perceived that the hospital could provide more attentive care for their dying family member with the availability of 24-hour nursing care and the availability of technology to assist with the satisfaction of the patient's need such as her need for nutrition. It was reassuring to the family to see that the needs of their dying loved one were attended to.

P: ... That is, (the family) think that she is already, there can't be any medications to help her, it's just that the hospital can, that is, take better care (of her) than we can.

R: Uh-huh. In what ways do you think the hospital can take better care of her?

P: Because there are nurses to watch (the patient) for 24-hour; sometimes at home when we sleep at night we can be negligent. And in there, there are, if she can't eat, she can be infused with normal saline and dextrose, spares her from not being able to take any food for the whole day. But if she was at home, if couldn't eat for a few days, we would be very worried.

R: Uh-huh, uh-huh, yeah. (With the patient) in hospital, you are not so worried.

P: Right, not so worried.

R: Uh-huh. Because there are somebody there all the time to look after her.

P: Right.

Because the satisfaction of the needs of their dying loved ones was perceived by some Chinese families as fundamental to good care, families expected health professionals to take action to meet the needs of patients. Nonetheless, sometimes there was incongruence in what health professionals and families perceived as important or unimportant needs for patients. Such an incongruence hampered the provision of attentive care that families expected for their dying family members. In the following, a daughter described how the family had expected health professionals to attend to her mother's unmet needs for nutrition. To the family, it was inhumane to let the patient suffer from hunger and malnutrition. The failure of health professionals to take action to meet the patient's nutritional need was perceived by the family as unacceptable and unsatisfactory care.

P: ... Yeah, like my mother, OK, she doesn't like to eat.

R: Doesn't like to eat.

P: No, no, she doesn't like to eat, but we'd like her she can eat; she cannot, like, she cannot eat. So we feel so sad, because she cannot eat, just like getting weaker and weaker, so we really like...to give her some shot, we don't like her in the last minute, let her just not eat and die, right? So, this, this kind, I don't, I really not agree, because they say, "Oh, they don't need the needles", or something...

R: You mean the intravenous?

P: Yeah, yeah, something or some kind of nutrition. We hope that, anyway, a human, right? We hope that before they die, get a longer time, for us we feel it's better...We talked to the doctor, we talked to the nurse, they said, "Oh, they don't need it because"...

R: They don't need the nutrition, you mean, the food?

P: Yeah, because she cannot eat, so we think ...

R: Give her the needle.

P: Give her the needle, right, maybe for the family, we feel better, feel not so, we are feeling so sad.

R: You feel sad.

P: Yeah.

R: About ... her not eating? Or about the whole situation?

P: Not eating.

R: Not eating.

P: Yeah. Of course we know she gets something doesn't, doesn't use, right? Useless, we know, or the medicine or something, it's useless for her, but we still like she can get something.

R: Um um, um um. So are you saying that, good care would mean that something can be done to help your mother eat or take some nutrition, is that what you mean?

P: Yeah. I know the last minute she doesn't like eat by herself.

To this family, it seemed that feeding the patient would not only reassure the family that the patient's bodily need for nutrition was satisfied, it would also nourish their hope for a longer life for the patient.

R: Can you tell me, Y, the reasons why you feel that eating is important for your mother?

P: Because she getting weak, weak, weak, right? Of course we know that the cancer sure makes her weak, right? But if you give her a little bit more, maybe she can live a little bit longer, for months and months, we feel it's better.

R: For the family, it's better.

P: Yeah.

R: The family would like to see her live longer.

P: Yeah. Even (if) we have to spend a hard time, we are willing to do, right?

Eating, or the ability of their dying family members to eat seemed to bear special symbolic meanings to some Chinese families. As one study participant has described, the patient's ability to eat signified good health and a hope for recovery, whereas his inability to eat would indicate to the family that he was seriously ill.

R: Mrs E, from my interview with some other families, Chinese families, to some of them, feeding their family members is very important ... Do you think that's important?

P: I think so because they'll have the strength so, to eat, that's the only way he'll get his strength. And you know a person is generally pretty good in health if he, they could eat, but if they don't eat, then you know something is wrong, doesn't it?

R: Um um, um um. What if they can't eat, or if he doesn't have the appetite to eat, what does that indicate to you?

P: To me I can't, I think then he must be getting really seriously ill, that's the way I assume it. I don't know I am right or wrong. I would feel, I feel if he's not eating and don't want to eat, he must be serious, he must be ill internally and doesn't know how to describe it himself.

(...)

P: ... But say a sick person, if a sick person can eat, I think that's a good sign. I mean when the children were the same way, when they were young, were sick, they won't eat; until they start eating, you know, oh ow! I look forward to a road to recovery, you know.

Twenty-four hour attentive care, though desired by Chinese families for their dying family members, could impose immense physical and emotional strain on the family caregivers. The strain in caregiving at home could be particularly harsh for those caregivers who were on their own with little support from other family members. Even if the patient might wish to stay home and to be cared for by his/her own family, the family's experienced strain in caregiving could play an important role in shaping their decision and preference for sending the patient away for care.

In the following account, one study participant spoke of the difficult reality of providing her dying mother with 24-hour care at home.

P: I consider that a person, that is, a patient at home, it is very hard on the caregiver ... A patient is not that easy to look after; it's easy if he/she has no problem, but if there is problem, it's very hard. It's best to be in the hospital; the hospital provides 24-hour service, (there are) nurses, she seems to be in a more proper state. At home, there are two hours of home-making, two hours pass quickly, I have to look after patient for 22 hours; in that 22 hours, sometimes when she has pain at night, you have to get up, don't get enough sleep ...

R: When she has pain ...

P: Yes, when she has pain, you don't get enough sleep; don't get enough sleep and you don't feel well, can't keep up sometimes. But it's better that someone is helping out, it'll even be harder if no one helps out.

R: At the moment, what sectors are helping you out?

P: At the moment, my sister from Hong Kong is helping me out. If she goes back (to Hong Kong), being on my own will even be more troublesome, comparatively harder.

Despite the patient's wish to stay home and to be cared for by her own family, the family preferred hospital care for the patient because of their perceived inability to provide 24-hour care for the patient at home.

P: The patient of course likes to be home, to be looked after by her own family. But the relatives looking after her of course hope to have the patient in the hospital, because there is too little manpower. Being on his/her own, a person cannot keep up with 24 hours, 22 hours without sleep.

Another study participant also found the provision of 24-hour care for his dying wife at home overwhelming. Although the study participant perceived that his wife felt more cared for under the care of her own family at home, he preferred to send the patient into a nursing home so as to release himself from the hardship of caregiving on his own.

R: You just mentioned that it's better to be at home.

P: Of course, because it's her own relatives caring for her at home, right? It's just not as good in the hospital. Although it, sometimes some people are just 'doing a job'.

R: Only 'doing a job'.

P: Yeah! Some are not truly, you know, right? Being, being in her own home, of course it's better, right? Her own relatives, right? But like all I have said earlier, having only one person at home, how can you, how much can you do? Sometimes maybe I can't keep up with it, right? It's very hard on me now. I have been doing it for her, that is, before she went into hospital, I did a lot of family work, because she was ...

R: Did a lot of family work, housework?

P: Housework, right. At that time she had pain, she couldn't quite move because of the pain, so I had to do that too. After she came home from the hospital, that is like

what she is now, her whole body is, that is, gone weak, again I have to do more, also to care for her. In the past, she could go to the bathroom, could go wherever, not anymore now, everywhere she goes I have to go with her and to take care of her.

R: That is, Mrs J needs your help to go to the bathroom, that's what you meant?

P: Yeah, yeah, yeah, that's it. So I can't even leave (her) for a minute.

(...)

R: If, for example, Mrs J could go into those nursing homes, in your opinion, why do you think that going into a nursing home is good for Mrs J?

P: Well, that is, that means that, that is, it relieves my workload. To go into there, I think she wouldn't like it too much, but for me, it will be better.

The hardship of caregiving on one's own was also experienced by another study participant who felt imposed upon to care for his dying wife at home. Although a family might expect 24-hour attentive care for their dying family member, the family itself might not be prepared to take on the caring responsibility nor ready for its associated hardship.

R: That is, only you to do the cooking.

P: Right, it ties me down at home.

R: Ties you down at home.

P: Ties me down; I am like a servant and take care of her.

R: That is, you are responsible for taking care of her daily activities.

P: That's right. If I don't take care of her, who would? Right? The government is unable to care (for her), right? The children have to go to work, that's right. There's only me, if I am not here, then there's no other way.

R: If you are not here taking care of her, then there's no other way.

P: No other way, right.

R: You said the government didn't care. In what ways do you expect the government to care for her? How do you want the government to look after her?

P: Of course wants it (to look after her), want to go into hospital or to have somebody looking after her, something like that. I can take my time to go and see her, then I will be less tied down. Everything needs me, everything by myself, it's harder than when I had to look after my business in the past, doing my own business was not as hard as this.

R: Doing your own business not as hard as this; you feel that it's harder now?

P: That's right. When I did my own business, I had people working for me.

R: That is, you have to do everything by yourself now.

P: Right. I dare to say that in my whole life, this is the hardest time.

For some families, their experiences of physical and emotional strain in providing the patient with 24-hour attentive care at home could be compounded by their fear about the actual dying process. Despite the fact that the patient might wish to stay home with his/her family, the strain of caregiving and the family's fear about death and dying could influence their decision about where to send the patient for care in his/her final days.

R: ... To your father, do you think that to receive care at home or in the hospital make any difference to your father or affect him differently?

P: To him, there should be some effects, because at home, my mother literally accompanies him for 24 hours a day, but not in the hospital; afterall, they need their families, need their families more. On the other hand, his needs and the needs of his spouse are different sometimes! Because, for example like my father, as a patient, of course would like to be at home more; sometimes for example, not that my mother doesn't want him to be home for example like when he is almost close to the

'ending', it will be harder for my mother to care for him or she has fears about it, so if there are health professionals around her all the time, it's easier for her to accept.

R: Easier for your mother to accept.

P: That's right But I feel that when my father is not home, my mother is comparatively more relaxed, the most is that she would miss him, but wouldn't be too nervous.

R: Can you briefly describe the problems that you mother has encountered?

P: Yes. Because when he is home, it's a lot harder on my mother, comparatively speaking, it's a lot harder. When he is in the hospital, afterall, the emotional burden on her is less.

R: Are you saying it's emotionally hard on her or ...

P: Emotionally, emotionally and physically. Because, for example like when he was at home, she then, our house has two floors, as soon as my father called or something, she would rush upstairs in a great hurry, whatever she had been doing she would rush upstairs. But if my father is in the hospital, she doesn't have this emotional burden, the most is for her, even if she has to cook for him to eat, she doesn't have the emotional burden that he might call her any minute, she worried that she might not hear him; so emotionally she doesn't have to diverge so much, won't be so nervous. But at home, she will be more nervous.

To summarize, some participants in this study perceived that the appropriate care for their dying family members was to provide them with 24-hour attention and care for the satisfaction of their needs and for their comfort. A common barrier to the provision of 24-hour attentive care at home was the inability of the families to attend to the needs of patients promptly while the families were asleep at night. As such, many families perceived that the patient would receive more attentive care in the hospital because of its availability of 24-hour nursing care.

Differences in perspectives between some families and health professionals could hinder the satisfaction of those needs which the family perceived as meaningful but which health professionals saw as unimportant to the patient. Because it could be intensive and exhausting to provide the patient with 24-hour attentive care at home, the physical and emotional strain experienced by the caregiving families could influence their decisions and expectations regarding where and from whom their dying family members should receive care.

Caring vs Uncaring

Attentiveness is more than the mere provision of 24-hour care for patients. Chinese families who expressed their desire to send patients into hospital for 24-hour care expected health professionals to be caring to their dying loved ones and identified behaviors perceived as uncaring. In the perception of the families, care delivered in a way that indicated caring to the patient could make the dying patient feel comfortable and cared for. One study participant described good care as being thorough and concerned about the patient.

R: B, what I would like to understand is that, from your perspective, what would good care to your father look like to you?

P: Um, being thorough.

R: Being thorough.

P: Being thorough. Um, that is, the most important is to show some concern to the patient, apart from being thorough also being concerned about the patient. That is, to give him a feeling that somebody care about him.

This study participant explicated her perception of caring further by describing how she had expected health professionals to show genuine concern for her father's needs and to be thorough in helping her father to meet his needs.

P: That is, to be more concerned about the patient. For example if they felt that the patient was weak, the simplest thing like asking the patient, "Do you need me to help you, to eat or whatever?", "Do you need my help?". But many nurses or health professionals, just put the things down! Because normally at dinner time or meal times, those people will just put the things down, but at least the nurse could follow up and see if the patient has appetite today, or if he can handle it himself, like opening the can of nutritional milk; but if they don't have enough strength, they can't open it up by themselves. A few times when I got there, the can of nutritional milk wasn't opened, she didn't pay any attention to him; ... the patient at such a stage really needs a lot of people, that is, the simplest is (to ask the patient), "Do you need me to help you? Do you need anything?"

Some Chinese families drew upon their experiences of the patient's hospitalization to explicate what they perceived as uncaring. While a caring nurse would be thorough and genuinely concerned about the patient's needs, an uncaring nurse was perceived as just 'doing a job'. A study participant expressed his dissatisfaction with a nurse's negligence in meeting the needs of his wife.

R: You have also mentioned that the people were just 'doing a job'.

P: Some of them, some of them, not saying all of them.

R: Who were those people that you were referring to?

P: Well, even like those, like that day in that hospital, at dinner time, I got there at about 6 p.m., dinner was over at that time, she was still sitting in bed. I asked her, "Have you eaten yet?", she said, "Not yet". I went out and looked,

everybody has already had their food taken away. I asked the nurse, she said, "Hasn't she eaten?", I said, "She hasn't eaten yet" ... How could the nurse be like that, of course everybody should have, to have given the neighbor, two people sharing one room, right? If the neighbor has eaten, then she should have eaten too, right? She hasn't eaten, sitting there, why didn't she give it to her to eat? I don't understand what (the nurse) was doing.

Moreover, a caring nurse was perceived as patient-centred, one who put the needs and comfort of the patient first. On the contrary, the nurse who was task-oriented, who put her own convenience and ease first, and who showed unwillingness to attend to the patient's needs was seen by the families as uncaring.

P: ... Like when he used the bedpan, simplest speaking like using a bedpan, there were some nurses who felt it's very disgusting; rang (the call bell) a few times, and just pushed it in, that is, wouldn't care about the patient, might have bumped him, whether has slipped it in the right place. There were some who would make sure he's OK before leaving, there were some who would just push it in and leave. Also like giving him a bath, there were some who would give you a bath when there was time, sometimes just gave you a wash, ... Some nurses, once they got into the ward, I noticed that they would give the patients a bath the first thing, except if the patients themselves didn't want it. But some nurses literally didn't want to give the patients a bath, because afterall it's more troublesome, had to put them in the commode chair and push them in.

R: It's troublesome to the nurse?

P: That's right!

The attitudes with which a caregiver provided care for the patient were perceived as affecting the feelings of the patient. A caregiver who was thorough and concerned about meeting the patient's needs would be emotionally comforting to the patient.

R: So to your father, would it make any difference to your father's feelings whether a nurse is thorough and concerned about him or not?

P: There were! There were differences to his feelings, because if the nurse on that day was nice, his mood would be better too.

In order to accurately assess and respond to the needs of patients, it was necessary for the caregiver to be able to communicate with them. The lack of communication and understanding between patients and health professionals because of their differences in language could hamper the provision of good care and the conveyance of caring to patients. One study participant expressed her dissatisfaction with the care that her mother received in a hospital. Because of the patient's inability to communicate with health professionals in the same language, the care provided to her was based on professional judgment of her needs and was incongruent with her actual needs.

P: Oh, at the moment, that is, worries about her, being here, still doesn't really know, that is, not so many Chinese, not so many people who know how to speak Chinese; also there is some problem with my mother's hearing, so sometimes when ask her something, she would, she would nod her head anyway, people wouldn't know if she says 'Yes' or 'No'. So, sometimes she, like a few days ago, 60, her Morphine has gone up to 60, it already...

R: 60 mg?

P: Right, it could control (the pain). But I didn't understand why the doctor increased it to 70 (mg), later increased to 75 (mg) again within the same day. So I asked the doctor, I said that everytime when I asked her if she had pain, she said 'No', why did it have to be increased? The doctor said, 'Although she said she had no pain, we felt that she was very uncomfortable' ... ; sometimes (the nurse) asked my mother if she had pain, she didn't know what (the nurse) was saying, so she nodded her head, (the nurse) again would think that she had pain, and increased the medication for her.

Because I feel that every time when the medication is increased a bit, her breathing gets more difficult, she gets less conscious.

As this study participant perceived, the misunderstanding of the patient's needs by health professionals because of language differences, and the provision of care incongruent with her actual needs had a negative impact on the patient's well-being. Moreover, language differences could be a barrier to caring interactions between the patient and health professionals. Care provided in the absence of communication in the same language provoked negative emotions such as fear in the patient.

R: Do you feel that, perhaps sometimes if the ward has Chinese-speaking nurses, would that make any difference to the care of your mother?

P: Yes.

R: Different in what ways?

P: That is, (the nurse) can ask her things, and she can understand. Sometimes she, she feels that she doesn't know why other people come in and what they are doing for/with her, she seems like she is very frightened.

Another study participant has also talked about her dying family member's nervousness about interacting with health professionals because of the patient's inability to communicate with them in the same language.

R: You said that she was nervous, she was nervous in the hospital, can you talk about that? ... What was she nervous about?

P: She was nervous about not being able to understand the language. In terms of language, she couldn't understand, so whatever the nurses said to her, she couldn't understand, or the doctors asked her about her condition, she wouldn't be able to say it (in English). Therefore she was nervous.

Conversely, the ability of health professionals to communicate with the patient in his/her mother language allowed the patient to express his/her needs spontaneously in his/her own language, which in turn gave the patient a feeling of emotional closeness to the health professional and enhanced the building of a caring relationship between them.

P: ... There were mainly Chinese doctors, so it's much easier to communicate, more cooperative, also that my father felt closer (to the Chinese doctors).

R: Because the doctors could speak Chinese?

P: Could speak Chinese, right, to him it felt closer.

R: Closer, uh-huh. It's in terms of feelings, felt more close?

P: In terms of feelings, felt more close, because it's the same language. That is, sometimes the reason is that, at this stage he is a bit weak, sometimes requiring him to speak English, not that he is unable to, he's like, just sort of answer you. But sometimes if (the doctors) speak Chinese, at least he doesn't have to think about what the doctor is asking him, he would feel it's easier.

To summarize, attentiveness was more than the provision of 24-hour care for dying patients. In caring for and attending to the patient's needs, care had to be delivered in a way that indicated caring to the patient. Caring was perceived by some Chinese families in this study as being concerned about patients' needs and being thorough in meeting these

needs. While a caring nurse would put the needs and comfort of the patient first, an uncaring nurse was perceived as just 'doing a job', one who was negligent in meeting the patient's needs, and one who put his/her own ease and convenience before the needs of the patient. Attentive care conveyed in a caring manner could make the patient feel physically and emotionally comfortable.

Language differences between the patient and health professionals, however, could be a significant barrier to the provision of attentive care and to the conveyance of caring to the patient. The inability of health professionals to communicate with the patient in the same language could result in care incongruent with the patient's actual needs. Moreover, it could provoke negative feelings such as fear and nervousness in the patient.

Responsiveness

Responsiveness was the second conceptualized theme of what some Chinese families in this study perceived as appropriate care for their dying family members. Responsiveness signified the family's expectation for prompt and knowledge-based responses to the patient's physical problems. While most families saw themselves as unable to respond to the patient's changing physical needs because of their lack of medical knowledge, the families perceived that health professionals could provide responsive care to patients with their professional knowledge and skills. Knowledge-based responses by health professionals were perceived by the families as beneficial to maintaining physical comfort in their dying family members.

Because most families in this study perceived themselves as incapable of responding to the physical problems that patients might experience, such perception has influenced the families' decisions and preference regarding where and from whom their dying loved ones should receive care. Moreover, their expectation of responsiveness from health professionals has shaped how some families evaluated the care that patients had received. The following is a detailed description of the theme responsiveness.

Knowledge-based Responses

When patients experienced problems or changes in their physical conditions, most Chinese families in this study saw that responses to patients' problems required medical knowledge and the skills of health professionals. The medical knowledge and skills possessed by health professionals, as those families perceived, enabled health professionals to respond to patients' physical changes and needs by knowing what to do and how to do it. With prompt and appropriate actions to effectively manage or solve the problems that patients were experiencing, knowledge-based responses by health professionals were perceived by the families as able to relieve patients' suffering and to maintain their comfort.

One study participant has distinguished between the ability of the family and that of health professionals to respond to the patient's physical problems and changing needs. In the perception of this study participant, she was unable to respond to changes in the patient's condition because of her lack of medical knowledge, whereas health professionals could provide prompt and knowledge-based interventions responsive to the patient's

problems. Because “responsiveness” was perceived by this study participant as important for maintaining the patient’s comfort, she preferred hospital care for her dying mother-in-law.

P: ... When she is seriously ill, I hope that she can be hospitalized, because in the hospital, only the nurses can really help her, because they can solve many problems immediately, can help her to relieve her sufferings. If at home, there isn’t very much that I can do, right?

(...)

R: You have also mentioned that if Mrs F’s condition deteriorates, becomes more serious in the future, you think that going into hospital is a more appropriate arrangement.

P: Of course, yes, of course. Because they can help her anytime, the hospital nurses, they can, that is, professionals, they know what to do and to have a decision right away. When at home, I only know how to do what they have taught me, for instance to help her to use the steam nebulizer, or to use, to take medications, something like that, I can’t do much about other things else.

R: That means that the boundary is that you can do what you have been taught, but if there is a crisis ...

P: That’s it, then I won’t be able to help her. Because firstly, I don’t have the equipment; secondly, I’m not in the medical-nursing, I don’t have too much medical knowledge.

The possession of medical knowledge was seen by some families as the essential factor which determined the ability of caregivers to respond to the patient’s problems, to relieve the patient’s suffering, and thereby to provide the patient with good care. One study participant expected that care provided in a nursing home would be superior to care

provided by the family at home because of the ability of professional caregivers to respond to and manage the patient's potential problems with medical knowledge.

R: If, for example, Mrs J could go into those nursing homes, in your opinion, why do you think that going into a nursing home is good for Mrs J?

P: Well, that is, that means that, that is, it relieves my workload. To go into there, I think she wouldn't like it too much, but to me, it will be better. Maybe going into there, those people, that is, their knowledge or whatever ...

R: Knowledge?

P: Ah, know more about the medical knowledge or whatever, maybe sometimes when she has some problems, can help her better. Like me, I know nothing, right? The doctor asked me to give her the medications, then I give her the medications according to the schedule. That is, if she has fever ...

R: Fever?

P: Ah, ah, fever, or has something else, I wouldn't know anything about that, right?

R: That is, if there are changes in her condition ...

P: Right, right, right, right.

R: Then you find it difficult to manage.

P: Yeah, yeah.

Another study participant preferred hospital care to home care for his dying wife also because of the presence of health professionals in the hospital who would be able to respond to patient's problems whenever the problems arose. In the perception of this study

participant, the family's lack of medical knowledge was a barrier to providing their dying family member with "responsive" care at home.

P: The hospital of course is better, in the hospital, of course it'll be better. Can't be in the hospital, can't do anything about it. Of course it's better to be in the hospital.

R: It's better. Can you talk about in what ways it'll be better?

P: In the hospital there are people to take care of her, there are doctors, if there is anything urgent there are the doctors, or there are the nurses; if there are any problems, there are the doctors to see her and to care for her. Because we don't have the knowledge, that's right.

R: Yeah, yeah ... So, you feel that it's also important to have the knowledge?

P: Knowledge, of course, to have the medical knowledge of course it's better, right ...

R: That is, to take better care of her?

P: We don't have the medical knowledge, right.

Knowledge-based responses to the patient's problems was an element of care commonly expected by study participants who have either opted for institutional care or home care for their dying family members. One family, who chose to care for the patient at home, expected health professionals to stay with the patient at night so as to respond to and handle the patient's problems with their professional knowledge. While the family was fearful about not being able to respond to the patient's sudden or unexpected problems on their own, the presence of health professionals to provide responsive care to the patient at home was perceived by the family as supportive to them.

R: Are there any, can you tell me, maybe some of the problems that you have in looking after your mother at home?

P: Yeah. At home of course we like her to stay at home than in hospital, we have to go and we don't have time, so we like her, if she can be at home, it's good. But we just so worry something happen, we don't know how to handle. Sometimes she vomit

...

R: Vomit?

P: Yeah, vomit, so scared, don't know how to do.

R: So have you had any experience, like something happened all of a sudden, and how did you cope, can you tell me one of your experiences, like what happened and what did you do?

P: Just, vomit, just let her until finish.

(...)

R: ... So you mentioned that you were worried that if something happens, you don't know how to handle.

P: Yeah, especially night time.

R: Especially night time, yeah, yeah. What kind, what are the things that you think might, might help you better in this aspect?

P: Yeah, we'd like a, we didn't go to the hospital, right? So we'd like somebody, like a nurse, or something like come and stay in my house.

(...)

R: ... Now, what are the things that you would like, or what kind of care that you would like to get at this, now like, that maybe able to help you? You mentioned that having a nurse to come maybe at night is helpful.

P: Yeah, that's the most.

R: That's the most important thing.

P: To give us some support.

R: Give you some support.

P: Yeah, yeah. If somebody there, we feel support.

R: Uh-huh, uh-huh. It's a, it's a professional that you want, right?

P: Yeah, we'd like a professional; like we think we can hire somebody come, but they are not professional, something like us! So ...

R: Uh-huh, uh-huh. So the support is to help you to deal with any problems or changes.

P: Problems, or if they are steady, they will not, or if something happen, somebody can handle, we don't get so scary.

To have to face and respond to the sudden physical problems experienced by their dying family members at home could be emotionally overwhelming to the families. One study participant perceived that because she was not a health professional, there was a limit to her cognitive and emotional ability to handle or to respond to the physical problems experienced by her dying husband. When the care required by her husband was beyond her perceived ability to handle, this study participant preferred to send the patient to the hospital for care.

P: I'm very happy to look after him to the point to what I can't do. I'm not a nurse, I'm not a medical person or a doctor. I'm quite frightened when I see reaction that is entirely, when a person is real sick, I get panicky. Like for instance, he was throwing up blood, that really got me panicky! Sometimes I lose sense, using my common sense to help that person; all I can do is to bring a, a container; aside from that, these things frighten me ... just to a point where he's really ill, and say, got to a point that I'm afraid to, I don't know how to handle, I would say, and that's a point to go to the hospital.

The appropriate care for their dying family members, as most Chinese families in this study perceived, was to have the patient's problems and/or changes in his/her condition responded to and handled by health professionals with their professional knowledge and skills. Nonetheless, the attitudes of health professionals towards caring for terminally ill patients could affect their willingness to provide patients with the responsive care that Chinese families have expected for their dying family members.

One study participant was frustrated by the family doctor's indifference to the patient's need for medical attention because the patient was terminally ill. The unwillingness of the family doctor to respond to the family's call for help could have delayed management of the patient's problems and thereby prolonged her suffering.

P: ... Sometimes call the doctor, (the doctor) doesn't come quickly; sometimes call and (the doctor) doesn't come. Doesn't happen that he'll immediately come upon calling. That is, this is very difficult. He said that she was at the terminal stage of cancer, he also said that she was near death, so you call him by phone, he isn't that willing to come, (that is when) calling the family doctor. When he likes then he will come once. But when it's urgent, the first thing is not being able to speak English; you call the ambulance here you have to register, you can't speak English so how to communicate with people? The doctor is not willing to come to the house. When arrived in the hospital, have to register, to write, and to have emergency treatment, again requires you to be able to speak (English); it's not easy to ask for people's help all the time. In the hospital, there are the resident physicians, they can give her emergency treatments, but at home there isn't any. To call people, to ask for people's help isn't that easy. This issue is the most difficult.

For this family, because of the unwillingness of their Chinese-speaking family doctor to respond to the patient's problems at home, they were put through the language difficulties

to access the mainstream health care system for medical help. This family perceived that neither were they able to respond to changes in the patient's condition themselves nor could they rely on the family doctor for 'responsive' care at home. As such, they preferred their dying family member to stay in the hospital in order to receive 'responsive' care from health professionals.

R: So in terms of medical care, do you feel that the way that they manage your mother's illness now, and if your mother was in hospital, their management of her medical care would have been different?

P: Different.

R: Can you explain that? Or in what ways do you feel that would be different?

P: She, for instance she as a patient, when she shows no other symptoms, we give her a regular, fixed dose (of medications) at home. If in the hospital, when she shows changes in her condition, she'll have the doctor to see her; at home, you call the doctor but the doctor doesn't come immediately. Once the condition changes, that is, don't know what to do.

R: Uh-huh, uh-huh. That is, in terms of management, you feel that if your mother is at home, it's very difficult to manage, because only the family members are here, maybe you don't have ...

P: You just don't know, when her condition changes and becomes serious, you wouldn't know how to deal with it, you wouldn't know to what extent has her condition changed. In the hospital there are doctors who would know the extent (of the patient's changes), to give her medication; at home there isn't.

Another study participant was also dissatisfied with the family doctor's lack of responsiveness to the patient's medical needs. The study participant perceived that because of the unavailability of the family doctor to assess and respond to the patient's

changing needs for symptom control, the patient had to endure unnecessary physical sufferings at home.

R: So in the hospital, do you think that her pain is better controlled than at home?

P: That's right.

R: What do they do different from what you did at home to make her pain better controlled?

P: Maybe is their medications; those pain medications are better, aren't they? Because when she was at home, the family doctor hasn't been to see her, so didn't know what the extent of her pain was and appropriately how much medications to prescribe for her.

R: The family doctor has not been to see her?

P: Hasn't seen her.

R: Hasn't been to the home to see her?

P: No, that's right. Now it's only the community nurse. So, when the nurse thinks she has pain, she'd ask the family doctor to increase the medication for her.

One study participant compared a physician who responded to the patient's problems by taking appropriate actions to relieve the patient's sufferings with another physician who lacked responsiveness to the patient's needs for symptom relief because she was terminally ill. In the perception of this family, the responsiveness of doctors was essential for the maintenance of comfort in their dying family member, and it was integral to good terminal care.

P: ... Our decision of sending her into hospital last time was right. Because at first has gone into Emergency, that doctor wouldn't, one of the doctors wouldn't admit her into hospital, he said, 'She won't be any different, may as well go home'. But he has arranged for that, gave one of that, an oxygen concentrator, said hoped that she would feel better by using the oxygen. But as a result, it was proved to be ineffective.

R: It was ineffective at the Emergency?

P: No, no, no. The oxygen concentrator was ineffective. It, it hasn't made her more comfortable; on the contrary, it has made her allergic, allergic as soon as the machine was put on, like sneezing, runny nose. Then, gone home later, gone home and she was really suffering, getting worse and worse, then I decided later that I wanted to send her to hospital ... Then we went again, still had to go through the Emergency first, but this time the doctor was very nice, a female doctor, I think you may know her too; oh, she is, she is very nice, also that very, very professional, a very, very good doctor. She said that, 'Yes, I also think that she should be admitted into hospital' ...

R: I, you mentioned earlier that the decision to go into hospital that time was right, was that because, why do you think that it was right?

P: Because eventually, the doctor looked into her condition in great detail, and then decided to ask her to see a lung specialist, those are called, what are they called? Respiratory, the specialist was, was able to help her. Now she has no more wheezing, no more whatever, so she is more comfortable, so she can live more happily.

R: Yes, yes, yes. If not because she went into hospital that time, maybe her symptoms wouldn't have been controlled so well?

P: Then maybe she would have deteriorated very soon, would have got worse, would have been the end, that is, basically would be that. Therefore I feel that, that time, that first time at the Emergency the doctor said, 'There isn't much that we could do', 'To go home' etc., it seemed to mean that he was telling her to go home to wait for the day, I feel that it wasn't right, was very irresponsible. Although his judgment was right, that is to say, her heart was at the last stage, towards the end, but such decisions, his way of management wasn't right.

R: Uh-huh. What do you think he should have done instead?

P: He should have asked her to go into hospital, admitted her into hospital, and then could have asked a lung specialist to see her. If she was seen (by the specialist) earlier, her suffering could have been relieved sooner, she wouldn't have to suffer for so long.

To summarize, subsumed within the theme responsiveness were the expectations of most study participants for prompt, knowledge-based responses to patients' physical problems, and their perception that health professionals could respond to patients' physical problems with their medical knowledge and skills. Because most families perceived themselves as incapable of responding to the changing physical needs of their dying family members, they either preferred institutional care for the patient, or expected health professionals to stay with the patient at home. The willingness of health professionals to provide patients with responsive care, however, depended on their attitudes towards caring for terminally ill patients. The families saw prompt, knowledge-based responses to patients' problems as essential to maintaining physical comfort, and as integral to good terminal care for their dying family members.

Protectiveness

Protectiveness was the third conceptualized theme of what some Chinese families in this study perceived as appropriate care for their dying family members. Protectiveness signified the desire of the families to protect their dying loved ones from the emotional pain associated with dying. It also signified the families' desire for a longer life for the patient by protecting the patient from giving up and from physical deterioration. Protective care involved maintenance of silence around the issue of death and/or maintenance of hope in the patient. The following is a detailed description of the theme protectiveness.

Silence Around the Issue of Death

Despite the fact that death might be imminent for their family members, some Chinese families in this study have refrained from discussing with patients, their terminal conditions and impending death. Silence around the issue of death within the family might have been initiated by the family or by the patient. In the perception of the families, such silence could protect patients from losing hope and/or from confronting the painful reality of dying, and it had the meaning of maintaining emotional comfort in their dying family members.

One study participant talked about her mother's unwillingness to talk to the family about her sufferings and terminal condition despite her full knowledge about her cancer diagnosis. In the perception of this family, the patient's silence about her condition reflected her strong will and her reluctance to succumb to the disease. To the family, to refrain from discussing the patient's impending death against her wish was meaningful for maintaining the patient's feeling of hope.

R: Does she know it herself what disease it is?

P: She knows it. When she first found out that it was nasopharyngeal cancer, she knew about it, she in turn deceived, that is, didn't want to tell me. She went and read all the time, she knew that the symptoms belonged to those types of diseases, therefore she didn't want to tell. At last, then it became more serious, then, you know.

(...)

P: ... But she has been very strong-willed.

R: Your mother herself very strong-willed.

P: That's right, very strong-willed. That is, in the past two years, she hasn't even mentioned a bit, that is, mentioned in front of us about any suffering, hasn't, hasn't mentioned anything. Even when we, that is, sometimes want to see her, because she hasn't mentioned anything herself, we want to talk to her about it, she doesn't, that is feels that she is still hopeful about getting well again, that is doesn't want to talk about anything else.

R: She herself also hopes that she can get well.

P: That's right. Even until now that she is in hospital, she still, that is, still hopes that she can get well.

Another study participant also maintained silence and respected the patient's wish not to talk about her impending death so as to protect the patient from the emotional pain of feeling sad.

R: Now, you mentioned that the family would like to see your mother live longer. Can you tell me, have you discussed with your mother what does she want?

P: No, because my mother doesn't like to say anything.

R: She doesn't like to say anything, about the cancer?

P: Yeah, so if she doesn't like to mention, we don't like to talk to her (about cancer) and make her sad.

R: Make her sad, uh-huh.

P: If she asks of it we would tell her, we would talk to her how to do or something. But I'm sure she know, because she's a nurse!

R: She's a nurse.

P: Yeah, and my father a medical doctor, of course she know everything, she just doesn't want to say, I know her character is like that.

R: Her character is like that, uh-huh.

P: She doesn't like to mention bad things.

One Chinese family perceived that because the patient had evasive attitudes towards death, telling the patient about her impending death would have a negative impact on her physical and emotional being. This family therefore has decided against disclosing the diagnosis of terminal illness to the patient in order to protect her from the emotional sufferings associated with dying and from possible physical deterioration as a result of losing hope.

R: OK, does Mrs F herself know about her condition?

P: She is, she herself is suffering a lot, she can, she can feel that, she can somewhat feel that she is very serious, but we still haven't told her about it, because she is, firstly, she is a very old fashioned person, and she is an introvert, whatever it is, she would keep inside with, with herself. So, therefore if we tell her, I am worried that she will, firstly, will be very frightened, will feel very hopeless, and also that she will have no, that is, lose all the hope. This is not good for her, she will be, I fear that she will soon deteriorate, the condition will get worse, therefore we haven't told her. Moreover, it doesn't help to tell her, she won't have to do anything, she won't have to make arrangement for anything ... That is, the Chinese are different from the Caucasians in that, Chinese cannot, that is, cannot face the issue of death face to face, that is, especially the elderly (Chinese). Therefore we, me and my sister-in-law and my husband, we have decided not to tell her about it. To say to her, "You don't have any hope any more, you are at the terminal stage" etc., I think it doesn't do her any good.

To maintain silence within the family around the issue of death might not only protect the patient from the emotional sufferings associated with dying, it might also protect the family from the emotional pain of confronting the impending death of their loved one. One

of the study participants perceived that imposing the subjects of cancer and death on the patient and the family would be meaningless and disruptive to their normal family life. Instead, he perceived that the best care would be to protect the patient from emotional bombardment by her impending death by maintaining silence about her terminal illness and by allowing her to live her normal life.

R: What I am interested to understand, Mr H, is that in your opinion, what would good care for Mrs H look like to you? What would you consider as good care for her?

R: (Pause). It's very difficult to answer, but I think the best care is to leave her alone.

R: To leave her alone.

P: Yeah. To leave her alone, try to get her to forget what she's having, because it have been, I don't know. Well, she know what she's having, OK, we all know what she's having, she just don't like to bring out the subject, OK. Um, leave her alone, let her get used to it, she knows she has to go for treatment.

R: Go for treatment.

P: Yeah. What we have, the way we handle it, the whole situation now is, pretends nothing happen, let the life go on, go on and go on, I think that probably would be the best way.

(...)

R: And Mr H, is it correct for me to say that, trying to keep the subject away from discussion within the family, is it to protect Mrs H from having worries and ... ?

P: Um, yes, you can say so, also protect us too.

R: Protecting the family too, um.

P: We are not escaping from it.

P: We are not escaping from the whole thing, we are trying to gather as much information as we can get, we all understand what's its outcome. But at this stage, whether it can be cured or not, there is nothing we can turn around for it, OK, nothing we can turn around as it is; all we can do is looking forward, OK, looking forward to prepare. It's no good to talk about it everyday, you can die tomorrow, you can die this minute, it's no good, no good for you, no good for us, no good for anybody; and let her have a simple, regular life, let us have a simple, regular life.

The negative connotations attached to cancer and terminal illness could have deterred some dying patients from disclosing their illnesses to people other than their family. For this patient, to remain silent about her cancer diagnosis outside her family meant maintaining her dignity as an ordinary, independent person, and protecting her from feeling embarrassed about being terminally ill and different from her peers.

R: Now, you mentioned that Mrs H is very independent, she's a very independent lady, and she is going to work, and having her regular life at the moment ...

P: Yeah, she is, she tries to hide this, hide what she's having.

R: Sorry, she is?

P: She like to hide what she's having, she feel embarrassed.

R: She like to hide.

P: Yeah, she feel embarrassed that her friends or her co-workers know she's having cancer.

R: So she doesn't let people know?

P: No, only the close family, only the close family.

R: Uh-huh, uh-huh. Can you tell me why she would feel embarrassed about that?

P: Um, why? It's bad luck, bad luck, and bad luck is nothing to talk about, she doesn't want to talk about it. And she don't, doesn't like to receive special treatment.

R: You mean like sympathy and ...

P: Yeah, things like that, she don't need that.

To summarize, despite the fact that death might be imminent for their family members, some families in this study have refrained from talking with patients about their impending death in order to protect patients from emotional sufferings such as sadness, fear and despair, or from possible physical deterioration as a result of losing hope. Silence around the issue of death could have been initiated by the family or by the patient. The family might have decided against telling the patient about her terminal condition because of the patient's negative and evasive attitudes towards death. The patient, on the other hand, might have chosen not to discuss his/her impending death because of his/her wish to get well, or because of the negative connotations associated with terminal illnesses. Silence around the issue of death might not only help to maintain emotional comfort in the patient, it could also protect the family from having to face the emotional pain associated with the anticipated loss of their loved one.

Maintenance of Hope

Despite the fact that their family members were terminally ill, some Chinese families in this study perceived that it was appropriate to maintain their family member's hope to live. In the perception of these families, the maintenance of hope could protect their dying loved

ones from the emotional pain of confronting death and/or from physical deterioration as a result of losing hope. Moreover, it was reassuring to the family to see that their dying loved one remained hopeful and was motivated to live.

One study participant talked about how the family tried to protect the patient from feeling hopeless and disappointed by making appointments for the patient to receive further cancer treatment. In reality, although the cancer treatment had no therapeutic value for the patient, the family perceived that it sustained the patient's feeling of hope and therefore was meaningful to her.

P: But she tried, she herself suggested and wanted the doctor to give her the injections. Sometimes the doctor said, that is, the doctor sometimes felt that her condition wasn't too good, that is, suggested her to rest, that is, (she) still wanted the doctor to continue treating her.

R: That is, the doctor suggested her to take a rest.

P: Uh-huh.

R: That is, to discontinue the chemotherapy.

P: Uh-huh, but she still wanted to continue. Therefore sometimes the doctor said, in the last chemotherapy the doctor said to her, he said, "There isn't any", that is, "The medications don't help you much, don't have to come next time; if there is any problem, contact the family doctor or go to hospital". But after having said that to her, I didn't dare telling her. I told the doctor to try his best to make an appointment for her, to let her be hopeful that next month she could, that is, to have an appointment in four weeks, after that, she could still be hopeful, that is, that is not to let her know that the medications were not effective for her.

In addition to protecting the patient from emotional pain, the maintenance of the patient's hope and confidence to live was perceived by this family as protecting the patient from giving up. The family felt less helpless to see that the patient was motivated to live.

R: ... Perhaps as you have mentioned earlier, to ask the doctor to make another appointment for your mother, to let her to, so she could, to let her like having a hope ...

P: That is not so disappointed. That is she, if so, to let her have a hope, so that she won't all of a sudden feel that she herself is incurable, and be out of confidence and out of will, something like that.

R: Uh-huh, uh-huh. So you feel that this confidence and will are important to her, they have importance.

P: That's right.

R: How?

P: Most of the time, it depends on her. That is, you, it can be very difficult even if you want to help her sometimes. Sometimes it's not possible for you to help, it depends on her. Perhaps if she had lost the confidence, (believing that) the disease had reached the stage of being incurable, "I don't want to have any more treatment", and she wouldn't eat, and wouldn't, anyway she gave up everything, you can't do anything about it, it depends on her. But we have to support her too, that is, to make her happy in every way, not to worry, not to let her worry about too many things.

R: Uh-huh. To support, can you talk about how to support her?

P: That is to tell her, "You will get well, you are already better now", that is to say that to her.

In the perception of another study participant, the patient's strong will to live and her hope for a longer life have motivated the patient to continue living and to make healthy changes in her lifestyle. As such, not telling the patient about her incurable condition

meant maintaining the patient's hope and will to live, and thereby protecting the patient from physical deterioration as a result of giving up and from the emotional pain of feeling frightened and worried.

R: Can you imagine if she knew that she was at the terminal stage now, how would that affect her?

P: She would be, I, I can't really tell, because she is a person who doesn't talk much normally, she is very, very quiet. So, I imagine she would be very frightened, very frightened, and very, that is, lose all her confidence. She would think, "Well, it's not going to, you know, anyhow, going to die soon". But she would be worrying about a lot of things, for example, worrying about her daughters, worrying about some other things.

R: That is, not telling her is to prevent her from worrying.

P: Not to worry so much.

R: On one hand ...

P: Right, and also I think it does good to her condition ... Because when she went into hospital last time, the doctor told her, told us, he said that, "Oh, for her condition, apart from heart transplant, that's no other way we could help her", I think that is true, the fact is like that; but then he said, "I can't say how much longer there is, maybe a few weeks, maybe a few months, maybe a year, hard to say, depends on her". Because she has had this condition for quite a while, normally her will of living is very strong, very quiet, but she is a very strong person. So therefore I think if this time like the asthma is cured, she is not suffering that much, she is to recover gradually, maybe she can still linger on for a while yet.

(...)

R: If Mrs F was told that her condition was serious, do you think that would affect her normal life?

P: I think it would, I think she would (think), "Oh, this is it anyway", maybe she would lose interest in everything, lose her appetite, therefore she would, her health would even be worse, and also her condition would change for the worse very soon I think, her condition would deteriorate.

R: Does it mean that her will would affect her condition? Is that what you mean?

P: It definitely would, right. Because she has a lot of will at the moment, she hopes for a longer life herself, to live longer, that's the best. That's why she is willing to listen to us, like not allowing her to take salt, to eat without salt, to eat only salt-less food, to her this is a very difficult thing, because she is used to eating very salty food. But now she agrees to that, that proves that she wants to live longer, right? Therefore if tell her, like, "I'm like that anyway, why bother putting up with so much?", that is, I fear that it would have such an effect on her.

One family tried to maintain the patient's confidence to live by playing down the seriousness of the patient's condition. For this family, maintaining the patient's confidence to live was a means to motivate the patient to eat, and feeding the patient meant protecting her from getting weak and dying soon.

R: ... I would like to go back to that idea of the family wanting to see that your mother can eat, and that's mainly, as you said that it's for the family that, if your mother can eat, the family would like to see her stronger and live longer ... Does your mother want to prolong her life, or like what is her feeling about the situation?

P: OK, I think my mother still has confidence.

R: Still have the confidence, that she might live.

P: Yeah. She rarely mention anything she will die or there's something later on or something, "I'm just a little bit sick", she always say that.

R: Just a little bit sick.

P: So we'll tell her, "Oh, you are just a little bit sick, then you have to eat; because you don't eat, so that's why you are weak".

Maintaining the patient's hope to live even when death was imminent was perceived by one study participant as humane care for his wife. Despite the fact that the patient knew about her terminal condition, this study participant was ready to lie to his wife in order to give her hope and to protect her from the emotional pain of confronting her impending death.

P: I'll tell her all the truth, at this moment. It's, maybe it's not the right time to lie to her yet.

R: It's not the right time to lie to her.

P: Yeah, I don't think it's the right time to lie to her yet.

R: May I ask what time do you think it might be necessary to lie to her?

P: When the, when the doctor give us a time table, that is the time for us to start to do some lie.

R: To do a lie.

P: Yeah. We, so far we haven't received any time table from the doctor yet.

R: Why do you think it's important because now, you told me that Mrs H know what is going on, why do you think it's important to lie to her?

P: Because right now she still have a regular life, yes. When she don't have a regular life, then she knows time is coming soon. If time is coming soon, why don't we, it's only humane to keep on giving her hope, it'll be, it'll be depressing to let her know her time has come.

R: Even though you know that she knows.

P: Yeah, even she knows, give her some happiness, peacefulness, dignity, yeah.

Another study participant saw that maintaining a person's hope was a good attitude for people. This study participant perceived that the maintenance of hope in her dying husband would motivate him to eat and to live, and thereby protect him from giving up and deteriorating. Even in the face of an incurable disease, the family valued a longer life for the patient. Maintenance of the patient's hope was perceived by the family as meaningful for extending the life span of their dying loved one.

R: Do you think that Mr E still have the hope to live?

P: For instance, I'm giving him that hope, like, um, I would say, "J, just eat the right thing, OK", I said. I'm not a can-opener, whatever I do, make a soup or, I start from scratch, and I said, "this is very healthy for you, keep you strong", and I said, as he likes going out, that is like him, going out to meet his friends and drink coffee, I said, "just get strong now", I said, "imagine when the snow goes away and you are not bleeding anymore or coughing", I said, "you'll be going out again, you know", just give him a good picture that way and hoping he, you know, does eat, and that's all I'll say to him. I mean, that's his, his love is to go out, so I try to give him a picture of anything about, you know, getting well and go out. But then I don't know whether he sense whether he will get well or not, that I don't know.

(...)

R: ... Um, why do you think giving him hope is important? Does it affect him in some ways that you, you think is important?

P: I think, I just thought, a person, to anybody I think, giving a person a little hope is always a good, an attitude to a person, isn't it?

R: It's an attitude to a person.

P: Don't you think so? Do you think? I don't know, I could be wrong, I could be wrong by giving a person hope but I don't think I could do any wrong by not giving, by giving a person a little hope. I mean, even to extend his life span, even say, sure, it's a thing that there's no cure, but then to extend his life a bit more, in that respect, you know.

R: You mean by giving him hope and motivating him to live?

P: That's the word, 'motivating', yeah.

To summarize, some study participants perceived that even when death was imminent, it was appropriate and humane to maintain the patient's hope to live. In the perception of these study participants, maintaining the patient's hope to live could protect the patient from the emotional pain of feeling hopeless, disappointed, worried and frightened. Moreover, it could motivate the patient to live and thereby protect the patient from giving up and from physical deterioration. For some families, to see the patient as motivated to live was reassuring to them and nourished their hope for a longer life for the patient.

Summary

Attentiveness, responsiveness, and protectiveness were the three conceptualized themes of what Chinese families in this study perceived as appropriate care for their dying family members.

Attentiveness is a description of the family's perception that their dying family members required 24-hour attention and care for the satisfaction of their needs and for their comfort. In order to attend to the patient's needs whenever the needs arose, the caregivers had to be readily accessible and available to the patient day and night. Nonetheless, many families perceived that they were negligent of the patient's needs while they were sleeping at night. Moreover, many were exhausted and overwhelmed by the strain of intensive, 24-hour caregiving at home. As such, despite the patient's wish to stay

home for care, many families preferred to send the patient to the hospital or nursing home for 24-hour attentive care.

Attentiveness is more than the mere provision of 24-hour care. As some families perceived, in order to make the patient feel cared for, care had to be delivered in a way that indicated caring to the patient. Families felt that attentive care provided in a caring manner would make the patient feel physically and emotionally comfortable.

Incongruence in what the family and health professionals perceived as important or unimportant needs for the patient resulted in the family's dissatisfaction with the care provided to the patient. Moreover, language differences between the patient and health professionals was a significant barrier to the accurate assessment of the patient's needs and to the conveyance of caring to the patient.

Responsiveness is a description of the family's expectation for prompt and knowledge-based responses to the patient's physical problems. While most families perceived themselves as unable to respond to changes in the patient's physical condition because of their lack of medical knowledge, they perceived that health professionals' knowledge-based responses to the patient's problems could relieve the patient's sufferings and maintain physical comfort in the patient. The willingness of health professionals to provide the patient with 'responsive' care, however, would depend on their attitudes towards caring for terminally ill patients. Because some families perceived that they could not rely on the family doctor for responsive care at home, they preferred to send the patient to the hospital for care.

Protectiveness is the description of the family's desire to protect the patient from emotional pain and/or from physical deterioration. Protective care could involve the maintenance of silence around the issue of death and/or the maintenance of hope in the patient. Some families perceived that silence around the issue of death could maintain the patient's emotional comfort by protecting the patient from confronting the painful reality of dying. Moreover, refraining from talking with patients about their impending death protected them from loss of hope and physical deterioration. Silence around the issue of death might be initiated by the family or by the patient.

Maintenance of the patient's hope, on the other hand, was perceived by some families as protecting the patient from the emotional pain of feeling hopeless. Moreover, maintenance of the patient's hope could protect the patient from giving up and motivate the patient to live. Even in the face of the patient's imminent death, some families perceived that it was humane to maintain the feeling of hope in their dying loved one.

CHAPTER 5: INTERPRETATION OF THE FINDINGS

In this study, attentiveness, responsiveness, and protectiveness were the three conceptualized themes of what Chinese-Canadians perceived as appropriate care for their dying family members. These themes could be interpreted as descriptions of the popular model of terminal care as held by Chinese-Canadians, based on the realities as subjectively perceived and experienced by the study participants. A person's reality, however, is constituted of individually interpreted experience and not pure experience (Oiler Boyd, 1993a). According to phenomenology, one's reality is defined by perception, and human experiences are always perspectival (Oiler Boyd, 1993a). In interpreting the perceptions and experiences of a given phenomenon by individuals, therefore, one must take into account the total context or the overlays that form an experience, and the perspective with which individuals interpret their world and give meaning to their experiences (Oiler Boyd, 1993a).

Although attentiveness, responsiveness, and protectiveness could be seen as themes of appropriate terminal care located within the Chinese culture, some of these themes could also be seen as transcending cultural boundaries. For instance, 'responsive' care for dying patients may be expected by families across cultures (Kristjanson, 1989). Nonetheless, these themes might be constructed differently in different cultural contexts. The meanings of attentiveness, responsiveness and protectiveness in this study should therefore be understood in relation to the contextual meanings within which these families' lives are enmeshed.

Appropriate Terminal Care - An Interpretation from a Cultural Perspective

Attentiveness

Attentiveness, which described the perception of study participants that 24-hour attention and care was appropriate for their dying family members, could be seen as a reflection of the practical needs of a dying patient for care because of the inevitable changes and deterioration in his/her physical condition. Nonetheless, there also seemed to be cultural meanings embedded within the desire of Chinese families to have their dying family members attended to day and night.

Attentiveness could be understood in relation to the sick role of a terminally ill Chinese patient. Sick role behaviors are not universal but they vary from one culture to another (Wilson & Ryan, 1990). In the traditional Chinese view, sickness is not a shortcoming (Kuo & Hopkins Kavanagh, 1994). For a Chinese patient, being sick entitles him/her to receive concern, sympathy, attention and care from others (Kuo & Hopkins Kavanagh, 1994). Sick Chinese adults have been observed to be treated like children and protected (Muller & Desmond, 1992). The sick Chinese patient is given the permission to be passive, to avoid difficult social situations, to be protected from criticism, and to have his/her personal failure legitimized (Kleinman, 1980; Kuo & Hopkins Kavanagh, 1994). Although the specific sick roles can vary by age, sex, and family role, it is a common expectation among the Chinese that social withdrawal indicates serious illness (Kleinman, 1980).

Attentiveness, perceived by some Chinese families in this study as an element of appropriate terminal care, was consistent with the sick role as defined within the Chinese culture. Attentiveness was fulfillment of the caring obligation for the dying patient in a way that was culturally relevant to the Chinese. Because the dying patient was entitled to be passive, to withdraw from responsibilities and to depend on others for care, it was a cultural expectation to provide the dying patient with 24-hour care in order to attend to his/her needs and comfort day and night. Attentiveness also implied protection of the dying patient, who was already sick and suffering, from further discomfort as a result of unmet physical needs. Because it is uncommon for the Chinese to communicate their emotion through words but to reveal concern through care of other's physical needs (Kuo & Hopkins Kavanagh, 1994), attending to the patient's needs and comfort was a culturally meaningful way to show concern to the dying Chinese patient and to make the patient feel cared for. Accordingly, as some Chinese families in this study perceived, being concerned about the patient's needs and being thorough in meeting the patient's needs would indicate caring to the dying patient, whereas being negligent in meeting the patient's needs would indicate uncaring to the patient.

One interesting finding from this study was that some Chinese families have perceived it as important or desirable to feed or to maintain the patient's nutritional intake even though the patient was gravely ill. Such perception could be understood in relation to the cultural expectation of, and the meaning in attending to, the physical needs of the sick person as discussed above. Nonetheless, food seems to mean more than oral gratification

in the Chinese culture. The Chinese recognise the close relationship of diet and health (Anderson & Anderson, 1974). For the Chinese, *ch'i* is the vital energy or the source of life, and food is seen as the major source of *ch'i* or energy that one absorbs everyday (Koo, 1984). The Chinese believe that good health is the product of sufficient accumulation and flow of *ch'i* in the body, which in turn depends on harmonious balance of hot/cold or yang/ying inputs to the body (Anderson & Anderson, 1974; Koo, 1984). Whether professionally prescribed or self-managed, modification of food patterns as diet therapy is used by the Chinese to maintain health and to manage illness (Anderson & Anderson, 1974). Feeding the sick person, therefore, is a culturally meaningful way by which Chinese families manage illness within the popular domain. Moreover, longevity is valued in the Chinese culture (Huang, 1989). Even in the face of a terminal illness, the use of food or nutrition to maintain the patient's *ch'i* is meaningful to some Chinese families for maintaining or even prolonging the patient's life, and for nourishing their hope for a longer life for their dying loved one.

Responsiveness

Responsiveness, which described the expectations of Chinese families for prompt and knowledge-based responses to the patient's physical problems, reflected the reality that the dying process was not necessarily uneventful and smooth. Instead, the dying patient could experience complex physical problems which required responses from health professionals with their medical knowledge and skills.

Responsiveness can be interpreted as caring actions that Chinese families expected of health professionals. Gaut (1983) has proposed that in order for an action or intervention to be described as caring, the carer must have knowledge about the patient to identify a need for care, he/she must have knowledge about what to do to improve the situation, and he/she must choose and implement an action based on that knowledge to bring about a positive change in the patient. Responsiveness implies that a caring health professional must be knowledgeable, and must be able and willing to take appropriate action to respond to the patient's physical problems and to maintain comfort in the dying patient.

Responsiveness was consistent with the findings in Kristjanson's (1989) study, in which families of terminally ill patients with cancer have also pointed to the patient's need for prompt and thorough medical care. The families in Kristjanson's (1989) study were mostly of European descent and none was reported to be Chinese. Families in both Kristjanson's (1989) and this study have emphasized the management of the patient's physical problems and maintenance of the patient's comfort. Even when there was no cure for the patient's disease, prompt and responsive care for the relief of suffering was expected by families of terminally ill patients across cultures.

Protectiveness

Protectiveness was the desire of some Chinese families in this study to protect their dying loved ones from the emotional pain associated with dying, and/or from physical deterioration as a result of giving up. In order to protect the patient, some families have

chosen to maintain silence around the issue of death within the family, and some perceived it as desirable to maintain the feeling of hope in the patient.

Protectiveness had to be understood in relation to the attitudes of the Chinese towards death and dying. Chinese people have both a 'naturalistic view' of death as well as a 'superstitious view' of death (Huang, 1989). Like people of other cultures, many Chinese believe that birth, aging, illness, and death are the four inevitable phases of human life (Huang, 1989). Because nobody can escape his Karma, one should accept his/her death graciously (Huang, 1989; Tung, 1990). Despite this 'naturalistic view' of death, Chinese people are uneasy about death, and many loathe to think of or to discuss it (Huang, 1989; Tung, 1990).

The negative connotation that the Chinese attach to 'death and dying' is reflected in the *yin* and *yang* dichotomy of death and life. *Yin* represents the negative force associated with darkness, emptiness, cold, and death, whereas *yang* represents the positive force associated with light, fullness, warmth, and life (Lee, 1986; Huang, 1989). The undesirability and fear of death among Chinese people are related to their 'superstitious view' of death, or their beliefs in immortality, ghosts, and heaven and hell (Huang, 1989). The belief in immortality was a distortion from the Taoist belief in cultivation and prolongation of life, in which the worldly desire for longevity was turned into a longing for 'no death' (Huang, 1989). The wish for everlasting life has had an impact on the belief of Chinese people that death is something bad and should be avoided (Huang, 1989). The anxiety of Chinese people about death is also shaped by the popular belief that a dead

person would turn into a ghost which is powerful yet ugly and wicked (Huang, 1989).

Moreover, the Buddhist systems of heaven and hell contribute to Chinese people's anxiety about being tortured in hell, and thereby their fear of death (Huang, 1989).

This 'superstitious view' of death, which associates death with suffering and horror (Huang, 1989), explains the evasive attitudes that some Chinese families and patients in this study had towards death and dying. The decision of some families against disclosing the terminal diagnosis to the patient could be understood as protecting their dying loved one from feeling frightened. Even if the patient knew that he/she was terminally ill, some Chinese families maintained silence about the patient's impending death in order to protect the patient from being burdened by discussion of his/her illness, and from the negative emotions which were inextricably associated with death and dying.

Silence around the issue of death as protection of the dying patient was consistent with the sick role of a terminally ill Chinese patient. The sick role, as defined within the Chinese culture, entitles the sick person to be treated like a child who deserves protection (Muller & Desmond, 1992). When a person is gravely ill and suffering, the need to protect the patient might seem even greater to the Chinese family (Muller & Desmond, 1992).

Silence around the issue of death is a manifestation of cultural phenomena other than protection of the dying patient. As this study has shown, silence about death and dying might have been initiated by the patients themselves. The unwillingness of some Chinese patients to talk about their impending death and suffering was congruent with the cultural rule for self-control and the traditional ideal of stoicism. The Confucian virtue of self-

control sets the expectation for a matured individual to exert restraint over one's emotions, to endure disturbed feelings, and to suppress expression of strong feelings (Kleinman, 1980; Lee, 1986). The ideal of stoicism, on the other hand, "promotes fortitude, discretion, or silence in the face of affliction and pain" (Tung, 1990, p.24). The cultural expectation for self-control and stoicism inevitably impacts on the behaviors of some terminally ill Chinese to maintain silence about their impending death and to strive to keep their miseries and sufferings to themselves.

Silence around the issue of death also seemed to serve a social function within the Chinese family. Chinese philosophy emphasizes balance; and within the collective-orientated family structure, high priority is given to family peace and harmony (Kuo & Hopkins Kavanagh, 1994; Kim, 1995). In conventional thinking, psychosocial equilibrium or peaceful coexistence among people depends on harmonious interpersonal relationships (Lee, 1990; Kuo & Hopkins Kavanagh, 1994). Because family harmony transcends personal concerns, Chinese people are expected to avoid direct confrontation, and to suppress strong and negative affects which might otherwise endanger harmonious interpersonal relationships, and upset the state of psychosocial homeostasis within the family (Kleinman, 1980; Lee, 1990; Kuo & Hopkins Kavanagh, 1994). Terminal illness and its consequences are "disordering events which provoke disruption and tension in the social nexus, the family, and the patient The cultural response to illness is an attempt to order this threatening stressor within a well-articulated conceptual framework, to control its disruptive psychosocial effect on the sick person and his social network ..." (Kleinman,

1974, p.601). Silence around the issue of death, then, could be seen to be culturally meaningful to the Chinese for preventing confrontation of extreme emotionalities between family members, and it served the social function of preserving balance and harmony within the Chinese family.

The behavior of silence around the issue of death has highlighted another cultural phenomenon, that is, Chinese patients are generally not encouraged or expected to enter into clinical communication about their dying with family members (Morgan, 1986). In the context of terminal illness, clinical communications are commonly in the form of practitioner-family and family-patient transactions instead of practitioner-patient transactions (Kleinman, 1980). The dominance of Chinese families in clinical communication is seemingly for protecting their dying loved one from facing the painful reality of terminal illness. Moreover, the patient's reliance on his/her family to make crucial decisions about illness management reflects the Chinese value of 'interdependence', which promotes highly interdependent relationships within the family, and sets the expectation for all family members to be responsible for each other (Kim, 1995). The dominance of Chinese families in clinical communication and in decision-making seems to benefit the dying patient in that the patient is not isolated from his/her family nor cut off from their contexts of meaning and support (Kleinman, 1980).

In addition to 'silence around the issue of death', protectiveness also subsumes the concept of 'maintenance of hope' for protecting the dying patient and for maintaining his/her comfort. The meaning of maintenance of hope has to be understood in relation to

the Chinese perspectives on death and dying. As discussed earlier, longevity is valued in the Chinese culture whereas death is feared by many Chinese who perceive it as something to be avoided (Huang, 1989). As such, maintaining the patient's hope to live even in the face of his/her impending death would be meaningful for protecting the patient from extreme and negative emotionalities such as despair and sorrow. In this sense, maintenance of hope is consistent with the Chinese value of balance. Moreover, to comfort a dying patient by maintaining his/her feelings of hope conforms to the Confucian virtue of benevolence, which teaches one to be aware of others and to treat others in a kindhearted manner (Lee, 1986).

The meaning of maintenance of hope as protection of the dying patient from physical deterioration seemed to be founded on the conceptualization of the person as a psycho-physical entity. The interrelationships between psychological and physiological functions are integral to Chinese medical thoughts (Kuo & Hopkins Kavanagh, 1994). While it is a popular belief among Chinese people that emotional balance corresponds to organ functioning, there is also a longstanding cultural belief that strong emotions such as anger and grief could cause people to sicken or die (Kuo & Hopkins Kavanagh, 1994). Maintenance of hope could therefore be understood as protecting the dying patient from despair, and thereby protecting him/her from physical deterioration and an early death. Similarly, hopefulness was perceived by some Chinese families as a positive emotion which motivated the patient to live and contributed to prolonging the patient's life.

Socio-cultural Construction of Illness Experience

Attentiveness, responsiveness, and protectiveness comprise the model of care that Chinese-Canadians in this study have perceived as appropriate for their dying family members. This popular model of care helps one to understand the expectation and the evaluation of terminal care by Chinese families. Moreover, it brings out the complex familial, social, and cultural nexus within which the dying Chinese patient experienced his/her illness.

The popular model of terminal care, as presented in this study, represents more than a mere framework of care. Instead, it reflects the personal, familial and cultural reactions to terminal disease within the Chinese culture. One cannot fully understand the meaning of this model without relating it to the socio-cultural background within which the Chinese families provided care and perceived care. This model of care was socio-culturally constructed in the sense that the Chinese families' perception of appropriate terminal care was influenced by a complex nexus of meanings, and rules for behaviors. As the interpretation of the model has shown, these socio-cultural processes influenced how the family attended to the dying patient, determined the sick role that the patient should assume, shaped the pattern of clinical communication, and affected social interaction between the dying patient and his/her family. These socio-cultural processes are inextricably linked in shaping the illness experience of the dying Chinese patient.

One cannot overemphasize the influence that the Chinese family has over the illness experience of their dying family member. The family, as one of the essential structures

within the popular health care sector, functions as the chief source and the most immediate determinant and evaluator of care (Kleinman, 1980). Within the Chinese culture, in particular, health care decisions are family decisions (Muller & Desmond, 1992). When a Chinese person is seriously ill, he/she often depends on the family to make crucial decisions and arrangements for treatment and care (Kleinman, 1980). Inevitably, the illness experience of a terminally ill Chinese patient is intertwined with family decision-making.

Just as illness experience is socio-culturally constructed (Kleinman et al., 1978), the decisions that the Chinese family made on behalf of their dying family member also seemed to be influenced by multiple social, cultural and political factors. In the province of British Columbia in Canada, the government is restructuring health care by providing care 'closer to home'. This health care policy has a significant impact on terminally ill patients in that it provides them with more community and health care support, and it enables them to stay at home and die in their familiar environment (McIntosh-Newberry, 1995). Concomitantly, underlying this policy is the government's expectation of families to be the major caregivers for the dying patient at home. As this study showed, however, not all families could cope with providing the intensive care that their dying family members required. The strain of caregiving was particularly harsh for those family caregivers who were caregiving on their own. Despite the Chinese emphases on family collectivity and interdependence (Kim, 1995), Chinese families in North America are facing inevitable changes in the family structure with family members scattered all over the

continent and too busy living their own lives (Tung, 1990). The harsh reality of caregiving with weakened family support could have urged some Chinese families to send the dying patients away to institutions for care. Moreover, the government policy which imposes expectations upon the families to provide terminal care at home could have resulted in family dissatisfaction with the professional sector of health care.

The experiences of Chinese families in managing terminal care at home could indeed influence their preferences and decisions regarding where to send the patient for care. The trajectory of terminal disease is not necessarily smooth but often involves emergence of unpredictable medical problems. As some Chinese families in this study have indicated, the lack of medical support from doctors could have rendered the family helpless in responding to the patient's physical problems at home, and resulted in unnecessary suffering in their dying family members. The unresponsiveness of some doctors to the medical needs of dying patients reflect the ideological emphasis on 'cure' which predominates Western medical practice. Moreover, it challenges one to examine the class and power relationships between immigrant families and health professionals. The experience of one Chinese family in this study who were frustrated by the unresponsiveness and indifference of their Chinese-speaking family doctor to the patient's medical needs seem to suggest that speaking the same language does not guarantee communication nor support (Anderson, Blue & Lau, 1991). What seems to be at issue here are the class relationships between the family/patient and health professionals, and the failure of health professionals to grasp or understand the life circumstances of caregiving

families and the difficulties that they faced in managing terminal care at home (Anderson et al., 1991). The gulf of social class between family/patient and health professionals could even be wider when family/patient are immigrants of lower social class status (Anderson et al., 1991). Moreover, because some families lacked English language skills, they had difficulty utilizing the mainstream health care system in an English-speaking society. Their dependence on Chinese-speaking family doctors for medical support could have widened the power differential between the family/patient and the doctor. From the report of one family, the medical care that their dying family member received at home was at the discretion of the family doctor, who, "when he likes then he will come once".

The family's experienced helplessness and frustration in caring for their dying family members with inadequate medical support at home could explain why some Chinese families preferred to send the patient to hospital for care. Moreover, the fear of some Chinese families about confronting the dying process could have shaped their decision to send the dying patient away from home during his/her final days. The decisions that Chinese families made on behalf of their dying family members, however, were not always congruent with the actual wish of the patient. As some Chinese families in this study have stated, the dying patients themselves preferred to stay at home and to be looked after by their families. In particular, the experiences of hospitalization were reported to be negative and frightening for those Chinese patients who lacked the English language skills to express their needs and to negotiate care with health professionals. The conflict of interests between the patient, who preferred to stay at home, and the family, who preferred

to send the patient to the hospital for care, created a moral dilemma for health professionals as they could be caught between the need to protect the patient's interests and the need to respect the family's decisions. Although the findings in this study have suggested that it was culturally acceptable for Chinese families to withhold information and to make decisions for their dying family members, there could be clashes between the family's perceived need to protect the patient and the patient's need for autonomy as this is defined within Western bioethics (Muller & Desmond, 1992). Family decision-making, which in itself was enmeshed with complex social, cultural, and political factors, added to the complexity of terminal illness as experienced by the Chinese patient.

CHAPTER 6: SUMMARY, CONCLUSION, AND IMPLICATIONS OF THE STUDY

Summary

This phenomenological study described what Chinese-Canadians perceived as appropriate care for their dying family members. This study arose from the need for nursing to respond to the health care needs of ethnoculturally diverse clients. As discussed in the background of this study, Canada is made up of people from different ethnocultural backgrounds. Nonetheless, the Canadian health care system, which is based on the Western ideology of health and illness, has been criticized as ethnocentric and insensitive to cultural differences (Anderson, 1985). Moreover, the medicocentric view of the Western biomedical model of clinical practice disregards illness problems and the socio-cultural context of illness experiences (Kleinman et al., 1978). In order to plan and provide culturally relevant care, therefore, it is imperative for health professionals to develop knowledge about the experiences and expectations of care by clients from different ethnocultural backgrounds.

The studies of 'care' have particular importance to nursing because care and caring are the emerging central concepts which provide significant directions to nursing practice and theory development (Bottorff, 1991). Review of selected nursing literature on the conceptualizations of caring, however, indicated that the concept of caring has remained poorly developed, and the theoretic link from nurse caring to patient outcome is tenuous (Morse et al., 1990; Morse et al., 1991). Moreover, a review of research studies on caring

revealed that there were significant discrepancies in the perceptions of caring by nurses and those by patients; while nurses emphasized the psycho-emotional aspect of care, patients emphasized the medical/physical aspect of care (Brown, 1986; Larson, 1986; Larson, 1987; Cronin & Harrison, 1988; Forrest, 1989; Mangold, 1991; vonEssen & Sjoden, 1991; Clark & Wheeler, 1992). It cannot be assumed that intended caring by the nurse is perceived as such by the patient. Since research efforts on caring have focused on the nurse, nurse researchers need to re-focus caring research on the patient, and to study the perception of care and caring from the perspective of care receivers (Morse et al., 1991).

One cannot overemphasize the important need for health professionals to understand the clients' perception of care. In palliative care, in particular, the nurse assumes the predominant caring role (Williams, 1982; Davies & Oberle, 1990). Although death is a normal process of life, the perception and expectation of terminal care can vary across cultures (Kalish, 1980; Ross, 1981). With the initiative of the provincial government in British Columbia to provide palliative care 'closer to home', nurses are challenged to be in partnership with families to provide terminal care to patients of diverse ethnocultural backgrounds. Knowledge about the perception of appropriate terminal care from different ethnocultural perspectives would provide an important basis for nurses to plan and provide culturally relevant terminal care.

The theoretical perspectives of Kleinman et al. (1978) on culture and care have provided directions for the conceptualization of this study in two important ways. First,

interactions between health professionals and clients are transactions between different explanatory models of health and illness. Kleinman et al. (1978) maintain that the professional, popular and folk domains of health care have their own explanatory model of health and illness which differ in terms of cognitive content, therapeutic values, expectations, and goals. The discrepancy in their models might even be greater when health professionals and patients come from different ethnocultural backgrounds (Anderson, 1987). Effective terminal care would therefore depend on the ability of the nurse to elicit and understand the discrepancies between the professional and the popular models of terminal care. Second, health and illness are socio-culturally constructed. Kleinman et al. (1978) have distinguished between disease and illness, and hold that "disease ... is malfunctioning or maladaptation of biological and psychophysiological processes in the individual, whereas illness represents personal, interpersonal, and cultural reactions to disease or discomfort" (P.252). Disease and illness, "do not stand in a one-to-one relation" (p.251); instead, illness experience is socio-culturally constructed (Kleinman et al., 1978). In particular, because decisions about care and evaluations of care occur most commonly in the family within the popular domain, patient's experience of terminal illness has to be understood within the complex social, cultural, and familial nexus. There is a large population of Chinese in Canada, yet little is known about their experiences and expectation of terminal care. This study was therefore intended to fill part of this knowledge gap by describing the popular model of terminal care from the perspective of Chinese-Canadians.

Phenomenology was the research design for this study because the aim of phenomenology is to investigate and describe phenomena as they truly appear or are experienced and perceived (Omery, 1983). In order to study the phenomenon of appropriate terminal care as subjectively perceived by study participants, the un-structured interview was the method for data collection in this study. A total of nine interviews were conducted with nine study participants respectively. All of the study participants were recruited from a community health nursing agency, and they were all Chinese-Canadians who had a dying family member either at home or in the hospital at the time of the interview. Collected data were analyzed by the method adopted from Colaizzi's (1978) method for phenomenological data analysis. The findings were organized into a model of care which was comprised of attentiveness, responsiveness, and protectiveness.

Attentiveness was the description of the perception of Chinese families that their dying family members required 24-hour attention and care for the satisfaction of their needs and for their comfort. In order for the patient to feel cared for, however, care had to be delivered in a caring manner such as being concerned about the patient's needs and being thorough in meeting his/her needs. 'Attentiveness' had to be understood in relation to the sick role of a terminally ill Chinese patient which allowed the patient to withdraw from social obligations and to be dependent on others for care. Moreover, the emphasis of Chinese families on the physical aspect of patient care could be understood in relation to the Chinese way to show concern through attending to other's physical needs.

Responsiveness was the description of Chinese families' expectation for prompt and knowledge-based responses to patients' physical problems. While most Chinese families saw themselves as incapable to respond to the patient's changing physical needs, they perceived that health professionals could maintain physical comfort in the patient by responding to the patient's physical problems with their medical knowledge and skills. 'Responsiveness' reflected the expectation of Chinese families for adequate medical care for the patient even when there was no cure for the patient's disease.

Protectiveness was the description of the desire of Chinese families to protect their dying loved ones from emotional pain associated with dying, and from physical deterioration as a result of giving up. 'Protectiveness' was consistent with the sick role of a dying Chinese patient who was seen as needing protection. 'Protectiveness' had to be understood in relation to the Chinese attitudes towards death and dying, in particular its superstitious view which associates death with horror and suffering. In order to protect their dying family members from feeling frightened, some families have therefore decided against disclosing the terminal diagnosis to the patient. The behavior of silence around the issue of death was also consistent with the cultural values of self-control and stoicism which discouraged expression of emotions. Moreover, by maintaining silence about the patient's impending death, confrontation of extreme emotionalities between family members could be avoided. Silence also seemed to serve the social function of maintaining balance and harmony within the Chinese family.

Maintenance of hope could be understood as the Chinese families' protection of patients from extreme negative emotion such as despair. The meaning of protecting the patient from physical deterioration by maintaining his/her feeling of hope had to be understood in relation to the Chinese belief about the interrelationship of psychological and physiological functionings. Because longevity is valued within the Chinese culture, some Chinese families saw it as desirable to maintain the patient's feeling of hope so as to comfort the patient, or even prolong the patient's life by motivating him/her to continue living.

Conclusion

From the preceding discussion of the findings of this study, the following conclusions can be drawn. First, the concept of appropriate terminal care is culturally constructed; personal and familial reactions to terminal illness are culturally shaped. In other words, how the dying patient behaves and interacts with others, and how the family manages terminal illness are influenced by a framework of cultural meanings. Second, families make the majority of the decisions regarding when, where, and from whom patients should seek care. Third, it is stressful for families to provide terminal care at home. Factors such as manpower, clinical support, and attitudes towards death and dying influence the family's ability to manage terminal care at home. Government resources and health care services from the professional sector are inadequate for meeting families' needs and expectations of care. The resulting strain and difficulty in managing terminal care at home can shape the family's decision to send the patient into an institution for care. Fourth, the

family's decision to send the patient into an institution for care can be discrepant from the patient's wish to stay at home to die. The decisions that families make on behalf of patients are influenced by complex social, cultural, political, and economic factors. Last but not least, the illness experience of dying patients is socio-culturally constructed, and it is intertwined with family decision-making.

Implications of the Study

This was a phenomenological inquiry into the perception of appropriate terminal care from the perspective of Chinese-Canadians. The findings of this study have implications for nursing practice, education, research and administration.

Implications for Nursing Practice

This study has four major implications for nursing practice. First, in planning and providing terminal care to dying patients and their families, the nurse has to understand clients' concepts of appropriate terminal care in relation to the framework of cultural meanings which shapes their expectations, perceptions and evaluation of terminal care. Second, in order to assist patients and their families to cope with terminal illness in a culturally appropriate way, the nurse has to understand the personal and familial reactions to terminal illness within the socio-cultural context of the client's life. Third, the nurse has to recognize that families make the majority of health care decisions for patients. Therefore, there is a need to work in partnership with families to provide terminal care to patients. Fourth, the nurse has to understand the ways in which the life circumstances of families influence their ability to provide terminal care at home and the decisions that they

make for patients. In particular, for immigrant families who lack English language skills and/or are unfamiliar with the social organization of health care services in this country, nurses have to enact their empowering and advocacy role in order to ensure the delivery of quality and adequate terminal care to clients.

Implications for Nursing Education

This study has three major implications for nursing education. First, nurses should be taught substantive knowledge about different cultures. Although nurses must not stereotype clients based on their ethnocultural origins, background cultural knowledge will enhance nurses' understanding of the ways in which cultural meanings influence the conceptualization of care and clients' reaction to illnesses. Second, nursing education should focus on both the disease and the illness aspects of sickness, so that nurses are not only prepared to care for patients' disease problems but also to deal with and heal illness problems. Last but not least, nursing education should prepare nurses with good assessment skills for eliciting the clients' expectation and perception of care, and with good communication skills for negotiating culturally meaningful and effective care with clients.

Implications for Nursing Research

The description of a socio-culturally constructed popular model of care in this study has pointed to the important need for nurse researchers to investigate 'care' and 'caring' from the perspectives of clients and in relation to their socio-cultural backgrounds. Specifically, findings of the present study have suggested a few research questions for future studies:

1. What do Chinese dying patients perceive as satisfying terminal care? How do patients' perception compare with Chinese families' perception of appropriate terminal care?
2. What is the ideology of terminal care from the perspective of professional nurses?
3. What are the illness experiences of dying Chinese patients who receive terminal care at home?
4. What are the illness experiences of dying Chinese patients who receive terminal care in health care institutions?
5. What are the perceptions of 'caring' and 'uncaring' from the perspective of Chinese-Canadians?
6. What are the experiences of non-English speaking Chinese clients in utilizing the mainstream health care system?

Implications for Nursing Administration

The difficulties experienced by some non-English speaking Chinese clients in this study in using health care services imply the necessity to hire nurses who have the language skills to communicate with clients from diverse ethnocultural backgrounds. In planning health care programs in the community, nurse administrators have to be aware of the differences in the conceptualization of care among ethnoculturally diverse clients. Moreover, nurse administrators have to take into consideration the problems that families could face in managing terminal care at home, and to ensure that adequate home care services and clinical support are in place to support families to care for their dying loved ones at home.

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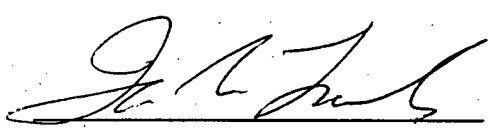

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Appendix A**Certificate of Approval for the Study**



Certificate of Approval

| | | | | | |
|---|--|------------------------------|--|---------------------------|--|
| PRINCIPAL INVESTIGATOR Anderson, J.M. | | DEPARTMENT Nursing | | NUMBER B95-0246 | |
| INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT Vancouver Health Department | | | | | |
| CO-INVESTIGATORS: Tang, S.Y.S., Nursing | | | | | |
| SPONSORING AGENCIES | | | | | |
| TITLE: What Chinese-Canadians Perceive as Appropriate Care for Their Dying Family Members | | | | | |
| APPROVAL DATE JUN 19 1995 | | TERM (YEARS) 3 | | AMENDED: | |
| | | | | MODIFICATION: | |
| CERTIFICATION: <p>The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.</p> <div style="display: flex; justify-content: space-around; align-items: flex-end;"><div style="text-align: center;"> Dr. R. Corteen or Dr. I. Franks, Associate Chairs</div><div style="text-align: center;"> Dr. R. D. Spratley Director, Research Services</div></div> <p>This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures</p> | | | | | |

Appendix B

Letter to the Nurse



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LETTER TO THE NURSE

Dear nursing colleagues,

I am a relief nurse and a student working toward the master of science in nursing at U.B.C. I am writing to ask for your kind cooperation in helping me to identify and recruit subjects for my M.S.N.'s thesis study, which is titled "What Chinese-Canadians perceive as appropriate care for their dying family member".

As the city of Vancouver is getting increasingly multicultural, health professionals frequently encounter and provide care to patients and families of diverse ethnocultural backgrounds. In palliative care where nurses play a predominant caring and supportive role, it is particularly important that nurses understand what their culturally diverse clients (patients and families alike) expect from care, and how they experience and perceive care. The purpose of my study is to describe what Chinese-Canadians perceive as appropriate care for their dying family member. It is hoped that the findings of this study will assist nurses to plan and provide effective care that is culturally acceptable to Chinese-Canadians, and will enhance nurses' understanding of the decisions that Chinese families make in relation to the care for their dying family member.

Page 1...
Continued on page 2...



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My study is qualitative in nature, and it will involve interviewing family member(s) of dying Chinese patients. The three criteria for selection of subjects in this study are:

- (1) the subject is a Chinese-Canadian who can communicate in Cantonese or English;
- (2) the subject has a dying family member who is a palliative care patient of home care nurses; and
- (3) the subject is willing to participate in this study.

I would like to ask for your cooperation to identify potential subjects who meet ALL of the three selection criteria, to briefly explain to them the purpose of the study, and to get their verbal consent to be contacted by me by phone. Upon your identification of a potential subject who is willing to be contacted by me, please kindly contact me at your earliest convenience (Home Tel:).

My study is supervised by Dr Joan Anderson (Tel:). I greatly appreciate your kind attention and help, and I very much look forward to hearing from you.

Yours sincerely,

Sannie Y. S. Tang

Appendix C

Information and Consent

THE UNIVERSITY OF BRITISH COLUMBIA¹⁴¹



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INFORMATION AND CONSENT

Title of M.S.N. thesis: "What Chinese-Canadians perceive as appropriate care for their dying family member"

Student: Sannie Tang (Tel:)

Faculty advisor: Dr Joan Anderson (Tel:)

Dear

My name is Sannie Tang and I am a Registered Nurse working toward a master's degree in nursing at the School of Nursing, U.B.C. Like many other nurses, I strongly believe that nursing is a caring profession and that nurses play an important caring role particularly in palliative care. I believe that cultural sensitivity is an important component in palliative care. I also believe that one of the best ways to ensure quality palliative care that is satisfying to both patients and their families is by understanding and describing how these patients and/or families see care and what they expect from care. The purpose of my study is to describe what Chinese-Canadians see as appropriate palliative care for a family member.

The procedure of the study will involve one to three, one-hour interviews, scheduled at our mutual convenience. I would be glad to answer any question about the study. If you wish to participate in my study, I WOULD LIKE TO

Page 1...
Continued on page 2...



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EMPHASIZE THAT YOU CAN REFUSE TO ANSWER ANY QUESTION, THAT YOU CAN STOP AN INTERVIEW AT ANY TIME, AND THAT YOU CAN WITHDRAW FROM THE STUDY AT ANY TIME. I WOULD ALSO LIKE TO EMPHASIZE THAT YOUR PARTICIPATION OR NON-PARTICIPATION WILL IN NO WAY INFLUENCE THE MEDICAL OR NURSING CARE OF YOUR FAMILY MEMBER.

Confidentiality of data and results will be maintained by coding participants' names with subject identity known only to me. Moreover, participants will never be identified with their responses and participants' identity will never be revealed. Because our conversations will be taped recorded, I want to emphasize that you have the right to request erasure of any tape or portion of a tape at any time during the study. Participants in the study will be asked not to mention any names during the interviews and any names accidentally mentioned will be erased. Published and unpublished material will not include any names of persons or institutions and I repeat that your name will remain absolutely confidential.

Sannie Tang.



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I hereby give my consent to participate in the study as described. I acknowledge that the study has been adequately explained to me and that I have a copy of this information and consent form.

Signed _____

Witness _____

Date _____

Appendix D**Information and Consent (Chinese)**



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同意書

碩士論文題目: "What Chinese-Canadians perceive as appropriate care for their dying family member"

學生: Sammie Tang (Tel:)

系教授: Dr Joan Anderson (Tel:)

親愛的 :

我是 Sammie Tang。我是就讀於「卑詩大學」護理系碩士課程的一名註冊護士。如其它很多的護士，我深信護理業是一門照顧、護理的專業。而護士尤其在善終服務中擔當一個重要的照顧、護理的角色。我相信善終服務其中一個重要的元素是對文化差異的靈敏性。我亦相信其中一個方法去保證病者及其家人得到滿意的高質素善終服務是去了解及描寫病者及/或其家人對照顧、護理的看法、感受及期望。我這篇論文的目的 是去描寫加籍華人認為對其家人適當的善終照顧及護理。

這項研究的過程會包括一至三個，在我們雙方同意的時間及地點下進行的一小時的面談。

第一頁...

第二頁續...



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我會很樂意回答任何有關這項研究的問題。
如閣下願意參與我的研究，我希望強調閣下
可以拒絕回答任何的問題，閣下可以在任何
時間終止面談，並閣下可以隨時退出這
項研究。我亦希望強調閣下參與這項研究
與否並不會影響府上病者的醫療及護理的
照顧。

我會把參與這項研究的人士的身份譯成
祇有我能明白的密碼，以保障參與者的身份
及他們所提供的資料得到保密。此外，參與者
的身份並不會和其所提供的資料連上。參與
者的身份也永不會被揭露。因為我們的交談
會被收錄在錄音帶上，我強調閣下有權在
這項研究的任何時間中要求擦除任何或部份
的錄音。參與者會被要求不要在面談中提及
任何的名字，而任何無意地被提及的名字將會
從錄音帶中被擦除。在被發表或未被發表的
文章中將不會記載任何人或機構的名字。
我重申閣下的名字會絕對保密。

Samie Tay.

第二頁...

第三頁續...



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我在此同意參與以上所描述的研究。
我承認我已得到關於這項研究的充分
解釋，我並得到這份同意書的副本。

簽名：

證人：

日期：
